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

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QUALITY UNTIL WE DIE

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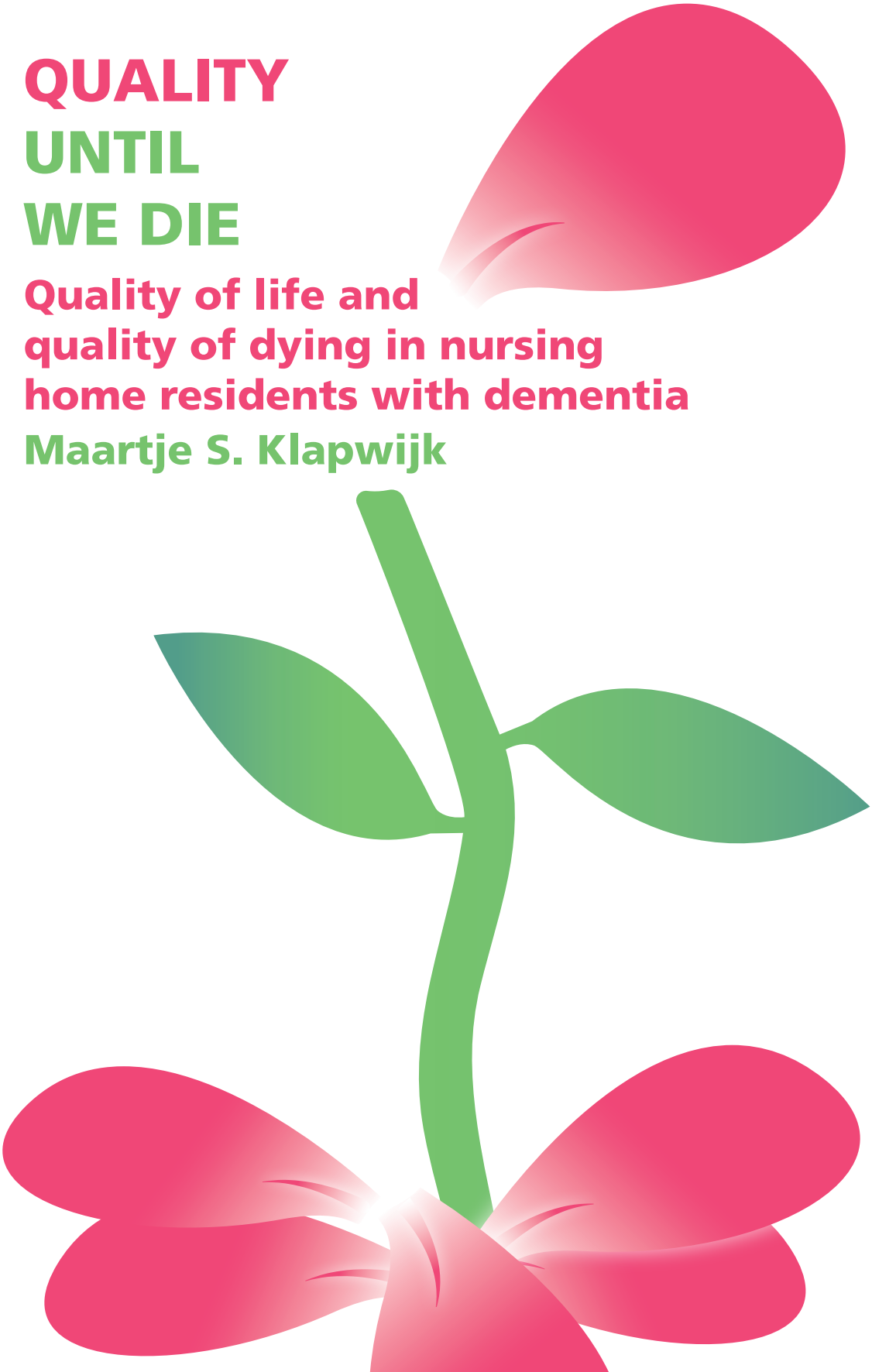
Maartje S. Klapwijk



Quality until we die

Quality of life and quality of dying in nursing home residents with dementia

Maartje S. Klapwijk

Academic network for research in elderly care
The studies in this thesis took place in the University Network for the Care Sector South Holland (UNC-ZH). In this network, the Leiden University Medical Center (LUMC) collaborates structurally with 12 elderly care organisations in South Holland (Marente, Pieter van Foreest, Florence, Topaz, Argos Zorggroep, Saffier, Laurens, Zonnehuisgroep Vlaardingen, Woonzorgcentra Haaglanden, Aafje, ActiVite, Haagse Wijk- en Woonzorg).

Caregivers, policy makers, researchers, students, residents and relatives work together to improve the quality of care and quality of life for vulnerable older people. The UNC-ZH is a regional platform, inspirator and learning network for innovation in long-term care. Research, education and training, and practice are closely related.

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Quality until we die

Quality of life and quality of dying in nursing home residents with dementia

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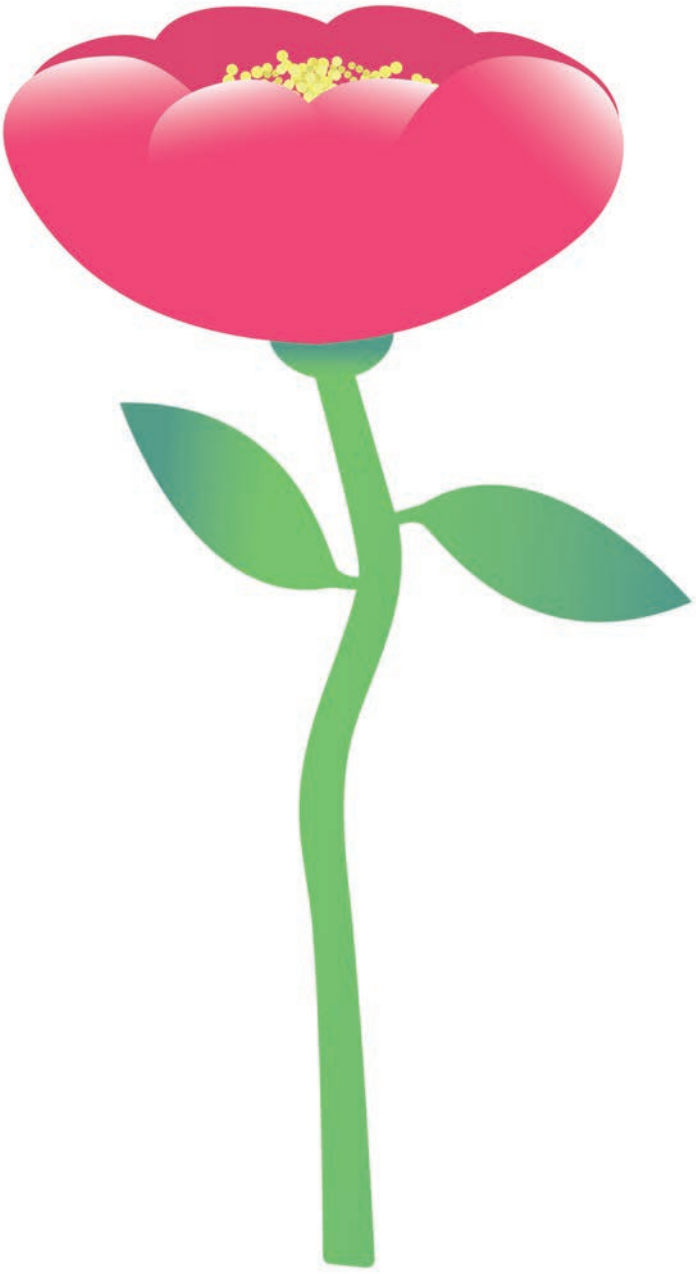
Prof. dr. L. Van den Block, Vrije Universiteit, Brussel, België

Dit proefschrift is voor alle mensen met dementie en de mensen die van hen houden. In de hoop dat met elk stukje onderzoek en aandacht voor deze ingrijpende ziekte er verbetering komt in jullie kwaliteit van leven.

Table of contents

Chapter 1	General Introduction	8
Chapter 2	Characteristics associated with quality of life in long-term care Residents with dementia. A cross-sectional study	18
Chapter 3	Change in QOL after a multidisciplinary intervention for people with dementia: a randomized controlled trial	40
Chapter 4	Experiences with the Liverpool Care Pathway for the dying patient in nursing home residents: a mixed-method study to assess physicians' and nurse practitioners' perceptions	56
Chapter 5	Symptoms and treatment when death is expected in dementia patients in long-term care facilities	84
Chapter 6	Trends in quality of care and dying perceived by family caregivers of nursing home residents with dementia 2005-2019	102
Chapter 7	General Discussion	130
Chapter 8	Summary	154
	Nederlandse samenvatting	161
	Dankwoord	167
	Curriculum Vitae	170
	List of publications	171



Chapter 1
General introduction

1.1 Dementia

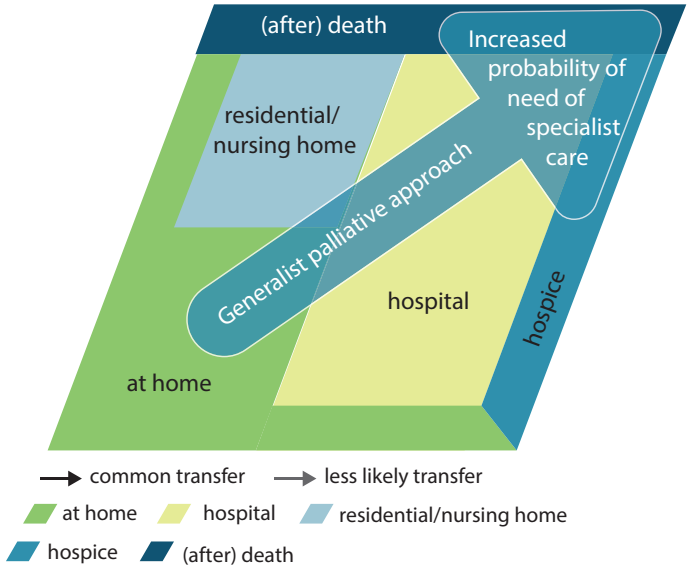
Despite a decline in incidence and prevalence, the total number of people with dementia is growing worldwide due to the increased life expectancy. [1-3] This tangible growth has led to a sharp increase in research on dementia as well as knowledge about the disease and its impact on the people with dementia 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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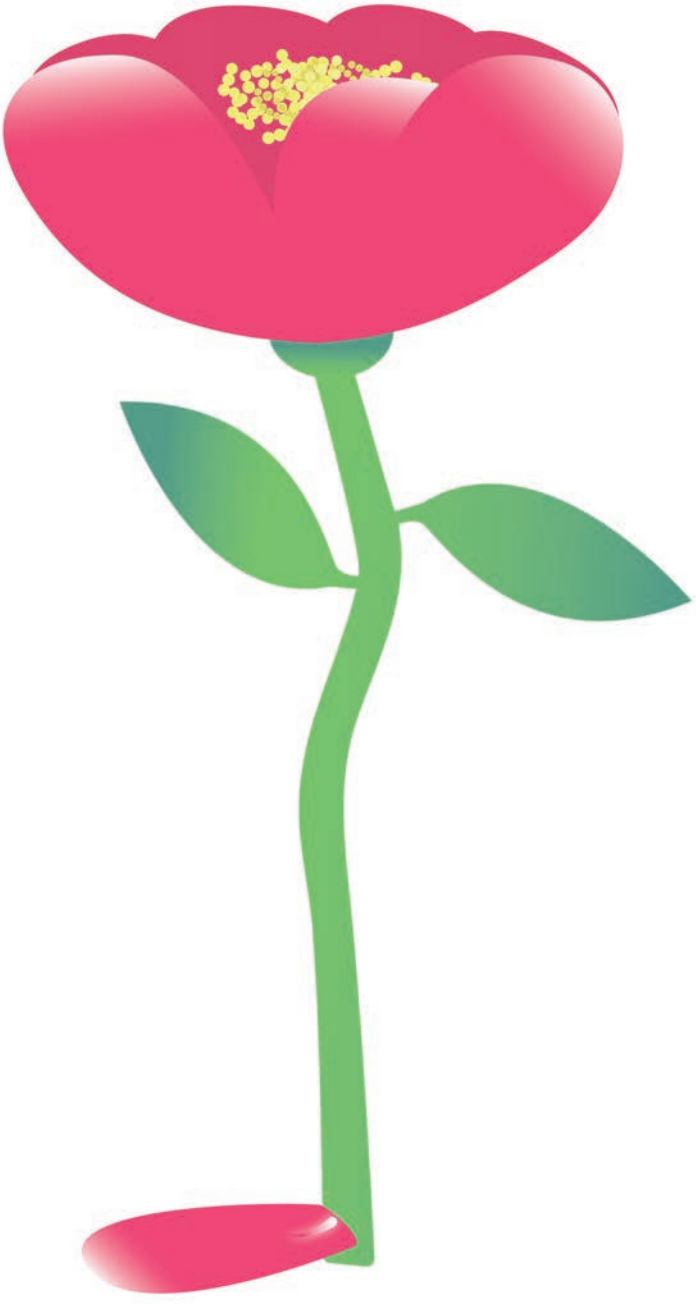

Chapter 2

Characteristics associated with quality of life in long-term care residents with dementia

A cross-sectional study

Klapwijk, M. S., Caljouw, M. A.A., Pieper, M. J., van der Steen, J. T., & Achterberg, W.P. (2016). *Dement Geriatr Cogn Disord, 2016;42(3-4), 186-197. doi:10.1159/000448806*

Abstract

Background

To determine which characteristics are associated with quality of life (QOL) in residents with moderate to very severe dementia in long-term care facilities (LTCFs).

Material and Methods

This was a cross-sectional analysis of a cluster randomized controlled study in 12 Dutch LTCFs that enrolled 288 residents, with moderate to severe dementia assessed with the Reisberg Global Deterioration Scale (Reisberg GDS) and QOL with the QUALIDEM. Characteristics that were hypothesized to be associated with the six domains of QOL (applicable to very severe dementia) included demographic variables, activities of daily living (Katz ADL), cognitive performance (CPS), pain (PACSLAC-D), neuropsychiatric symptoms (NPI-NH) and co-morbidities.

Results

Multivariate logistic regression modelling showed associations with age in domain Social isolation (OR 0.95 [95%CI 0.91-0.99]), ADL level in domain Positive affect (OR 0.89 [95%CI 0.83-0.95]) and domain Social relations (OR 0.87 [95%CI 0.81-0.93]), severity of dementia in domain Social relations (OR 0.28 [95%CI 0.12-0.62]) and in domain Social isolation (OR 2.10 [95%CI 1.17-3.78]), psychiatric disorders in domain Positive affect (OR 0.39 [95%CI 0.17-0.87]) and pulmonary diseases in domain Negative affect (OR 0.14 [95%CI 0.03-0.61]) of the QUALIDEM. Neuropsychiatric symptoms were independently associated with all six domains of the QUALIDEM (OR 0.93 [95% CI 0.90-0.96] to OR 0.97 [95% CI 0.95-0.99]). Pain was associated with the domains Care relationship (OR 0.92 [95% CI 0.84-1.00]) and Negative affect (OR 0.92 [95% CI 0.85-1.00]).

Conclusion

QOL in dementia is independently associated with age, ADL, dementia severity, pain, psychiatric disorders, pulmonary diseases and neuropsychiatric symptoms. It is possible to detect persons with dementia at risk for a lower QOL. This information is important to develop personalized interventions to improve QOL in persons with dementia in LTCFs.

Introduction

With the decrease in functional independency in people with dementia and the need for specialized care, admission to a long-term care setting is often inevitable in later stages of the disease. [1, 2] Because there is no cure for dementia, care, research and management in long-term care facilities (LTCFs) are primarily focussed on improving or maintaining quality of life (QOL) in these vulnerable persons. [3, 4] In the general population QOL is often defined as 'individuals' perception of their position in life in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards and concerns. [5]

Measuring QOL in dementia is more challenging due to the fact that persons with dementia can often not give their own perception, especially when people are in a moderate to severe stage of dementia. Therefore, the definitions of QOL in studies measuring QOL in dementia generally use several dimensions, which reflects that QOL in dementia is a multidimensional concept. Depending on their theoretical background these different domains can include items related to physical and psychological wellbeing, social interaction, and positive/negative affect. [6-9]

To improve QOL for persons with dementia, the factors associated with QOL need to be identified. However, no consistent association has been found between socio-demographic factors (age, gender, race, marital status) and QOL in persons with dementia. [10-13] On the other hand, psychosocial factors such as sadness [14], depression [4, 10, 15, 16], and agitation [10, 16, 17] have a negative association with QOL, whereas functional characteristics (e.g. ADL impairment and dementia severity) show inconclusive evidence for associations with QOL. [10, 12, 18-20]

Moreover, data are inconclusive regarding physical characteristics. Although some studies confirm a relation between pain and a lower psychological wellbeing in dementia, the exact relation between pain and the various domains and the effect on QOL remains unclear. [20-23] In addition, although chronic diseases can have an impact on QOL, information is lacking on their relationship with QOL in persons with dementia. [24, 25]

More insight into the factors associated with the different domains of QOL in residents with moderate to very severe dementia in LTCFs may help to better identify persons with dementia with a low QOL on a specific domain. Therefore, this cross-sectional study aims to explore in more detail which patient characteristics (demographic, psychosocial, functional and physical) are associated with the domains of QOL in people with moderate to very severe dementia in LTCFs.

Material and Methods

Setting and study population

This cross-sectional study uses baseline data of the STA-OP! study, a cluster randomized controlled trial which implemented an intervention to address pain and challenging behaviour. [26, 27] LTCFs were recruited within the 'University Network for Organizations of Elderly care' of the VU University Medical Center. The aim of this and other academic LTCF

networks in the Netherlands is to generate knowledge on the best multidisciplinary care for vulnerable older persons.[28, 29] Participating LTCFs had to meet the following criteria: at least one dementia ward willing to participate, and no major organizational changes or building activities planned or performed during the study period.

Inclusion and exclusion criteria

Residents with moderate to very severe dementia were eligible. Dementia severity was assessed with the Reisberg Global Deterioration Scale (Reisberg GDS) by the treating elderly care physician.[30] Residents with a Reisberg GDS score of 5 (moderate dementia), 6 (moderately severe dementia) or 7 (severe dementia) were eligible for this study.

Informed consent

Written informed proxy consent was obtained from family/caregivers for all residents meeting the inclusion criteria. The study was approved by the Medical Ethics Review Committee of the VU University Medical Center Amsterdam. (Registration no. 2009/119) and was registered in the Dutch Trial Register (NTR-1967).

Data collection

Elderly care physicians and registered or certified nurse assistants collected the data. [27] All the following instruments have also been tested and extensively used in the Netherlands.

Quality of life

QOL was assessed with the QUALIDEM: this is an observational instrument that measures QOL in persons with dementia and is filled out by the nursing staff, preferable by two nurses.[31] The QUALIDEM is based on the theoretical framework of the adaptation-coping theory. The scale is reliable, easy to administer and provides a QOL profile of persons with dementia in an LTCF setting. [18, 32, 33] The QUALIDEM consists of 37 items describing observable behaviour in nine domains: Care relationship, Positive affect, Negative affect, Restless tense behaviour, Positive self-image, Social relations, Social isolation, Feeling at home, and Having something to do. The QUALIDEM (of 37 questions) takes about 15 min to fill out and is based on an observation window of one week. [18] The response options are: never, rarely, sometimes, and frequently. We used the 6 domains (Care relationship, Positive affect, Negative affect, Restless tense behaviour, Social relations, and Social isolation) that include 18 questions that are also applicable for very severe dementia (GDS 7).[32] The individual item scores for each domain are processed such that a higher composite score reflects a better QOL. On the domains Care relationship, Restless tense behaviour, Social relations and Social isolation the scores range from 0-9, Positive affect scores range from 0-12, and Negative affect scores from 0-6. For the logistic regression analysis, two groups were created (high and low QOL) based on the median score for each domain.

Functioning

ADL functioning was measured with the Katz Index of Independence in activities of daily living (ADL), commonly referred to as the Katz ADL. The Katz ADL is a

reliable and valid instrument to assess functional status. [34, 35] The index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. The scores on each function are summed; the total range is 6-24 with higher score indicating more dependency in ADL.

The 7-category Minimum Data Set Cognitive Performance Scale (CPS) was used to determine cognitive function and was assessed by the elderly care physician. The CPS is a valid measure for cognitive performance and ranges from intact (level 0), borderline intact (1), mild (2), moderate (3), moderately severe (4) and severe impairment (5) to very severe impairment (level 6) [36]

Comorbidity
Comorbidity was assessed by the elderly care physician with the MDS-RAI comorbidity list that contains the following groups of diseases; endocrine diseases, visual impairments, cardiovascular diseases, psychiatric disorders, pulmonary diseases, diseases of musculoskeletal system, neurological diseases (without Alzheimer disease or other types of dementia), other and infection in the last 7 days.[37]

Pain
The PACSLAC-D is a validated and shortened Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate. [38-40] The observation was done during morning care by the nursing staff and was filled in afterwards. A total score of $\geq$ 4 is indicative for pain. [41]

Neuropsychiatric symptoms
The Neuropsychiatric Inventory-Nursing Home Version (NPI-NH) was developed to characterize the psychopathology of patients with dementia. It scores 12 behavioural and psychological areas such as delusions, hallucinations, agitation/ aggression, depression/ dysphoria, anxiety, euphoria/elation, apathy/ indifference, disinhibition, irritability/ lability, aberrant motor behaviour and two types of neurovegetative changes i.e. sleep and night time behaviour disorders, and appetite and eating disorders. The product of the frequency and severity ratings provide an overall score for each of the 12 items in a total score ranging from 0-144. [42-44] A higher score indicates more (severe) neuropsychiatric symptoms.

Statistical analysis

Descriptive statistics were used to describe the study population, results are reported as mean and standard deviation (SD) for normally distributed variables and median and interquartile range (IQR) when non-normally distributed.
Only the 18 questions of the QUALIDEM that are also applicable for persons with advanced dementia (GDS 7) were used; the score was dichotomized at the median score at each domain. A univariate logistic regression was performed for each characteristic and each separate domain of the QUALIDEM. Results with a p-value $\leq$ 0.10, and age and gender, were included in the multivariate logistic regression model for each domain.

The relation between the remaining variables in each domain was calculated using the Pearson's correlation coefficient. In this multivariate model a p-value < 0.05 was considered statistically significant. The association between the characteristics and QOL were reported as Odds ratio's (OR) and 95%Confidence intervals (95%CI).
All analyses were performed with SPSS statistical software, version 20, 2011 (SPSS Inc., IBM, USA).

Results

Study population

Between January 2010 and June 2012, in 12 Dutch LTCFs covering a total of 21 nursing home units, 363 residents were eligible for participation. Of these residents, 56 (15.4%) were not willing to participate, 13 (3.6%) died before start of the study, 3 (0.8%) did not meet the inclusion criteria of the STA-OP! study, and 3 (0.8%) were transferred to another LTCF, leaving 288 participants for the present analysis. Mean age was 83.8 (SD 7.1) years and the median length of stay in the LTCF was 22.4 (IQR 11-40) months (Table 1).
All participants were highly dependent regarding ADL: median Katz score was 18 (IQR 14-22). About half of the participants (52.1%) had severe (CPS 5) or very severe cognitive (CPS 6) impairment (Table 1), 80 (28%) participants had very severe dementia (GDS 7) and 208 (72%) had moderate to severe dementia (GDS 5 and 6) (Table 1).
Regarding comorbidity, 30 (10.4%) participants had lung diseases, 152 (52.8%) cardiovascular diseases, and 18 (6.3%) had an infection in the last 7 days (Table 1).
The median pain score (PACSLAC-D) was 3 (IQR 1-7) and the median NPI-NH total score was 12 (IQR 4-23).

Quality of Life

QUALIDEM scores per domain
The median score on the domain Care relationship was 7 (IQR 5-8), on Positive affect 9 (IQR 7-11), on Negative affect 5 (IQR 4-6), on Restless tense behaviour 5 (IQR 2-7), on Social relations 6 (IQR 4-8) and on the domain Social isolation the median score was 7 (IQR 5-9).

QUALIDEM univariate and multivariate analysis
The univariate logistic regression showed different results for each domain of the QUALIDEM (Table 2). Pain and Neuropsychiatric symptoms were univariately associated with all six QUALIDEM domains, ranging for pain from OR 0.82 (95% CI 0.76-0.89) to OR 0.90 (95% CI 0.84-0.96) and ranging for neuropsychiatric symptoms from OR 0.92 (95%CI 0.89-0.94) to OR 0.97 (95%CI 0.95-0.98).
The functional variables (Katz and CPS) were associated with the domains Positive Affect (Katz; OR 0.88 [95% CI 0.83-0.92]); (CPS: OR 0.44 [95% CI 0.28-0.71]) and Social Relations (Katz: OR 0.82 [95% CI 0.78-0.87]); (CPS: OR 0.31 [95% CI 0.19-0.51]). Compared to lower dementia severity (GDS 5 and 6), very severe dementia (GDS 7)

was associated with the domains Positive affect (OR 0.42 [95% CI 0.25-0.72]), Social Relations (OR 0.17 [95% CI 0.09-0.33]) and Social Isolation (OR 2.20 [95% CI 1.33-3.71.

The multivariate logistic regression model (Table 3) showed that neuropsychiatric symptoms are independently (negatively) associated with all six domains of the QUALIDEM (OR 0.93 [95% CI 0.90-0.96] to OR 0.97 [95% CI 0.95-0.99]). Pain was (negatively) associated with the domains Care relationship (OR 0.92 [95% CI 0.84-1.00]) and Negative affect (OR 0.92 [95% CI 0.85-1.00]), and ADL level (negatively) associated with the domains Positive affect (OR 0.89 [95% CI 0.83-0.95]) and Social relations (OR 0.87 [95% CI 0.81-0.93]). Dementia severity was (negatively) associated with the domains Social relations (OR 0.28 [95% CI 0.12-0.62]) and (positively) associated Social isolation (OR 2.10 [95% CI 1.17-3.78]). Age, psychiatric disorders and pulmonary diseases were independently (negatively) associated with one domain of the QUALIDEM, i.e. Social isolation, Positive affect and Negative affect, respectively. The Pearson's correlation coefficients between the characteristics and the QUALIDEM domains were all below 0.55.

Discussion

This cross-sectional study explored the association of QOL in persons with dementia in LTCFS with demographic, psychosocial, functional and physical patient characteristics. Interestingly, different domains showed different associations, which suggests that also interventions to improve QOL might benefit from knowledge of low QOL scores on these specific domains. QOL in persons with dementia is independently associated with different patient characteristics across the QOL domains. In the domain Care relationship a lower QOL was associated with pain and neuropsychiatric symptoms. In the domain Positive affect an association with a lower QOL was found with more ADL dependency, psychiatric disorders, and neuropsychiatric symptoms. In the domain Negative affect an association was found with a lower QOL and pulmonary diseases, pain and neuropsychiatric symptoms. In Restless tense behaviour an association was found with neuropsychiatric symptoms. In the domain Social relations an association was found with a lower QOL and more ADL dependency, a more severe dementia and neuropsychiatric symptoms. In the domain Social isolation an association was found between a lower QOL and a higher age and neuropsychiatric symptoms, and remarkably a higher QOL was associated with more severe dementia.

The present study confirms that QOL should be approached and measured as a multidimensional construct and not as a single construct. [8] The study also shows that it is possible to detect which people are at risk for a lower QOL across different QOL domains. These QOL domains, with their own specific relations with functional and other patient characteristics, should be taken into account when selecting person-centered interventions to improve QOL in persons with dementia.

With a decrease in ADL functioning, the domain Positive affect and Social relations are threatened. Higher age and less severe dementia implies that persons with dementia are more vulnerable for social isolation. Interventions on neuropsychiatric symptoms may have a beneficial influence on all domains of QOL, and the potential of especially non-pharmacological interventions are very promising [45].
To our knowledge this is the first study to examine QOL in relation to pain and comorbidity in a large group of persons with dementia in LTCFs. The relationships found between QOL and pain and comorbidity is highly relevant to improve QOL in persons with dementia in LTCFs. Since pain can be related to neuropsychiatric behaviour this may influence QOL. [46-48] Treatment of pain and optimization of symptom control for patients with a psychiatric disorder or pulmonary disease may result in a higher QOL, which is also suggested by studies in the general population [49]. Comorbidity in general however seems to have little impact on QOL in persons with moderate to severe dementia.

Strengths and limitations

Although self-report is the preferred method of assessing QOL, persons with dementia are often incapable of evaluating their own QOL, especially in the later stages of the disease. Different observational methods are available and validated to measure QOL in persons with moderate to severe dementia in LTCFs [7, 50-53] and some have good psychometric properties. [8, 9] These observational instruments employ different domains of QOL that are important for persons with dementia. The QUALIDEM is recommended to evaluate QOL in severe dementia [9] and focuses on the QOL domains that are judged important for persons with dementia, even in severe end-stage dementia. [54] Although other QOL instruments, such as the QUALID, are also developed to measure QOL in this population, the specific characteristic of the QUALIDEM is the differentiation in separate domains of QOL. A strength of the present study was the use of the QUALIDEM in a large group of people with moderate to severe dementia. Although the QUALIDEM is a reliable instrument to measure QOL it takes 15 min to complete all 37 questions. Due to the pragmatic character of this study, reflecting daily care for persons with dementia in LTCF, only one (contact) nurse of the patient (instead of two nurses) filled the instrument, this is a limitation of the study because the developers of the QUALIDEM advice to use the answers reached by consensus of two nurses. In the present study only the 18 questions suitable for very severe dementia (GDS 7) were used, because these questions are reliable for use in patients with mild dementia as well as those with very severe dementia. [18, 32, 55] A short instrument that can be filled out by one person would be more feasible. [20, 56] For future studies and implementation in LTCFs, we recommend to use the shorter version (18 items) of the QUALIDEM that is applicable for all levels of dementia severity. Such an easy-to-use instrument would stimulate use in clinical practice and research on QOL in persons in LTCFs, including those with very severe dementia. In the present study, almost 30% of the participants had very severe dementia. These advantages should however be evaluated against a less in depth evaluation of QOL in less advanced dementia patients. Although this study was embedded in a cluster randomized controlled trial with possible selection bias, almost all patients met the inclusion criteria and about

85% agreed to participate. The average age and the proportion of males/females are comparable to other studies performed in LTCF. [2, 18] Moreover, the QUALIDEM scores were also similar to those in other studies on persons with dementia. [18, 57, 58] Family members often rate the QOL of their relative lower compared to self-reported ratings.[59, 60] The differences in the rating of QOL between self-report and proxy report generally depend on variables such as depressive symptoms and severity of dementia and should be recognized. [55, 61-64] The QUALIDEM was developed to measure QOL in persons with dementia; however, observational instruments always have the possibility of observer-bias. [65] The QUALIDEM was the last instrument filled by the nurse, and recall of earlier items could have influenced the answers. Finally, because we used several outcomes in different domains with several potential determinants we acknowledge that multiple testing may have led to some results being the result of chance.

