Summary
This thesis reports on research about dying in dementia in long-term care (LTC) facilities. This thesis consists of two parts preceded by a general introduction. A general discussion concludes this thesis. The first part 'Measuring quality of end-of-life care and quality of dying in dementia' describes the results of research into the best way to measure quality of end-of-life care and quality of dying for people with dementia in LTC facilities. The second part 'Advance care planning and establishing a comfort care goal for patients with dementia' describes the process and timing of advance care planning (ACP) in dementia and factors associated with timing and content of ACP. In addition, it deals with the moment that a comfort care goal is established and the possible benefit of such care goal for the quality of end-of-life care and quality of dying.

Chapter 1, the general introduction, reports on the background and the aims of this study. The number of older people is increasing as is the number of people with dementia. In the Netherlands there are currently 260,000 people with dementia and by 2050 more than half a million Dutch people will suffer from dementia. Dementia is a progressive life-limiting disease and is characterized by a progressive loss of decisional capacity. When a patient is no longer capable of making a decision about care and treatments, family will have to do it for them. Dementia is burdensome not only for the person with dementia, but also for their family/loved ones.

Most people with dementia live at home, but many will be admitted to an LTC facility at some point in the disease trajectory and they will die there. For 92% of the Dutch patients with dementia a LTC facility is the place of death. The LTC facility is generally a nursing home (89%) and sometimes a residential care home (11%). A total of about 100,000 people live in Dutch residential care homes and 65,000 in Dutch nursing homes. Most nursing homes have ‘somatic’ units for people with physical limitations, and separate ‘psychogeriatric’ units. Most patient 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 live 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. Residential care home residents and community-dwelling older people receive care from their general practitioner. 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. Overall the number of older people is increasing, but the number of available beds in LTC facilities is limited. Nursing homes will remain available for people with severe limitation or severe dementia.
who need intensive care. This suggests that the older people will be admitted to an LTC facility at a later stage and their mean length of stay until death will be shorter.

End-of-life care is care provided to a person at any time in their final stages of life 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 for death. Each person who dies in an LTC facility should have had a ‘good’ end of life with ‘good’ end-of-life care. Unfortunately the quality of end of life of patients with dementia in LTC facilities is not optimal.

Measurement of quality of end of life of patients in the last months of life in LTC with appropriate instruments provides possibilities to identify and address the shortcomings. Several instruments were available to measure the quality of end of life of patients in the last months of life in LTC facilities. However, little was known about validity, reliability and feasibility of the instruments. An important aspect of the evaluation of the available instruments was also to know what is measured with the instruments. Quality of end of life can be differentiated in ‘quality of end-of-life care’ and ‘quality of dying’. Quality of dying may be considered synonymous with quality of life while dying, quality of life at the end of life or quality of life in the last months, weeks or days of life. Quality of care reflects elements of the facility in which dying takes place, such as the amount of information provided by caregivers about the condition and provided care or the patient. 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.

The intention of ACP is to provide end-of-life care that is more in accordance with the wishes of the patient, resulting in a better quality of (end of) life. 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. Planning ahead is especially relevant for patients with dementia considering that, in time, they will lose the mental capacity to make decisions. ACP is early planning of care in the last phase of life. ACP makes plans in anticipation of future deterioration in a person’s condition. ACP is used in nursing homes. However, family first need to get used to the patient’s admission to the nursing home, and the terminal nature of dementia is not always clear to every family and every professional caregiver. As a result, ACP is not always started at admission and care planning does not always focus on future care, but only on current care.

It is often said that ACP is a prerequisite for good palliative care in the last phase of life, because the intention of ACP is to provide care in accordance with the wishes
of the patient. The 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.** The palliative care approach was first promoted for cancer patients and subsequently was taken over for other diseases, such as dementia. Later on, a palliative care model was published. In the palliative care model, symptom management and palliative care does not follow disease-modifying care and curative care, but both curative and palliative treatments can be given from the start of the disease. The emphasis increasingly shifts to palliative care and symptom management as death approaches. The idea behind this model is good, however it was developed for all patients with a life-threatening illness. An adapted model for patients with dementia is presented with three care goals: prolongation of life, maintenance of function and maximization of comfort. The goals maintenance of function and maximization of comfort are most compatible with palliative care. The three goals can occur at the same time and should be prioritized in the course of the disease. During the trajectory from mild to moderate to severe dementia, the focus should shift increasingly to maximization of comfort. A care goal focused on comfort gives direction to future care decisions, but does not guarantee a comfortable death.

