Chapter 1

General introduction
This thesis reports on research about end of life with dementia in long-term care facilities. The first part is about research into the best way to measure quality of end-of-life care and quality of dying for people with dementia in long-term care facilities. The second part addresses advance care planning and establishing a comfort care goal with dementia.

This introduction chapter outlines the background information about dementia, long-term care facilities, end-of-life (care), advance care planning, setting care goals and palliative care (goals). Subsequently the main questions and the structure of this thesis are presented.

BACKGROUND

Dementia

Worldwide the number of older people is increasing and with it the number of people with dementia.1 In 2010 there were an estimated 35.6 million people with dementia worldwide, and this number is expected to double by 2030 and more than tripled by 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, that is one new case every four seconds. In the Netherlands currently 260,000 people with dementia on a total of 16.8 million inhabitants.2 By 2050 more than half a million Dutch people will suffer from dementia. A few studies, however, have reported that this increase may be slightly less explosive than predicted because there will be fewer new cases of dementia.3,4 However, there is also evidence that with good health care and healthy behavior people can live longer with dementia.5

Dementia is a progressive life limiting disease, which is characterized by gradual loss of mental and physical capacities. Classical complications often occur, such as pneumonia, pain, problem behavior, tonus disorders and food intake problems.6 The most common form of dementia is Alzheimer’s disease. Approximately 60-70% of patients with dementia suffer from Alzheimer’s disease. Other common forms include vascular dementia, dementia with Lewy Bodies and frontotemporal dementia. The boundaries between the different forms of dementia are ‘grey’ and mixed forms occur.1,7

Dementia is characterized by a progressive loss of decisional capacity. A patient is incapable of making decisions when he/she is unable to take informed decisions on specific questions about care and treatment.8 Dementia is burdensome not only for the persons who have it, but also for their family. Because the patient is no longer capable to make a decision, family will have to take decisions for their family
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member. For example, family have to decide whether a treatment is given or not, when they do not always know what the patient wants in a specific situation.

Long-term care facilities in the Netherlands

Most people with dementia live at home, but many will be admitted to a long-term care (LTC) facility at some point in the disease trajectory and they will die there. The EAPC taskforce ‘Palliative care in LTC settings for older people’ defined a LTC facility as: a collective institutional setting where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time; the care provided includes on site provision of personal assistance with activities of daily living; and nursing and medical care may be provided on-site or by nursing and medical professionals working from an organization external to the setting.9

For 92% of the Dutch patients with dementia a LTC facility is the place of death.10 The LTC facility is generally a nursing home (89%) and sometimes a residential care home (11%). In 2011, about 165,000 people were living in a Dutch LTC facility; some 100,000 in a residential care home and 65,000 in a nursing home.11 Just over half of the patients in nursing homes have dementia, in residential care homes this proportion is lower.12 Most nursing homes have ‘somatic’ units for people with physical limitations, and separate ‘psychogeriatric’ units. Most patients on psychogeriatric units have some form of dementia. Some residential care homes have special units for patients with dementia, while in other homes patients with dementia are living in the same units as patients with somatic problems.

Dutch nursing homes have physicians on staff who have completed a specialized training program to become a qualified elderly care physician in nursing homes.13 This training differs from the training for clinical geriatricians. Residential care home residents and community-dwelling older people receive care from a general practitioner. Care is taken over by an elderly care physician after admission to a nursing home. However, an elderly care physician is also often consulted for residential care home residents with dementia.

Dutch government policies encourage older people to live at home longer with the help of home care or informal caregivers. In addition, residential home care is being scaled down. Some residential care homes are being converted into nursing homes,14 resulting in a small increase in nursing home beds. Overall, however, the number of older people living in an LTC facility has been decreasing for years due to a decrease in the number of beds.11 Compared to the increasing number of older people, the number of available beds in LTC facilities is limited. Nursing homes will remain available for people with severe limitations or severe dementia.
who need intensive care. This suggests that the admission of older people to an 
LTC facility is delayed and their mean length of stay until death will be shorter.