It is difficult to study QOL in people with a progressive disease that is characterized by loss of various cognitive functions. Many studies in persons with dementia have resulted in more knowledge on different aspects of QOL and the various factors that can help to improve or maintain QOL. This study shows that it is possible to detect which persons with dementia are at risk for a lower QOL across different QOL domains; therefore, it seems possible to target interventions to improve QOL. Interventions such as group cognitive stimulation therapy (GCST) [66], integrated emotion-oriented care[67], emotional adaptation[68], improving pain management [23], and research on the effect of organization of LTCF [69] and the effect of an outdoor space such as a garden[70], show promise with regard to the aim of improving QOL in persons with dementia. A Cochrane analysis showed a positive effect of exercise on ADL and depression but, unfortunately, many of the included studies did not specifically include QOL as a primary outcome. [71, 72] Also, because different methods (with different components) were used to measure QOL, it is difficult to compare the results of studies on QOL.

In the present study, the QUALIDEM data are the results of a one-week observation period in the life of a person with dementia. The next step is to repeat the measurements and test whether the QOL changes over time with the progression of the disease. Another possibility is to examine the individual characteristics of persons with dementia that are related to QOL and follow the effects of interventions on the different domains of QOL. [73] The different domains that are relevant in QOL may respond differently to various interventions.

Conclusion

QOL in dementia is independently associated with age, ADL, dementia severity, pain, psychiatric disorders, pulmonary diseases and neuropsychiatric symptoms. It is possible to detect persons with dementia at risk for a lower QOL. This information is important to develop personalized interventions to improve QOL in persons with dementia in LTCFs.

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Disclosure Statement
The authors declare that they have no conflict of interest.

Table 1 Characteristics of the study population N=288

	n	%
Demographic variables		
Female	207	71.9
Mean age years (SD)	83.8	(7.1)
Median length of stay in months (IQR)	22.4	(11-40)
Marital status		
Married/Partner	87	30.2
No partner	201	69.8
Functional variables		
Katz range 6-24 median (IQR)	18	(14-22)
CPS Level 0 intact to level 4 Moderate severe impairment	138	47.9
CPS Level 5+ 6 severe and very severe impairment	150	52.1
Disease specific measurements		
Dementia severity		
Reisberg GDS 5 and 6	208	72
Reisberg GDS 7	80	28
Comorbidity (≥1)		
Endocrine[a]	78	27.1
Vision impairment[b]	53	18.4
Heart/cardiovascular disease[c]	152	52.8
Psychiatric/Mood[d]	44	15.3
Lung disease[e]	30	10.4
Diseases of musculoskeletal system[f]	75	26.0
Neurological diseases[g]	71	24.7
Other[h]	42	14.6
Infection in last 7 days[i]	18	6.3
Pain; PACSLAC-D range 0-24, median (IQR)	3	(1-7)
Behaviour; NPI range 0-144, median (IQR)	12	(4-23)

SD=Standard deviation, IQR=Inter Quartile range, CPS=Cognitive Performance Scale, Reisberg GDS=Reisberg Global Detoriation Scale, PACSLAC-D=Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dementia, NPI=Neuropsychiatric Inventory

a=Diabetes Mellitus, hypothyroidism and/or hyperthyroidism

b=Cataract, diabetic retinopathy, glaucoma, and/or macular degeneration

c=Arteriosclerotic disease, heart rhythm disorders, heart failure, hypertension, hypotension, peripheral vascular disease, other

d=Anxiety disorder, depression, manic depression, schizophrenia

e=Asthma, Emphysema/COPD

f=Rheumatic diseases, hip fracture, amputation, osteoporosis, pathologic bone fracture

g=Aphasia, cerebral palsy, stroke, hemiplegia/hemiparesis, paraplegia, multiple sclerosis, Parkinson disease, seizures, passagere cerebral ischemia, traumatic brain injury, quadriplegia

h=Allergies, anemia, cancer, renal failure

i=Pneumonia, respiratory tract infection, urinary tract infection; last 30 days

Table 2 Univariate logistic regression for each variable and domains of QUALIDEM

	Care relationship			Positive affect			Negative
	OR	95% CI	p	OR	95% CI	p	OR
Demographic variables							
Age (years)	1.01	0.98-1.04	0.62	1.01	0.98-1.05	0.39	1.03
Gender (female)	1.53	0.89-2.64	0.12	0.74	0.44-1.23	0.24	1.09
Marital status (single)	1.25	0.74-2.10	0.41	1.03	0.62-1.70	0.92	1.61
Length of stay (months)	1.00	0.99-1.01	0.61	1.00	0.99-1.00	0.40	1.00
Functional variables							
Katz (continue)	1.01	0.96-1.06	0.73	0.88	0.83-0.92	<0.01	0.97
CPS (level 5/6)	1.07	0.67-1.72	0.78	0.44	0.28-0.71	<0.01	1.11
Disease specific measurements							
Reisberg GDS (7)	1.49	0.89-2.52	0.13	0.42	0.25-0.72	<0.01	0.80
Comorbidity							
Endocrine diseases[a]	1.28	0.76-2.17	0.36	1.32	0.78-2.22	0.30	0.84
Visual impairments[b]	1.24	0.68-2.26	0.49	1.18	0.65-2.14	0.59	0.77
Cardiovascular diseases[c]	0.68	0.42-1.09	0.11	1.38	0.86-2.19	0.18	1.07
Psychiatric disorders[d]	0.87	0.45-1.67	0.67	0.46	0.23-0.91	0.03	0.93
Pulmonary diseases[e]	0.75	0.34-1.67	0.49	0.96	0.45-2.05	0.92	0.14
Diseases of musculoskeletal system[f]	0.90	0.52-1.54	0.70	0.95	0.56-1.61	0.86	0.91
Neurological diseases[g]	1.38	0.80-2.37	0.25	1.27	0.74-2.18	0.38	1.19
Other[h]	1.34	0.69-2.58	0.39	1.00	0.52-1.93	0.99	0.57
Infection in last 7 days[i]	1.26	0.48-3.29	0.64	1.11	0.43-2.88	0.83	0.85
PACSLAC-D (continuous)	0.82	0.76-0.89	<0.01	0.87	0.82-0.93	<0.01	0.87
NPI total score (continuous)	0.92	0.89-0.94	<0.01	0.93	0.91-0.95	<0.01	0.96

CPS=Cognitive Performance Scale
Reisberg GDS=Reisberg Global Detoriation Scale
Pacslac-D=Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dementia
NPI=Neuropsychiatric Inventory
a=Diabetes Mellitus, hypothyroidism and/or hyperthyroidism
b=Cataract, diabetic retinopathy, glaucoma, and/or macular degeneration
c=Arteriosclerotic disease, heart rhythm disorders, heart failure, hypertension, hypotension, peripheral vascular disease, other

affect		Restless tense behaviour			Social relations			Social isolation		
95% CI	p	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
0.99-1.06	0.17	1.02	0.99-1.06	0.17	1.03	0.99-1.06	0.13	0.98	0.95-1.01	0.18
0.62-1.90	0.77	1.79	1.03-3.11	0.04	1.35	0.80-2.28	0.26	1.48	0.86-2.53	0.15
0.91-2.85	0.10	1.79	1.05-3.06	0.03	1.22	0.73-2.03	0.44	0.98	0.59-1.64	0.95
1.00-1.01	0.33	0.99	0.99-1.01	0.85	0.98	0.97-0.99	<0.01	1.00	0.98-1.01	0.26
0.93-1.02	0.21	1.02	0.98-1.07	0.37	0.82	0.78-0.87	<0.01	1.03	0.98-1.08	0.24
0.68-1.84	0.67	0.85	0.53-1.36	0.49	0.31	0.19-0.51	<0.01	1.07	0.67-1.71	0.79
0.45-1.41	0.44	1.39	0.83-2.35	0.22	0.17	0.09-0.33	<0.01	2.20	1.3-3.71	<0.01
0.47-1.49	0.55	1.28	0.76-2.17	0.36	1.43	0.85-2.41	0.18	1.23	0.73-2.08	0.44
0.39-1.50	0.44	1.36	0.74-2.48	0.32	1.49	0.82-2.70	0.19	0.89	0.48-1.65	0.72
0.65-1.77	0.79	1.22	0.76-1.96	0.42	1.57	0.98-2.50	0.06	0.81	0.50-1.29	0.37
0.46-1.87	0.83	0.87	0.45-1.69	0.67	0.83	0.43-1.59	0.57	0.94	0.49-1.81	0.85
0.03-0.60	<0.01	1.04	0.48-2.24	0.93	0.58	0.26-1.30	0.19	0.86	0.39-1.88	0.70
0.51-1.61	0.73	1.21	0.71-2.07	0.48	1.38	0.81-2.33	0.24	0.86	0.50-1.48	0.59
0.68-2.11	0.54	1.61	0.93-2.76	0.09	0.81	0.47-1.39	0.44	1.33	0.77-2.28	0.31
0.26-1.24	0.16	1.50	0.77-2.89	0.23	1.02	0.53-1.97	0.95	0.81	0.41-1.60	0.55
0.29-2.47	0.77	0.76	0.28-2.09	0.60	0.77	0.29-2.05	0.60	0.74	0.27-2.03	0.56
0.81-0.94	<0.01	0.90	0.84-0.96	<0.01	0.88	0.83-0.94	<0.01	0.88	0.82-0.94	<0.01
0.94-0.98	<0.01	0.93	0.90-0.96	<0.01	0.97	0.95-0.98	<0.01	0.93	0.91-0.96	<0.01

d=Anxiety disorder, depression, manic depression, schizophrenia
e=Asthma, Emphysema/COPD
f=Rheumatic diseases, hip fracture, amputation, osteoporosis, pathologic bone fracture
g=Aphasia, cerebral palsy, stroke, hemiplegia/hemiparesis, paraplegia, multiple sclerosis, Parkinson disease, seizures, passagere cerebral ischemia, traumatic brain injury, quadriplegia
h=Allergies, anemia, cancer, renal failure
i=Pneumonia, respiratory tract infection, urinary tract infection; last 30 days

Table 3 Multivariate logistic regression for each variable and domains of QUALIDEM

	Care relationship			Positive affect			Negative affect		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Age (years)	0.98	0.94-1.02	0.24	0.98	0.94-1.02	0.38	1.00	0.96-1.05	0.89
Gender (female)	1.52	0.82-2.82	0.18	0.73	0.39-1.37	0.32	0.79	0.42-1.49	0.46
Marital status (single)							1.70	0.88-3.30	0.11
Length of stay (months)									
Katz (continuous)				0.89	0.83-0.95	<0.01			
CPS (level 5/6)				1.01	0.51-2.01	0.98			
Reisberg GDS (7)				0.58	0.27-1.23	0.15			
Cardiovascular diseases									
Psychiatric disorders				0.39	0.17-0.87	0.02			
Pulmonary diseases							0.14	0.03-0.61	<0.01
Neurological diseases									
PACSLAC-D (continuous)	0.92	0.84-1.00	0.05	1.02	0.94-1.10	0.69	0.92	0.85-1.00	0.05
NPI (continuous)	0.93	0.90-0.96	<0.01	0.93	0.90-0.95	<0.01	0.97	0.95-1.00	0.04

OR=Odds ratio, CI=confidence interval, CPS= Cognitive Performance Scale, Reisberg GDS=Reisberg Global Deterioration Scale, PACSLAC-D=Pain Assessment Checklist for Seniors with Limited Ability to Communicate in Dutch, NPI-NH=Neuropsychiatric Inventory -Nursing Home Version

Restless tense behaviour			Social relations			Social isolation		
OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
0.99	0.95-1.03	0.63	1.00	0.96-1.04	0.96	0.95	0.91-0.99	<0.01
1.64	0.87-3.10	0.13	1.65	0.88-3.12	0.12	1.58	0.86-2.91	0.14
1.64	0.87-3.09	0.13						
			0.99	0.98-1.00	0.12			
			0.87	0.81-0.93	<0.01			
			1.12	0.58-2.19	0.73			
			0.28	0.12-0.62	<0.01	2.10	1.17-3.78	0.01
			1.40	0.80-2.45	0.24			
1.59	0.87-2.90	0.13						
1.00	0.93-1.08	0.92	0.97	0.89-1.05	0.40	0.96	0.89-1.04	0.31
0.93	0.90-0.96	<0.01	0.97	0.94-0.99	0.01	0.93	0.91-0.96	<0.01

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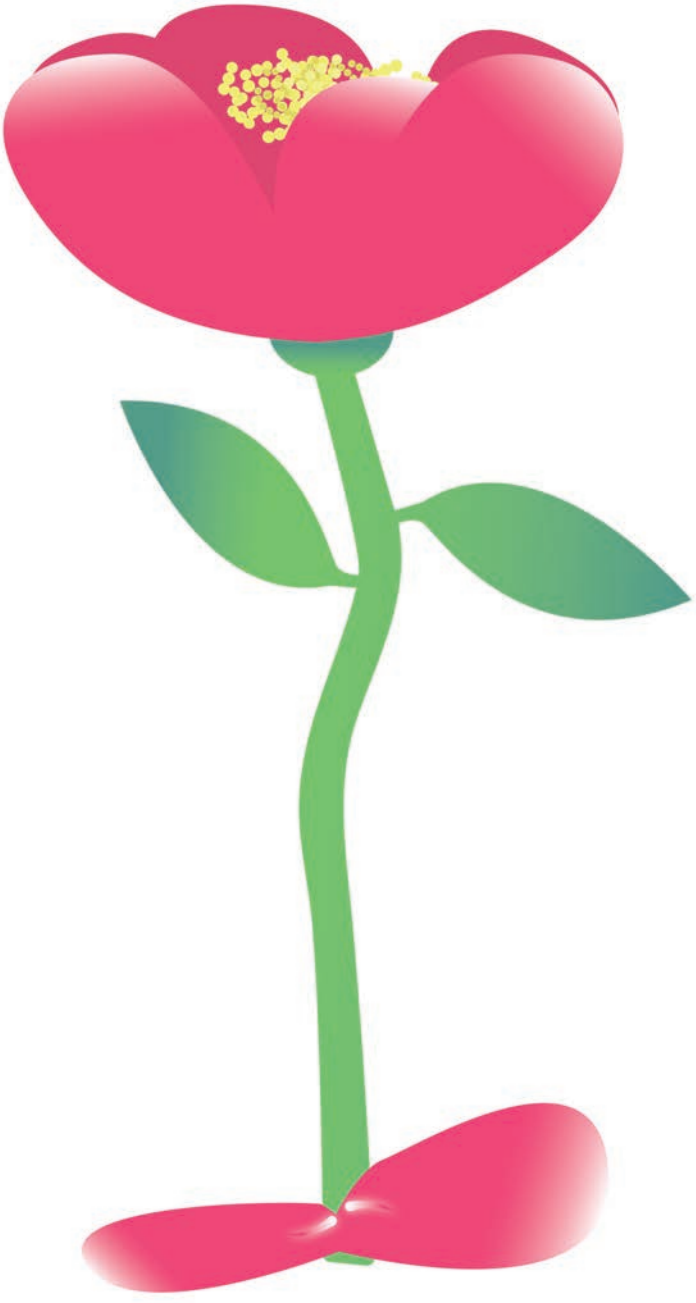

Chapter 3

Change in QOL after a multidisciplinary intervention for people with dementia

A randomized controlled trial

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Abstract

Objective
The objective of this study was to examine whether implementation of a stepwise multicomponent intervention (STA OP!) for challenging behavior and pain affects quality of life (QoL) of nursing home residents with moderate to severe dementia after 3 and 6 months.

Methods
A cluster randomized controlled trial was conducted in 12 nursing homes. Both control (n=140) and intervention group (=148) received training, the intervention group was also treated using the STA OP! intervention. At baseline, 3 and 6 months QoL was assessed using the six QUALIDEM domains applicable to moderate and severe dementia. Linear mixed models were used to compare changes in QoL domains between the two groups over time.

Results
After both 3 and 6 months there was no change, and no difference in change, between the two groups in the domains Care relationship, Positive affect, Negative affect and Social relations.
Between 0 and 3 months a positive effect was seen in the domain Restless tense behavior with a regression coefficient of β: 0.95 (95% confidence interval, CI, 0.36;1.54). Between 3 and 6 months a negative effect was seen on the domain Restless tense behavior β: -0.98 (95% CI -1.60; -0.36) and a positive effect in the domain Social isolation, β: 0.64 (95% CI 0.12;1.17).

Conclusion
The stepwise intervention STA OP! affects the QUALIDEM domains in different ways: there was a lowering of Restless tense behavior in the short term which reverted back to the initial level in the longer term, and a lowering of Social isolation in the longer term.

Key Points
- There is an urgent need for evidence-based interventions to improve the quality of life in people with dementia living in nursing homes
- After a stepwise multicomponent intervention (STA OP!) for challenging behavior and pain, two domains of quality of life, Restless Tense Behavior (between 0 to 3 months) and Social isolation (between 3 to 6 months) showed a positive effect
- The other domains (Care relationship, Positive affect, Negative affect, Social relations) showed no significant change in quality of life between 0 to 3 and 3 to 6 months post-interventions. The domain Restless Tense Behavior showed a negative effect on quality of life 3 to 6 months post-intervention

Introduction

With the global increase of ageing populations, dementia has become a major concern. One challenge is how to care for people who have lost the ability to take care of themselves and may need specialized care and/or admission to a nursing home. As there is no cure for dementia, quality of life (QoL) is an important and appropriate goal. In the general population, QoL can vary depending on different characteristics such as age, gender, marital status and morbidity.[1,2] Fortunately, more knowledge has become available regarding how to measure and follow the course of QoL, both at home and in a nursing home.[3,4] Various theoretical models form the basis of the development of these QoL instruments and, for many, a multidimensional concept has been used.[3] To observe a change in QoL it is important to look for differences within these different domains of QoL.
Several scenarios have been found regarding the course of QoL in dementia over time, ranging from a decrease in QoL, a stable QoL but also an increased QoL.[5,6,7,8,9,10,11] A higher QoL rating has been shown in people with dementia living at home compared to those in a nursing home, also after stratifying for dementia severity.[12,13] These results indicate that there is room for improvement and, therefore, a need for implementation of interventions that can improve QoL for people with dementia living in a nursing home.

A relation has been found between the various factors that can influence the measured QoL in people with mild cognitive impairment and dementia, living at home or in a nursing home.[14,15,16-18] Studies on neuropsychiatric symptoms also show a large influence on QoL of people with dementia, and the need for effective non-pharmacological interventions is clear.[16,19,20,21] The implementation of a stepwise multicomponent intervention (STA OP!) showed an overall effect on lowering challenging behavior, observed pain, depression, and a reduction in the use of psychotropic medication.[20,21] Both challenging behavior and depression are mediators of QoL and both may influence QoL domains such as relationships or affect. Therefore, the present study explores whether implementation of the STA OP! intervention improves the domains of QoL of nursing home residents with moderate to severe dementia over time.

Methods

Setting and study population

The STA OP! study is a cluster randomized controlled trial in which 12 nursing homes participated (trial registration NTR-1967). The STA OP! study assessed the implementation of a stepwise multidisciplinary intervention to address pain and challenging behavior.[20] Participating nursing homes had to meet the following inclusion criteria: at least one dementia ward willing to participate, and no major organizational changes or building activities planned or performed during the study period.[20,23]

The attending elderly care physician assessed the severity of dementia with the Reisberg Global Deterioration Scale (Reisberg GDS).[24] Residents with a Reisberg GDS score of 5 (moderate dementia), 6 (moderately severe dementia) or 7 (severe dementia) were eligible to participate. Furthermore, participants were eligible to participate when having a behavioral problem or an indication of being in pain and screened for the absence of a psychiatric diagnosis. The sample size was calculated based on one of the primary outcomes of the STA OP! study, the Cohen-Mansfield Agitation Inventory (CMAI), a behavioural observation scale. To detect a 15% difference between the intervention and control condition with an α of 0.05 and a β of 0.80, also taking into account a 50% dropout rate and design effect (cluster randomisation) of 1.5, 168 participants were needed. Details on the study design, the steps of the STA OP! intervention and the inclusion criteria is provided elsewhere.[23] STA OP! is based on the Serial Trial Intervention in the USA.[25] For all participants, written informed proxy consent was obtained from the family/caregivers. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center Amsterdam.

Data were provided or collected by research assistants, elderly care physicians and registered nurses. Both the intervention and control teams received training on challenging behavior in dementia and pain management. The multidisciplinary intervention team received additional training during the first 3 months on: working with the stepwise component method, the STA OP! assessments and methods to enhance communication. The goal at the start of the protocol was to identify pain and challenging behavior. The care teams determined the order of inclusion of each of the participants.[22,23] The STA OP! intervention contains the following steps: Step 0: perform a basic care needs assessment and determine whether basic care needs are fulfilled. Step 1: perform a pain and physical needs assessment including an observational Pain Assessment Checklist (PACSLAC-D). Step 2: perform affective needs assessment that focuses on the needs of people with dementia. Step 3: administer a trial of non-pharmacological comfort treatment. Step 4: administer a trial of analgesic agents but also administer the prescribed as-needed analgesic agent. In Step 5, either a consultation was initiated with other disciplines, or a trial of prescribed as-needed psychotropic drugs was started. The STA OP! process stopped when behavioral symptoms decreased by 50% or more. If behavioral symptoms continued after completion of the 5 steps, the process was repeated. The trial was single blinded. An independent researcher allocated the nursing homes for the intervention or control condition using a computer-generated sequence program. The intervention was multidisciplinary and training was given to the nursing home staff. The research assistant that interviewed the staff was unaware of the randomization and blinded.

Outcome measures

Quality of life

At baseline, and at 3 and 6 months, QoL was assessed using the QUALIDEM: this is an observational instrument to measure QoL in people with moderate to severe dementia.[26-29] The QUALIDEM describes observable behavior in nine domains: Care

relationship, Positive affect, Negative affect, Restless tense behavior, Positive self-image, Social relations, Social isolation, Feeling at home, and Having something to do. The QUALIDEM does not provide a validated calculated total score.
The QUALIDEM (total of 37 questions) is based on an observation window of one week.[28] The response options are: never, rarely, sometimes, and frequently. For the present study we used the 6 domains (Care relationship, Positive affect, Negative affect, Restless tense behavior, Social relations, and Social isolation) that include 18 questions that are also applicable to very severe dementia (GDS 7) [17,27,28] In the domain Care relationship question 7, 14, 31 were used, in the domain Positive affect question 5, 8, 21, 40, in the domain Negative affect question 6, 23, in the domain Restless tense behavior question 2, 19, 22, in the domain Social relations question 3, 12, 25, and in the domain Social isolation question 16, 20, 32. The individual item scores for each domain were processed such that a higher domain score reflects a better QoL.

Functioning
The Katz Index of Independence in Activities of Daily Living (Katz ADL) was used to measure ADL functioning. The Katz ADL is a reliable and valid instrument to assess functional status. [30,31] The index ranks adequacy of performance and scores on each function are summed (total range: 6-24). A higher score indicates a lower ADL function, i.e.a higher dependence on care.

Pain
The Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D), a reliable and valid observational pain instrument, was used to assess pain. [32-34,35]

Neuropsychiatric symptoms
Behavioral and psychological problems were scored using the reliable and valid Neuropsychiatric Inventory-Nursing Home Version (NPI-NH), which scores 10 behavioral and psychological areas and two types of neurovegetative changes. [36,37,38]

Statistical analysis

Descriptive statistics included means and standard deviations (SD) for normally distributed variables, and median and interquartile range (IQR) when non-normally distributed. Differences at baseline between control and intervention group items were analysed using chi-square test for categorical variables, the T-test for normally distributed variables, and the Mann-Whitney U-test for non-normally distributed variables. [20,22] To account for clustering of measurements within individuals and nursing home units, a linear mixed model analysis was performed, with time (categorical), intervention and their interaction as fixed effects, and individual and nursing home unit as random effects. The final model 2 is also adjusted for the Reisberg GDS and the Katz index because of a significant difference between the two groups at baseline.

All descriptive analyses were performed with SPSS statistical software, version 23, 2015 (SPSS Inc., IBM, USA) and linear mixed model analyses with the lme4 package within R statistical software, version 3.3.1, 2016. [39,40]

Results

Study population

In 12 nursing homes, 21 units were eligible for inclusion in the study. In these 21 units, 363 residents were eligible, and 288 residents were included in the STA OP! study: 148 in the intervention condition (11 units) and 140 in the control condition (10 units). [20]

Demographic and clinical characteristics of the participants are presented in Table 1. There was no significant difference between the groups in age, length of nursing home stay, marital status and gender. However, more participants in the intervention condition had less severe dementia, 115 participants Reisberg GDS 5 and 6 and 33 Reisberg GDS 7 in the intervention group compared to 93 participants Reisberg GDS 5 and 6 and 47 people Reisberg GDS 7 in the control group (p-value 0.04). Also, participants in the intervention group were less dependent regarding ADL with a median Katz score of 17 compared to the control group with a median Katz score of 19 (p-value 0.01).
Of the 148 residents in the intervention condition, 39% were actually assessed by the team with the stepwise component of the STA OP! protocol. The mean number of steps assessed was 2.8 (SD $\pm$ 1.2).
During the 6-month study period, 29 participants in the control group died and 30 in the intervention group were lost to follow-up (29 died, 1 was transferred to another unit/ institution). [20,22]

Quality of life

The median score on the six domains is presented in table 1. [28] At baseline, there were no significant differences between the two groups.

Change in Quality of life

After implementation of the STA OP! intervention, changes in QoL over time for the two 3 month-periods for each QUALIDEM domain were compared between the two groups; the results are shown in Table 2.

Short-term effect: first 3 months
In the domains Care relationship, Positive affect, Negative affect, Social relations and Social isolation, no effect was found on change in QoL between the two groups in the period 0 to 3 months. In the domain Restless tense behaviour, a positive effect was found between 0 and 3 months, with a regression coefficient, β, of 0.95 (standard error (SE) 0.30 and 95% confidence interval (CI) 0.36 to 1.54). Adjustment for the Katz index and Reisberg GDS (model 2) did not essentially change these results.

Long-term effect: second 3-month period
In the domains Care relationship, Positive affect, Negative Affect and Social relations no effect was found on change in QoL between the two groups in the period 3 to 6 months. In the domain Restless tense behaviour, a negative effect with a β of -0.98 (SE 0.32, 95% CI -1.60 to -0.36) was found. In the domain Social isolation a positive effect was found with a β of 0.64 (SE 0.27, 95% CI 0.12 to 1.17). Adjustments for the Katz index and Reisberg GDS (model 2) did not essentially change these results.

Discussion

This study shows that some aspects of quality of life improved after the STA OP! intervention compared to the control condition. In the domains Restless tense behavior and Social isolation, a positive effect was found in both the first and second 3 month periods, respectively, after start of the intervention. This indicates that an intervention in a nursing home that involves nursing/medical staff and using the stepwise method to manage pain/challenging behavior, can have a beneficial effect on several domains of QoL in people with dementia. This is relevant since dementia care should also aim to improve the QoL of people affected by this progressive and disabling syndrome. However, the positive effect was not maintained in the second 3-month period in the domain Restless tense behavior. Although the reason for this is unclear, it might be related to the end of the training of the teams after 3 months. However, there was a positive effect on the domain Social isolation after 3 months, which shows an emerging, delayed, longer-term positive effect in contact with other people. In this latter domain, two (out of three) questions relate to rejection by other people, or rejection of contact with other people. This effect might be explained by the effect of the stepwise component on lower observed pain and the changes in behavior; both of these can be followed by improvement in interaction with other people and result in an improvement in this specific domain of QoL in the longer term.

Strengths and limitations

This randomized controlled trial in a large group of people with dementia in a nursing home setting, shows that the stepwise intervention STA OP! had a beneficial effect on the secondary outcome measure QoL. Although other intervention studies also reported a positive effect on QoL of people with dementia, it is difficult to make meaningful comparisons due to the different observational methods used and the different levels of dementia included in the studies. [41,42] In the present study, the positive effects on QoL were found in the domains Restless tense behavior and Social isolation; this is relevant, as this indicates that QoL can be improved in people with dementia living in a nursing home. This effect might be explained by providing medical staff with increased knowledge of pain and behavior in dementia, and the stepwise multicomponent intervention that provides directions for assessments as well as for interventions. Another strength is the high number of participating nursing homes, resulting in the inclusion of a large group of people with moderate to very severe dementia.