A total of four care goals can be distinguished in the Dutch LTC sector, namely curative, rehabilitative, palliative and symptomatic. In the population of patients in the LTC facilities, the focus is on a palliative and symptomatic care goal. Both are focussed on comfort and we talk about comfort care goal in this thesis, it refers to both a palliative care goal and a symptomatic care goal. The following definitions of a palliative and symptomatic care goal are used:

**A palliative care goal:** Aimed primarily at safeguarding optimal wellbeing 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:** Aimed primarily at safeguarding optimal wellbeing and an acceptable quality of life of the patient. A life-extending side-effect as a result of medical treatment goal is undesirable.

The relation between comfort care goals and outcomes has not been extensively studied for patients with dementia. Despite the lack of clear evidence on favorable effects, a comfort care goal is preferred for patients with dementia. The moment of establishment of such a care goal depends on patient, family, professional and setting factors.
Part I Measuring quality of end-of-life care and quality of dying in dementia

Chapter 2 describes the results of a qualitative content analysis evaluating the content of available instruments to assess quality of end-of-life care and quality of dying of patients dying in LTC facilities. A total of 11 instruments (questionnaires) were available to assess quality of end-of-life care and quality of dying. Instruments were identified as relevant if all of the following criteria were met: 1) used to measure quality of care and/or dying; 2) used in LTC facilities; 3) were developed, or validated, in a population with dementia or widely used in populations that include many people with dementia or cognitive impairment; 4) possibility to calculate (sub)scale scores or ongoing effort to develop these scales. Qualitative content analyses based on the classification system of Stewart et al. (Stewart, 1999), showed that five of the eleven instrument measure quality of end-of-life care, namely, the End-of-Life in Dementia With Care (EOLD-SWC), the Family Assessment of Treatment at the End-of-Life Short Version (FATE-S), the Family Perception of Physician-Family Caregiver Communication (FPPFC), the Family Perception of Care Scale (FPCS), and the nursing home version of the Toolkit of Instruments to Measure End-of-Life Care (TIME) after-death bereaved family member interview. Four other instruments measure quality of dying: the End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD), the End of Life in Dementia Symptom Management (EOLD-SM), the Mini-Suffering State Examination (MSSE), and the Palliative Care Outcome Scale (POS). Most of these instruments do not measure quality of end-of-life care or quality of dying only, but they measure one construct for at least 80% of the items. The Quality of Dying in Long-Term Care (QOD-LTC) measures both quality of end-of-life care and quality of dying, and the Minimum Data Set – Palliative Care (MDS-PC) measures quality of dying but also patient factors. The instruments differed regarding specificity for dementia, type of respondent (patient, family or professional caregiver), timing of administration, recall period, setting in which the instrument was developed or applied, number of items and type of response option.

Chapter 3 deals with the psychometric properties of ten of the eleven instruments that measure quality of end-of-life care and quality of dying for Dutch LTC patients with dementia.

Results of the Minimum Data-Set Palliative Care (MDS-PC) were not included, because specific quality indicators or scales were not yet available for the palliative care version to use for validity and reliability analyses.

We performed observations of 24 LTC patients who were expected to die within one week. An after-death questionnaire with the available instruments were completed by family (N=70) and professionals (N=103; physician and/or nurse) of 222
119 LTC decedents with dementia in the Netherlands. Some of the instruments were completed by family in a telephone interview. Validity was assessed in four ways: 1) instrument scores are compared to an overall rating, 2) the instrument scores were compared with other instruments measuring the same construct, 3) factorial validity and 4) the instrument scores of professionals were compared to the scores on the instruments with the observations. Internal consistency was assessed and additionally differences in ratings of family, physicians and nurses were tested when family and professional data were available.