**End of life and End-of-life care**

End-of-life care is care provided to a person at any time in their final stages of life\textsuperscript{15} 
or, in other words at the end of life. This concerns persons with a chronic disease, 
whose disease or its symptoms could lead to death. End-of-life care can be 
provided in the last years of life and not just in the last hours, days or weeks before 
death. Each person who dies in an LTC facility should have had a ‘good’ end of life 
with ‘good’ end-of-life care. Unfortunately, numerous shortcomings in quality of end 
of life, including patient suffering and unmet family needs such as lack of 
knowledge to make decisions and personal needs with grieving, have been 
reported on end-of-life of patients with dementia.\textsuperscript{16-18}

Measuring quality of end of life of patients in the last months of life in LTC with 
appropriate instruments provides possibilities to identify and address these 
shortcomings. Several instruments are available that have been developed or used 
in a population including a substantial number of people with dementia. However, 
little is known about the psychometric properties of these instruments and 
instruments were not compared with each other. An important part of the 
evaluation of available instruments should also be the construct that is measured 
with the instruments. Quality of end of life can be perceived as comprising two 
constructs: ‘quality of end-of-life care’ and ‘quality of dying’.\textsuperscript{19} Quality of dying may 
be considered synonymous with quality of life while dying or quality of life in the last 
months, weeks or days of life. Quality of life is defined as the general well-being of 
individuals. The word ‘general’ indicates that it is a broad multidimensional concept 
that evaluates both positive and negative aspects of life.\textsuperscript{20}

Quality of care reflects elements of the setting in which dying takes place, such as 
the patient and family knowing which physician is responsible for the patient’s care 
or the amount of information provided by caregivers about the patient’s condition 
and provided care. Quality of dying on the other hand includes symptom burden 
and other patient experiences that can be influenced by care and various patient-
related factors. For example, a patient may have experienced pain (quality of 
dying) that was treated with medication (care) but which was not completely 
relieved. Insight into the quality of end-of-life care can give focus to quality 
improvement and the deployment of interventions, while insight into the quality of 
dying allows evaluation of the effect of these interventions.
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The first part of this thesis (chapters 2, 3 and 4) addresses the available instruments for measuring the quality of end of life with dementia in LTC and compares the validity, reliability and feasibility of these instruments.

Advance care planning and setting care goals for patients with dementia

Advance care planning (ACP) is defined by Teno et al. as ‘a process of ongoing communication among patients, family and professional caregivers about care that will be considered appropriate when the patient cannot make decisions anymore’. In 1998, Singer et al. published four assumptions about ACP based on literature: ‘1) the purpose of ACP is preparing for incapacity; 2) ACP is based on the ethical principle of autonomy and the exercise of control; 3) the focus of ACP is completing written advance directive forms; 4) ACP occurs within the context of the physician patient relationship’. In subsequent years, ACP is defined by others as ‘a process that begins with physicians helping their patients to articulate and prioritize their goals of care’ or ‘a process of discussion about goals of care and means of setting on record preferences for care of patients who may lose capacity or communicating ability in the future’ or ‘main objective of advance care planning is to prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions’. The definitions differ slightly, but all indicate that ACP is careful anticipatory decision-making on future care with all stakeholders, in which goals and boundaries for future care are set, taking into consideration the patient’s preferences, and prognosis for his/her condition. The intention is to provide care more in accordance with the wishes of the patient, resulting in a better quality of (end of) life and therefore it is often said that ACP is a prerequisite for good palliative care. Palliative care is elaborated in the next paragraph. Planning ahead is especially relevant for patients with dementia considering that, in time, they will lose the mental capacity to make decisions. Autonomy and self-determination are underlying principles of ACP. ACP makes plans in anticipation of future deterioration in a person’s condition.

Before the concept of ACP was introduced in 1994 by Joan Teno et al., preparing an advance directive had long been supported by the medical world. Joan Teno and colleagues indicated in a consensus document on behalf of the Squam Lake conference participants (New Hampshire, United States) that an advance directives (AD) is only one component of the broader concept of ACP. An AD can be classified into two categories: a treatment directive and a proxy directive. In a treatment AD, individual wishes of patients about unwanted and wanted care are described; a proxy directive designates a health care proxy for when the patient can no longer decide. However, ADs have several disadvantages: wishes may change over time while an AD is a static document and patients cannot anticipate
all possible problems or changes in their condition. Besides, the overall frequency of ADs is low and if an AD is available, it is often not complied with because it contains vague or ambiguous instructions. Professional caregivers are often not involved in preparing the ADs. Also, it is often not clear whether the patient wants the AD to be complied with or that family is allowed to overrule the AD. However, for family it appears to be difficult to interpret an AD. ACP, unlike the static AD, should be a dynamic process of joint establishment of care goals and identification of care patients want to receive in their current and later stages of life as they are confronted with a progressive illness trajectory. Communication between patient, family and professional caregivers is the most important element of ACP, which should ensure informed decision making and generate the best possible outcomes of care in the whole disease trajectory. An AD misses the oral communication element; however, an AD may support oral communication.

