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

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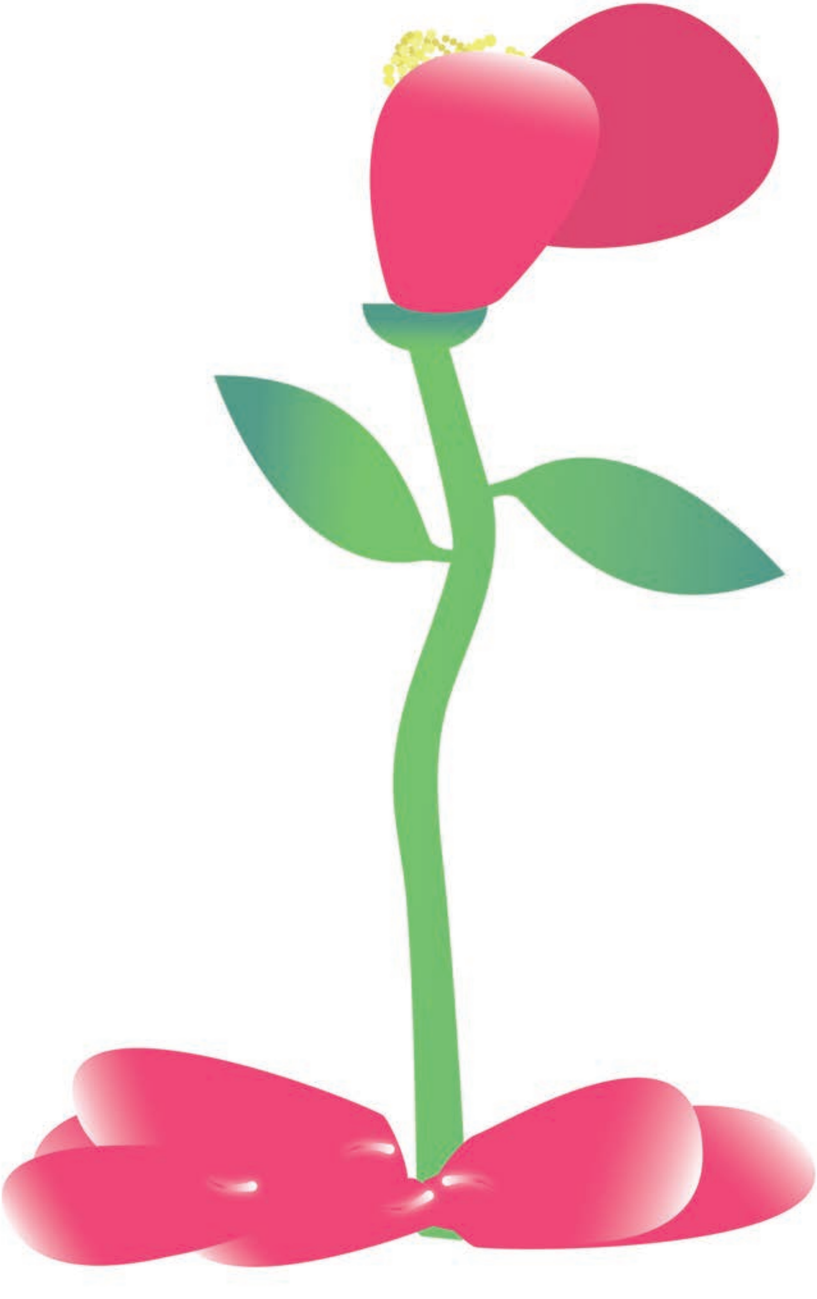

Chapter 7

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.

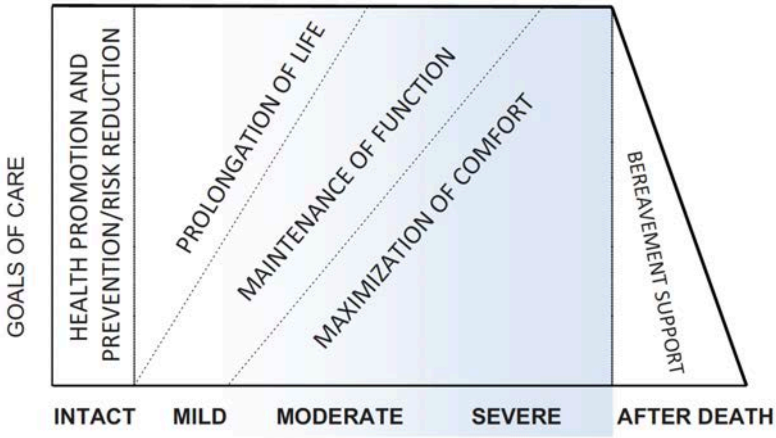

Figure 1. Dementia progression and suggested prioritizing of care goals. White paper, van der Steen et al., 2014. (replicated with permission)

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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