Of the five instruments measuring quality of care, the EOLD-SWC and the FPCS showed better validity and internal consistency than the FPPFC, which in turn performed better than the FATE-S and the TIME. Validity and reliability of the four quality-of-dying instruments were best in the EOLD-CAD and MSSE. They were followed by the EOLD-SM. The POS was not judged as a valid measure. The QOD-LTC measures both quality of end-of-life care and quality of dying, and compared to the other instruments showed a mean validity and internal consistency. Concordance between individual and mean scores of family, physician and nurse was low for the EOLD-CAD, EOLD-SM, POS and QOD-LTC. For the MSSE, concordance was moderate. High concordance was not expected, as assessments by family and professionals do not necessarily correspond because they each have their own perceptions.

Chapter 4 gives an overview of the performance of the ten available instruments in terms of the validity, reliability and feasibility in the Netherlands and the United States, and indicates which is the best instrument to measure quality of end-of-life care and quality of dying in research and practice. Retrospective survey and interview data of 119 Dutch patients with dementia and 264 U.S. LTC patients, of whom 48% had dementia, were used. In both countries family provided data. In the United States data were collected with a post-death interview and in the Netherlands most data was collected with a written survey 2 months after death, except for the FATE-S, FPCS and TIME, which were administered by telephone after completion of the written survey. The response rate of family was 80% in the United States and 53% in the Netherlands. In the Netherlands, professionals also provided data with an after death written survey. In addition to the after-death data collection in the Netherlands 24 patients were observed by a physician when death was expected within one week. We determined validity, reliability and feasibility for each country separately based on 12 criteria, and afterwards we recommended the best instrument to measure quality of care and quality of dying for both countries. Overall, we recommend the EOLD-SWC as the instrument to measure quality of end-of-life care, because it has the best overall performance in both countries. Of the instruments measuring quality of dying, the EOLD-CAD and the MSSE
performed best on the criteria. We prefer the EOLD-CAD for research purposes as it measures only quality of dying, and the MSSE for practice, as it performed better on feasibility.

Part II Advance care planning and establishing a comfort care goal for patients with dementia

Chapter 5 describes the results of an international literature review on factors associated with initiation of advance care planning (ACP) in dementia. We defined initiation of ACP as: 1) starting a discussion about end-of-life issues, 2) starting the decision-making about end-of-life issues and 3) having a patient-written, documented advance directive available to professional caregivers. We searched the most common electronic databases for articles published up to January 10, 2013. 4,647 unique articles were found and 178 full-text articles were assessed. Thirty-three articles were considered relevant. Most studies were performed in the United States (58%) and focused on LTC facilities (mostly nursing homes). We found an increase in relevant articles in the last years compared to earlier years. An exclusively qualitative design was most frequently found and family perspectives were more often examined than professional caregiver perspectives. The 33 articles reported on a variety of factors related to initiating ACP. Half of the articles reported on factors related to starting a discussion, just over 60% reported on factors related to starting decision-making and just over 60% on having a patient-written documented advance directive. Family-related factors dominated in the included articles. In several studies family’s (lack of) initiative, willingness and reluctance were described as hampering initiation of ACP. In addition, professional caregiver initiative and patient’s health condition were important factors that affect initiation of ACP. We also found continuity of care and health care system factors to be related to initiation of ACP.

In Chapter 6 we present the results on which care goals are established for patients with dementia and which factors are related to establishing a comfort care goal. Data of the End-of-Life in Dementia (DEOLD) study were used. In this study, patients’ families and physicians provided data about treatment, care, and outcomes from nursing home admission until death or the end of data collection. The on-staff elderly care physician reported the main care goal in a written questionnaire 8-weeks after admission, every 6 months afterwards and after death. Within 8-weeks after admission (shortly after admission) to a Dutch nursing home a main care goal focused on comfort was established for just over half of the patients with dementia (56.7% of the 326 newly admitted patients). Almost a quarter of the patients had a care goal shortly after admission that focused on maintaining or improving function, life prolongation or a care goals classified as other. No care
goal has been determined shortly after admission for 19% of the patients with dementia. For three quarters of patients without a care goal, directives and care goals were not discussed between family and physicians. At death, the large majority of patients (89%) had a comfort care goal. No care goal was determined for 4% of the patients.