Table 1 Characteristics of the study population at baseline

	Control (n=140)		Intervention (n=148)		p-value
Demographic variables					
Female	100	71.4 %	107	72.3 %	0.87 [a]
Mean age in years (SD)	83.3	(6.9)	84.3	(7.4)	0.25 [b]
Median length of stay in months (IQR)	24.6	(12-42)	18.8	(10-40)	0.14 [c]
Marital status: Married	37	26.4 %	50	33.8 %	0.42 [a]
Functional variables					
Katz range 6-24 median (IQR)	19	(15-22)	17	(12-20.8)	0.01 [c]
Quality of Life					
QUALIDEM					
Care relationship range 0-9 median (IQR)	7	(5-8)	7	(5-9)	0.93 [c]
Positive affect range 0-12 median (IQR)	9	(7-11)	10	(7-12)	0.18 [c]
Negative affect range 0-6 median (IQR)	5	(4-6)	4	(3-6)	0.20 [c]
Restless tense behavior range 0-9 median (IQR)	5	(3-7)	4.5	(2-7)	0.53 [c]
Social relations range 0-9 median (IQR)	6	(5-8)	6	(4-8)	0.15 [c]
Social isolation range 0-9 median (IQR)	7	(5-9)	7	(5-9)	0.77 [c]
Disease specific measurements					
Dementia severity					
Reisberg GDS 5 and 6	93	66 %	115	78 %	0.04 [a]
Reisberg GDS 7	47	33 %	33	22 %	
Pain; PACSLAC-D range 0-24, median (IQR)	3	(1-6)	4	(1-7)	0.18 [c]
Behavior; NPI range 0-144, median (IQR)	12	(4-21)	12	(5-24)	0.24 [c]

SD=Standard deviation
IQR=Interquartile range
QUALIDEM; a higher score indicates a better QoL
Reisberg GDS=Reisberg Global Deterioration Scale
PACSLAC-D=Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dementia
NPI=Neuropsychiatric Inventory
p-value: [a] Chi-square, [b] t-test, [c] Mann-Whitney

Table 2 Average change in quality of life domains of the QUALIDEM at 3 and 6 months post of the intervention

	Model 1			Model 2		
	β	SE	95% CI	β	SE	95% CI
Care relationship						
0-3 months	0.19	0.21	-0.22 to 0.61	0.19	0.21	-0.22 to 0.61
3-6 months	0.03	0.22	-0.40 to 0.47	0.03	0.22	-0.40 to 0.47
Positive affect						
0-3 months	0.06	0.31	-0.55 to 0.66	0.05	0.31	-0.54 to 0.66
3-6 months	-0.21	0.32	-0.84 to 0.43	-0.20	0.32	-0.84 to 0.43
Negative affect						
0-3 months	0.27	0.18	-0.07 to 0.62	0.28	0.18	-0.07 to 0.62
3-6 months	-0.10	0.19	-0.47 to 0.26	0.10	0.19	-0.47 to 0.27
Restless tense behavior						
0-3 months	0.95	0.30	0.36 to 1.54	0.95	0.30	0.36 to 1.53
3-6 months	-0.98	0.32	-1.60 to -0.36	-0.98	0.32	-1.60 to -0.36
Social relations						
0-3 months	0.45	0.24	-0.02 to 0.91	0.45	0.24	-0.01 to 0.92
3-6 months	0.23	0.25	-0.26 to 0.72	0.23	0.25	-0.26 to 0.72
Social isolation						
0-3 months	0.01	0.26	-0.49 to 0.51	0.01	0.26	-0.49 to 0.51
3-6 months	0.64	0.27	0.12 to 1.17	0.65	0.27	0.12 to 1.17

Reference category for the intervention effect is the control condition. Regression coefficients (β) reflect the average differences in quality of life domains of the QAULIDEM 3 and 6 months after intervention.
SE=standard error, CI=confidence interval
Model 2 includes adjustment for Katz ADL index and Reisberg GDS.

A limitation of this study is that it was not possible to start the stepwise component in all patients in the intervention group at the same time, i.e. after 6 months, 39% were included in the stepwise component of the study. However, this indicates that, although only some of those were assessed utilizing several steps (mean 2.8) of the stepwise component, an effect was found on QoL for the entire group. This could mean that those people that were assessed first with the stepwise component, were monitored on pain, behavior and unmet needs in a more intensive way. In turn, this could have resulted in better overall skills that also benefited other persons on the unit. Another limitation lies in a potential bias due to lack of blinding of the control versus intervention condition. i.e. due to the more intensive training and evaluation of the stepwise component, the nursing staff were aware that they were working on the intervention unit. Although we cannot rule out the possibility that the results found in two domains are due to chance our results are in line with the other positive effects found on improved behaviour and less pain. [20,22]
In studies measuring QoL in people with dementia, different domains are often used, depending on the theoretical background of the different instruments used. Studies on the evaluation and use of the QUALIDEM show that six domains are applicable and often used for people with severe dementia. However, one study reported that Social relations have a low result on scalability, and that Negative affect is scalable but has a low reliability. [28] We found no effect of the STA OP! protocol on these two latter domains of the QUALIDEM. The scalability and reliability of the domain Restless tense behavior and Social isolation are acceptable. Others have used a total score of the QUALIDEM; however, since the reliability and interpretation of a total score has not yet been validated, it is debatable whether it should already be used in research.
It would be interesting to further compare the effect of interventions in different stages of dementia. Although some differences have been reported in stages ranging from mild to severe dementia [18], the groups in the present study were too small to allow meaningful comparisons.

Implications for practise

This study shows that an intervention that has an effect on challenging behavior, pain, and the use of analgesics/psychotropic medication can also lead to an improvement of QoL in people with advanced dementia living in a nursing home. [20,22] This type of intervention changes the knowledge, skills and approach of the entire multidisciplinary team towards people with dementia. (Pieper et al., manuscript under review). Therefore, we also recommend further use of this stepwise method for other nursing homes. We think that the regular application of a short and reliable QoL observational instrument can be used to improve the care for people with dementia. Scores in different domains, rather than a total score, may be more comprehensible for the caregivers, and help them better reflect on the intervention and its effects. The knowledge we get from this study can be used in other care settings in other countries because the effects found are the effects of a basic care assessment, a pain and physical needs assessment, an affective needs assessment, a trial of non-pharmacological comfort treatment(s) and sometimes a trial of analgesic agents or other disciplines. Most people never used step 5 (other disciplines)

and the first 4 steps are possible in all care settings if you train healthcare professionals. The STA OP! intervention is based on the Serial trial Intervention, which was successfully implemented in the US.

Conclusion

It is important to improve QoL for people with dementia in nursing homes. The present study shows that this stepwise intervention leads to lowered Restless tense behavior in the short term and less Social isolation in the longer term.

Conflict of interest
All the authors declare that there are no conflicts of interest. The work presented here has not been published elsewhere.

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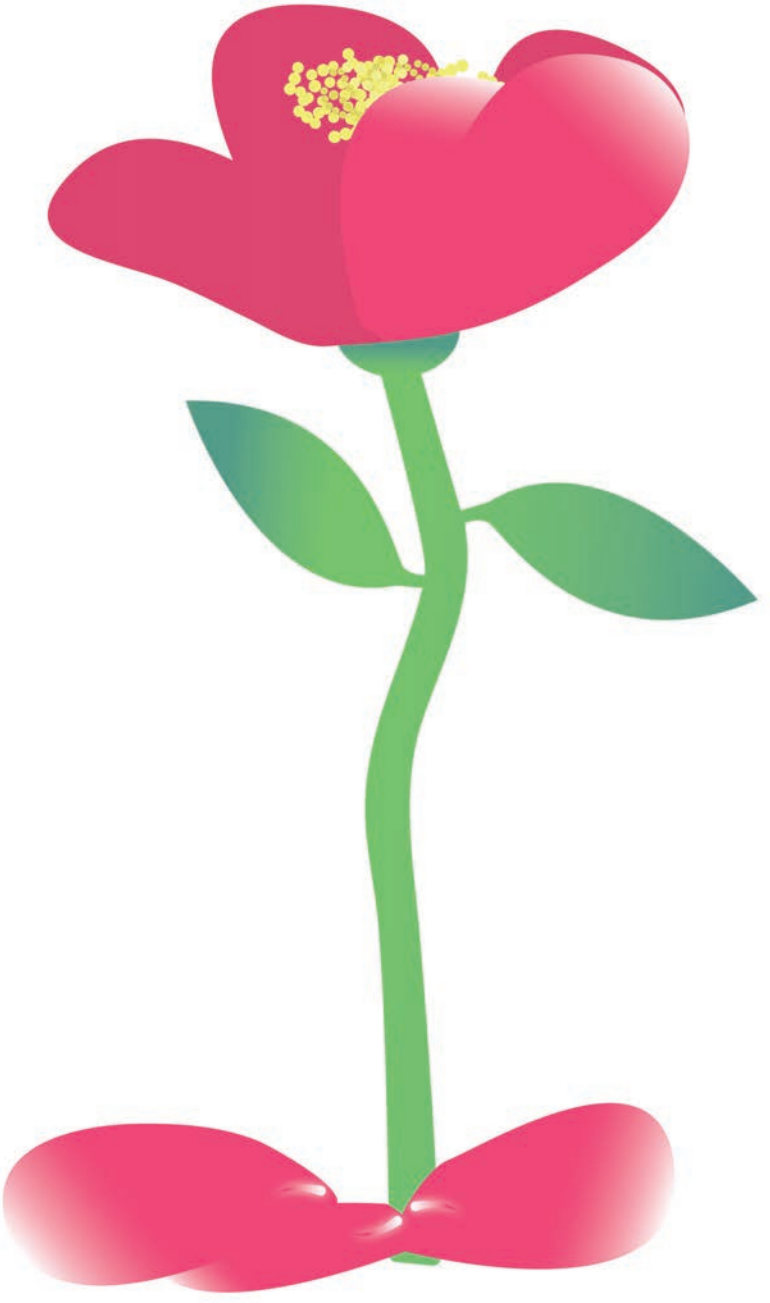

Chapter 4

Experiences with the Liverpool Care Pathway for the dying patient in nursing home residents

A mixed-method study to assess physicians' and nurse practitioners' perceptions

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Abstract

Background
The Liverpool care pathway (LCP) is a multidisciplinary tool developed for the dying patient for use in palliative care settings. The literature reports divergent experiences with its application in a nursing home setting related to its implementation and staff competencies. The aim of this study is to understand how the LCP is being used in the context of the nursing home, including for residents with dementia, and experienced from the perspectives of those responsible for medical treatment in nursing homes.

Methods
A mixed-methods approach was used, consisting of a survey followed by interviews. A link to a 9-item online survey with closed and open-ended questions was emailed to all physicians and nurse practitioners of 33 care organisations with nursing homes in three regions of the Netherlands (North, West and South). In addition, 10 respondents with particularly positive or negative experiences were selected for semi-structured interviews.

Results
The survey was completed by 159 physicians and nurse practitioners. The respondents were very positive on the content and less positive on the use of the LCP, although they reported difficulties identifying the right time to start the LCP, especially in case of dementia. Also using the LCP was more complicated after the implementation of the electronic health record. The LCP was judged to be a marker of quality for the assessment of symptoms in the dying phase and communication with relatives.

Conclusion
An instrument that prompts regular assessment of a dying person was perceived by those responsible for (medical) care to contribute to good care. As such, the LCP was valued, but there was a clear need to start it earlier than in the last days or hours of life, a need for a shorter version, and for integration of the LCP in the electronic health record. Regular assessments with an instrument that focusses on quality of care and good symptom control can improve palliative care for nursing home residents with and without dementia.

Background

In the last days of life of nursing home residents, the focus often shifts from optimizing quality of life towards optimizing quality of dying. Identifying and managing symptoms such as pain and dyspnoea becomes paramount, in addition to care for relatives, addressing possible spiritual needs, and other needs that people may have in these last days or hours. [1, 2]

The 'Liverpool care pathway for the dying patient' (LCP) is a multidisciplinary tool that was developed in the United Kingdom (UK) and introduced in hospices in 1997. [3] It aims to improve care in the last days of life by facilitating decision making and improving communication between the care team and relatives and organizing the care that is needed. Over the last decades, the LCP has been introduced in other countries including the Netherlands, where it was implemented nationally by the Netherlands Comprehensive Cancer Organisation (IKNL) in 2009. [4-6]

The LCP is supposed to start when the patient is expected to die within a few days, and is initiated as this is agreed upon by the multidisciplinary team (typically a physician or nurse practitioner and a member of the nursing staff). The Dutch version of the LCP (in Dutch: Zorgpad Stervensfase, translated: Care pathway for the dying phase) starts with criteria that can help make this decision: the patient is bed bound, is semi-comatose, is only able to take sips of fluids and/or no longer able to take tablets. The LCP consists of three parts. The first part contains items regarding the patient's physical condition, how to improve comfort, and preferences regarding religious and spiritual needs. In this part, the patient and relative are assessed on awareness of diagnoses and the impending death. Part 2 prescribes regular assessment of symptoms such as pain and dyspnoea carried out every 4 hours. Any symptom assessments and other actions by health care professionals (physicians and nursing staff) should be recorded in this part. Part 3 assesses care for the relatives and communication regarding procedures after death. (Examples of care goals in supplement 1)

In the UK, the original instrument for use in hospices was also used to improve care for people dying in hospitals or at home. Inadequate implementation by staff with little understanding of palliative care in these settings led to assumptions that the instrument was used to hasten death and to deprive people of food or fluids. The national outrage this caused resulted in its withdrawal and it was no longer used in the UK after 2012. [7-9]

In the literature divergent experiences have been described, ranging from positive experiences of care professionals and relatives regarding involvement in end-of-life care to criticism based on findings that indicate that the LCP is not adapted for certain groups, such as persons living in nursing homes and people with dementia. [10, 11] Research into validity and reliability of the assessments in the nursing home setting is limited. A 2017 review article by Husebo et al. on the research done in nursing homes on adaptation and validation on the LCP shows that while several studies have addressed the use of the LCP in this setting, no studies were identified

that addressed adaption of the LCP to improve fit with the nursing home setting, that no randomized controlled trial, prospective or blinded studies were done in this setting, and no studies were found specifically describing strategies for evaluation of medication, nutrition/hydration or clinical recommendations. Studies that have addressed the use of the LCP in nursing homes outside the UK, have focused on the perceptions of professional and informal caregivers regarding the LCP, suggesting that the LCP is perceived to improve regular assessment of symptoms, as well as communication between and among care professionals and family. [12-17]

In 2009, a paper version of the LCP was introduced in the Netherlands and a digital version was issued in 2014. [18] Three versions with the same content are available; for the home setting, the hospital and the nursing home. There are two differences; first, the nomenclature for the person, which is patient in the hospital version, resident in the nursing home version and client in the home care version. Second, the frequency of symptom assessment with six times a day (every four hours) recommended in the hospital and nursing home versions and four times a day (morning, afternoon, evening, night) in the home care version.

In nursing homes, the educational level of nursing staff (registered nurses, and levels comparable to certified nursing assistants and nurse aids) is mixed but generally lower (only 17% registered nurses in nursing homes) than in hospice and hospital settings with mainly registered nurses. [19] The difference in medical and nursing education, and therefore experience, may impact on the use of the instrument and interpretation of the observations by both nursing and medical staff. Information on the current use and experience with the LCP from the perspectives of those responsible for medical care in nursing homes is therefore vital. Further, in the Netherlands, at the end of life, 61% of nursing home residents have dementia and therefore it is important to better understand the usefulness of the LCP for residents with dementia or cognitive impairment. [20] They are often incapable of verbally expressing their needs, for instance when they are in pain. Therefore, specific pain indicators are available based on research in pain observation in dementia, and a single pain item in the LCP may not acknowledge developments in this field of research. [21] Therefore, a better understanding is needed as to how the LCP is being used and evaluated in practice for nursing home residents including those with dementia, from the perspectives of those responsible for medical treatment in nursing homes.

Methods

We used a mixed-methods design, combining results from an online survey that solicited for quantitative and qualitative data, with qualitative data gathered in semi-structured interviews. Based on earlier ethnographic research [15] and clinical experience we developed the online survey, with 9 questions regarding knowledge of and experiences with the LCP. This type of research does not fall under the scope of the Medical Research

Involving Human Subjects Act (WMO) in the Netherlands. The protocol was reviewed by the Scientific Committee of the department of Public Health and Primary Care of the Leiden University Medical Center. In compliance with the General Data Protection Regulation (GDPR) it was sent via an internet link to three Academic Networks of Elderly Care in the North (UNO-UMCG, 17 care organizations), West (UNC-ZH, 11 care organizations) and South (AWO-ZL, 7 care organizations) of the Netherlands. Academic Networks are networks of nursing home organizations linked to a university medical center with a specific goal to stimulate teaching, research and best-practices in long-term care. [22] Nursing home care in the Netherlands can be defined as 24/7 care for care dependent with on-site nurses and medical staff. [23] Seven care organizations did not respond.

The coordinator of each academic network sent the survey to the coordinator of the nursing home organizations affiliated with the network, who in turn, sent it to all physicians, physician assistants, nurse practitioners, including those in training. Four organizations provided only one or two completed surveys, but they did not report how many people they sent the link to. A total of 499 practitioners received the internet link to the online survey.

In the Netherlands, certified elderly care physicians, physician assistants and nurse practitioners are part of the nursing home staff and deliver most of the medical care to residents. The physicians, physician assistants and nurse practitioners together with a member of the nursing staff agree upon the decision when to start the LCP. The first section of the survey asked about professional specialization, gender, age, number of years of experience working in a nursing home, the organization and the type of unit they are working in, all exclusive to nursing homes. The survey subsequently inquired about experiences working with the LCP, and its availability and motivation for use. The survey was discontinued for respondents who reported they did not know the LCP. Finally, we included questions related to which items respondents would want to keep or change in the LCP, whether they thought nursing staff had enough knowledge about palliative care, and whether this influenced the effect of the LCP. Most items featured a multiple-choice format, some were open-ended. (Survey in supplement 2) The responses were entered online by the participants and managed in Castor EDC, version 2019.2.8.

The data were processed anonymously, but at the end of the survey participants were asked to indicate if they would allow the researchers to contact them for a brief semi-structured interview. Two researchers (MK, elderly care physician and NLD, anthropologist) selected ten interviewees with particularly negative or positive experiences with use or content of the LCP to best understand divergent perspectives. The number of ten was based on literature regarding sample size in qualitative interview studies needed to achieve saturation with otherwise fairly homogenous samples such as those involved in medical care of nursing home residents dying with dementia in the Netherlands. [24, 25] The interviews were recorded with permission; next, they were transcribed as input for thematic analyses. The interview guide covered four questions about the practical use of the LCP such as whether it was used alongside the medical

record or if it replaced the medical record as originally intended. Specific questions based on the responses to the open-ended items in the survey were intended to elicit details about the negative or positive experiences they reported in the survey and reasons as to why they felt the LCP was or was not a valuable instrument to improve end-of-life care. Furthermore, the use of other instruments for the dying phase and perceptions of the nursing staff-knowledge of palliative care were explored. Sampling of diverse viewpoints was prioritized above gender distribution. The interviews were semi-structured to give interviewees the opportunity to explain their experiences and the interviewers the opportunity to probe for increased depth if needed. The questions concerned were all LCP-related rather than patient-related or personal. We expected that asking physicians and other health care professionals who frequently manage care for dying people about use of a care path in general would not induce unmanageable levels of stress. All interviewees had completed the survey before and indicated they would volunteer for an additional interview. Health care providers can be expected to be able to reflect on whether considering the topic in the survey would induce any distress and not volunteer for a subsequent interview. We emphasized that the interview can be stopped at all times, and the interviewers would be able to refer to after care if needed.

For thematic analysis, the open-ended survey items along with the interviews were all independently coded by NLD and MK and in part by JTS. All answers to each question in the survey and interviews were coded. An open coding method was used for the interviews. First, the authors independently coded answers by breaking down the answers into relevant fragments and codes. The authors than compared resulting codes and the data was further categorized into themes. The respondents' characteristics were described based on descriptive analysis with the statistical program SPSS Inc, version 24, IBM, USA.

Results

The online survey was accessed 159 times; by 103 elderly care physicians, 29 nurse practitioners, 8 general practitioners (2 were also elderly care physician), 18 medical school graduates, 2 physician assistants, and 1 healthcare psychologist. The professionals in training are specified in Table 1. The majority of the respondents were women (70%). The mean number of years of experience was 12 years (standard deviation 10.6 years). Most respondents worked on a psychogeriatric (dementia) unit (91%), many also worked on various other units. Many respondents (50%) were (also) working in a hospice or palliative care unit.

Table 2 shows responses from the 118 respondents (79%, nine missing answers) who indicated knowing the LCP. Availability and readiness to use of the LPC were higher than its actual use in all units. For example, in 39% of the psychogeriatric units the LCP was available, but it was used in only 29%; and it was available in 54%, but only used in 44% of hospice/palliative care units (Table 2).

The paper version LCP was used by 21% of the respondents, 41% used the digital version, while 9% used both (30% neither). Mainly positive experiences with the content of the LCP were reported by 72% of the respondents and only 3% had mainly negative experiences. Regarding the use of the LCP, 62% reported mainly positive experiences, and 18% mainly negative while 20% had no experience at all. Of the 118 respondents who indicated knowing the LCP most elaborated on their responses in the open-ended items (77 on experiences with the content, 79 with experiences on the use, 88 on adaptations and 98 on what to keep). Regarding the last question, related to the level of palliative care knowledge of nursing staff in the organization, a total of 41% of participants answered that this knowledge was sufficient and 34% that it was insufficient. In 23% of the cases the answer was that the knowledge of nursing staff was insufficient and that this impacted the effect of the use of the LCP.

Interviews

From the 42 respondents who gave permission to be contacted for an interview, we selected ten respondents. We interviewed six elderly care physicians, of whom one was in training, and four nurse practitioners, of whom one was in training. Only one of these was negative on both the LCP content and its use. All others were positive on content; therefore we selected four respondents who held negative viewpoints on use only. (Table 3)

Three themes emerged from the analysis of the interviews and the open-ended survey questions: (1) Timing: a need to identify the right moment to start the LCP, (2) Changing use of the LCP over time in response to digitalisation, and (3) The use of the LCP as a marker of quality.

Theme 1: Timing: need to identify the right moment to start the LCP

The moment the multidisciplinary team recognizes that the resident is expected to die within the next days is the moment the LCP should be started. Identifying this moment can actually be very difficult, as many respondents and interviewees indicate. The LCP offers some guidance in this. Several interviewees observed that in a nursing home setting it is more difficult to determine if a person is dying because this period can take longer, from weeks to months. The gradual decline complicates decisions as to when to start the LCP.

> *- 'It's a little strange to say, the dying phase starts now. It is often a kind of gradual process. At a certain point your treatment focusses on comfort and wellbeing anyway. Quite often you have agreed on such a palliative policy, and things deteriorate slowly but surely, and the intake also diminishes slowly but surely.' (interview 1, elderly care physician)*

Another problem mentioned was the relevance of the subjects and questions in part 1 of the LCP. Nursing home residents are frequently admitted for the long term, and stay for several months or years. They often have cognitive impairments or dementia. Many respondents mentioned that part 1 consisted of too many questions,

Table 1 Baseline characteristics of the study population, 159 respondents

Profession		
Elderly care physician, n (%)	103*a	(65)
Of whom in training, n	*17*	
Of whom specialized in rehabilitation, n	*3*	
Of whom specialized in dementia care, n	*2*	
Of whom specialized in palliative care, n	*9*	
General practitioner (GP), n (%)	8*	(5)
Of whom in training	*2*	
Medical School Graduate n (%)	18	(11)
Nurse practitioner n (%)	29	(18)
Of whom in training	*2*	
Physician assistant n (%)	2	(1.3)
Healthcare psychologist, n (%)	1	(0.6)
Gender, n (%)		
Female	111	(70)
Age category, n (%)		
20-30 years	21	(13)
31-40 years	37	(23)
41-50 years	44	(28)
51-60 years	42	(26)
61 or older	15	(9)
Mean number of years of experience (SD)	12.0 (10.6)	
Response by region, n (%)*b		
UNC-ZH (West), 11 organizations	87	(57)
AWO-ZL (South), 7 organizations	21	(14)
UNO-UMCG (North) 17 organizations	45	(29)
Units in organization of practice, n (%) (more possible)		
Psychogeriatric (dementia) unit(s)	144	(91)
Unit(s) for chronically ill	134	(84)
Geriatric rehabilitation unit(s)	117	(74)
Hospice/palliative care unit(s)	79	(50)
Social gerontology/Geriatric psychiatry unit(s)	64	(40)
Unit(s) for people with young-onset dementia	49	(31)
Other unit(s)*c	43	(27)
Units practitioners' practice, n (%) (more possible)		
Psychogeriatric (dementia) unit(s)	105	(66)
Unit(s) for chronically ill	71	(45)
Geriatric rehabilitation unit(s)	42	(26)
Hospice/palliative care unit(s)	18	(11)
Social gerontology/Geriatric psychiatry unit(s)	7	(4)
Unit(s) for people with young-onset dementia	9	(6)
Other unit(s)*c	22	(14)

SD= Standard deviation, UNC-ZH=Universitair Netwerk voor de Care Sector Zuid Holland, AWO-ZL=Academische werkplaats Ouderenzorg Zuid Limburg, UNO-UMCG=Universitair Netwerk Ouderenzorg Universitair Medisch Centrum Groningen *a Total number education 161, 1 respondent was both an elderly care physician and a GP, 1 respondent was both an elderly care physician in training and a GP *b Missing 6 organizations
*c e.g. Huntington dis., Parkinson dis., acquired brain injury, short stay

Table 2 Experiences with the Liverpool care pathway (LCP; n= 118 respondents who reported to know the instrument)

	n	%
LCP available and ready to use *(more responses possible, % units in organization indicated in Table 1)*		
Psychogeriatric/dementia unit	56	39
Unit for chronically ill	51	38
Geriatric rehabilitation unit	30	26
Hospice/palliative care unit	43	54
Gerontopsychiatric unit	22	34
Young onset dementia unit	20	40
Other	9	21
Not available	31	
LCP actually used, *(more responses possible, % units in organization indicated in Table 1)*		
Psychogeriatric/dementia unit	42	29
Unit for chronically ill	35	26
Geriatric rehabilitation unit	16	14
Hospice/palliative care unit	35	44
Gerontopsychiatric unit	14	22
Young-onset dementia	13	27
Other	9	21
Not ready to use	26	
Available but not used	22	
LCP format in use[*a]		
Paper version	23	21
Digital version	46	41
Both paper and digital versions	10	9
Neither version	33	30
Experiences with content LCP[*b]		
Mainly positive	85	77
Mainly negative	3	3
No experience	22	20
Experiences with use LCP[*c]		
Mainly positive	67	62
Mainly negative	19	18
No experience	22	20
Missing	10	
In your organization is the knowledge level of nursing staff regarding palliative care sufficient to be able to see positive or negative effects of the use of the LCP[*d]		
Knowledge sufficient, and this supports effect of LCP	31	30
Knowledge sufficient, but does not support effect of LCP	12	11
Knowledge insufficient, but does not affect the effect of LCP	11	11
Knowledge insufficient, and this affects the effect of LCP	24	23
No experience with LCP	27	26

[*a] Missing n=6
[*b] Missing n=8
[*c] Missing n=10
[*d] Missing n=13

Table 3 Characteristics of the interviewees

		Interviewee number									
	n	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Profession											
Elderly care physician (in training)	6	X					X	X	X	X	X
Nurse practitioner or physician assistant (in training)	4		X	X	X	X					
Gender											
Female	7	X	X		X	X		X	X		X
Male	3			X			X			X	
Age category, years (%)											
20-50 years	5		X	X				X	X		X
51 or older	5	X			X	X	X			X	
Content of LCP positive + or negative -		+	+	+	+	+	+	+	+	-	+
Use of LCP positive + or negative -		+	-	-	-	+	+	+	+	-	-

some of which were irrelevant, especially for people with dementia. Others thought the questions were relevant but should be asked earlier, before the dying phase, to help improve care. Furthermore, this information was often already available in the electronic health record and duplicating it was considered a waste of time.

-'Some people, in my eyes, when you see that someone is going into a phase, he only deteriorates. The difficulty is that we have all these people with dementia who all die here with us sooner or later. But we all have this moment that you say, now we are really in a phase that we are going to approach things symptomatically and we just, when a person gets sick then things go wrong. Some of those steps should already be taken in that phase. And maybe even sooner than that.' (interview 9, elderly care physician)

Some respondents felt that being clear about the resident's medical condition and acknowledging that the person was going to die helped the team and relatives. Others felt that declaring the start of a dying phase was slightly artificial, and it was important to only do this when they were absolutely certain. The participants felt uncomfortable about starting the LCP and then having to withdraw it if the person turned out not to be dying in the next days. Wanting to be absolutely sure that the person would be dying soon, and to avoid confusion among relatives motivated nursing staff to start the LCP relatively late. One respondent even expressed hoping that the expectation of the person dying soon would be met:

- 'I sometimes suspect that that, I see it sometimes in different situations around dying, that this fear is there, that once you have said that the

end seems to be drawing near, that you hope this expectation is met, so you don't confuse people.' (interview 4, nurse practitioner)

Theme 2: Changing use of the LCP over time in response to digitalisation
Many respondents were bothered by the change in use of the LCP after the introduction of the electronic health record. Before, the LCP (paper version) was used together with the paper version of the electronic health record, or was available in the resident's room. However, with the introduction of the electronic health record, the practical use of the LCP changed. Some organizations digitalized the LCP and included it in the electronic health record, while others have a separate system. Many respondents claim that the previous advantage of visibility of a paper version either in the health record or in the resident's room has been lost. The interviewees shared solutions to be able to continue using the LCP as it was, such as scanning the forms completed in ink and including them in the electronic health record.

-'I thought it was quite inconvenient that you had to open it separately, and so you don't have the overview anymore. Quite often before you start up that Care Pathway it's like, have there been any more discussions, and you are used to one electronic health record, you know all its ins and outs, and I just like to have everything in one, also because when a person eventually dies, the Care Pathway would be closed and, like, scanned, so ultimately it does end up in the record, but in that sense too late. If the family want to follow up on something, then for me it was simply less practical to have to search in two different systems.' (interview 2, elderly care physician)

Other problems mentioned as a result of this change in practice was uncertainty as to what to report in which system and the necessity to report in two systems, both the electronic health record and a separate LCP. Several other difficulties mentioned were: a variable availability of the LCP on different wards, but no reasons were given for the system not being available in the whole organization. Uncertainty about the actual use of the LCP and what to complete when, especially if information was not available yet; often respondents indicated not knowing whether they filled in the LCP correctly; it took too much time to complete all items. It would also take time to re-familiarize themselves with the items, as the LCP was used infrequently.

Overall, the respondents were very positive about the content of the LCP and less positive on its use; many would prefer a less complicated instrument that is integrated in the actual digital system. Integrating the LCP in the usual way of working on the ward would also enable users to use it in a more proactive way and keep an overview of all the information needed, such as medical history and actual use of medication, including during the night or weekend.

-'I personally wasn't very impressed with it, but that was primarily because it was not integrated into the electronic health record and so I would regularly run into that the

team used it as they should, but subsequently did not report anything, so I would be unable to anticipate anything at all during my shift.' (interview 9, elderly care physician)

Theme 3: The use of the LCP as a marker of quality
Another important theme mentioned in the survey and interviews was quality of care. The need to care for a dying person and to make sure that the symptom burden is as low as possible increases the relevance to promptly recognise and treat symptoms. Many physicians and nurse practitioners were positive about the concept of regular symptom assessment. They wanted the dying person to be assessed regularly and felt that the LCP was an appropriate tool. The interviewees referred to the comprehensiveness and structure of the pathway and that it made nursing staff more aware of the process of dying and the need to provide more comfort in this phase. Many described the regular assessment as the main motive to continue working with the LCP. One of the interviews also highlighted that the LCP increased awareness for less common symptoms. No other end-of-life instruments were used when asked in the interviews, apart from a pain instrument that was mentioned once.