Domain 3 in the EAPC white paper ‘Palliative care in dementia’ describes the following seven recommendations on setting care goals and ACP:

- Prioritizing of explicit main care goals helps guide care and evaluate its appropriateness;
- Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited;
- Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual;
- In mild dementia, people need support in planning for the future;
- In more severe dementia and when death approaches, the patient’s best interest may be increasingly served with a primary goal of maximization of comfort;
- Advance care planning is a process and plans should be revisited with the patient and family on a regular basis and following any significant change in health condition;
- Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Scientific evidence for the benefit of ACP and setting care goals for patients with dementia on outcome is scarce so far. International research that includes patients with dementia, shows that ACP helps to adjust care to the wishes of the patient and family, and to document and comply with these wishes. ACP can also increase communication with health providers, decrease decisional conflicts and increase family overall satisfaction with care. Establishing a care goal helps determine what is most important when making decisions. A care goal is not a direct reflection of the actual delivered care, but gives direction to this care. In
addition, ACP can prevent unnecessary or undesirable medical actions, such as stressful hospital admissions and hospital deaths, and ensures that palliative care is applied more often. A literature review on the benefits of ACP interventions on the general adult population showed that ACP interventions increase the occurrence of ACP discussion and concordance between patient wishes for care and received care. In addition, the interventions, including ACP showed improved agreement between patient’s preference and received care. This review only included one intervention study with patients with dementia. That study, as well other studies, shows that a complexity of factors is related to (initiating) ACP. However, we lack evidence to support professional caregivers in initiating ACP for patients with dementia at home or in an LTC facility and to optimally design ACP interventions.

Despite a lack of evidence regarding the benefits of ACP in dementia and the lack of an overview of the factors that promote and hinder the initiation of ACP, there is consensus among experts that ACP is preferred early in the disease, perhaps as early as at time of diagnosis, and should anticipate the deteriorating health condition of the patient. An early start is even more salient in dementia, to give patients the opportunity to participate in the discussions before they lose mental capacity to do so. The patient’s ability to imagine decreases, such as the ability to imagine scenarios, and they take up the initiative to discuss and make decisions less often. At most 36% of patients with cognitive impairment and dementia have the capacity to participate in ACP at admission to a nursing home, according to a literature review with data from Australia, Canada and the United States. Research in Flanders, Belgium, showed that 26% of all nursing home patients were capable and 35% were partly capable of medical decision making at the time of admission. The exact percentage of Dutch patients with dementia who have the capacity to participate in ACP at admission to a nursing home is unknown, but it is expected to be similar. An early start is important because if family has to make decisions, it is difficult for them to distinguish their own wishes from the wishes of the patient. Last but not least, it is very difficult to predict mortality in dementia.

Chapters 5 and 8 in the second part of this thesis address advance end-of-life care planning in dementia.

Palliative care & palliative care goal

The most recent definition of palliative care by the World Health Organization (WHO) is: palliative care is an approach that improves the quality of life of patients and their families facing the problems associated 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.\textsuperscript{53} In the early 1980s, WHO started to promote a palliative care approach for cancer patients. Later on, this approach was taken over for other diseases. The term ‘life-threatening’ seems more relevant for cancer patients than for patients with dementia. Dementia is perhaps less life-threatening as it is life-limiting. However, the 1990 WHO definition stated more clearly that palliative care can also be applied in patients with dementia. The WHO definition of palliative care in 1990 was: \textit{The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.}\textsuperscript{54} Others define palliative care slightly differently.\textsuperscript{55-57} The definition of the European Union Geriatric Medical Society (EUGMS) for older people fits most for care in dementia: \textit{Geriatric palliative medicine is the medical care and management of older patients with health related problems and progressive, advanced disease for which the prognosis is limited and the focus of care is quality of life.}\textsuperscript{55}

Palliative care, for a long time, focused mainly on pain relief. Pain relief is still an important aspect of physical needs of patients, but other physical needs, emotional needs and spiritual needs of patients are also considered important in palliative care. In addition, palliative care is increasingly viewed as care that should be provided as early as possible, because symptom burden at the end of life often has its origin earlier in the disease. Previously palliative care was only assumed to be relevant for terminal patients. However, many health professionals, family and patients still equate palliative care with terminal care, relevant for the patient who will die within a short period of time.\textsuperscript{58}