Establishing a care goal focused on comfort shortly after admission or later during nursing home stay was associated with patient-, family- and physician factors. Adjusted for the severity of the illness, patients with a comfort care goal shortly after admission were more likely to have a religious affiliation, to be less competent to make decisions on medical treatments and to have a short survival predicted by the physician. Their families were less likely to prefer life-prolongation and more likely to be satisfied with the family-physician communication. Compared to patients with a comfort care goal established at a later moment during the patient’s stay, or only at the day of death or not at all, patients with a comfort care goal shortly after admission had a more highly educated family member who completed the questionnaires. The family member who completed the questionnaire was the contact person for professional caregivers of the nursing home.

Sixty-five percent of families indicated that professional caregivers held ACP discussions with them at some point during patient’s stay. Most families reported that the first ACP discussion was within 8 weeks after admission of their relative. Almost 70% of the families thought the timing of the first discussion was just right in relation to patient’s health. However, the timing was too early for 8% of the families and too late for 4.7% of the families. The remaining families had no opinion about the timing of ACP discussions.

Chapter 7 reports on the potential benefit of establishing a comfort care goal shortly after admission for the quality of end-of-life care and quality of dying as measured with the EOLD-SWC and EOLD-CAD. The Quality of end-of-life care was higher or, in other words, family was more satisfied with end-of-life care when a comfort care goal was established shortly after admission. We found this association only for patients who died within 6 months after admission. This and the following finding were adjusted for several factors to balance the group with and without a comfort care goal shortly after admission. We adjusted for factors that were associated with having a comfort care goal shortly after admission (based on findings of Chapter 6). We also adjusted for patient gender and age, and highest completed educational level of the family member who completed the questionnaires. Our findings suggest that the potential benefit of establishing a comfort care goal at an early stage may be larger for quality of end-of-life care when the patient will die within six months after admission. However, it is hard to
predict whether patients will die within six months after admission. Furthermore, care goals may have been adjusted or revised to comfort care goals for those who survived longer than six months after admission, which could be beneficial for the quality of end-of-life care. However, our focus was only on early establishment of a comfort care goal.

Our study found no association between quality of dying and establishing a comfort care goal shortly after admission. Establishment of a comfort care goal in itself does not guarantee high quality of dying or, in other words, a comfortable death. A comfort care goal should guide the provided care. ACP in Dutch nursing homes may focus more on limiting treatments to improve comfort than starting a treatment. In the Netherlands, there is possibly room for improvement in quality of dying. Measured with the EOLD-CAD and other instruments, the quality of dying is better in the United States than in the Netherlands. Nevertheless, perhaps not all symptoms can be relieved despite optimal treatment and monitoring of symptoms.

Chapter 8 of this thesis presents the results of a qualitative interview study, which investigated the experiences of families, physicians and nurses of nursing home patients with dementia with regard to ACP and factors related to ACP. A total of 65 in-depth interviews were held with 20 family caregivers, 21 physicians and 24 nurses about 26 patients with dementia who died in a nursing home that participated in the ‘Dutch End of Life in Dementia’ (DEOLD) study. All interviews were transcribed verbatim, and a qualitative methodology was used to analyze the interviews.

The interviews showed that family and professionals had multiple contact moments about care goals and treatment decisions during nursing home stay. The interviews indicated that admission to the nursing home is the starting point for ACP of patients with dementia. Our findings suggests that general practitioners pass on little to no information about patient wishes and advance treatment decisions when a patient is admitted to a nursing home.

Professionals of the nursing home almost always had advance discussions about cardiopulmonary resuscitation (CPR) and hospitalization with family. In general, ACP discussions in which CPR and hospitalization were discussed took place within 6 weeks after admission. These discussions generally resulted in a do-not-resuscitate and do-not-hospitalize order. Care goals discussed and established varied during nursing home stay and the terminology to describe the care goals varied between nursing homes.