- 'I think that it is a reminder for the physician and nursing staff that those symptoms in particular should also receive attention. There are some symptoms that are better known or more obvious and then there are some 'poor relations'. And if these do not get attention, or they are never reported.' (interview 2, elderly care physician)

The importance of good communication between nursing staff and physician was also acknowledged as contributing to quality. Some respondents had concerns about nurses not always recognizing all the symptoms and residents being treated late for some symptoms as a consequence. Another respondent thought the knowledge of the nursing staff on care in the dying phase is adequate but that some fellow physicians responded insufficiently to signals from the nursing staff regarding symptom management.

- 'Yes I think the knowledge is there, absolutely. Certainly among the nursing staff, and in my shifts I encounter stories about arrogant doctors who do not listen to nurses and who think the suffering observed by the nursing staff is not that bad, and I have regularly come across situations that I think, well, they could have started better symptom treatment sooner and more adequately.' (interview 1, elderly care physician)

Clear communication about the actual expected death and informing relatives and colleagues was named as a positive aspect of the LCP. Also adding to the quality of care was the possibility to literally show the relatives that their loved one was on the LCP, by placing the paper version of the LCP in the resident's room, visualizing for the relatives that they were completing forms. The LCP was felt to reassure the relatives that the team was working very diligent.

- I sometimes suspect that that, I see it sometimes in different situations around dying, that this fear is there, that once you have said that the end seems to be drawing near, that you hope this expectation is met, so you don't confuse people.' (interview 4, nurse practitioner)

One respondent mentioned the name of the LCP and its introduction in the Netherlands by the IKNL (Netherlands Comprehensive Cancer Organisation), indicating that it is only for cancer patients, and suggested an instrument be developed for nursing home residents. However, the same person appreciated the completeness of the LCP and stated that almost all questions are also relevant in the nursing home setting. Especially the awareness of the dying phase and the heightened alertness to possible discomfort in this phase were often mentioned in the answers. Some felt that the LCP's contribution to quality of care was largest in teams where knowledge on palliative care was insufficient, and that the LCP might add less in a setting with more experience with dying, such as a hospice. One respondent added that the increase in quality diminishes as use of the LCP becomes more frequent.

Another concern raised was the risk of the LCP being used as a checklist and the specific knowledge necessary to recognize pain or shortness of breath being lost. These symptoms can go unrecognized, while the boxes can still be ticked.

- 'Yes and I also feel it is important that there is something, that everyone has a kind of checklist, like have we done everything now? What I said, some doctors give little information, some nurses give little information and then the family are in a constant state of stress and tension, while this could easily be done differently. On the other hand there are also situations where everything is so easy, so gradual, that the whole list, at some point it is like a checklist and then it feels a bit bureaucratic to me.' (interview 9, elderly care physician)

Use of the LCP by nursing staff reassured the physicians that a sudden change in symptom burden would not be missed by the health care team, and nurses would learn about the importance of monitoring symptoms. Related to nursing staff being poorly educated in identifying and managing symptoms and physicians not being fully able to remedy this problem, the physicians would favour the opportunity to improve quality of care for the dying with the LCP, the only instrument they knew.

Discussion

This study shows an overall positive perspective on the part of many of the respondents on the use and content of the LCP. Some points of critique were found, mainly regarding the use in the electronic health record format. Another important outcome of this study is the need to start an end-of-life pathway in the nursing home setting at an earlier stage and to connect a pathway to the knowledge and care goals that are already available in the electronic health record. Many respondents indicate the

necessity of an instrument that can be used in the dying phase, but point out that it is difficult to find the right moment to start the LCP. They are reluctant to start the LCP too early and then have to withdraw it, which leads to late starts of the LCP. The requirement of agreement within the multidisciplinary team can also delay the start of the LCP. This means its use and possible benefits are available for an even shorter period of time, which implies there is room to improve the quality of end-of-life care.

The four criteria in the LCP that can help the multidisciplinary team decide if a person is in the dying phase are extra difficult to apply to people with dementia. They have often already been bedridden, drink very small amounts and are no longer capable of taking tablets for longer periods. This is certainly true for people in a more advanced stage of dementia. [26] So in those cases three of the four criteria are not helpful to determine if a person is in the dying phase.

Several respondents indicated that the usual care in a nursing home is already focused on comfort and well-being, and that this focus of care does not change after the start of the LCP. Although several studies show no clear evidence regarding effectiveness of the use and outcome of the LCP [27, 28], many respondents agreed on the helpful structure to improve communication. This is in line with the findings from earlier studies in nursing home settings. [11-13, 15] Interestingly, while these studies also point to possible improvements in symptom management, not one respondent in our study mentioned results related to earlier or better symptom control.

Although the use of the LCP lead to a positive view among 77% of the respondents, one might question the quality of the assessments as guided by the LCP instrument. Research on assessment of symptoms has shown it can be difficult to interpret symptoms such as pain, especially in people that may have difficulty verbally expressing themselves, such as people with dementia. [29] Some indicated the risk of the LCP becoming a list of boxes to be ticked off, a risk already pointed out in connection with the use of the LCP. [8]

Use of the LCP as a marker of quality, to the organization and to the relatives was found to be a motivation to use the pathway. Many respondents also indicated that use of the LCP improved communication within the care team and with the relatives.

Another important issue was the impact of repeated use of the instrument. Would more frequent use result in more benefits for the resident in a linear fashion with no ceiling effect, or would quality increase the most when it is used infrequently by inexperienced care staff? Other research showed that it was more difficult to work with the LCP when it was not used frequently. [15] It is important to teach care staff how to work with an instrument and use it in the intended manner. [8, 30] This is even more important when, as in the case of dementia, recognizing symptoms is already extremely challenging.

The interviews showed that the respondents did not use other end-of-life pathways alongside or as a replacement of the LCP. This lack of pathways for end-of-life care

in the nursing home setting is worrying and may indicate room for improvement through implementing instruments tailored to the nursing home setting.

The LCP was developed to transfer principles of hospice care to other settings such as hospitals and nursing homes to improve care for people dying.[31] One of the important lessons from the critique and withdrawal of the LCP in the UK is the clear need for adequate education and implementation. In Dutch nursing homes, the (elderly care) physician or nurse practitioner start the LCP together with a member of the nursing staff when they both believe a resident is dying. Compared to hospital and hospice settings, nursing home residents are cared for during a longer period of time which may facilitate recognizing changes in health status and communication to prepare for dying. At that point, wishes regarding end of life have often already been discussed with the resident or their family caregiver and this may lower the risk of inappropriate use of the LCP. The withdrawal of the LCP in the UK did not lead to a national debate in the Netherlands. However, the results of this study together with the clear lessons and recommendations from the Neuberger review [32] regarding communication and involvement in a care plan indicate that there is room to improve the LCP for the nursing home population.

Strengths and limitations

This mixed-methods study presents the results of the use and experiences of the LCP reported electronically by a large number of respondents who were reached via a link sent to various organizations. Due to the GDPR we could not collect email addresses to send individual invitations to participate in the survey. This is also why we could not determine the exact number of persons who received the link, but almost 90% of the contacted organizations informed us about how the link had been distributed. We approached three Academic Networks of Elderly Care in the Netherlands to include different parts of the country. It is possible that the associated organizations are used to work more with pathways and tools than other organizations and therefore the results may not be representative for the Netherlands. The focus in this study was on those responsible for medical treatment in nursing homes, therefore we did not collect data from the perspective of the nursing staff and the relatives.

Nevertheless, we believe that the high number of respondents reflects a relevant perspective on the actual use in Dutch nursing homes in different regions in the country. This is the first study to give an insight into actual use and application of the LCP. We were surprised to find that 20% of the respondents were not familiar with the LCP. The positive but also negative perspectives reported in the interviews added valuable information to complement the results of the survey.

Benefits and limitations of the LCP in practice

Many respondents recognized benefits of the LCP in that it facilitated communication within the team and with relatives. It also reassured physicians that the patient was being monitored. As such, and mainly through regular symptom assessments and the importance of also involving an educational component, the LCP was experienced as a

marker of quality. This motivated continuing the use of the instrument. Disadvantages referred to administrative burden, practical limitations in recording on paper or digitally in more systems and use merely as a tick-off exercise that did not really help to improve quality. Research in six European countries showed that knowledge of nurses and care assistants concerning basic palliative care issues was variable but suboptimal in all participating countries. [33] Future projects could use this information and also focus on (repeated) training and educational programmes in nursing homes, with the aim to improve communication between nursing staff and physician.

Implications for practice
Overall, this study shows that practitioners who are responsible for the medical treatment in the nursing homes feel a need for a care pathway. This pathway should be integrated in the electronic health record to better support anticipation, recognition and treatment of symptoms. There is also a need to start such a pathway at an earlier stage, so as to improve palliative care not only in the last days or hours of life, but in the last weeks to months, and to make it more applicable to the nursing home population, which includes people with dementia. Regular evaluation of care goals is necessary, and instruments such as the IPOS-Dem or use of heuristics for nursing staff [34, 35] can be used to improve quality of palliative care for people with dementia. Frequent symptom assessment can be performed several times a day when death is expected within weeks or days.

Conclusion

This mixed-methods study with 159 survey respondents and ten interviews provides an understanding of how the LCP is being used and experienced in practice for nursing home residents, including those with dementia. Those responsible for (medical) care perceived an instrument that prompts regular assessment of a dying person as contributing to good care. As such, the LCP was valued, but there was a clear need to start it earlier than in the last days or hours of life-perhaps related to many residents having dementia. There was also a need for a shorter version and for integration of the LCP in the electronic health record. Such regular assessments with an instrument that focusses on quality of care and good symptom control can improve palliative care for nursing home residents with and without dementia.

Abbreviations
LCP= Liverpool Care Pathway for the dying patient
UK= United Kingdom
IKNL= Integraal Kanker Centrum Nederland or Netherlands Comprehensive Cancer Organisation
GDPR= General Data Protection Regulation

Declarations

Ethics approval and consent to participate
Research based on health professionals filling in a survey regarding the use of a tool does not fall under the scope of the Medical Research Involving Human Subjects Act (WMO) in the Netherlands. This was confirmed by the Scientific Committee of the department Public Health and Primary Care that reviewed the protocol and other documentation. In compliance with the General Data Protection Regulation (GDPR), the survey was sent via an internet link and respondents remained anonymous unless they choose to disclose their email address or phone number to offer participation in a subsequent interview. The landing page of the survey explained that responses would be recorded in the protected university environment without any identifiers. Before starting an interview, the participant verbally confirmed consent to record the interview. The data were processes without identifiers. The process was described in the protocol that was approved by the Scientific Committee of the department Public health and Primary Care of Leiden University Medical Center, Leiden, The Netherlands.

Consent for publication
Not applicable. Signing as proof of consent would unnecessarily disclose the participants' personal information and identify and completing the survey was regarded as informed consent to use the anonymous data for this research. The interviewees provided informed consent to be interviewed and publish about the result without the interviewees being recognizable in any publication.

Availability of data and materials
The datasets generated and analysed during the current study are not publicly available due not having explicit permission from survey respondents and interviewees to provide access; however, the survey data from the respondents who choose to not provide contact details are anonymous and are available from the corresponding author on reasonable request.

Competing interests
The authors declare that they have no competing interests

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Authors' contributions
MK and NLD had full access to all data in the original study and take responsibility for the integrity of the data. MK, NLD, MC, WA and JvdS contributed to the study concept and design, analysis and interpretation of the data, drafting and critical revision of the manuscript. All authors have read and approved the final version of the manuscript.

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Supplement 1 Examples of care goals per section of the Liverpool care pathway

Source: Geijteman EC, Dekkers AG, van Zuylen L. [10 years after implementation of the Liverpool care pathway for the dying patient; important improvements in end-of-life care]. Nederlands tijdschrift voor geneeskunde. 2013;157(37):A6174.

Part 1: Assessment at start of dying phase

- the resident and his or her family know that the resident is dying
- the treatment team have the correct contact information for the family
- the resident and his family have been given the opportunity to discuss what is important to them at that moment, e.g. regarding keeping watch, religious/spiritual customs or rituals
- currently prescribed medication has been assessed and unnecessary medication discontinued
- if necessary, medication has been prescribed for symptoms that may occur in the final days to hours
- a syringe driver is available to enable continuous or intermittent administration of medication
- an infusion needle has been placed subcutaneously for intermittent subcutaneous administration of medication
- current interventions have been assessed and unnecessary interventions discontinued, e.g. routine blood tests and assessment of vital functions
- a do-not-resuscitate policy has been agreed; any internal defibrillator has been deactivated
- involved health care professionals have been informed that the resident is dying e.g. the GP, specialist or specialists, and paramedics

Part 2: Assessment of resident-related problems

- the resident is pain free (move resident only for comfort)
- the resident's breathing is not hindered by secretions (in case of rattling, repeated explanations to the family if necessary)
- the resident has no micturition problems (consider inserting a urinary catheter in case of retention, incontinence or weakness)
- when administering medication, the safety and comfort of the resident are ensured (check the syringe driver and the insertion site of the subcutaneous infusion needle at least once every 4 h)
- attention is paid to the psychological well-being of the resident (explain interventions and care, attention for communication and religious/spiritual support)
- attention is paid to the well-being of those close to the resident (among other things, explain the possible symptoms of the resident and what they mean, and ascertain the needs of the persons staying with the resident)

Part 3: Care after death

- the institution's procedures after death have been followed, e.g. the resident has been cared for with dignity and respect and the spiritual, religious and cultural needs of the resident and family have been met
- involved healthcare providers have been informed of the death of the resident, such as the GP, the specialist or specialists, and paramedics

Supplement 2 Survey regarding the use and experiences of the Liverpool care pathway

1.1 You are: (more than one answer possible)
- Elderly Care physician
- General Practitioner
- Nurse practitioner
- Medical resident in training to become elderly care physician
- Medical resident in training to become general physician
- Nurse practitioner in training
- Elderly Care physician with Special Interests - Rehabilitation
- Elderly Care physician with Special Interests - Psychogeriatrics
- Elderly Care physician with Special Interests - Palliative care
- Medical School Graduate
- Other, namely: …….

1.2 You are:
- Female
- Male

1.3 Your age:
- 20-30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61 years or older

1.4 Number of years of experience in the nursing home: please fill in the number of years and/or months (only whole numbers, no decimal points please)
- .. years and/or …. months

2.1 You work in an organization that is part of one of the Academic Networks of Elderly Care
- UNC-ZH, Leiden (University Network for the Care Sector)
- UNO-UMCG, Groningen (University Elderly Care Network- *University* Medical *Centre Groningen*)
- AWO-ZL, Maastricht (The Living Lab in Ageing & Long-Term Care Zuid-Limburg)

2.2 You work within the organization (UNC-ZH): (please fill in)
- …….

2.2 You work within the organization (AWO-ZL): (please fill in)
- …….

2.2 You work within the organization (UNO-UMCG): (please fill in)
- …….

2.3 You work at the following location(s): (please fill in)
- …….

3.1 Can you indicate what types of units your care organization consists of: (more than one answer possible)
- Psychogeriatric (dementia) unit(s)
- Unit(s) for chronically ill
- Social gerontology/Geriatric psychiatry unit(s)
- Geriatric rehabilitation unit(s)
- Hospice/Palliative care unit(s)
- Unit(s) for people with young-onset dementia
- Other unit(s), namely……..

3.2 Can you indicate at what types of units you are working as regular physician/nurse practitioner? (more than one answer possible)

- Psychogeriatric (dementia) unit(s)
- Unit(s) for chronically ill
- Social gerontology/Geriatric psychiatry unit(s)
- Geriatric rehabilitation unit(s)
- Hospice/Palliative care unit(s)
- Unit(s) for people with young-onset dementia
- Other unit(s), namely……..

4. Are you familiar with the Liverpool care pathway?
- No: I am not familiar with the Liverpool care pathway. (If you do not know the Liverpool care pathway you can select this answer and then close the questionnaire by closing the link.) This is followed by the message: Thank you for your cooperation!
- Yes, I am acquainted with the Liverpool care pathway (please continue with the next question).

5.1 Is the Liverpool care pathway AVAILABLE and ready for use in the care organization where you work? (more than one answer possible)
- Yes; in the psychogeriatric unit(s)
- Yes; in the unit(s) for chronically ill
- Yes; in the social gerontology/geriatric psychiatry unit(s)
- Yes; in the geriatric rehabilitation unit(s)

- Yes; in the hospice/palliative care unit
- Yes; in the unit(s) for people with young-onset dementia
- Yes; in other unit(s), namely: …….. (please enter below)
- No; it is not available

5.2 1 Is the Liverpool care pathway actually being USED in the care organization where you work? (more than one answer possible)

- Yes; in the psychogeriatric unit(s)
- Yes; in the unit(s) for chronically ill
- Yes; in the social gerontology/geriatric psychiatry unit(s)
- Yes; in the geriatric rehabilitation unit(s)
- Yes; in the hospice/palliative care unit
- Yes; in the unit(s) for people with young-onset dementia
- Yes; in other unit(s), namely: …….. (please enter below)
- No; it is not ready for use; please indicate below why the care pathway cannot be used.
- No; it is available, but not used (everywhere). If you select this answer, please indicate the reason why it is not being used: ……

6. If the Liverpool care pathway is being used, is this a paper version or a digital version of the care pathway?

- Paper version
- Digital version
- Both
- No use of care pathway

7.1 Are the experiences you have with the CONTENT of the Liverpool care pathway mainly positive or mainly negative?

- Mainly positive experiences
- Mainly negative experiences
- No experience using care pathway

7.2 Please describe your most important experiences with the CONTENT of the Liverpool care pathway

-……..

7.3 Are your experiences with the USE of the Liverpool care pathway mainly positive or mainly negative?

- Mainly positive experiences
- Mainly negative experiences
- No experience using care pathway

7.4 Please describe your most important experiences with the USE of the Liverpool care pathway

-……..

8.1 If you could change anything about the Liverpool care pathway, or how it is applied, what would you change?
[Link with option to download the Liverpool care pathway, nursing home version] (https://shop.iknl.nl/shop/zorgpad-stervensfase-verpleeghuisversie/54902)
[Example of English version, accessed 31 May 2020, slightly different from Dutch version] (http://healthcare.trinityhospice.co.uk/wp-content/uploads/2014/11/D6a-NEoLCP-LCP-1-example-of-the-Liverpool-Care-Pathway-LCP.pdf)
(examples of care goals in the LCP in supplement 1)

-…….

8.2 What would you definitely keep?

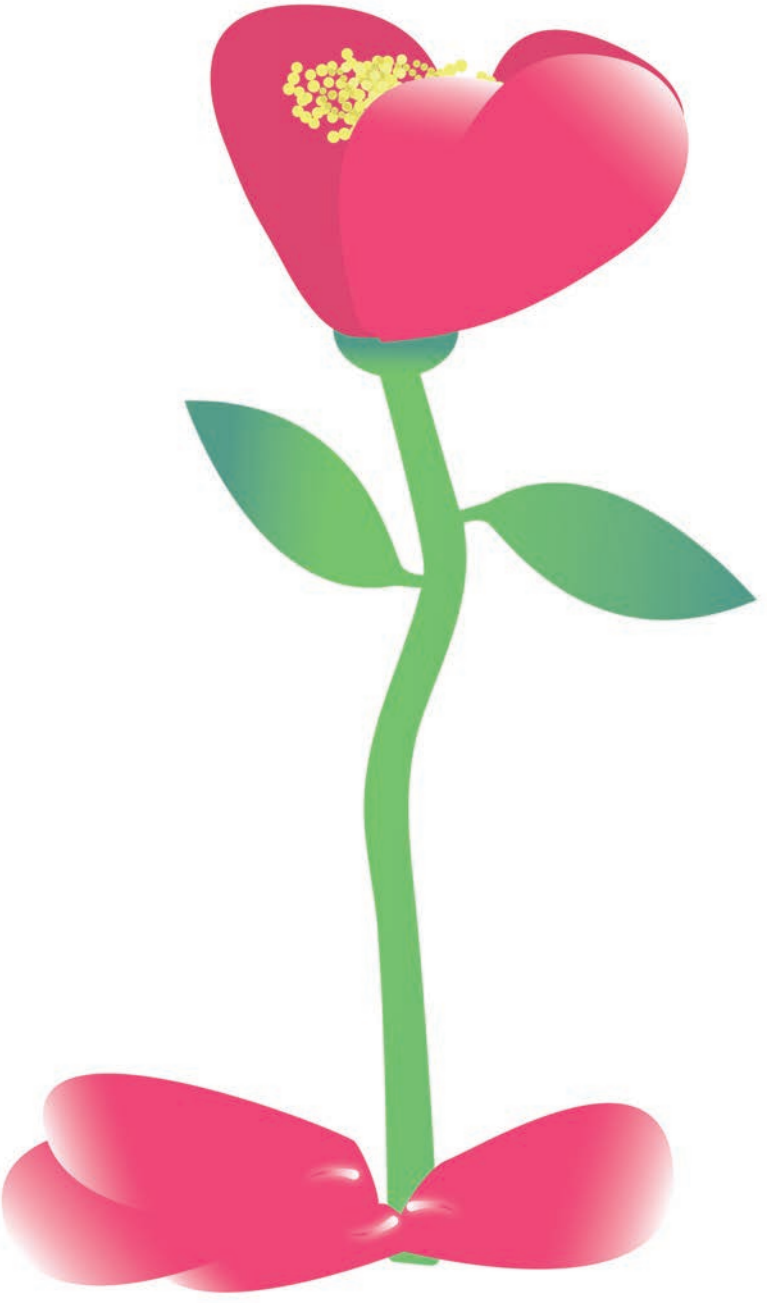
-…….

8.3 Earlier research shows that the level of knowledge on the part of the care staff is also relevant for the use of the Liverpool care pathway. Is the knowledge level of the care staff in your organization sufficient to be able to see positive and negative effects of the use of the pathway for the dying phase?
Choose the option that is BEST REFLECTS the situation in your organization

- Yes; knowledge of palliative care is sufficient, and this supports the effect of the care pathway
- Yes; knowledge of palliative care is sufficient, but this does not support the effect of the care pathway
- No; knowledge of palliative care is insufficient, but this does not affect the effect of the care pathway
- No; knowledge of palliative care is insufficient, and this affects the effect of the care pathway
- No experience using the care pathway

9.1 Thank you very much for answering the questions. Would you be willing to answer some additional questions? Do you consent to being approached via e-mail of telephone to make an appointment?

- No
- Yes. Please enter your e-mail address or the telephone number we can use to contact you (you hereby give your consent that we temporarily store this information in the secure environment of the LUMC network) …….



Chapter 5

Symptoms and treatment when death is expected in dementia patients in long-term care facilities

Klapwijk, M. S., Caljouw, M. A.A., van Soest-Poortvliet, M. C., van der Steen, J. T., & Achterberg, W.P. (2014). BMC Geriatr, 2014 Sep 2;14:99. doi:10.1186/1471-2318-14-99

Abstract

Background
Although dementia at the end of life is increasingly being studied, we lack prospective observational data on dying patients. In this study symptoms were observed in patients with dementia in the last days of life.

Methods
When the elderly care physicians in two Dutch nursing homes expected death within one week, symptoms of (dis)comfort, pain and suffering were observed twice daily. For this the Pain Assessment in Advanced Dementia (PAINAD; range 0-10), Discomfort Scale-Dementia of Alzheimer Type (DS-DAT; range 0-27), End-Of-Life in Dementia-Comfort Assessment in Dying (EOLD-CAD; range 14-42) and an adapted version of the Mini-Suffering State Examination (MSSE; range 0-9), were used. Information on care, medical treatment and treatment decisions were also collected.

Results
Twenty-four participants (median age 91 years; 23 females), were observed several times (mean of 4.3 observations (SD 2.6)), until they died. Most participants (n=15) died from dehydration/cachexia and passed away quietly (n=22). The mean PAINAD score was 1.0 (SD 1.7), DS-DAT 7.0 (SD 2.1), EOLD-CAD 35.1 (SD 1.7), and MSSE 2.0 (SD 1.7). All participants received morphine, six received antibiotics, and rehydration was prescribed once.

Conclusion
In these patients with dementia and expected death, a low symptom burden was observed with validated instruments, also in dehydrated patients without aggressive treatment. A good death is possible, but might be enhanced if the symptom burden is regularly assessed with validated instruments. The use of observation tools may have influenced the physicians to make treatment decisions.

Background

It is estimated that, worldwide, about 35 million people have dementia. Currently, 5% of people aged > 65 years are diagnosed with dementia, increasing to more than 50% in the group aged 90 years and over. [1-3] In the first stages of dementia people tend to live at home; however, when the disease becomes more progressive, many people with dementia are admitted to a long-term care facility (LTCF).[4] In the Netherlands, and also in other parts of the world [5], LTCFs have specialized dementia care units. Daily medical care is provided by an elderly care physician specialized in care for vulnerable older people and the chronically ill living in a LTCF.[4,6-8]

The period between ascertainment of the diagnosis dementia and death can take several years, with phases of slight to moderate decline or fast decline in cognition and functioning, depending on the type of dementia.[9]

Internationally, many people with dementia die in LTCFs; e.g. in the USA 67% and in the Netherlands up to 92%.[10] The 6-month mortality rate in LTCF residents with advanced dementia is reported to be 18-37%.[11,12]

The cause of death while dying with dementia has been studied in the USA and the Netherlands.[13,14] The most frequently mentioned cause of death is cachexia with dehydration (35%).[15] Pneumonia and complications of cardiovascular disease were the second and third mentioned cause of death, respectively, both around 20%.[15]

In the period before death patients can suffer from pain, dyspnea, agitation, anxiety, fear, crying, moaning, choking, gurgling or difficult swallowing. During this period, mouth care and the prevention of pressure ulcers, constipation and urinary retention are also important.[16-18] People with dementia are often incapable of expressing themselves verbally when they are uncomfortable or when they suffer from symptoms. Therefore, observational or proxy-rate instruments have been developed for people with serious cognitive impairment to measure the quality of dying; some of these instruments have good psychometric properties.[19]

Differences in treatment during the final phase of patients with dementia have been acknowledged. In many countries (including the USA and some European countries) patients in the terminal phase too often receive aggressive treatments that may be of limited clinical benefit.[14, 20-24] Especially the belief among many relatives and health-care workers about an unpleasant death when dehydrated, or the imagined effects of rehydration, may hamper a dignified and evidence-based palliative care. [25,26]

Many studies have retrospectively described the symptoms in patients dying with dementia.[14, 18, 20, 27,28] In these studies, data were collected retrospectively before and after death, to describe the experienced symptoms in the period before death. However, prospective observational studies that systematically observe dying patients with validated instruments are still lacking. Therefore, this prospective observational follow-up study was performed to describe the incidence and course of observed symptoms and treatment in people with dementia in the last days before their expected death.

Methods

Setting and study population

This prospective observational follow-up study was part of a study to validate methods of measurement of quality of care and quality of dying with dementia in long-term care facilities (LTCFs) in the Netherlands.[19,29] From January 2008 to February 2009 two elderly care physicians in two LTCFs included patients if they met the following inclusion criteria: residing in a LTCF for $\geq$ 30 days, a physician's diagnosis of dementia and expected to die within the next 7 days. The expectancy of a patient to die within 7 days is based on an estimation made by the treating physician and the nurses caring for the patient, and is often related to the fact that a patient has stopped eating and drinking.[30]

The Medical Ethics review Committee of VU University Medical Center Amsterdam approved the study. Families were asked for permission for study participation by the coordinating physician who also observed the patients. Neither of the observing elderly care physicians were part of the research group.

Data collection

Two elderly care physicians collected data by filling out observation instruments, i.e. the Pain Assessment In Advanced Dementia (PAINAD), Discomfort Scale-Dementia Alzheimer type (DS-DAT), End-of-Life in Dementia scales-Comfort Assessment in Dying (EOLD-CAD), and the Mini Suffering State Examination (MSSE).

Prior to the start of this study, these two physicians were trained with an instructional video on the use of the DS-DAT and the PAINAD. The observations of the patients expected to die within 7 days were scheduled twice a day. During the observation periods, the patients were in rest. In the morning the PAINAD, the DS-DAT and the EOLD-CAD were scored. The physician in charge of the medical care observed the patient while sitting next to the patient for 10 minutes per observation.

The second observation was in the afternoon. Again, the physician observed the patient for 10 minutes and then filled out the PAINAD, DS-DAT and the MSSE, and additional questions regarding the course of the day. Therefore, the DS-DAT and PAINAD were scored twice a day (if possible), and the MSSE and EOLD-CAD once a day.

The PAINAD is an instrument that is validated to observe pain in non-communicative patients with advanced dementia.[31] The PAINAD contains 5 items which can generate a score from 0-2. The total score ranges from 0-10, with 10 indicating severe pain. A score of 2 or higher is used to give an indication of pain.[32-34]

The DS-DAT measures discomfort in advanced dementia patients. It consists of 9 items with four response options ranging from 0-3. The total score ranges from 0-27, with 0 indicating 'no discomfort' and 27 indicating 'the highest level of discomfort'.[35-37]

A tool to measure comfort at the end of life is the EOLD-CAD. This observation scale scores symptoms while dying with dementia and contains 14 items that can be scored with a 1, 2 or 3 score. The symptoms in the EOLD-CAD are the symptoms actually noticed at the time of the observation. The total score ranges from 14-42, with a higher score indicating a higher level of comfort for the patient.[38,39]

Suffering was measured with the MSSE. The MSSE measures symptoms in end-stage dementia patients and gives an indication of suffering over the course of the whole day.[40,41] The MSSE has 10 items. One item is the family's judgment regarding the suffering of the patient. Because data regarding suffering as seen by family members were retrospectively collected, these question in the MSSE was not used to calculate the total score; therefore, only the first 9 items were used for the present study. The total score ranges from 0 (indicating a low level of suffering) to 9 (indicating the highest level of suffering).