In 2003, the influential white paper of Lynn and Adamson was published about a palliative care model.\textsuperscript{59} In this model, symptom management and palliative care do not follow disease-modifying care and curative care. Both palliative and curative treatments can be given from the start of the disease. However, the emphasis will shift increasingly to palliative care and symptom management as death approaches. The idea underlying the palliative care model is sound, however, it was developed for all patients with a life-threatening illness, but the illness trajectory of, for example, cancer is very different from COPD or dementia. In the EAPC white paper ‘Palliative care in dementia’ an adapted model is presented specifically for patients with dementia.\textsuperscript{34} In this adapted model three care goals for patients with dementia are presented: prolongation of life, maintenance of function and maximization of comfort. These care goals can help guide care decisions. The
goals maintenance of function and maximization of comfort are both focussed on quality of life and are therefore most compatible with palliative care. The three care goals can occur at the same time and should be prioritized in the course of disease. The model indicates that during the trajectory from mild to moderate and severe dementia, the focus shifts more and more to maximization of comfort.

The development of palliative care in the Netherlands started in the beginning of the 1990s with the introduction of the hospices. Later on special units for palliative care were established in nursing homes. The Dutch government has supported this development since the mid-1990s. A palliative care framework was formulated and one basic principle was that palliative care should be general in nature. Thus, palliative care should be available for all patients with a life-threatening illness, or according to the WHO definition of 1990: patients with an illness that is no longer responsive to curative treatments. Dutch professional organizations for health care workers (NVVA, now Verenso) published a practical guide for medical decision making in the last phase of life in dementia. In this practical guide, the NVVA stated that decision making in the last phase of life with dementia has a strong similarity with decision-making situations in the context of palliative care in patients with cancer. In the Netherlands, the model of Lynn and Adamson was introduced in the 2007 policy letter 'Palliative care; beyond the pioneering phase' of the Ministry of Health, Welfare and Sports. Also in the same period, a report by several Dutch professional organizations for health care workers (the NVVA, Sting and V&VN) commissioned by the Ministry of Health, Welfare and Sports was published, which includes descriptions of relevant concepts at the end of life, for example palliative care. This report is a follow-up to above-mentioned 1997 practical guide of the NVVA. The report uses the 2002 WHO definition of palliative care and it emphasized that palliative care is not one type of care; palliative care is a concept, and it can include a whole range of actions and treatments. In the Netherlands a distinction is made between a palliative care goal and a symptomatic care goal in the palliative care for people with dementia, because there is a discussion about the acceptability of life extension as a side effect of palliative care. Both are focused on comfort and a comfort care goal in this thesis refers to both palliative care goal and symptomatic care goal. The following definitions of a palliative and symptomatic care goal are used:

A palliative care goal ("palliatief beleid" in Dutch): Aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient. Extending life as a potential side effect of a treatment is not contraindicated- or is even part of the care goal.
A symptomatic care goal (“symptomatisch beleid” in Dutch): Aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient. A life-extending side-effect as a result of medical treatment is undesirable.

In total, four care goals can be used in the long term care facilities, namely curative, rehabilitative, palliative and symptomatic. In the population of patients in the LTC facilities, the focus is on palliative and symptomatic care goals.62

The Dutch Dementia Care Standard also indicates that palliative care is needed in advanced stages of dementia and that ACP is the model to anticipate future developments and to provide appropriate palliative care.63 However, in practice, (palliative) care at the end of life and a palliative care goal are certainly not always discussed, or it is postponed.64 A recent report from ZonMw indicated that the question ‘Do we need to do everything that we can do?’ should be asked more frequently.65 The same report indicated that ACP is used especially in the LTC and palliative care. However, family first need to get used to the patient’s admission to the nursing home and the terminal character of dementia is not clear to every family and professional caregiver. As a result ACP is not always started at admission and care planning is not always focussed on future care.

So far, the relation between comfort care goals and outcomes has not been extensively studied for patients with dementia.66 Most studies employed a retrospective design, or studied care systems. For example, family of people with dementia who received hospice care in the United States reported higher satisfaction with end-of-life care and better quality of dying than family of people with dementia who did not receive hospice care.67,68 However, we cannot translate this directly to LTC, as hospice care is different from LTC. In a hospice situation the death of patients is more often expected and care is likely to differ depending on the expectation of death.69 More research has been performed on the effects of palliative care in cancer patients. Palliative care helps to better address the concerns and needs of patients and their family.56,70 Early access to palliative care for patients with cancer helps to improve the quality of life and may even prolong life.71 In Chapter 7 of the second part of this thesis, the results of our prospective quantitative study are presented regarding whether quality of end-of-life care and quality of dying of dementia patients is associated with a comfort care goal established shortly after admission compared with the absence of a comfort care goal.