Patient characteristics and treatment

Within two weeks after death, the physician collected information about the participants' gender, age, marital status, length of stay at the LTCF, and duration of dementia. Information on care, medical treatment (including pain, and antipsychotic and anti-depressive medication), and treatment decisions in the last 7 days before death were also collected.

Cognition

In addition, the 7 category Minimum Data Set Cognitive Performance Scale (CPS) was used to determine the cognitive performance status. The CPS was scored within 2 weeks after death and concerned the last month of life. The CPS is a valid measuring scale for cognitive performance. This scale can range from intact (level 0), borderline intact, mild, moderate, moderately severe and severe impairment to very severe impairment (level 6).[42] Also, the 7-item Bedford Alzheimer Nursing Severity-Scale (BANS-S) was used to measure the severity of dementia in the last month before death. Scores on the BANS-S range from 7-28; a score of 17 and higher is regarded as severe dementia.[43,44]

Statistical analysis

Descriptive statistics were used to describe the study population and observed symptoms; results are reported as mean and standard deviation (SD) for normally distributed data, and median and interquartile range (IQR) for non-normally distributed data. The t-test was used to compare age, duration of stay at the LTCF and years of dementia between the observed and non-observed patients.

To dichotomize the presence of symptoms in the EOLD-CAD the scores 1 = 'a lot' and 2 = 'somewhat' are combined.

Descriptive statistics reported the mean and SD of the observational instruments at each observation point before death.

All analyses were performed with SPSS statistical software, version 20 (SPSS Inc., IBM, USA).

Results

Study population

During the study period from February 2008 to February 2009 in two Dutch LTCFs, a total of 36 patients died on the wards in which the physicians were working. Of these, 12 patients could not be included in the present study because of sudden death (n=5) or because the physician did not have the opportunity to perform the observations (n=7), resulting in 24 participants available for this study. Of these participants, 11 were observed only one time and 13 were observed more frequently; the mean number of observations was 4.3 (SD 2.6). In total, 80 observations were conducted by the two physicians. All 24 participants died within 5 days; 12 of them died within the first 2 days.

Of the 24 observed participants (23 females) the mean age was 90 (SD 6.9) years. Mean length of stay in the LTCF was 32 (SD 27.8) months. The mean duration of dementia was 49 (SD 41.7) months. No difference in age and length of stay was found between the 24 participants and the 12 non-participants.

Cognition and severity of dementia before dying

About half of the participants (52.4%) had very severe cognitive impairment. The mean BANS-S score was 19 (SD 5.4) (Table 1).

Table 1 Baseline characteristics of the study population (N=24) and course of mortality

Socio-demographic factors		
Female, n (%)	23	(95.8)
Dutch, n (%)	23	(95.8)
Widowed, n (%)	16	(66.7)
Mean age in years (SD)	90	(6.9)
Mean length of stay in months (SD)	32	(27.8)
Medical information		
Dementia mean duration in months (SD)	49	(41.7)
Cognition		
CPS		
Level 0 Intact, n (%)	0	(0)
Level 1 Borderline intact, n (%)	1	(4.2)
Level 2 Mild impairment, n (%)	0	(0)
Level 3 Moderate impairment, n (%)	1	(4.2)
Level 4 Moderate severe impairment, n (%)	0	(0)
Level 5 Severe impairment, n (%)	9	(37.5)
Level 6 Very severe impairment, n (%)	13	(54.2)
BANS-S mean score (SD)	19	(5.4)

SD=Standard deviation
CPS=Cognitive Performance Scale
BANS-S=Bedford Alzheimer Nursing Severity-Scale

Symptoms of dying

The PAINAD was completed 61 times (missing 19 times); for 39 of these ratings (63.9%) no indication of pain was observed. There were 69 DS-DAT ratings (11 missing), 31 MSSE ratings (9 missing) and 40 EOLD-CAD ratings.

The mean PAINAD score was 1.0 (SD 1.7), the mean DS-DAT score was 7.0 (SD 2.1), the mean EOLD-CAD score was 35.1 (SD 1.7), and the mean MSSE score was 2.0 (SD 1.7). Figure 1 shows the course of the total scale scores until death, which overall implies a low prevalence of symptoms.

The scores of the PAINAD for each participant resulted in a total of 6 participants (26%) that always scored zero (no indication of pain). All 24 participants scored one or more points on the DS-DAT. Two participants (10%) scored no symptoms of suffering on the MSSE.

Table 2 shows the symptoms of dying scored with the MSSE and EOLD-CAD in the 7 days before death. The MSSE was conducted 31 times, 7 of these ratings (22.6%) had a score of 0, and 24 ratings (77.4%) had a score of 1-9, indicating some symptoms of suffering. In multiple observations, symptoms such as pain were present 11 times (35.5%), malnutrition was present 13 times (41.9%), eating disorders 12 times (38.7%) and suffering according to medical opinion 10 times (32.3%).

For example, the observational instrument EOLD-CAD scored discomfort among participants 15 times (37.5%), shortness of breath 12 times (30%), serenity 34 times (85%), peace 36 times (90%), and calmness 35 times (87.5%).

Treatment and medication

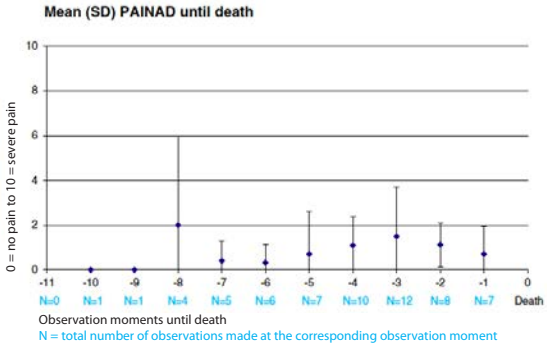
In the last days before death, 12 of the participants lost consciousness. According to the physicians, 22 participants (91.7%) passed away quietly in the last 6 hours before death and 2 (8.3%) were aware of symptoms.

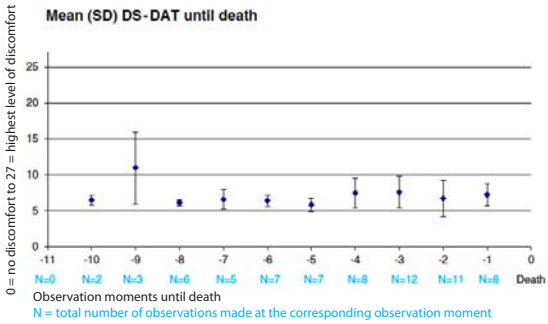
All 24 participants received morphine (one received a dose that was higher than necessary for symptom control); for 19 participants (79,1%) it was not necessary to increase the dose of morphine in the course of the terminal phase. In 4 patients (16.7%) there was a gradual increase in the dosage of morphine and, in one patient (4.2%), there was a substantial increase in the dosage on the last day. Two participants were pharmacologically kept sedated, in order to relieve the symptom burden. The exact dosages of paracetamol, NSAIDs, anti-depressive and antipsychotic medication, were not available for all patients.

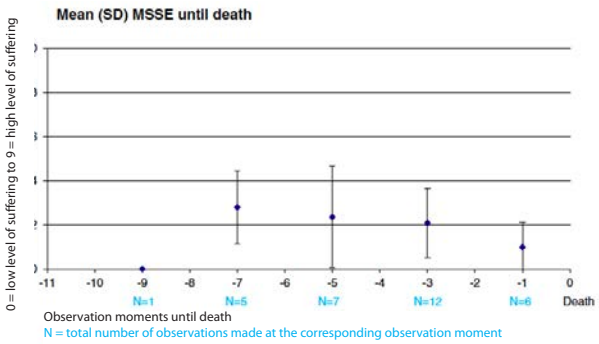
Six participants (25%) received antibiotics and one (4.2%) received subcutaneous rehydration. The physicians reported that they stopped antibiotics or oral medication or rehydration in 13 (54.2%) of the participants, for one participant (4.2%) they decided not to start antibiotics, two participants were not sent to the hospital for surgery, and for one participant no further diagnostic exploration was started (Table 3).

The physicians also reported that no treatment was stopped or withheld to induce death.

Figure 1 Mean score of observational instruments (with standard deviation) in last days to death







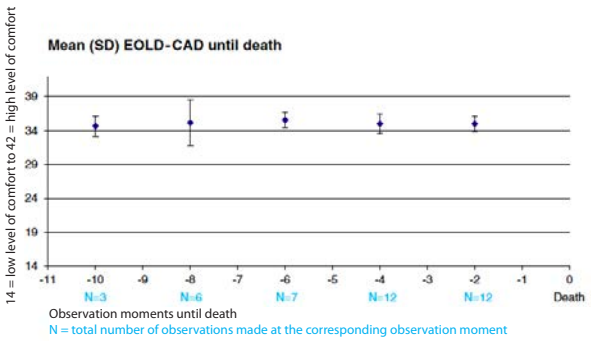


Table 2 Symptoms present in multiple observations in ≤ 7 days before death in all 24 patients

	N	%
MSSE	31	100
Restlessness/not calm	6	19.4
Screams	2	6.5
Pain	11	35.5
Decubitus ulcers	2	6.5
Malnutrition	13	41.9
Eating disorders	12	38.7
Invasive action	1	3.2
Unstable medical condition	4	12.9
Suffering according to medical opinion	10	32.3
EOLD-CAD	40	100
Discomfort	15	37.5
Pain	6	15.0
Restlessness/not calm	7	17.5
Shortness of breath	12	30.0
Choking	4	10.0
Gurgling	2	5.0
Difficulty swallowing	8	20.0
Fear	2	5.0
Anxiety	5	12.5
Crying	0	0
Moaning	6	15.0
Serenity	34	85.0
Peace	36	90.0
Calm	35	87.5

MSSE=Mini-Suffering State Examination; missing n=9,
EOLD-CAD=End-Of-Life in Dementia-Comfort Assessment in Dying.

Table 3 Medication/palliative care and cause of death ≤ 7 days before death in the study population (N=24)

	N	%
Medication/palliative care		
Antibiotics, oral tablets	6	25.0
Morphine	24	100
Rehydration, hypodermoclyse	1	4.2
Stop antibiotics, oral medication or rehydration	13	54.2
Not starting treatment with antibiotics	1	4.2
Not starting treatment with surgical operation	2	8.3
Not starting further exploration in diagnosis	1	4.2
Missing	3	12.5
Cause of death		
Cachexia/dehydration	15	62.5
Pneumonia (acute pulmonary disease)	3	12.5
Disease of the digestive system	4	16.7
Renal failure	1	4.2
Brain injury after a fall	1	4.2

Five participants had an indwelling urinary catheter and two received oxygen. All participants received mouth care, and 19 treatments for the prevention of pressure ulcers were conducted.

Cause of death

Fifteen participants (62.5%) died of cachexia/dehydration, three of pneumonia (12.5%) and four (16.7%) due to a disease of the digestive system, one from renal failure and one died from brain injury after a fall (4.2%) (Table 3).

Discussion

This is one of the few studies that prospectively and through direct physician observation explored the symptomatology and treatment in the last days of life of patients with advanced dementia.

The low level of burdensome symptoms in the days before death, also in patients dying from dehydration/cachexia, the low rate of aggressive curative treatment and the high rate of palliative treatment with morphine are striking results. These data strengthen the recommendations for a better tailored, less curative aggressive approach to palliative care in dementia.[24,45]

A strength of this study is the prospective study design. Retrospective designs in end of life care are particularly sensitive for bias.[46] Particularly when people are easily identified to be at risk of dying (which was the case in this study), this prospective approach is recommended.[47]

Another strength is that this study used structured observations twice a day (with validated instruments) by physicians specialised in the care for dementia patients.[19,48] The results of the total scores of the observational instruments showed no increase in symptom burden over time, not even on the last days prior to death. This is a remarkable contrast to the results seen in other retrospective studies, which showed an increase in burdensome symptoms in the time prior to death.[14,49]

This study also has some limitations. It was a relatively small sample, there were missing observations, and the observations were performed by the elderly care physicians who also were responsible for the treatment decisions. Therefore, an important issue to consider is whether these findings have been influenced by the study itself. Having a physician who performs a structured observation of symptoms twice a day, might lead to an improved awareness and assessment of symptomatology and, hence, to better palliative treatment.

Studying symptoms of dying in patients with dementia is challenging. Although differentiation between pain and, for instance, anxiety or discomfort is difficult, in the present study specific observational instruments were used. The DS-DAT was specifically developed to measure discomfort in advanced dementia, and the PAINAD was developed and validated for the assessment of pain in people with dementia.[31-37] The PAINAD has not been validated for use in the last days of life. The item 'breathing' in the PAINAD covers 'noisy labored breathing', 'long periods of hyperventilation' or 'Cheyne-Stokes respirations'. Cheyne-Stokes respirations are often seen in the last days of life and can be part of the normal physiological process of dying. However, because we cannot differentiate between the three symptoms observed under 'breathing', we cannot state exactly how many people exhibited Cheyne-Stokes respirations.

The EOLD-CAD includes gurgling/death rattle but does not include, for instance, nausea or vomiting, two symptoms that can also be unpleasant in the last days of life. Also, the presence of a death rattle cannot differentiate between the underlying cause, for instance pneumonia or the absence of coughing. The best treatment for death rattle in dementia is morphine or an anticholinergic drug, like scopolamine. However, more studies are needed to determine the most effective treatment. It would be interesting to repeat the present study and include independent, objective observers and also include observations after a change in treatment. At the time of this study, the validated instruments used were the best available. These observational instruments help to structurally assess symptoms in these patients, and can help to observe symptoms and to assess the effect of the treatment received for these symptoms.

All patients received morphine and, in 19 (79.1%) of these patients, the dosage was not raised. We do not want to imply that the use of morphine in the last days of life with dementia is always necessary, but it is often used to alleviate the burden of pain or dyspnea. In the Netherlands, many patients receive the starting dose of morphine (10-30 mg subcutaneously a day), for a considerable period of time (days, weeks, sometimes

even months). Death is not considered to be a direct side-effect of this medication in these dosages, and (as far as we know) there is no evidence for any association between this treatment and death.

Elderly care physicians in the Netherlands are in charge of the medical care of patients in the long-term care facility. [8] They have received extensive training in elderly care medicine, which includes palliative care. In this study we decided to observe the patients when death was expected within 7 days. The moment of death can be more accurately predicted when the intake of fluid or food has severely diminished; in the present study, the result was that 50% of the patients died within 2 days after the start of the observation. The cause of death was assessed by the elderly care physicians who were fully knowledgeable about the patient's condition in the last phase of life.

In the discussion about a good death, physician involvement such as physician-assisted suicide, euthanasia, palliative sedation and withholding curative treatment are heavily debated. In 2010, of all deaths in the Netherlands, 2.8% were the result of euthanasia, and 12.3% of the deaths were the result of continuous deep sedation until death.[50] In a study covering the period 2007 to 2011 in dementia patients, 21% received deep sedation.[18] However, euthanasia is very rare in patients with dementia (although under Dutch law dementia is not an exclusion criterion per se) and in the present study there were no such cases. Also, for none of the patients in the present study, was starting or withholding treatment performed with the intention to induce death. This is in line with the observation that, in the Netherlands, active physician involvement in inducing death in dementia patients in long-term care is extremely rare.[50] Therefore, active physician involvement in this setting seems to mainly consist of pertinent palliative care principles.

Conclusion

In this study in patients with advanced dementia and expected death, a low symptom burden was observed with validated instruments, also in dehydrated patients without aggressive treatment. A good death is possible, but this might be enhanced in a situation where symptom burden is regularly assessed with validated instruments. Therefore, we support others who recommend that proper symptom assessment should be implemented in long-term care. The use of observation tools may help physicians to take appropriate treatment decisions. All symptoms and preventive measures should feed into a personalised tailored care plan to help the patient and the (in)formal caregivers in the process of dying with dementia.

Authors' contribution
MCvSP and JTvdS had full access to all data in the original study and take responsibility for the integrity of the data. MSK, MAAC, MCvSP, JTvdS and WPA contributed to the study concept and design, analysis and interpretation of the data, drafting and critical revision of the manuscript. All authors have read and approved the final version of the manuscript.

Competing interest
The authors declare that they have no competing interests.

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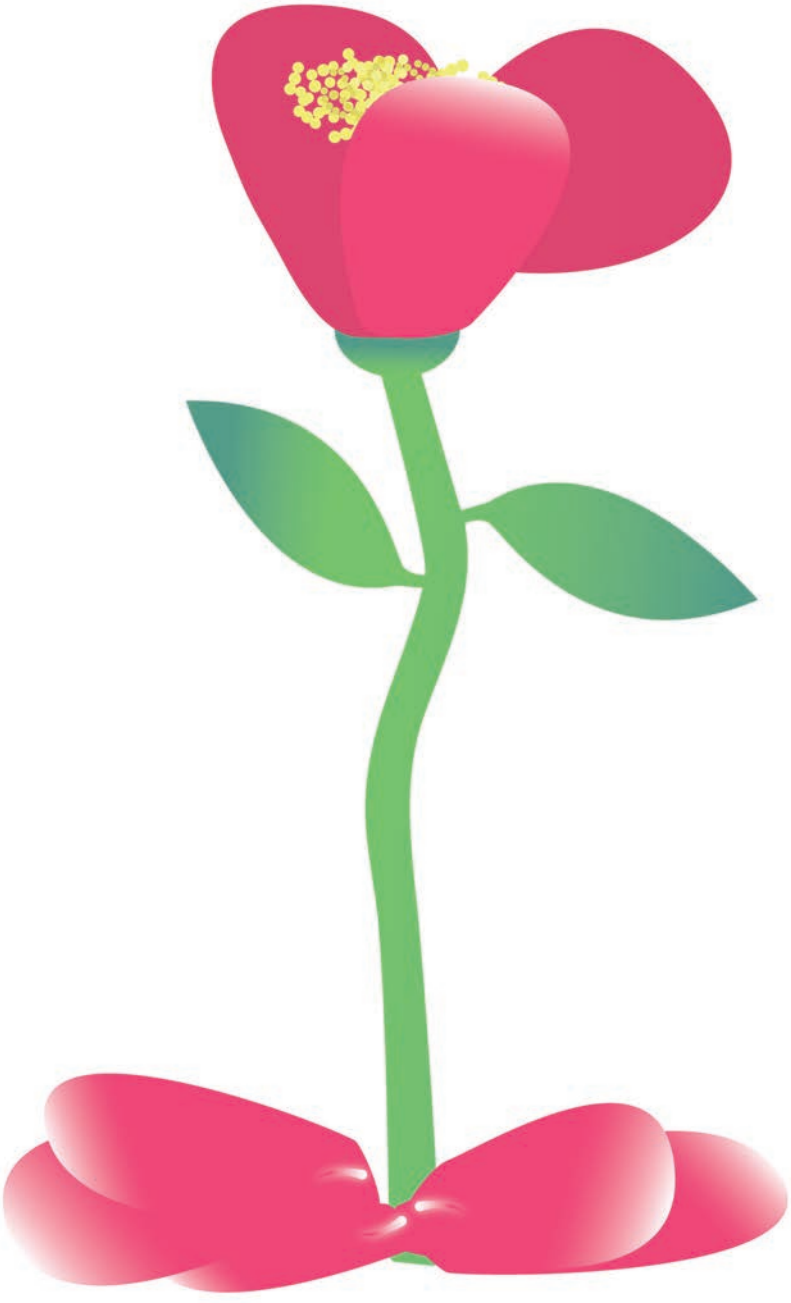

Chapter 6

Trends in quality of care and dying perceived by family caregivers of nursing home residents with dementia 2005-2019

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Abstract

Background
Dementia palliative care is increasingly subject of research and practice improvement initiatives.

Aim
To assess any changes over time in the evaluation of quality of care and quality of dying with dementia by family caregivers.

Design
Combined analysis of eight studies with bereaved family caregivers' evaluations 2005-2019.

Setting/participants
Family caregivers of nursing home residents with dementia in the Netherlands (n=1189) completed the End-of-Life in Dementia Satisfaction With Care (EOLD-SWC; quality of care) and Comfort Assessment in Dying (EOLD-CAD, four subscales; quality of dying) instruments. Changes in scores over time were analysed using mixed models with random effects for season and facility and adjustment for demographics, prospective design and urbanized region.

Results
The mean total EOLD-SWC score was 33.40 (SD 5.08) and increased by 0.148 points per year (95% CI, 0.052 to 0.244; adjusted 0.170 points 95% CI, 0.055 to 0.258). The mean total EOLD-CAD score was 30.80 (SD 5.76) and, unadjusted, there was a trend of decreasing quality of dying over time of -0.175 points (95% CI, -0.291 to -0.058) per year increment. With adjustment, the trend was not significant (-0.070 EOLD-CAD total score points, 95% CI, -0.205 to 0.065) and only the EOLD-CAD subscale 'Well being' decreased.

Conclusion
We identified divergent trends over 14 years of increased quality of care, while quality of dying did not increase and well-being in dying decreased. Further research is needed on what well-being in dying means to family. Quality improvement requires continued efforts to treat symptoms in dying with dementia.

Key statements

What is already known about the topic?
- Dementia is an incurable condition and in Western countries, most people with dementia die in nursing homes.
- The knowledge base concerning palliative care for people with dementia has expanded.
- Bereaved family caregivers' experiences and perceptions of the dying phase and the quality of care of their relatives are relevant, as they need to live on with memories.

What this paper adds
- This study shows that from 2005 to 2019, family caregivers increasingly appreciated the quality of care provided to their relative with dementia dying in a nursing home. -Family caregivers' evaluation of quality of dying, however, did not improve, indicating that families did not perceive fewer symptoms over time, and even perceived lower well-being while dying (items on serenity, peace, and calm).

Implications for practice, theory or policy
- Monitoring trends in the palliative care for people with dementia may aid our understanding of the influence of policy and societal developments.
- Research is needed to explain trends and help to decrease symptom burden and improve quality of dying for people with dementia.

Introduction

In Western European countries such as the UK and the Netherlands, most people with dementia eventually move to a nursing home, where they reside until death.[1-3] Nursing home residents may benefit from palliative care with a focus on comfort and quality of life.[4, 5] The cognitive impairment associated with moderate or advanced dementia often leads to limited verbal expression of needs. This complicates the assessment of specific palliative care needs and addressing of symptoms.[6, 7] Family caregivers of people with dementia fulfill important roles as spokespersons, care partners, informants and proxy decision-makers.[8-11] Their role continues after nursing home admission.[12, 13] Staff should acknowledge the family caregivers' role in the care for people with dementia, especially at the end of life.[14-16] Families' experiences with end-of-life care and their interactions with professional caregivers potentially influence their post-bereavement outcomes.[17] "How people die remains in the memories of those who live on" is a famous quote in palliative care literature.[18] Memories of family members reflect the dying experience and may expose specific points for improvement in end-of-life care.[19] Family caregivers are important judges of the quality of end-of-life care provided to residents with dementia and of their quality of dying.[20, 21] Validated instruments are available to measure quality of care and quality of dying from the family perspective.[22, 23]
A small study that investigated data from 2005 to 2010 showed a positive trend in families' reports of quality of end-of-life care for nursing home residents with dementia.[24] Exploring such trends can aid our understanding of how the experiences of family caregivers with end-of-life care may have changed, which informs future initiatives to improve palliative and end-of-life care. The present study examines trends in quality of care and quality of dying up to 2019 as judged by family caregivers of residents with dementia in Dutch nursing homes. Various national initiatives aimed to improve knowledge on palliative care in the Netherlands over the last decade. Therefore, the hypothesis is that these trends over a period in which development of dementia palliative care continued, are positive.

Methods

Study population

Data from eight studies conducted in the Netherlands in overlapping time windows between 2005 and 2019 were combined for trend analyses (Table 1).[22, 24-30] For seven of the studies, it concerned a secondary analysis of data collected to address various research questions (Supplement). The main goal of the eighth and most recent study was to enhance assessment of trends over time. Some studies employed nationally representative sampling, whereas other studies were regional. All studies collected data retrospectively, and one study also collected data prospectively (Table 1).[22, 24-30] Data collected during any intervention condition were excluded. The data concern 1189 persons with dementia who died in 117 nursing home facilities. One facility contributed to two studies (studies 1 and 3, Table 1). The family caregivers who were the primary contact persons were

invited to complete a questionnaire; within 1.5 to 2 months after death in most studies, and up to about a year after death in two studies (studies 6 and 8, Table 1). All nursing home residents included in these studies received medical care by a certified elderly care physician.[31]

Instruments

Quality of end-of-life care was measured with the End-of-Life in Dementia Satisfaction With Care (EOLD-SWC) instrument.[20 23] It has the most favourable psychometric properties as compared to other such instruments and it comprises 10 items regarding experiences on quality of care from the perspective of the family caregiver.[22] The items cover decision-making, communication, understanding the resident's condition and medical care. The response options are: strongly disagree, disagree, agree, and strongly agree. Three items are negatively phrased statements, which require reverse coding before summing to total scores that range from 10 to 40. A higher score indicates better quality of end-of-life care.

The End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD)[20] was used to measure quality of dying.[23, 32] The EOLD-CAD comprises 14 items on symptoms such as pain, shortness of breath, choking, and fear. It also includes three positive items in a 'Well being' subscale. This subscale consists of items serenity, peace and calm, which require reverse coding. The three response options are: a lot, somewhat and not at all. Total scores range from 14 to 42, a higher score indicating a better perceived quality of dying. Most studies (6 out of 8) referred to the last week of life. One study used a skip pattern for the EOLD-CAD if the relative was not present during dying, setting a higher bar with regard to actual presence to observe comfort. (Table 1)

Cognition

All residents had a physician's diagnosis of dementia and resided in a psychogeriatric unit. Studies 1, 2, 3 and 5 (Table 1) included staff assessment using the Bedford Alzheimer Nursing Severity-Scale (BANS-S) to measure the severity of the dementia in the months before death. BANS-S scores range from 7 to 28. A score of 17 or higher represents severe dementia.[33, 34] In studies 1 to 5, staff assessed whether residents were fully dependent in eating. Full eating dependence indicates very severe cognitive impairment and is equal to the highest level of impairment on the Cognitive Performance Scale (CPS 6).[35, 36]

Trend analysis

The EOLD-SWC and EOLD-CAD scores in the combined dataset were analysed with mixed models, using time of death relative to the first death in the first study as the independent variable. The models included random effects for season (as seasonality in cause of death might vary between years) and for clustering of residents within nursing homes. [37, 38] In study 7, only the month of death was available due to privacy regulations, and we imputed the 14th for February and the 15th for other months. We provide 95% confidence intervals around the estimate for time. Models were adjusted for characteristics of residents (age and gender), and family caregivers (gender, relationship to resident), region (urbanised Western and central region

Table 1 Overview of datasets combined for trend analyses on quality of care and quality of dying

Study	Main reference for study/ included in early combined analyses	Period	Design	Number of nursing homes, area in Netherlands
1. Gijsberts et al.	Ned Tijdschr Geneeskd[24] Palliat Med[25] Int Psychogeriatr[26]	Sept 2005-june 2007	Retrospective, observational	4 facilities, West/Central
2. Van Soest-Poortvliet et al. Psychometric instrument study	Ned Tijdschr Geneeskd[24] JAMDA[22]	Feb 2008-April 2009	Retrospective, observational	14 facilities, West/Central
3. DEOLD Study	Ned Tijdschr Geneeskd[24] ADAD[27]	Feb 2007-July 2010	Prospective and retrospective, observational	40* facilities of 17 health care organisations, nationwide
4. FOLlow-Up Study	Palliat Med[28]	Jan 2012-June 2014	Retrospective, cluster RCT	18# facilities, nationwide
5. PACE, European study	JAMDA[29 30]	Dec 2014-Nov 2015	Retrospective, 6 countries also non-dementia, observational	25 facilities, stratified sampling, nationwide
6. Proeftuin Dementie	No publication yet	Feb 2017-Oct 2017	Retrospective, observational (intervention not implemented in nursing homes)	4 facilities of 1 health care organization, North of NL
7. DEDICATED (Desired Dementia Care Towards End of Life)	No publication yet	Feb 2018-Sept 2019	Retrospective, observational	7 facilities of 1 health care organization, South of NL
8. Marente, New data collection	No publication yet	April 2018-Dec 2018	Retrospective, observational	6 facilities of 1 health care organization, West of NL

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, DEOLD=Dutch End Of Life in Dementia, FOLlow-up=Feedback on End-of_Life care in dementia, PACE=Palliative Care in care Homes Across Europe,

Number of residents with dementia (response rate)	Time questionnaire sent to family caregiver after death	Study aim	Timeframe, last:	
			EOLD-SWC	EOLD-CAD
54 (61%)	2 months	Validate Dutch translation. Compare anthroposophical nursing homes to nursing homes without affiliation. Comparison of after-death scores of family caregivers and nurses, and of Dutch and US family caregivers.	Last 90 days	During his/her dying
70 (59%)	2 months	Assess psychometric properties of instruments to evaluate quality of care and death in long-term care	Last month	Last week
248 (58%)	6 weeks	Asses factors associated with quality of care and quality of dying	Last week	During his/her dying, only if present
537 (65%)	6 weeks	Assessment of effect of feedback strategies in perceived end of life care and comfort	Last month	Last week
89 (62%)	2 to 4 months	Comparison of palliative care in nursing homes in 6 European countries	Last week	Last week
16 (43%)	6 to 13 months	Improving palliative care with mobile palliative care teams	Last week	Last week
125 (62%)	6 to 8 weeks	Improving palliative care for people with dementia and caregivers	Last 3 months	Last week
50 (58%)	3 to 12 months	Additional data to address research question of possible trend in evaluation end of life care	Last week	Last week

DEDICATED=Desired Dementia Care Towards End of Life, *=included nursing homes after move, #=only pre-test and control group in trend analysis

of the country with greater staffing problems versus other region), and design (prospective enrolment of residents versus retrospectively after death). We conducted sensitivity analyses with additional adjustment for severity of dementia measured with the BANS-S or the eating dependence item (CPS 6) and family caregiver's age. We also added a quadratic term for time to assess the fit of a non-linear model. Descriptive statistics were used for respondent characteristics. If less than one third of EOLD items missed, the items were imputed with the patient item mean to generate a total score. All analyses were performed in SPSS Inc, version 25, 2017, IBM, USA.

Results

The mean age of the residents was 85.5 years; 67.9% were female (Table 2). A little over half (53.7%) had severe dementia and almost a third (29.4%) were fully dependent in eating (no data available for the studies covering 2018 and 2019). Distributions of age, gender and dementia severity were fairly homogeneous between the eight studies (Table 2). Of the family caregivers, the majority were female (62.8%), and most were sons or daughters (in-law) of the resident (65.8%). The EOLD-SWC (quality of care) mean total ranged from 31.9 to 34.1, and the EOLD-CAD (quality of dying) mean total score ranged from 27.2 to 33.3 across studies (Table 3). The correlation between the EOLD-SWC and the EOLD-CAD for quality of dying was weak (+0.27, $P<0.001$). Figure 1a shows unadjusted quality of care means per 2 years; the curve is steeper in earlier years and flattens over time when variable error bars are taken into consideration. The EOLD-SWC total score significantly increased by 0.148 points per year (CI, 0.052 to 0.244), and in the adjusted model the trend was an additional 0.170 points per year (CI, 0.055 to 0.285) (Table 4). The EOLD-CAD total score significantly decreased by -0.175 points per year (CI, -0.291 to -0.058; Table 4 and Figure 1b) but in the adjusted model the trend was not significant with a decrease of -0.070 points per year (CI, -0.205 to 0.065). The difference of EOLD-CAD with the adjusted model (-0.070 versus -0.175 unadjusted; Table 4) was driven by adjustment for prospective versus retrospective design. The subscale 'Well Being' significantly decreased by -0.076 points per year (CI, -0.114 to -0.039) in the unadjusted model, and in the adjusted model by -0.073 points per year (CI, -0.119 to -0.028). The other subscale scores showed no significant trend. Trend models in EOLD-SWC and EOLD-CAD for separate studies are shown in Supplementary figures 1 and 2. The sensitivity analyses showed similar estimates. A quadratic term for time was significant for the EOLD-SWC in both the unadjusted ($P=0.002$) and the adjusted model ($P<0.001$; Supplementary figure 3). A quadratic term for change over time was not significant in the unadjusted model for EOLD-CAD ($P=0.096$) or the adjusted model ($P=0.223$).

Figure 1a EOLD-SWC means per 2-year intervals with 95% CI bars
EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, CI=Confidence Interval

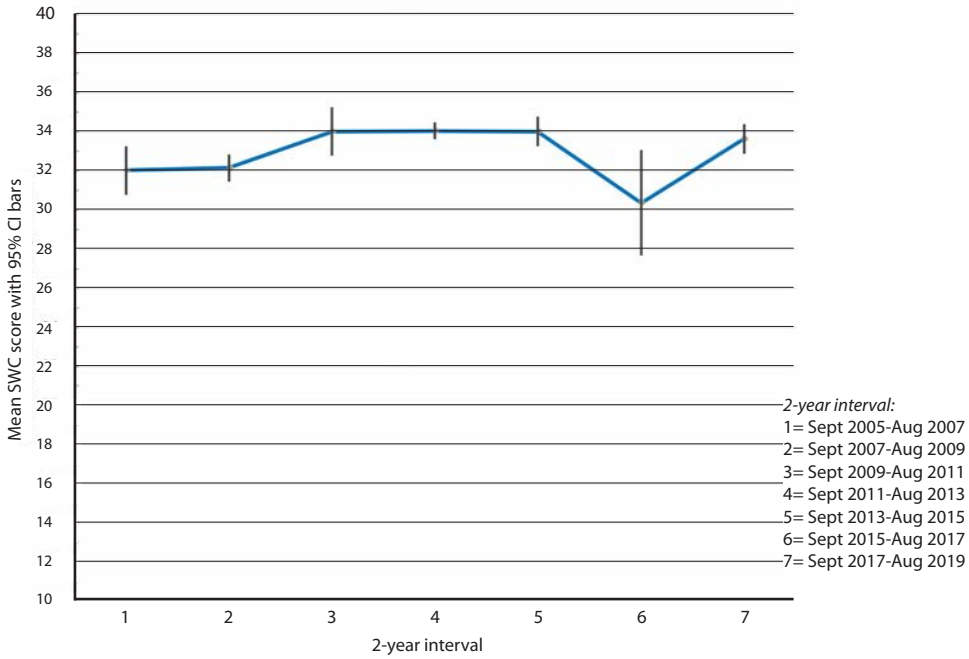

Figure 1b EOLD-CAD means per 2-year intervals with 95% CI bars
EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, CI=Confidence Interval

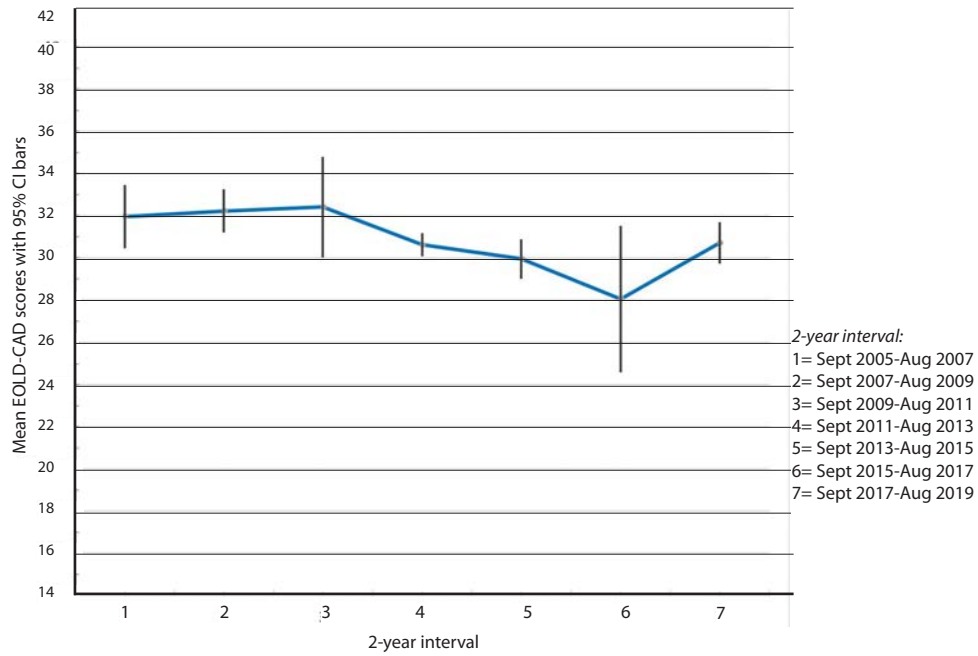

Table 2 Characteristics of nursing home residents who died with dementia and their relatives

Mean (SD) or %, [n]	Total all studies	Gijsberts	Van Soest	DEOLD
Number of residents	1189	54	70	248
Age, mean number of years; (SD) [n]	85.5 (7.6) [1178/1189]	85.1 (5.8) [54/54]	88.8 (5.9) [67/70]	85.6 (7.1) [244/248]
Female, % [n]	67.9 [807/1189]	80 [43/54]	89 [62/70]	67 [165/248]
Severity of dementia, BANS-S mean score, (SD), [n]	17.1 (4.0) [428/461]	18.6 (3.3) [54/54]	17.9 (4.2) [70/70]	16.3 (3.7) [248/248]
Severe dementia, BANS-S score 17 or higher % [n]	53.7 [230/428]	83 [45/54]	73 [51/70]	41 [102/248]
Full eating dependency (CPS 6), % [n]	29.4 [271/923]	33 [16/48]	38 [21/54]	26 [61/237]
Caregiver female, % [n]	62.8 [747/1186]	61 [33/54]	67 [47/70]	61 [151/246]
Age caregiver, mean number of years (SD) [n]	62.0 (11.2) [1126]	Not available	60.6 (8.5) [70/70]	60.6 (11.2) [246/248]
Relationship caregiver, % [n]				
-spouse	18.5 [220]	12 [6]	6 [4]	19 [46]
-child	65.8 [782]	71 [37]	87 [61]	66 [161]
-other	15.3 [181]	17 [9]	7 [5]	16 [38]

SD=standard deviation, BANS-S=Bedford Alzheimer Nursing Severity-Scale

Table 3 Total scores for quality of care (EOLD-SWC; n=1169) and quality of dying (EOLD-CAD; n= 903) across studies

Study/ project, mean (SD)	EOLD-SWC	n/total n	EOLD-CAD	n/total n
1. Gijsberts	31.9 (4.7)	54/54	32.0 (5.4)	52/54
2. Van Soest-Poortvliet	32.1 (5.8)	68/70	30.7 (5.3)	59/70
3. DEOLD	32.6 (5.3)	242/248	33.3 (5.9)	88/90
4. FOLlow-up	34.1 (4.8)	535/537	30.6 (5.6)	466/537
5. PACE	33.8 (5.2)	86/89	29.7 (5.6)	80/89
6. Proeftuin Dementie	30.2 (6.3)	16/16	27.2 (7.2)	13/16
7. DEDICATED	33.7 (5.0)	118/125	30.6 (6.2)	101/125
8. Marente	33.4 (4.8)	50/50	30.8 (5.5)	44/50

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying

FOLlow-up	PACE	Proeftuin Dementie	DEDICATED	Marente
537	89	16	125	50
84.9 (8.1) [535/537]	85.6 (7.2) [89/89]	85.4 (7.5) [15/16]	85.7 (7.7) [125/125]	85.5 (7.0) [49/50]
68 [366/537]	60 [53/89]	50 [8/16]	60 [74/125]	72 [36/50]
Not available	17.9 (4.9) [56/89]	Not available	Not available	Not available
Not available	57 [32/56]	Not available	Not available	Not available
29 [155/529]	33 [18/55]	Not available	Not available	Not available
62 [331/537]	68 [60/88]	63 [10/16]	61 [76/125]	78 [39/50]
62.7 (11.8) [533/537]	63.4 (11.0) [88/89]	65.3 (9.8) [16/16]	62.4 (10.5) [123/125]	59.8 (9.6) [50/50]
21 [113] 63 [338] 16 [86]	23 [20] 60 [53] 18 [16]	19 [3] 50 [8] 31 [5]	18 [22] 70 [87] 12 [15]	12 [6] 74 [37] 14 [7]

CPS=Minimum Data Set Cognitive Performance Scale

Table 4 Trends in total and item quality of care scores (EOLD-SWC) and in total and subscale quality of dying scores (EOLD-CAD)

	Mean (SD) [n]	Trend; coefficient (95%-CI) unadjusted	Trend; coefficient (95%-CI) adjusted
EOLD-SWC total[a]	33.40 (5.08) [1169]	***0.148 (0.052 to 0.244)***	***0.170 (0.055 to 0.285)***
a. I felt fully involved in all decision making	3.41 (0.66) [1171]	***0.017 (0.005 to 0.029)***	***0.017 (0.002 to 0.032)***
b. I would probably have made different decisions if I had had more information	3.30 (0.73) [1137]	0.006 (-0.008 to 0.019)	0.011 (-0.006 to 0.027)
c. All measures were taken to keep my relative comfortable	3.47 (0.66) [1167]	***0.024 (0.012 to 0.037)***	***0.030 (0.016 to 0.045)***
d. The health care team were sensitive to my needs and feelings	3.35 (0.65) [1146]	***0.019 (0.007 to 0.031)***	***0.015 (0.001 to 0.030)***
e. I did not really understand my relative's condition	3.35 (0.78) [1150]	0.011 (-0.002 to 0.024)	0.010 (-0.005 to 0.026)
f. I always knew which doctor or nurse was in charge of my relative's care	3.03 (0.78) [1165]	0.014 (-0.000 to 0.029)	0.011 (-0.006 to 0.029)
g. I felt that my relative got all necessary nursing assistance	3.42 (0.66) [1170]	***0.019 (0.007 to 0.031)***	***0.026 (0.011 to 0.040)***
h. I felt that all medication issues were clearly explained to me	3.27 (0.71) [1155]	***0.016 (0.004 to 0.029)***	***0.021 (0.005 to 0.036)***
i. My relative was receiving all treatments or interventions that he or she could benefit from	3.38 (0.66) [1164]	***0.015 (0.004 to 0.027)***	***0.016 (0.002 to 0.030)***
j. I feel that my relative needed better medical care at the end of his or her life	3.42 (0.76) [1159]	0.005 (-0.008 to 0.019)	0.010 (-0.006 to 0.026)
EOLD-CAD total[b]	30.80 (5.76) [903]	***-0.175 (-0.291 to -0.058)***	-0.070 (-0.205 to 0.065)
1. Physical distress[c] (item 1, 2, 3, 4, score range 4-12)	8.34 (2.09) [935]	-0.037 (-0.079 to 0.004)	0.00001 (-0.048 to 0.048)
2. Dying symptoms[d] (item 4 (part of two subscales), 5, 6, 7, score range 4-12)	8.85 (2.20) [922]	-0.017 (-0.059 to 0.025)	0.017 (-0.032 to 0.067)
3. Emotional distress[e] (item 8, 9, 10, 11, score range 4-12)	9.54 (2.19) [904]	***-0.061 (-0.104 to -0.019)***	-0.026 (-0.077 to 0.025)
4. Well being[f] (item 12, 13, 14, score range 3-9)	6.14 (1.98) [908]	***-0.076 (-0.114 to -0.039)***	***-0.073 (-0.119 to -0.028)***

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, SD=standard deviation, CI=confidence interval, ***italics and bold***= p<0.05, EOLD-SWC item scores are presented because the total score trend is significant
Cronbach's α: [a]= EOLD-SWC total: 0.90, [b]= EOLD-CAD total: 0.83, [c]= EOLD-CAD subscale Physical distress: 0.62, [d]= EOLD-CAD subscale Dying symptoms: 0.68, [e]= EOLD-CAD subscale Emotional distress: 0.78, [f]= EOLD-CAD subscale Well being: 0.91

Discussion

Main findings

This study investigated trends in family caregivers' assessments of quality of end-of-life care and quality of dying of nursing home residents with dementia in the Netherlands. From 2005 to 2019, quality of care improved, in particular in the earlier years. Quality of dying did not significantly change in adjusted analyses that included adjustment for prospective design, but scores on the subscale 'Well being' nevertheless decreased, also after adjustment.

The statistically significant changes are relevant long-term changes as they may represent ongoing change, and a 2.4 increase in EOLD-SWC total score, for example, nears 3 used in power calculations. [39] The progressive and terminal nature of dementia and the complex care needs that accompany dementia underpin a palliative approach to care.[5, 40] The evidence-base for palliative dementia care is still small but will expand over the coming years.[41] The early increase in quality of care in the Netherlands may be related to political developments in palliative care from the late 1990s onward.[42] A 1997 policy programme aimed to integrate palliative care into the regular healthcare system, to increase practitioners' skills and knowledge.[43] In Dutch national dementia plans, however, palliative or end-of-life care is not mentioned.[44] Treatments for symptom relief in nursing home residents with dementia increased in 2006-2007 compared to the late 1990s.[45] Reasons for this increase, according to physicians, included growing attention and awareness regarding symptom relief, clearer treatment goals and a focus on quality of life.[45] Palliative care specialists are consulted for residents in Dutch nursing homes with dementia, in only 2.5% of the cases.[46] Compared to five other European countries, however, the treating physician in Dutch nursing homes is involved in palliative care more often (in 98.8% of the cases).[30, 47]

In the context of increasing quality of end-of-life care as perceived by family and increasing awareness regarding palliative care as perceived by physicians[45], finding no improvement on the quality of dying scale and a decline on the 'Well being' subscale is counterintuitive. Further, scores on the quality of care items, regarding measures taken to improve comfort and regarding nursing assistance showed the highest increase. Other studies also found weak to moderate associations between quality of care evaluated by families and perceived quality of dying.[48, 49] An interesting artefact may have been introduced by a design issue, with a negative trend for a prospective design (Supplement figures 1 and 2). Repeated completion of questionnaires on symptom burden in the prospective study may also have increased family caregivers' awareness of symptoms in the dying phase. These family caregivers may have been prompted to report more symptoms. Nevertheless, controlled for design, the trend was also negative for the subscale 'Well Being' that comprises the items 'serenity', 'peace' and 'calm'. Family caregivers may hold negative perceptions about the end of life with dementia as being undignified, especially in Western societies where autonomy is highly valued.[50] Increasing media exposure and public campaigns on 'living well with dementia', in combination with

the Dutch debate on the acceptability of euthanasia in dementia in recent years might influence such perceptions. Lemos Dekker found that family caregivers of nursing home residents with dementia may feel powerless due to a lack of control over relief of their relatives' suffering.[50] Higher expectations and standards of care, and increased focus on control and dignity might explain a decrease in their assessment of well-being in dying, while their assessment of concrete symptoms remained unchanged. Future research is needed to disentangle what well-being in dying means to families.

Strengths and limitations

This study used perspectives from more than one thousand family caregivers of nursing home residents with dementia, over a period of 14 years. It does not evaluate a single reform as there were various initiatives to improve palliative care. Identifying of individual items that did or did not change further enhances the study's relevance to clinical practice. The EOLD-SWC has strong psychometric properties, whereas there is some ambiguity about the psychometric properties of the EOLD-CAD regarding feasibility, validity and reliability.[22, 51] Although the EOLD-CAD items all assess aspects of quality of dying, the instrument does not cover the full concept of quality of dying, which may include aspects that are more difficult to assess such as retaining identity or dignity.[52] Nonetheless, other such measures do not perform better or properties are unknown. The EOLD-SWC and EOLD-CAD scales have been widely used after an early comparison of psychometric properties,[22] which facilitates comparison between countries.[30, 53] This study was limited to the Netherlands, but its EOLD scores are fairly representative for recent European research.[30] Sample sizes, recruitment methods and the period before death referred to in the EOLD instruments varied between the individual studies in the analyses. There may be residual confounding by unmeasured confounders. However, any confounding by dementia severity is unlikely as adjusted estimated were unchanged in sensitivity analyses.

Conclusion

This study observed a positive trend in family caregivers' assessments of the quality of end-of-life care for nursing home residents with dementia over a period of 14 years. Family caregivers' assessments of quality of dying did not change with regard to symptoms during dying, but according to their assessments the well-being during dying decreased over time. There may be a growing gap between family caregivers' expectations and actual symptoms and well-being at the end of life. These observations call for further monitoring of quality perceived by family and research to investigate contemporary ideas about what constitutes a 'good and comfortable death' at the end of life with dementia.

Author contribution

MK, WA and JvdS developed the original concept for this study. MK and JvdS analysed the data. BM advised on the statistical analysis. MK, SB and JvdS wrote the manuscript, and all authors reviewed and commented on the subsequent drafts. All authors read and approved the final manuscript.

Declaration of conflicting interest

The authors(s) declared the following potential conflicts of interest with respect to the research, authorschip, and/or publication of this article: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Data availability statement

The data sets generated and analyzed during the current study are not publicly available. The combined data are available upon reasonable request and permission granted from the owners of all datasets.

Supplemental material

Supplemental material for this article is available online.

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Supplement 1
Description of each study on inclusion of residents and study aims

Study 1 Gijsberts et al. [1-3]
The 54 residents enrolled after death in this study were living in 4 nursing homes in the Western and central regions of the Netherlands. All deaths occurred between September 2005 and June 2007. The first study aim was to translate and validate the End of Life in dementia (EOLD) scales, the second aim was to compare anthroposophical nursing homes with nursing homes without religious or spiritual affiliation on quality of care, dying and symptom burden. The third aim was to compare after-death scores of family caregivers and nurses in the Netherlands and the US. Nurses identified family caregivers who had been most involved in the last months of life of residents diagnosed with dementia. An informed consent form was sent by postal mail 6 weeks after the death of their relative. After receiving consent, a printed questionnaire was mailed and was completed around 2 months after death. The response rate was 61%. The study protocol was approved in 2005 by the Medical Ethics Committee of VU University Medical Center in Amsterdam (number 05/098).

Study 2 Psychometric instrument study, Van Soest-Poortvliet et al. [4]
In this study, 70 residents were included after death. They had resided in 8 nursing homes and had been admitted at least 30 days before death between February 2008 and April 2009. This psychometric properties study was designed to test and compare all available instruments to measure quality of care and quality of death with dementia in long-term care. All residents had a physician's diagnosis of dementia and were admitted to a psychogeriatric unit (units with almost all patients having dementia) in nursing homes and residential homes. Informed consent was provided by family caregivers. The response rate was 59%. The Medical Ethical Committee of VU University Medical Center, Amsterdam, reviewed the protocol in 2008 as an extension of study 3. (number 06/179, 2006), and provided advice, declaring that the extension also did not fall under the Medical Research Involving Human Subjects Act (WMO).

Study 3 DEOLD= Dutch End Of Life in Dementia, van der Steen et al. [15]
The 491 residents in 19 nursing home organizations covering 34 facilities, enrolled in this study were included using a prospective design in 28 facilities (17 organizations) and a retrospective design in 6 other facilities (2 organizations, after-death questionnaires only). Family after-death questionnaires were returned for 183 residents who resided in the facilities involved in the prospective data collection, and 65 were returned for residents of facilities based on retrospective data collection only. Some residents moved and so the completed after-death questionnaires concerned 6 more facilities, resulting in a total of 40 facilities. Residents with completed after-death questionnaires died between February 2007 and July 2010. The main study aim was to assess factors

associated with quality of care and quality of dying. Other aims were to described comfort, symptom burden, pain, decision making and treatment at the end of life. A total of 26 nursing home organizations were invited to participate, 17 agreed, representing a response rate of 65% (2 more nursing home organizations participated after taking the initiative and expressing an interest in participating). The family caregiver received a questionnaire around 2 months after the death of their relative. The response rate was 58%. The study protocol was judged not to fall under the scope of the Medical research Involving Human Subjects Act (WMO), as declared by the Medical Ethics Committee of VU University Medical Center in Amsterdam, in 2006 *(number 06/179 (2006)*.

Study 4 FOLlow-Up= Feedback on End-of_Life care in dementia [6]
The 537 residents enrolled in this study all died on a psychogeriatric ward in 18 different nursing homes and were admitted at least 16 days in the last month of life. The time of death was between January 2012 and June 2014. The study aim was to assess the effect of (patient or generic) feedback strategy on perceived end-of-life care and comfort and the study design was a cluster-randomised 3-armed trial. For this trend analysis the residents who resided in the facilities assigned to the control condition (pre-intervention phase and intervention phase) and all residents who died in the pre-intervention period of the intervention groups (patient and generic feedback strategy) were included for analyses. Residents were included if they had stayed in the nursing home at least 16 days in the last month of life and had a dementia diagnosis in their medical file. Around 6 weeks after death the family care giver received an information letter and questionnaire, the response rate was 65%. This cluster-randomised controlled trial is registered in the Netherlands Trial Registration, NL3777 (NTR3942). The research protocol of the Follow-up study was reviewed by the Medical Ethics Review Committee of VU University Medical Center (number 2012/173; judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO)).

Study 5 PACE= Palliative Care in care Homes Across Europe [7 8]
This study conducted in 6 countries included 329 people of whom 143 were residents of 25 nursing homes on a psychogeriatrics unit (mostly for people with dementia) at the time of death and 89 family caregivers returned the questionnaires, response rate 62%. These residents died between December 2014 to November 2015. The organizations were invited to participate through a random sampling procedure in each country, based on at least region/province and facility size (number of beds). The aim of the PACE study was to compare palliative care in nursing homes in 6 European countries. The study was funded in the European Commission FP7 program. Consent to participate was obtained when the questionnaire was returned. The Medical Ethics Review Committee of the VU University Medical Center Amsterdam provided a waiver from review as it was judged to not fall under the scope of the Medical Research Involving Human Subjects Act (WMO), 2015.

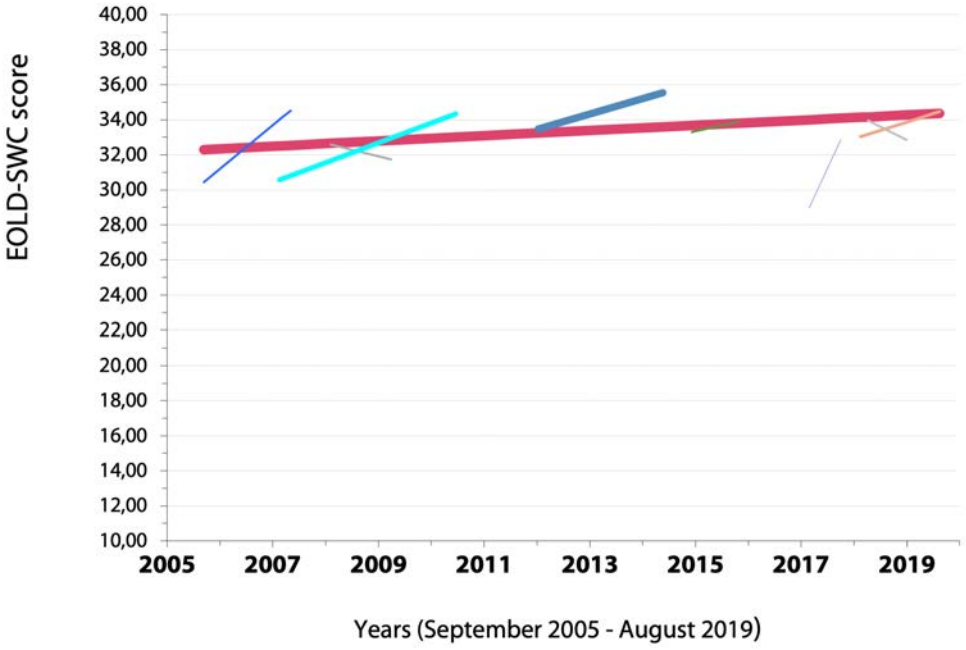
Study 6 Proeftuin Dementie
This study aimed at setting up palliative care team specialised in palliative care for people with dementia and evaluate it effects in 4 nursing homes. Family caregivers of nursing home residents completed questionnaires before the intervention was pilot tested, and the mobile team was consulted only for home-dwelling persons with dementia. The 16 residents with dementia included in this study (response rate 43%) had been admitted to a psychogeriatric ward of one of four nursing homes in the region where the study was conducted and died between February 2017 and September 2017. Relatives were contacted in March 2018 and asked to complete the questionnaire. Ethical review for the research protocol was provided by the Medical Ethics Review Committee of the Leiden University Medical Center (number (P17.214; judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO)).

Studie 7 DEDICATED= Desired Dementia Care Towards End of Life
Between February 2018 and September 2019, 206 residents were included in this ongoing end-of-life study. The DEDICATED project aims to improve palliative care for people with dementia. The researchers collect quality of care and quality of dying data over time in one of the participating organizations. The current dataset includes 126 residents who resided on a psychogeriatric unit. For this analysis, we included 125 residents, excluding one resident with a missing date of death from the analysis. The family caregivers in this study received an information letter and questionnaire between 6 to 8 weeks after the residents' death, as part of the routine post-death assessment of the organization. The response rate was 61%. The study protocol was approved by the Medical Ethics Committee of the Maastricht University Medical Center (number METCZ20180026), judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO).

Study 8 Marente
This study was conceived for the purpose of addressing the research question about trends in family perspectives on quality of care and quality of dying. All caregivers who served as contact persons for staff received questionnaires if their family who resided on a psychogeriatric (mostly dementia) unit and died between first of March 2018 and 31st of December 2018 in one of six facilities of a care organization in the West of the Netherlands. The questionnaires were sent end of March 2019 to 86 relatives and 50 were returned between the first of April and 25th of May 2019, response rate 58%. We enquired with the Medical Ethics Review Committee of the Leiden University Medical Center; because of use of the same questionnaire as used in study 6, they regarded the ethics review for study 6 as leading and study 8 as an extension with more facilities of the observational part of study 6.