Despite the lack of clear evidence for favorable effects, a palliative care goal is preferred for patients with dementia. However, actually establishing of such a care goal depends on factors related to patient, family, professionals and setting. Studies including patients with dementia have demonstrated that several factors
may relate to applying ACP in general, or more specifically to establishing a palliative care goal. As expected, patient’s health decline may facilitate starting ACP discussions.\textsuperscript{72,73} However, patient’s health decline can only facilitate starting decision making when the professionals involved in care planning with family are frequently present in the LTC facility and have time to discuss care planning with the family.\textsuperscript{73-77} In addition, professionals taking time and building a relationship with the patient and family is positively related to applying ACP and care directed towards palliation.\textsuperscript{73,76,78,79} However, most of the published studies about factors related to establishing palliative care goals only examined one factor or examined factors from only one perspective. Chapter 6 of the second part of this thesis reports on our quantitative research in which we have examined patient, as well as family and physician factors and we also performed multivariable analyses to examine whether factors were independently associated with a baseline comfort care goal.

**MAIN RESEARCH QUESTIONS AND STRUCTURE OF THIS THESIS**

**Part I (Chapters 2, 3, 4)**

Measuring quality of end-of-life care and quality of dying in dementia is the central topic in the first part of this thesis. The research questions are:

1. **What is the content of available measurement instruments to assess the quality of end-of-life care and quality of dying for patients dying in long-term care (LTC)?**

Chapter 2 describes the results of a qualitative content analysis evaluating the contents of available instruments to assess quality of end-of-life care and quality of dying.

2. **What is the validity and reliability of ten available instruments commonly used to evaluate quality of end-of-life care and dying in long-term care, tested for LTC decedents with dementia in the Netherlands?**

Chapter 3 deals with the psychometric properties of ten instruments to measure quality of end-of-life care and quality of dying for LTC patients with dementia. We performed prospective observations and retrospective interviews and surveys of family and professionals of Dutch LTC decedents with dementia.
3. Which of the available instruments best measure quality of end-of-life care and quality of dying in long-term care, in terms of validity, reliability and feasibility?

Chapter 4 compares validity, reliability and feasibility of the ten available instruments and investigates which instrument best measures quality of end-of-life care and quality of dying in LTC. Retrospective survey and interview data of Dutch and U.S. LTC patients with and without dementia were used.

Part II (Chapters 5, 6, 7, 8)

The second part of this thesis focuses on planning of end-of-life care in dementia. The research questions addressed in this part are:

4. What factors are described in the literature as being associated with initiation of advance care planning (ACP) regarding end-of-life issues in dementia?

Chapter 5 describes the results of a systematic literature review to provide an overview of factors described in literature.

5. What care goals are established for nursing home patients with dementia and which factors are associated with establishing a comfort care goal?

Chapter 6 covers results of the quantitative part of the Dutch End of Life in Dementia (DEOLD) study. In this study, patients’ family and physicians provided data about treatment, care, and outcomes from nursing home admission until death or the end of data collection. Care goals of nursing home patients with dementia reported by physicians are presented and regression analyses were performed to identify factors that are associated with having a comfort care goal.

6. Is quality of end-of-life care and quality of dying associated with a comfort care goal established shortly after admission compared with the absence of such a goal?

Quantitative data of the DEOLD study were used to perform regression analyses for chapter 7. Main outcomes were quality of end-of-life care (End-of-Life in Dementia-Satisfaction With Care scale, EOLD-SWC) and quality of dying (EOLD-Comfort Assessment in Dying, EOLD-CAD). We added the factors identified in question 5 to the regression analyses to adjust for the probability of receiving a comfort care goal.
7. How is advance care planning experienced by family and professional caregivers of Dutch nursing home patients with dementia and which factors are related to timing and content of advance care planning?

A total of 65 in-depth qualitative interviews were held with families, on-staff elderly care physicians, and nurses of 26 deceased nursing home patients. The qualitative interview study was part of the “Dutch End of Life in Dementia” (DEOLD) Study. The results of this interview study are described in chapter 8.

Chapter 9 presents a general discussion of the major findings, and recommendations for research and practice.

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