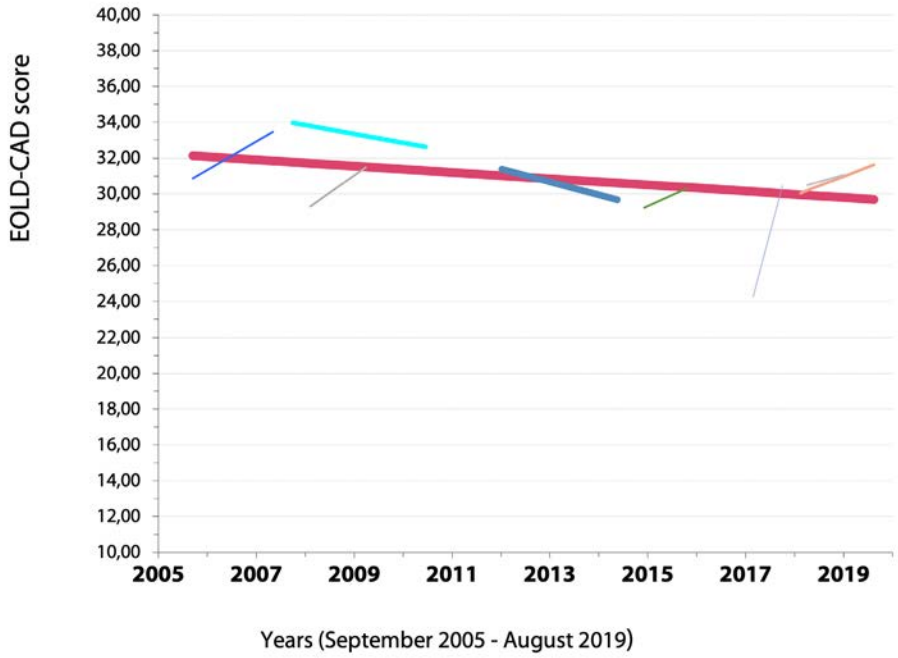
Supplement Figure 1 EOLD-SWC score unadjusted for covariates, with random effects for season and facility

EOLD-SWC= End-of-Life in Dementia Satisfaction with Care, DEOLD=Dutch End Of Life in Dementia, FOLlow-up=Feedback on End-of-Life care in dementia, PACE=Palliative Care in Care Homes Across Europe, DEDICATED=Desired Dementia Care Towards End of Life

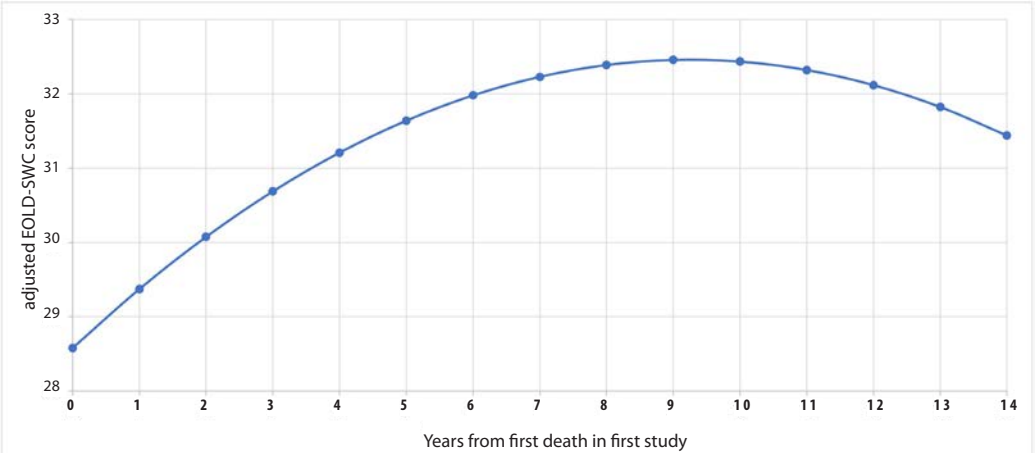


Supplement Figure 2 EOLD-CAD score unadjusted for covariates, with random effects for season and facility

EOLD-CAD=End-of-Life in dementia Comfort Assessment in Dying, DEOLD=Dutch End Of Life in Dementia, FOLlow-up=Feedback on End-Of-Life care in dementia, PACE=Palliative Care in Care Homes Across Europe, DEDICATED=Desired Dementia Care Towards End of Life



Supplement Figure 3 Quality of care (EOLD-SWC=End-of-Life in Dementia Satisfaction With Care) adjusted model with additional quadratic term for time



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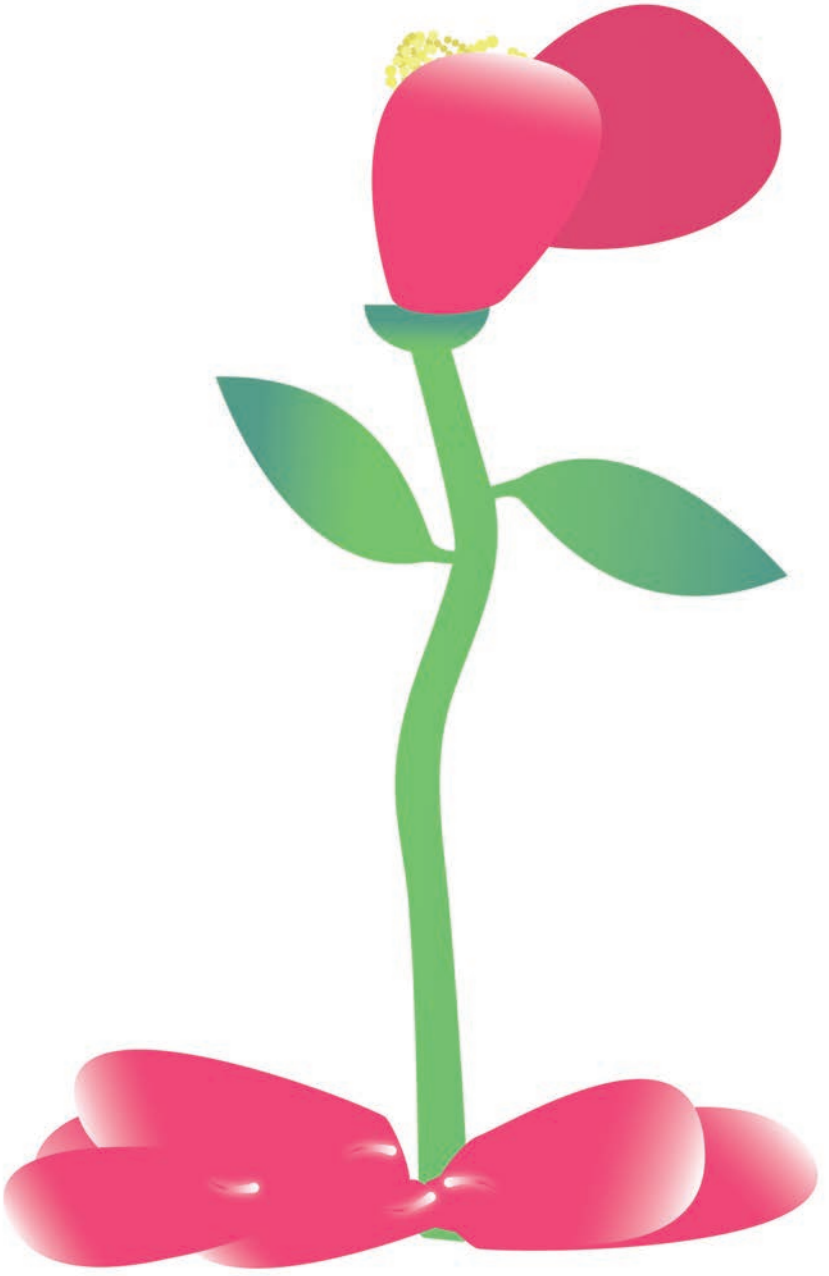

Chapter 7
General discussion

7.1 Main findings

Research question 1: Can we identify patient characteristics associated with a lower quality of life in people with moderate to very severe dementia in nursing homes?
To answer this question, we used the cross-sectional baseline data of the STA-OP! study to evaluate a stepwise multicomponent intervention for challenging behavior and pain. The QUALIDEM is a 37-item observational instrument to measure quality of life in persons with dementia. In this study we used the 18 questions from the six QUALIDEM domains ('Care relationship', 'Positive affect', 'Negative affect', 'Restless tense behavior', 'Social relations' and 'Social isolation') that also apply to people with very severe dementia. The results in **Chapter 2** showed that a lower quality of life is independently associated with pain, neuropsychiatric symptoms, more ADL dependency, higher age, psychiatric disorders, and pulmonary disease. Interestingly, quality of life was higher in the QUALIDEM domain 'Social isolation' for those with more severe dementia.

Research question 2: What is the effect of the STA-OP! intervention on the different domains of quality of life measured with the QUALIDEM over time?
The cluster randomized controlled trial in **Chapter 3** evaluated the effect of the implementation of the stepwise multicomponent intervention for challenging behavior and pain (STA-OP!) on quality of life over time as compared to usual care. In the short term, between 0 and 3 months, no difference was found between the group receiving the STA-OP! intervention and the control group on the QUALIDEM domains 'Care relationship', 'Positive affect', 'Negative affect' and 'Social relations'. In the first 3 months a positive effect was seen in the domain 'Restless tense behavior'. In the long term, 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'.

Research question 3: What are physicians' and nurse practitioners' experiences using the 'Liverpool care pathway for the dying patient' in nursing home residents, including those with dementia?
The mixed-method study in Chapter 4 describes the results regarding the use of and experience with the Liverpool Care Pathway (LCP) based on a survey completed by 159 physicians and nurse practitioners and ten additional semi-structured interviews. The respondents were very positive about the content and less positive about the use of the LCP. Also, identifying the right moment to start the LCP was found to be difficult. The practical application of the LCP was different after the implementation of the electronic health record. Nonetheless, the LCP was considered an important marker of quality for the assessment of symptoms in the dying phase and communication with relatives. There was a clear need for a tool that includes symptom assessment and an earlier (than the last days of life) focus on quality of life and care. This study provided insight into the mainly positive associations and experiences with the use of an instrument in end-of-life care, despite less actual use and considerable problems with the use of the instrument in its digital form.

Research question 4: What is the incidence and course of observed symptoms and treatment in the last days before an expected death in people with dementia?
The prospective observational follow-up study in Chapter 5 was part of a study to validate several methods to measure quality of care and quality of death with dementia in nursing homes. A total of 24 people with dementia with an expected death within a week were followed until death. Direct physician observations explored the symptoms and treatment in these last days. The results showed less pain and discomfort (low total scores on the observational instruments PAINAD, DS-DAT, EOLD-CAD and MSSE) and no increase in symptom burden in the period towards death. As regards medical treatment, over 50% of prescribed antibiotics, oral medication or rehydration were stopped in this group and all residents received palliative treatment with morphine. This is in line with a palliative approach for people dying with dementia, especially people with an expected death in a nursing home.

Research question 5: 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?
The study in Chapter 6 combines the results of eight Dutch studies in which experiences of family caregivers with the quality of care and quality of the death of their relatives with dementia were examined over a period of 14 years (2005-2019). The results were surprisingly counterintuitive, with an increased experienced quality of care, especially over the first years, but no experienced increase in quality of death.

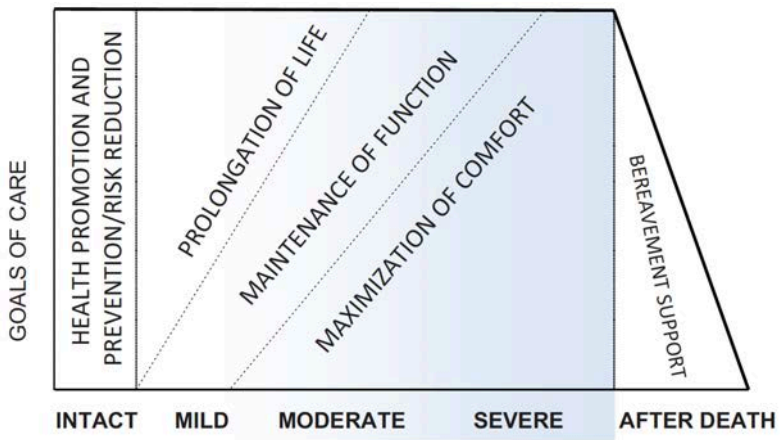

Figure 1. Dementia progression and suggested prioritizing of care goals. White paper, van der Steen et al., 2014. (replicated with permission)

The figure was reproduced with permission form the authors ffrom van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L; European Association for Palliative Care (EAPC), White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care, Palliative Medicine, Copyright (C The Authors, 2013).

7.2 Interpretation and critical discussion of findings and methodology

The concept of quality of life in dementia

People with dementia undergo a transition through different phases of the disease that are roughly associated with different goals of care, i.e., prolongation of life, maintenance of function, and maximization of comfort. (Figure 1). [1] Progression of dementia and decline in cognitive function lead to an increase in care dependency. [2] This process causes stress and puts a burden on people with dementia and their relatives. Additionally, many people with behavioral and psychological symptoms of dementia (BPSD) who are admitted to a nursing home also display hugely challenging behaviors that have considerable impact on professional caregivers.

Quality of life is even more threatened in people with dementia living in a nursing home when compared to living at home. [3] The WHO defines quality of life 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.' [4] Many of the building blocks in the first part of this definition are difficult for people with advanced dementia, because they refer to complex and abstract themes. As dementia is a non-curable disease, quality of life is the most important outcome of care and treatment. It is therefore an important topic in research on people with dementia in general, and on people with more advanced dementia living in a nursing home in particular. [5]

Assessing quality of life in dementia

Several models have been developed to support measuring and improving quality of life in people with dementia [6], and all refer to its multidimensionality. [7-9] Ideally, quality of life is reported by the person with dementia, but due to the progression of the disease this often becomes impossible. Proxy-reporting, by observation, then is the only way to assess perceived quality of life. However, research shows that outcomes may differ between self-report and staff or family report. [10, 11] Behavior observation and rating instruments have been developed for proxy assessment of quality of life in people with dementia, especially nursing home residents, many of whom have advanced dementia. [12] Reviews have identified several instruments to assess quality of life in people with dementia based on different conceptual models. [12-14] In the Netherlands, the QUALIDEM [15, 16] is often used in research on nursing home residents with dementia. This observational instrument is based on the theoretical framework of the adaptation-coping model of Dröes [17], which uses the level of adaptation, which is assumed to be the result of the process of adapting to the consequences of the disease, as an indicator for quality of life.[18] We chose this specific conceptual model for our studies in Chapters 2 and 3, because it is best suited to the continuous adaptation to the changing consequences of the disease. [19] The QUALIDEM includes the relationship with

nursing staff, which is very relevant in a nursing home setting, and contains questions that are applicable to people in a more advanced stage of dementia. Other quality-of-life instruments are based on different theoretical models, for instance the proxy-rated Alzheimer Disease Related Quality of Life (ADRQoL) instrument [20] which is based on 3 sectors of Lawton's generic quality of life definition; psychological well-being, perceived quality of life and the social component of behavioral competence, but it also evaluates physical and cognitive functioning and the external environment. [7] The use of different theoretical models leads to a different focus in each quality-of-life instrument, which hampers comparability of study results related to people with advanced dementia.

Psychometric properties of quality-of-life observation instruments

The measurement properties of the QUALIDEM vary with regard to internal consistency, reliability, content validity, and construct validity. Internal consistency was rated poor to excellent [21 22], test-retest reliability was rated as good, inter-observer reliability was poor and content validity was very good. [15, 16] As described in Chapter 3, scalability of the domain 'Social relations' was low and the domain 'Negative affect' had a low reliability. Despite these concerns, several studies show the QUALIDEM to be a reliable and valid instrument for measuring quality of life in a nursing home setting, because psychometrics have been tested and are also easily accessible online. [12, 22] The original QUALIDEM requires items to be rated by two nurses (who must agree on the item score) but in many studies, including those reported in Chapters 2 and 3. This rarely occurs in practice, which may affect reliability. In a large group it will probably not affect the mean total score, but research on increasing inter-rater reliability (IRR) of the QUALIDEM shows the positive effect of the use of a user guide. [23]

What is good quality of life in people with dementia?

When measuring quality of life with an observational instrument, in this thesis the QUALIDEM, it is important to discuss how we define good or poor quality of life for people with dementia. This is of particular importance, as research shows a decrease in quality of life after admission to a nursing home for people with dementia compared to home-dwelling people. [3, 24, 25] The results of the QUALIDEM scores in Chapters 2 and 3 at baseline show that the mean scores of the separate domains are comparable to other studies regarding quality of life in Dutch nursing homes. [21] In the future, more comparison may be possible because the Netherlands Institute for Social Research (Sociaal en Cultureel Planbureau SCP) also included the QUALIDEM as a measurement instrument in their social science research in 2019. [26] The total scores on each QUALIDEM domain do not have a specific cut-off or threshold value and the sum score does not necessarily represent an overall quality-of-life score. We analyzed the results of our study in each separate domain based on the median score to compare the group with lower quality of life versus the group with higher quality of life. It is therefore difficult to estimate the general overall quality of life of people with dementia in terms of good or poor. This underlines the difficulty, maybe even impossibility of making a real and valid overall judgement of the quality of life of people with limited mental capacities.

Use of quality-of-life domain scores or a quality-of-life composite score?

If interpreting an overall judgement or score for quality of life is not straightforward, how should quality-of-life scores be used in studies? In our study (Chapters 2 and 3) we did not use a sum score, but there are authors who do. They often linearly transform total scores to 100 for each QUALIDEM domain in the analysis. [27-29] Using a total score would be useful to enable comparison of different populations and results from other studies. [30, 31] Structural implementation of the use of a total score to compare outcomes of different care practices in comparable populations and to detect change in overall quality of life in individuals could also be helpful in the future. It may provide opportunities for practice-based research designs that can lead to more and increasingly effective intervention studies. [32] However, the validity of such an approach will first have to be established.

Length of QUALIDEM in relation to stages of dementia

Although the QUALIDEM has been developed for people with dementia living in a nursing home, only 18 of the 37 items are applicable to people with very severe dementia (Reisberg GDS [33] score 7). This meant that, to be able to compare groups (Chapters 2 and 3), we could use only these 18 items in the studies that also included residents with less severe dementia. Recently, a shorter eight-item version of the QUALIDEM was presented [34] but further research into its psychometric properties is needed. In particular its responsiveness, because the eight items cover only four subscales ('Positive affect', 'Negative affect', 'Restless tense behavior' and 'Social relations'). Dementia severity (including residents with Reisberg GDS 7) determined the selection of these scales, but the choices were predominantly pragmatic, based on the length of the items for easier use on a touchscreen-based assessment instrument, not on reliability data of the items related to dementia severity. It was also assumed that all items belonging to the same scale were equivalent and interchangeable. This means that the eight-item instrument by Junge contains items 5, 6, 10, 11, 12, 19, 22 and 34 of the original QUALIDEM, of which only items 5, 6, 12, 19 and 22 are considered applicable to people with very severe dementia. [16] This makes the eight-item version less reliable for use among all residents in a nursing home setting. A future short QUALIDEM should be reliable, valid and responsive, and easy to use. It should also facilitate implementing standard quality-of-life assessment as an outcome measure in research in nursing home settings for people with dementia.

Medical correlates of quality of life in dementia

People with dementia have comorbidity, 61% of people with Alzheimer's disease across various care settings had three or more comorbidities. [35] Not many studies have been conducted that include both comorbidity and quality of life, especially in people with dementia in nursing homes. Better recognition of type and impact of comorbidity in these persons is needed to maintain and improve their quality of life. [36] The study in **Chapter 2** shows important results concerning the relationships of comorbidity and quality of life. Comorbidity was assessed with the MDS-RAI comorbidity list [37, 38] and quality of life with the QUALIDEM. The results showed no relationships between quality of life and endocrine diseases, visual impairments, cardiovascular diseases,

diseases of the musculoskeletal system, neurological diseases, or infections. But there were associations between quality of life and psychiatric disorders, pulmonary disease, pain, and neuropsychiatric symptoms. These are explained below. The assessments in this study for comorbidity were related, as described in the MDS-RAI manual, to the actual functioning of the resident in terms of daily activities, cognition, mood and behavior, medical treatment, monitoring of care, or risk of dying.

Psychiatric disorders
Residents with psychiatric disorders had a significantly lower quality of life in the domain 'Positive affect'. Positive affect is defined as an experience of sensations, emotions, and sentiments and how people interact with others and with their surroundings. [39] The psychiatric diagnoses in this study (**Chapter 2**) included anxiety disorder and depression. Psychiatric disorders may result in impaired facial expressions and apathy due to the disease itself or as a result of medication. Further research on associations with quality of life should differentiate type of psychiatric diagnosis in people with different types of dementia. [40] This is also important regarding the use of medication; the use of antidepressants, antipsychotics and anxiolytics is still very high. [41, 42]

Pulmonary disease
In the QUALIDEM domain 'Negative affect' a significantly lower quality of life was found in people with dementia who also had a pulmonary disease, such as Chronic Obstructive Pulmonary Disease (COPD). For people with dementia, anxiety or crying, resulting from shortness of breath can be even more difficult, as they often lack the ability to verbally explain their physical problems, which can result in more anxiety. The results in **Chapter 2** are in line with literature that shows a high prevalence of depression and anxiety in people with COPD. [43, 44] In addition, a small study indicates a relationship between a higher incidence of depression in people with Alzheimer's disease and COPD. [45] The prevalence of a pulmonary disease such as COPD is 12.5% in people with dementia. [46] Understanding and targeting possible causes of a lower quality of life for people with dementia and COPD is therefore relevant in (future) interventions.

Pain
Pain is one of several factors that influence quality of life. [47] Although a correlation between pain and quality of life is to be expected, it was not linear. Pain is frequently present in people with dementia living in nursing homes, prevalence ranging from 32% to 57%. [48, 49] Our study showed that pain was negatively associated with the QUALIDEM domains 'Care relationship' and 'Negative affect'. A study by colleague van Dam et al. showed that quality of life was significantly lower in residents with dementia who used pain medication. [50] Another recently published study by van Dalen-Kok et al. showed that pain and ADL were associated [51], which may indicate the importance of pain-related resistance to care and the relevance of the relationship of the care team with the person with dementia. It would be of great interest to further explore this relationship and find non-pharmacological ways to improve quality of life for people who suffer pain and dementia.[52]
Neuropsychiatric symptoms

Neuropsychiatric symptoms were independently negatively associated with all six domains of the QUALIDEM, namely 'Care relationship', Positive affect', Negative affect', 'Restless tense behavior', 'Social relations', and 'Social isolation'. Other studies investigating the association between quality of life and neuropsychiatric symptoms, also found a significantly lower quality of life on all QUALIDEM domains, but in particular with regard to agitation and depressive symptoms. [53] Literature has already suggested a relationship between neuropsychiatric symptoms and pain. [54 53] Nursing staff often observe neuropsychiatric symptoms (behavior) or changes in behavior of the person with dementia, especially nurses who are familiar with their residents. The individual interaction between a nurse and a resident can influence the observations, and the nurse's own behavior may affect the quality of life of the resident. As in the relationship between pain and quality of life, the relationship between neuropsychiatric symptoms and quality of life calls for a wider implementation of stepwise non-pharmacological interventions.

Malleability of quality of life in dementia

The results found in **Chapter 3** demonstrate the possibility to positively influence specific domains of quality of life. STA-OP! was a complex intervention involving training of the entire multidisciplinary team on a dementia care unit in a stepwise protocol for recognition of Behavioral and Psychological Symptoms of dementia (BPSD), recognizing pain, and (non-)pharmacological treatment options. The implementation of the STA-OP! method showed that it is possible to reduce behavioral problems, pain, depression and the need for psychotropic medication. [55, 56] Nursing home staff experienced increased awareness of pain cues and challenging behavior. The knowledge gained from this complex intervention led to a variety of results regarding behavior, pain, and also quality of life (**Chapter 3**). It shows that these concepts are closely related, which is hopeful for many types of complex interventions that aim to improve them. This reinforces the need to structurally implement non-pharmacological interventions in the daily care of nursing home residents with dementia. Recent research indicates that multicomponent interventions should focus on quality and quantity of interaction between care home staff and people with dementia. [57] Future studies should use these insights regarding interaction with people with dementia and adapt research methods that focus on long-term change within the entire care team. [58]

Resident perspective in dementia studies

Including the perspective of the individual residents in the development of interventions and research is very important. It can provide relevant information on their emotional and spiritual needs and wishes in relation to quality of life, as shown in recent research. [59] The two studies in **Chapters 2** and **3** lack the personal perspective of the people with dementia on quality of life; self-report measures should also be tried and used in (the evaluation of) interventions. [60-62] In all five studies (**Chapters 2, 3, 4, 5, and 6**) presented in this thesis, the perspectives of the nurses, nurse practitioners, physicians or family caregivers were used but the perspective of the resident was absent. Kitwood's framework of person-centered care is relevant and describes personhood as an ongoing

process, deeply influenced by social relationships and interactions. [63] Kitwood based his research mainly on people with moderate to severe dementia living in institutional care settings and on the perspectives of close relatives and professional caregivers. To provide person-centered care it is paramount to try to include the perspective of the people with dementia themselves for as long as possible. [64] Structural involvement, from the start and as long as possible, means a more prominent representation of the resident perspective in research - it may not be easy, but it is necessary. The University Nursing Home Network UNC-ZH is working on a model to ensure co-creation in further studies. [65]

What is the difference between quality of life and quality of dying?

As described before, quality of life is defined by the WHO as a broad concept, affected in a complex way by the person's physical health, the individual's perception of their position in life in a broad context and in relation to their goals, expectations, standards and concerns. [4] This definition is applicable in all stages of life, including when someone has dementia, but the focus changes as death approaches. In the last days of life, the focus often shifts towards symptom control and prevention of physical distress. This is also visible in the instruments frequently used to determine quality of end-of-life care and quality of dying; the Liverpool Care Pathway (**Chapter 4**), Mini-Suffering State Examination (MSSE), Pain Assessment in Advanced Dementia Scale (PAINAD), Discomfort Scale-Dementia of Alzheimer Type (DS-DAT), End-of-Life in Dementia-Comfort Assessment in Dying (EOLD-CAD) (**Chapter 5**) and the EOLD-CAD and End-of-Life in Dementia-Satisfaction With Care (EOLD-SWC) (**Chapter 6**). The term 'quality of dying' was specifically chosen in **Chapter 6** because the term 'comfort', which is also frequently used in literature in the terminal phase [66], often refers to the presence or absence of physical symptoms and less to spiritual needs or invasive medical actions that can also be relevant in this last phase of life. The term 'quality of dying' is also regularly found in literature [67, 68] but the used instruments predominantly include relevant symptoms in the dying phase that should be recognized and prevented or treated. All above-mentioned instruments (**Chapters 4, 5** and **6)** are not specifically adapted for people with (very) severe dementia, for instance with specific items on facial expression, body movements and vocalization for better recognition of pain. [69]

Can we tell if a person is going to die?

In the last days of life, family members often want to know when a person with dementia is going to die. We are not able to predict the exact moment a person will die. Only if life expectancy is seven days or less can death be predicted more accurately, as shown in **Chapter 5** and in results from earlier research in Dutch nursing homes. [70] There are some signs that are associated with the dying phase: e.g. the person is semi-comatose, the person becomes bedbound, the person is able to take only sips of fluid, and the person is no longer able to take oral drugs [71]; in people with dementia the last three signs are often already present over a longer period of weeks or months. This may result in a very late recognition of an expected death, varying from only hours to two to three days before death. **Chapter 3** showed it is necessary to implement a tool such as the LCP much earlier than the last hours or days before death. The focus

on communication and improvement of symptom control implies a better start of the dying process. In addition, the last phase of life and inevitable upcoming death should be discussed soon after (within the first weeks of) admission to a nursing home in order to clarify expectations and better align care goals and personal wishes. This so-called advance care planning (ACP) in long-term care facilities is frequently reported in literature but there is a wide variety in practice, both in the Netherlands and across Europe. [72, 73] Despite these differences, conversations about advance care and wishes regarding quality of life in the nursing home must take place, and not only with family caregivers. It is also important to include the perspective of persons with dementia. [74] Results from studies on ACP in people with dementia [75] can be used to further develop optimal palliative care for people with dementia in a nursing home.

Treatment decisions regarding hospitalization, medical treatments and opioid use in the nursing home

Several studies showed no decrease in symptom prevalence or hospital transfers after ACP implementation. [76-78] This may be because communication should take place earlier in the dementia process and soon after admission to a nursing home. ACP with people with dementia and their relatives should address the expected course of dementia, provide a realistic picture of the disease, and also discuss the possibilities and outcomes of treatments in the nursing home. The study in **Chapter 5** expands the knowledge on avoiding aggressive and burdensome treatment in end-of-life care. Literature indicates that treatment decisions regarding hospitalization, hydration and feeding tubes for people with advanced dementia differ between several countries. [79-81] The choices regarding hospitalization, hydration and absence of a feeding tube established in **Chapter 5** highlight the common palliative choices made for residents with advanced dementia in nursing homes and expected death in the Netherlands. [82] The high opioid use (100%) in people with expected death in **Chapter 5** is similar to a recent study on opioid use in people dying in Dutch nursing homes. [83] An in-depth study of cause of death, indication and dosage would be interesting to determine whether this high opioid use constitutes adequate treatment. This information is needed to create more specific guidelines to improve symptom control and care in the last days before death.

How do people with dementia die?

The death of a loved one can have a huge impact on relatives and the care team. Research shows that dyspnea, pain, sleep problems, agitation, anxiety and death rattle are frequently observed in people with dementia dying in nursing homes [84, 85]. Many people equate a good death with a death free from avoidable distress and suffering for the patient, family and caregivers, which also includes the perspective of the dying individual. [86, 87] The study in **Chapter 6**, in which the trend in quality of care and dying was described, included the perspective of the family caregiver in the period before death. Increased satisfaction with the quality of care was evident, in particular in the first years between 2005 and 2010. It is worth noting that no positive trend regarding quality of death was found, but rather the opposite. A negative trend for the subscale 'Well being' was found that remained unchanged after

adjustment for characteristics of residents and family caregivers, region and design. The increased satisfaction regarding quality of care can be interpreted as a result of increased attention for palliative care and improved communication with the family caregiver. However, the absence of improved quality of death, as measured with the EOLD-CAD, which contains items related to possible burdensome symptoms in the dying phase, leaves a very unsatisfactory imprint, as one would expect and hope that symptom burden would diminish over time. Observational research is required to gain more clarity about the amount, course and duration of symptom burden of dying in people with dementia, to identify what causes family caregivers to experience the reduction in well-being, to shed more light on how people die, and to determine which aspects of the dying process we should address to improve quality of death.

Challenges in measuring quality of life or quality of death

Organizing and conducting a cluster randomized study (**Chapters 2** and **3**) in a nursing home is quite a challenge. E.g., because of the study design, the care team know whether they worked on the intervention ward or not, they were not blinded, and the study included residents from the STA-OP! intervention. Also, the complexity of the intervention for people with advanced dementia with different types of behavioral problems and proxies filling out observational instruments raises the question of the reliability of the results. Part of the data were collected by independent research assistants, but data about quality of life were collected, e.g. via QUALIDEM, by nurses. These professional caregivers knew the residents best, which may have influenced the results. Apart from these points, there are clear outcomes related to a better quality of life similar to experiences in other reports related to pain and the use of antipsychotics.[55, 56] The effect of a comprehensive training program (**Chapters 2** and **3**) for the care team contributes to a better implementation of the intervention. The results in **Chapters 2** and **3**, as well as **Chapter 5,** may indicate that additional education with clear steps and extra attention by means of specific additional observation moments might influence quality of life and dying in a nursing home for people with dementia. Education of the care team can help raise awareness and improve communication within the care team and with family members.[88] It is important to involve family caregivers in the care plan for their relative but also to evaluate the received care after the relative's death (**Chapter 6**). Structural after-death evaluation of received care is necessary to help evaluate and improve future care for people with dementia. It is also necessary to monitor on which model the instrument to observe quality of life or dying is based, and what information it provides, so as not to draw the wrong conclusions. This is particularly relevant when terminology regarding quality of life, quality of dying, well-being and comfort is open to multiple interpretation.

7.3 Recommendations for future research

Measuring quality of life and quality of dying

Structural measuring quality of life with a short, validated instrument
One of the first recommendations based on the studies presented in this thesis is that quality of life should be measured with the same validated instrument in intervention studies that aim to improve quality of life. This validated instrument should be brief and easy to use in daily practice and should be able to determine an individual's quality of life. Ultimately, we should strive for an instrument that can be used structurally in daily practice and at an individual level in order to enable the application and evaluation of care goals and interventions that can improve quality of life. These regular quality-of-life assessments can help the care team and relatives to shift to different care goals when dementia progresses as shown in Figure 1.

Research into expectations regarding dying with dementia
With the increased attention for palliative care in dementia we recommend studying the expectations regarding the imminent death of a loved one with dementia in the nursing home. This research should include observational studies that provide more insight into the course of symptoms and treatment in the last days of life, as well as studies that look into the actual use of specialist palliative knowledge in the nursing home setting. Quantitative and qualitative research can provide more in-depth information on the expectations with regard to the approaching death from the perspectives of family and professional caregivers, but also from the point of view of the person with dementia.

Questionnaires after death to evaluate end-of-life care and death
Family caregivers seemed willing to share their experiences and nearly 60% of those invited responded to the opportunity to complete the questionnaire. This suggests that approaching all family caregivers after the death of their relative with dementia in the nursing home setting is also a way to conduct research on a structural basis. This can facilitate a thorough evaluation of experiences regarding the care received and the death of their loved one, which may provide valuable lessons for future care. This is certainly important in times of rapidly changing circumstances, as is the case currently with the COVID-19 virus, which has a major impact on residents and family members in nursing homes. [89]

Palliative care is a necessary part of dementia care

Although there is more awareness of the need to think in terms of palliative care for people with dementia [1], many people still think palliative care is only applicable in the dying phase. We need to be more focused on changes in functioning over time and discuss necessary changes in care goals. Research results should be used and incorporated into daily practice, as was done for example, with the positive results from the STA-OP! study and the criticisms, including points for improvement, relevant to working with the Liverpool Care Pathway. We recommend developing a

'Dementia Care Pathway' that can be used soon after admission to the nursing home and can help the care team and family caregivers formulate advance care planning, prevent burdensome symptoms and improve communication during the person with dementia's stay in the nursing home. Available instruments that could help to achieve this include, e.g., the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem).[90, 91] This instrument needs to be translated and validated in the Dutch nursing home setting. In addition, we need to know which meaningful medical treatments and care goals we can provide in the dying phase. Often there are concerns about negatively labeled choices such as not sending someone to the hospital or not giving someone antibiotics or intravenous therapy. However, many possible choices or actions that are not yet mapped properly often receive a great deal of attention, such as prevention of physical and psychological symptoms, offering fluids and nutrition as desired, offering sensory stimulation such as music, and offering spiritual care as desired. This Intensive Individualized Comfort Care (IICC) as described by Lopez [92] can be used to help determine which care goals are available for the last days of life with dementia.

Focus on symptom burden and treatment

Future research should focus on the results of structural education of care teams in the nursing home on both dementia and pain, and on developing clear non-pharmacological and pharmacological treatment steps for the treatment of physical symptoms and challenging behavior. In addition, we need to implement more knowledge regarding palliative care for people with dementia. Both education and knowledge can help improve communication in care teams on how to detect burdensome symptoms using instruments developed or adapted for people with dementia, resulting in more awareness within the team.
Beside awareness regarding symptom recognition and treatment to improve quality of life, we also have to investigate whether to adapt our nursing home care in certain situations, e.g. during the outbreak of viruses such as COVID-19, and learn from care teams and family caregivers how this affects them. [89]
Future studies should also specify the kind, amount and duration of symptom burden as well as response to initiated treatments, and focus on the relationships within the care team and communication between physicians and nursing staff. These studies should also include after office hours data, in other words, a 24-hour basis, seven days a week. This information should be clear to all people involved in the care team and used to draw up concise care plans that include steps to take when disturbing symptoms present themselves, especially in the dying phase.
We need plans for how and when to evaluate treatment and how to tailor care to individual needs of nursing home residents with dementia. In this research, cultural, religious and spiritual differences and wishes must also be addressed.[93, 94]

Improve participation of all participants in the care triangle

As dementia progresses, the family's role as the voice for the resident with dementia becomes more important, due to the often diminished verbal capacity of their loved one. The care team together with the family and the resident are regularly

described as the care triangle. Research [95, 96] and guidelines from the Dutch national organization for long-term care Vilans [97] also point out the importance of paying extra attention to the important role of the family caregiver. It is necessary to raise awareness of this triangle in all members of the care team, because it can help to better understand the perspective of the family caregiver and the person with dementia. The renewed definition of palliative care [98] shows some significant changes. In addition to the shift from disease-centered to a more person-centered approach to palliative care, the new definition stresses the importance of all parties of the care triangle in palliative care by including the intended improvement in quality of life of patients, their families and caregivers. It is important to include the perspective of the people with dementia themselves for as long as possible. In addition, it would be interesting to include the relationship between residents and professional caregiver in quality-of-life research ,and also how it affects job satisfaction and quality of life of the professional caregiver.[99] Although research reflects increased awareness and knowledge regarding palliative care in dementia, this awareness must also be passed on to the care teams and family members of people with dementia. At present they are not always aware of the course of dementia, the average length of stay in a nursing home, what to expect with regard to the actual death of the persons they care for or their loved one. Including experiences of family members and care teams with the death of a person with dementia as a regular part of evaluation with validated instruments can provide useful information on experiences and can help detect patterns that can be used in future care for people with dementia. It might also provide information on how to give structural bereavement support for family caregivers.

7.4 Implications for practice/education/ organization

One of the first implications resulting from this thesis is that implementation of an intervention with a fixed structure with clear steps and structural training on dementia, behavior and pain is indicated. This intervention should be implemented using validated observation tools that can measure quality of life and pain at the level of the resident of a psychogeriatric ward in a nursing home. The structural training that supports the implementation should be accessible to all members of the care team including physicians, physiotherapists, occupational therapists, dieticians, nurses at the undergraduate and postgraduate levels, and also volunteers. The acquired knowledge on comorbidity as being an important factor to influence quality of life should also be included in educational programs.

An instrument such as the Liverpool Care Pathway must be adapted for application in people with dementia who die in a nursing home. In addition, a care pathway for the dying phase must be initiated at an earlier stage than the last two or three days before death. This will help to better understand and use the information

already gathered during the resident's stay in the nursing home. It will also promote communication, allowing timely discussions on what actions will not be taken, but also on what can be provided in terms of good palliative care. To improve symptom assessment and treatment with the use of an instrument, additional training aimed at improving symptom recognition in people with dementia must be developed.

Education and communication are as important within the care team as education and communication for another side of the care triangle. Family members must be more involved in care and medical decisions to improve quality of life and quality of dying for people with dementia in a nursing home.

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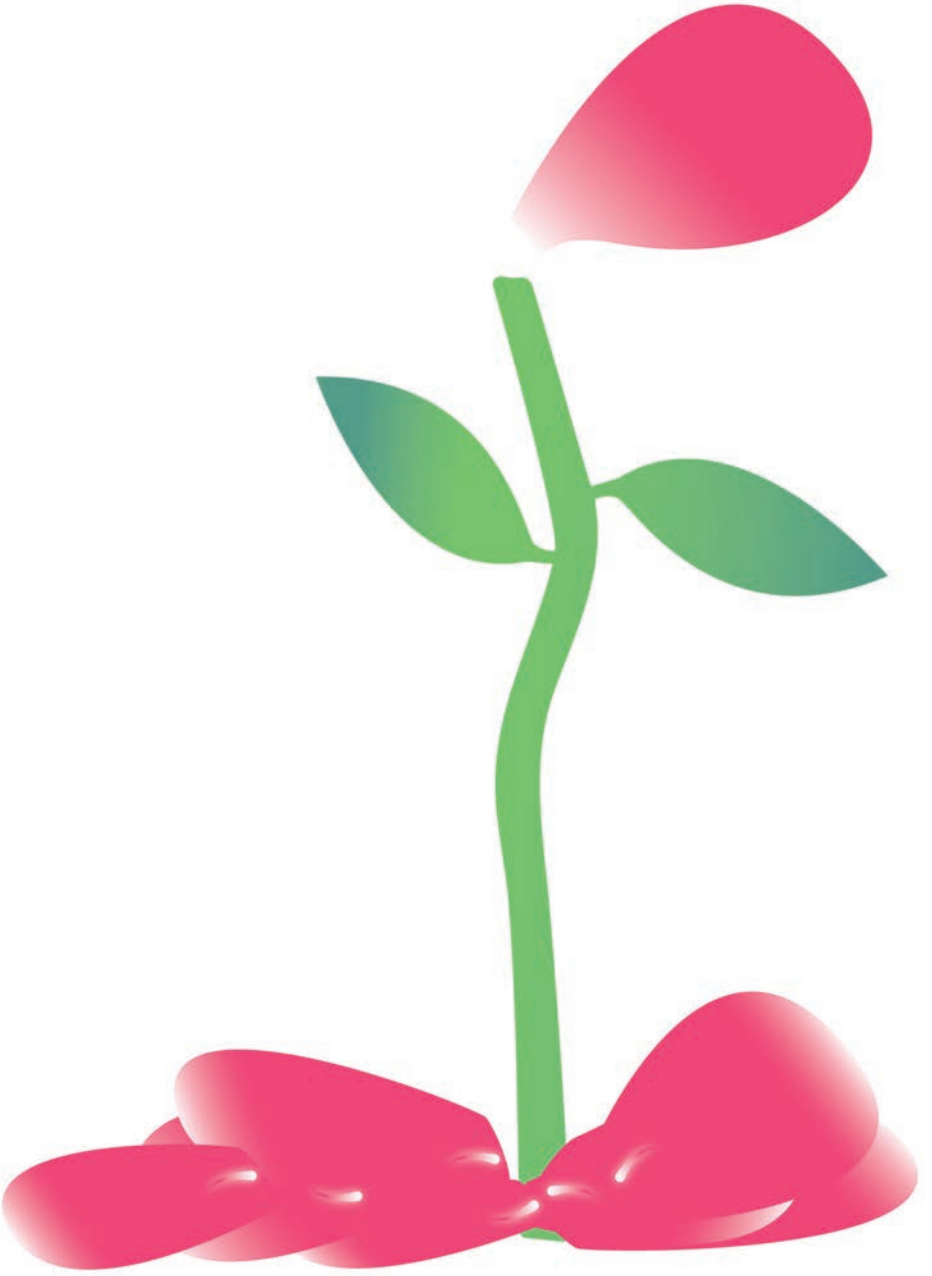

Chapter 8
Summary

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 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 path 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.

Nederlandse samenvatting

Met een verwachte toename van het aantal mensen met dementie neemt ook de noodzaak toe om meer onderzoek te doen bij mensen die deze ziekte reeds hebben. Het is belangrijk meer inzicht te krijgen in hun kwaliteit van leven en hun kwaliteit van sterven en hoe we die beiden kunnen verbeteren. In de inleiding van dit proefschrift, **Hoofdstuk 1**, staat beschreven hoe veranderingen in het brein bij mensen met dementie kunnen leiden tot verschillende uitingen van het ziektebeeld met vermindering in lichamelijk en cognitief functioneren. Vaak geven deze veranderingen ook een veranderingen in gedrag van de persoon met dementie. Progressie van de ziekte geeft een toename van zorgafhankelijkheid met vaak een opname in het verpleeghuis tot gevolg om 24 uur toezicht en zorg te kunnen bieden. Dementie is een terminale aandoening. Het beloop van het ziekteproces en de levensverwachting zijn moeilijk te voorspellen. Daarom is het juist belangrijk om op tijd bij mensen met dementie een palliatieve benadering te gebruiken. Met een palliatieve benadering wordt bedoeld zorg gericht op kwaliteit van leven in plaats van op genezing, die immers niet meer mogelijk is. Bij een palliatieve benadering gaat het dus niet puur om zorg in de stervensfase maar ook om de best passende zorg gedurende de gehele laatste levensfase. In dit proces worden keuzes gemaakt, die gericht zijn op het verhogen van de kwaliteit van leven van de persoon met dementie, familie en naasten. Zeker in een ver gevorderde fase van dementie gaat het vaak niet meer om levensverlenging. In Nederlandse verpleeghuizen heeft net iets meer dan de helft van de bewoners ernstige tot zeer ernstige cognitieve stoornissen, onder andere problemen met het geheugen. Zij overlijden vaak binnen twee jaar na opname in het verpleeghuis. Gezien het progressieve beloop van de ziekte dementie kunnen palliatieve zorgdoelen snel veranderen en moeten regelmatig geëvalueerd worden. Richting de stervensfase is het van belang om te weten dat de bewoner met dementie in een verpleeghuis meer comfortabel sterft als de mantelzorgers en de zorgverleners zich bewust zijn dat dementie een progressieve en terminale ziekte is.

Zowel uit onderzoek als in de praktijk blijkt dat er een noodzaak is de zorg en de kwaliteit van leven voor mensen met dementie in het verpleeghuis te verbeteren. Kwaliteit van leven wordt door de WHO als volgt gedefinieerd: '*De perceptie van individuen op hun levenspositie in de context van de cultuur en het waardensysteem waarin zij leven en de relatie tot hun doelen, verwachtingen, standaarden en belangen*.' Maar hoe kunnen wij weten hoe mensen met dementie hun kwaliteit van leven beleven? Doordat zij zich minder goed verbaal kunnen uiten, kunnen zij bijvoorbeeld niet meer goed aangeven of zij pijn hebben. Om meer zicht te krijgen op kwaliteit van leven bij mensen met dementie zijn er verschillende observatie instrumenten ontwikkeld. Deze zijn vaak gebaseerd op verschillende modellen en definities om kwaliteit van leven te meten (kwantificeren). Het is belangrijk om deze instrumenten te gebruiken bij de zorg voor mensen met dementie. Het verbeteren van kwaliteit van leven is een van de kernelementen van palliatieve zorg. Palliatieve zorg is namelijk zorg die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een

levensbedreigende aandoening of kwetsbaarheid. Dit gebeurt door het voorkomen en verlichten van lijden, door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van problemen van fysieke, psychische, sociale en spirituele aard. Er zijn verschillende dimensies van belang bij kwaliteit van leven, variërend van aspecten gerelateerd aan fysiek en psychisch welbevinden, tot sociale interactie en bijvoorbeeld positief of negatief affect. Om meer kennis te krijgen over de ervaren kwaliteit van leven van mensen met dementie die in een verpleeghuis wonen en om te bepalen of er methoden beschikbaar zijn om hun kwaliteit van leven te verbeteren, hebben we een reeks onderzoeken uitgevoerd. Het algemene doel van dit proefschrift was het onderzoeken van verschillende aspecten van kwaliteit van leven en kwaliteit van sterven voor mensen met vaak een ver gevorderde dementie in het verpleeghuis.

Hoofdstuk 2 van dit proefschrift probeert de vraag te beantwoorden of er patiëntkenmerken te herkennen zijn die samenhangen met een lagere kwaliteit van leven bij mensen met matige tot zeer ernstige dementie in verpleeghuizen. Kwaliteit van leven werd gemeten met de QUALIDEM, een observatie instrument bestaande uit 37 vragen die over een specifieke bewoner ingevuld kunnen worden. De vragen hebben betrekking op zes verschillende domeinen van kwaliteit van leven. De studie is gedaan bij 288 verpleeghuisbewoners, de zorgteams kregen extra scholing over gedrag en pijn. Verschillende kenmerken waarvan wordt verondersteld dat ze verband houden met de zes domeinen zijn onderzocht. Analyse van de data toonde associaties met leeftijd in het domein 'Sociaal isolement', activiteiten in het dagelijks leven (ADL-niveau) in het domein 'Positief affect' en het domein 'Sociale relaties', met de ernst van de dementie in het domein 'Sociale relaties' en in het domein 'Sociaal isolement', met psychiatrische stoornissen in de domein 'Positief affect' en met longziekten in het domein 'Negatief affect' van de QUALIDEM. Neuropsychiatrische symptomen waren onafhankelijk geassocieerd met alle zes domeinen van de QUALIDEM en pijn was geassocieerd met de domeinen 'Zorgrelatie' en 'Negatief affect'. Deze resultaten laten zien dat kwaliteit van leven bij dementie onafhankelijk geassocieerd is met leeftijd, ADL, ernst van dementie, pijn, psychiatrische stoornissen, longziekten en neuropsychiatrische symptomen. Dat betekent dat het mogelijk is om personen met dementie te herkennen die risico lopen op een lagere kwaliteit van leven door te onderzoeken of zij één of meerder van deze kenmerken hebben. Tevens laat het onderzoek zien dat onderliggende aandoeningen en pijn van invloed kunnen zijn op kwaliteit van leven. Bovendien zien we dat je kwaliteit van leven op verschillende domeinen moet beoordelen en niet alleen door het berekenen van een totaal score. Deze informatie is belangrijk voor de ontwikkeling van gepersonaliseerde interventies om de kwaliteit van leven bij personen met dementie in verpleeghuizen te verbeteren.

In **Hoofdstuk 3** wordt gekeken hoe de verschillende domeinen van kwaliteit van leven veranderen tijdens de inzet van een interventie studie over de tijd, na 3 en na 6 maanden. Hierbij is er dus in de helft van de afdelingen extra scholing gegeven ten aanzien van gedrag en pijn en is er per individuele bewoner volgens een stapsgewijze multidisciplinaire en multicomponente methode gehandeld. Opnieuw werd de kwaliteit

van leven gemeten met het observatie instrument QUALIDEM. Na zowel 3 als 6 maanden was er geen verandering en geen verschil in verandering tussen de twee groepen op de domeinen 'Zorgrelatie', 'Positief affect', 'Negatief affect' en 'Sociale relaties'. Na 3 maanden werd er wel een positief effect gezien in het domein 'Rusteloos gespannen gedrag'. Tussen 3 en 6 maanden werd een negatief effect gezien op het domein 'Rusteloos gespannen gedrag' en een positief effect in het domein 'Sociaal isolement'. Mogelijk heeft dit te maken met het stoppen van de studie na 6 maanden en konden bij de stapsgewijze methode niet alle bewoners geïncludeerd worden. Uiteindelijk werd er in de studieperiode 39% van de bewoners geïncludeerd. Toch zijn de resultaten gevonden in de hele studiegroep en heeft de studie mogelijk bijgedragen aan een positief effect voor alle bewoners op de afdeling, mogelijk ten gevolge van de scholing van het hele team waarbij er tevens een effect kan zijn geweest voor andere bewoners op de afdeling. Deze studie laat ook zien dat het belangrijk blijft om naar de verschillende domeinen van kwaliteit van leven te blijven kijken en bij mogelijke toekomstige interventies hier op te letten. Daarnaast is het voor de toekomst belangrijk om naar de effecten van interventies op kwaliteit van leven bij verschillende stadia en vormen van dementie (ziekte van Alzheimer, Lewy Body dementie, Frontotemporale dementie) te kijken.

Tijdens het verblijf in het verpleeghuis verschuiven de zorgdoelen vaak als gevolg van de progressie van de dementie. De doelen kunnen zo veranderen van het op niveau houden van functioneren naar zorg gericht op comfort. Met dit comfort wordt vaak de afwezigheid van negatieve symptomen bedoeld, zoals pijn of benauwdheid. Zeker in de stervensfase is het beperken van symptoomlast een belangrijk doel. De kwaliteit van sterven wordt vaak bepaald door de aan- of afwezigheid van symptoomlast in deze periode. Hierbij wordt soms het 'Zorgpad Stervensfase' gebruikt. Dit Zorgpad bestaat uit drie delen. In deel 1 worden algemene zaken en zorgdoelen uitgevraagd en vastgelegd. In deel 2 wordt elke 4 uur de symptoomlast met behulp van een lijst in kaart gebracht en deel 3 bevat vragen voor de periode na overlijden. Het 'Zorgpad Stervensfase' kan door alle disciplines (verzorging, arts, geestelijk verzorger, psycholoog etc.) gebruikt worden en komt oorspronkelijk uit de meer oncologische gerichte zorg in het hospice. Er zijn ook versies uitgebracht voor de verpleeghuizen en de thuiszorg. In **Hoofdstuk 4** is onderzocht hoe het gebruik van dit Zorgpad ervaren wordt door artsen en verpleegkundig specialisten die werken in het verpleeghuis en die verantwoordelijk zijn voor de medische zorg. Met behulp van een digitale enquête bestaande uit negen vragen aangevuld met tien semigestructureerde interviews, is in kaart gebracht hoe het gebruik van het Zorgpad in de praktijk werd ervaren en wat men vond van de inhoud. Uiteindelijk hebben 159 artsen en verpleegkundig specialisten in drie verschillende regio's in Nederland de vragenlijst ingevuld. Uit de analyse van de vragenlijsten kwam naar voren dat het moeilijk was om te bepalen wanneer iemand daadwerkelijk nu echt in de stervensfase was aangekomen, zeker in het geval van een persoon met dementie. Men was terughoudendheid om het 'Zorgpad stervensfase' te vroeg te starten uit angst om het weer in te moeten trekken. Ook was men erg tevreden over de inhoud van het 'Zorgpad Stervensfase' waarbij werd aangegeven dat het als een belangrijk hulpmiddel werd ervaren bij het geven van

kwalitatief goede zorg. Minder positief was men over het praktische gebruik van het Zorgpad, met name sinds de invoering van het elektronisch patiëntendossier (EPD). Het Zorgpad is vaak niet geïntegreerd in het EPD, dit verhoogt in de drukke dagelijkse praktijk de drempel om het Zorgpad te starten en leidde ertoe dat het niet regelmatig meer werd gebruikt. De regelmatige controle op symptoomlast werd als erg belangrijk onderdeel van goede zorg gezien. Er was echter een duidelijke behoefte aan een korter instrument dat eerder ingezet kan worden, niet pas in de laatste uren of dagen voor overlijden. Ook was behoefte aan een duidelijke integratie van het Zorgpad in het EPD zodat iedereen het op de juiste manier kan gebruiken. Een aangepaste versie van het Zorgpad die al eerder gestart kan worden, maakt het minder van belang om het exacte moment van de start van de stervensfase te bepalen. Bij mensen met gevorderde dementie zijn drie van de vier criteria die in het 'Zorgpad Stervensfase' gebruikt worden om te bepalen of iemand in de stervensfase is namelijk al aanwezig. Een zorgpad voor de stervensfase in het verpleeghuis moet dus aangepast worden, specifiek voor bewoners in het verpleeghuis, en zeker voor mensen met dementie.

Met het onderzoek in **Hoofdstuk 5** wilden we de frequentie en het vóórkomen van symptoomlast voorafgaand aan overlijden van mensen met dementie in kaart brengen. De onderzoeksvraag van dit onderzoek was het in beeld brengen van het vóórkomen en het beloop van geobserveerde symptomen waaronder pijn en benauwdheid. Daarnaast is er gekeken naar de keuze van behandelbeslissingen in de laatste dagen voor een verwacht overlijden bij mensen met dementie in het verpleeghuis. In twee verpleeghuizen werd door de specialist ouderengeneeskunde bij de bewoners met dementie en een verwacht overlijden binnen een week twee keer per dag de symptoomlast gescoord op verschillende onderdelen van kwaliteit van leven en kwaliteit van sterven met vragen over comfort en symptomen. Daarnaast werden vragen ingevuld over behandelbeslissingen in deze periode. Vierentwintig bewoners werden gedurende meerdere dagen tot overlijden geobserveerd. De meeste van hen overleden aan uitdroging/ondervoeding (dehydratie/cachexie) en dit verliep zonder hoge symptoomlast. De gemiddelde scores op alle vier de instrumenten lieten een vrij lage symptoomlast zien. Echter, de individuele symptoomscores lieten zien dat er redelijk frequent pijn, benauwdheid en discomfort gescoord werden. Bij dit onderzoek werd twee keer per dag naar symptoomlast gekeken. Er werd geen toename in symptoomlast gevonden vlak voor overlijden. Eén van de conclusies van deze studie is dat het doen van onderzoek waarbij structureel twee keer per dag werd geobserveerd leidde tot een positief effect en meer aandacht voor palliatieve zorg van het zorgteam en de behandelende artsen.

Hoofdstuk 6 beschrijft onderzoek naar de ervaringen van familie en naasten (mantelzorgers) over hun ervaringen met de geleverde zorg en de kwaliteit van sterven van de bewoners met dementie. Mantelzorgers zijn onderdeel van de zorgdriehoek (bewoner/zorgverlener/mantelzorger) en dus een belangrijke partner van gesprek. Dit is bij uitstek het geval bij de zorg voor mensen met dementie, waarbij zij zich vaak niet meer goed verbaal kunnen uiten. Mantelzorgers kennen de bewoner met dementie

vaak al lang en geven vaak intensieve zorg aan de persoon. In het onderzoek waarbij de mantelzorgers zijn betrokken, is er gevraagd naar hun ervaringen met de geleverde zorg met behulp van twee vragenlijsten. Eén met vragen over de kwaliteit van zorg vlak voor overlijden en één met vragen over kwaliteit van sterven. Om trends in ervaringen van mantelzorgers te kunnen vinden over een langere periode zijn de gegevens van acht verschillende studies die deze vragenlijsten hadden gebruikt gecombineerd. In al deze studies ontvingen de mantelzorgers een vragenlijst in de maanden na overlijden en werd hun gevraagd deze in te vullen en te retourneren. Hiermee kon een analyse gedaan worden van gegevens van 2005 tot en met 2019. Uit dit onderzoek kwam naar voren dat er in deze jaren een verschil werd gezien in tevredenheid van zorg, maar geen verschil in kwaliteit van sterven. Er is dus aanvullend onderzoek nodig om duidelijker te krijgen hoe sterven, en eventueel lijden, gezien wordt door mantelzorgers en om te onderzoeken hoe de symptoomlast bij sterven toch nog verder verminderd kan worden.

In **Hoofdstuk 7** staan conclusies en aanbevelingen voor toekomstig onderzoek beschreven. Naar aanleiding van de studies in dit proefschrift concluderen wij dat het belangrijk is om kwaliteit van leven te onderzoeken en een gevalideerd, kort en praktisch instrument te ontwikkelen dat geschikt is voor de verpleeghuis setting. Dit instrument moet het mogelijk maken op persoonlijk niveau conclusies te trekken over kwaliteit van leven van een individu en dat daarnaast ook aanbevelingen gedaan kunnen worden voor interventies om kwaliteit van leven te verbeteren. Daarnaast is observationeel onderzoek noodzakelijk dat kijkt naar de symptoomlast in de dagen voor het sterven van bewoners met dementie in het verpleeghuis. Hierbij wordt aanbevolen om ook het perspectief van de mantelzorgers mee te nemen. Een manier om ervaringen van mantelzorgers te onderzoeken zou kunnen zijn hen op structurele basis na overlijden vragenlijsten te versturen. Dit kan extra van belang zijn op momenten van verandering van de omstandigheden van het verblijf in het verpleeghuis voor de bewoner en familie door bijvoorbeeld infectieziekten zoals recent tijdens de COVID-19 pandemie. Hoewel er reeds meer aandacht is voor het palliatief perspectief, menen wij dat bij dementie al in een eerder stadium aandacht moet zijn voor het denken over keuzes en mogelijkheden gericht op kwaliteit van leven. Een instrument als het 'Zorgpad Stervensfase' wordt nu in de praktijk vaak te laat ingezet doordat het onvoldoende is aangepast aan de dagelijkse praktijk van de zorg voor mensen met dementie in het verpleeghuis. Er is behoefte aan een 'Zorgpad Dementie' dat de bewoners in het verpleeghuis vanaf opname volgt en praktische handvatten biedt aan het gehele zorg- en behandelteam en mantelzorgers op het gebied van anticiperende gesprekken (advance care planning), symptoomcontrole en het verbeteren van communicatie. Eén van de mogelijkheden hiertoe is het vertalen van de IPOS-Dem, een in Engeland ontwikkeld instrument, en dit te implementeren in de Nederlandse situatie. Daarnaast is het goed om niet alleen de focus te hebben op dingen die er niet gedaan worden, zoals een behandeling in het ziekenhuis, maar ook juist beter te laten zien wat er wel allemaal gedaan wordt op het gebied van lichamelijke en psychische symptomen, tijdens de gehele opname en in de dagen voor sterven.

In het verpleeghuis is het van groot belang het zorgteam en de mantelzorgers/ familie vanaf het begin van de opname te betrekken en hen te informeren over verwachtingen ten aanzien van beloop van dementie. Elke bewoner met dementie is uniek, de persoon met zijn eigen karakter en persoonskenmerken in combinatie met het type dementie waarvan sprake is, bepalen voor een groot deel het beloop van het ziekteproces. In de praktijk blijkt dat het zorgteam en de mantelzorgers/ familie vaak nog onvoldoende op de hoogte zijn over het te verwachten beloop bij de ziekte dementie. Van het in een vroeg stadium betrekken van de bij de zorg betrokken personen, kan een positief effect verwacht worden op het verblijf en de kwaliteit van leven van de bewoner met dementie op de afdeling in het verpleeghuis. De onderzoeken zoals beschreven in dit proefschrift zijn verricht om meer inzicht te genereren in en kennis te verkrijgen over kwaliteit van leven en kwaliteit van sterven bij mensen met dementie in het verpleeghuis. Hierin zit ook een duidelijke boodschap voor de toekomst: er is meer onderzoek nodig om kwaliteit van leven en kwaliteit van sterven te verbeteren voor de groeiende groep mensen met dementie.

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Afscheid. Pen, inkt, aquarel, 1985. Fer Hakkaart
Geschonken aan Maartje Klapwijk door Fer Hakkaart en Ineke Wesseldijk.

Curriculum Vitae

Maartje Sanderijn Klapwijk was born on November 17, 1973 in Amsterdam. She attended secondary school in The Hague in a 'Leidse' class at the Montessori college where she obtained her VWO diploma in 1992. That same year she started her study Medicine in Leiden and worked for several years as a student assistant at the Eurotransplant Foundation, where she was responsible for the recruitment and registration of organ donors. She obtained her Medical Doctor's degree in 1997 after which she spent a year researching rheumatoid arthritis in San Diego. In 2001 she graduated cum laude from her medical school in Leiden. After this she went to work at the Department of Clinical Immunology and Rheumatology of the Academic Medical Center in Amsterdam. In the summer of 2002 she decided to change direction and began training to become an elderly care physician in the nursing home 'Van Wijckerslooth' in Oegstgeest and the nursing home 'Marienhaven' in Warmond. She continued to work on 2 new wards specialized in care for people with dementia in the nursing home 'Van Wijckerslooth', which later became one of the locations of care group Marente. During her training she discovered the diversity and challenge in the medical care for residents of psychogeriatric departments. In view of her interest in medical ethics, she also completed the post-academic training 'Ethics in the Care Sector' in 2010 at the University Medical Center St. Radboud in Nijmegen. In 2012, she started her PhD research, outsourced by Marente to the Department of Public Health and Primary Care (PHEG) of the Leiden University Medical Center (LUMC). Since the summer of 2016 she has been working in the nursing home 'Huis op de Waard' in the center of Leiden. From April 2020 she has been a researcher at the University Network for the Care sector South Holland (UNC-ZH), associated with the PHEG department with the research theme 'Quality of life and quality of dying in people with dementia'. Maartje is married to Chris and together they have 2 children, Casper (2003) and Pieter (2006).

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