Based on the interviews it appeared that elderly care physicians take the initiative for ACP discussions, and we found two underlying strategies that guided elderly
care physicians in initiating care planning discussions: 1) waiting for a reason to initiate discussions such as a change in condition or families bringing it up themselves (responsive) and 2) taking the initiative to discuss possible treatments (proactive, including describing scenarios). Within, this second strategy, there is a difference in the level of detail in which advance treatment decisions are discussed and made by physicians.

In addition to the two strategies that guided elderly care physicians in initiating care planning discussions in nursing homes, we also identified other factors related ACP: the patient’s condition, wishes expressed by the patient or family; family’s willingness; family involvement; continuity of communication; consensus with or within family; and general nursing home policy. Many of these factors may be modifiable factors but change over time and may be influenced by anticipation and information provision by professional caregivers.

The last chapter of this thesis, Chapter 9, summarizes and discusses the main findings of this thesis and presents relevant methodological considerations regarding the conducted research. Subsequently, recommendations are presented for dementia care practice and future research. Based on the results of the first part of this thesis, we recommend that nursing homes and residential care homes to start structurally evaluating the quality of end-of-life care and quality of dying in dementia to get a solid impression of the quality of end-of-life care and quality of dying and make plans to improve this quality. The quality measurement can also be used as a starting point for a final conversation with family about their experience with care in the nursing home or residential care home. We recommend the EOLD-SWC, EOLD-CAD and MSSE for measuring quality of end-of-life care and quality of dying, because of their validity, reliability and feasibility. However, the overview of all instruments can be used to select the most suitable instrument for specific purposes. We prefer the family as respondent for both instruments, but it is also a possibility to ask the physician and/or responsible nurse to complete the EOLD-CAD or MSSE in addition to family completion of the EOLD-CAD or MSSE. This provides the opportunity to compare answers on the EOLD-CAD or MSSE items between family and professional caregivers. Discrepancies are important to reflect on, because scores by family that are lower than those of professional caregivers may indicate the need for better communication between professional caregivers and family.

Only measuring quality of end-of-life care and dying is not enough to improve quality; a clear plan about what to do with this feedback on the quality is also needed. Therefore an implementation project has been developed; the FOLLow up project. In the FOLLow-up project two audit- and feedback strategies are designed
and tested in a three-armed Randomized Controlled Trial (RCT): a generic feedback strategy using cumulative EOLD-scores of a group of patients and a patient-specific feedback strategy using EOLD-scores on a patient level. The results of this project will provide insight into the best way to use quality of end-of-life care and quality of dying instruments to evaluate and improve the quality where necessary.

In addition, it would be interesting to investigate whether trends in quality of end-of-life care and quality of dying have continued over recent years and will continue in the years to come. Analyses of combined data of 3 studies on 372 LTC patients with dementia (including the 70 patients with a completed family questionnaire who were included in research reported in part I of this thesis) over the period 2005-2010 showed a consistent trend of increasing quality of end-of-life care over the years. We found indications that the quality of dying was also higher according to family.

Finally, also more research is needed about providing customized aftercare for families of patients with dementia who die in a LTC facility. Aftercare is part of providing good palliative care. However, aftercare is rarely provided and often not in a structured manner.

Based on the results and conclusions of the second part of this thesis, we recommend that elderly care physicians, but also general practitioners and dementia case managers, take note of the identified factors that play a role in ACP and establishing comfort care goals. It is important that professional caregivers realize that the initiative for ACP discussions should come from them. These factors and the benefits of ACP and focus on palliative care should be addressed in the education. Society should pay more attention to the timely discussion of end of life, so patients and family are aware of the importance of talking about end of life and talking about the end of life become more common in society.

Prediction of the life expectancy of patients with dementia is difficult, so it is recommended to start with ACP discussion as early as possible. If the patient or family are not ready for a conversation about the care in the last stage of life, professional caregivers can provide information about the importance of ACP and they may also discuss why the patient or family find it difficult to talk about the end of life. A continuous dialogue between the patient if still able to communicate, the family and physician is very important. Care planning is a process rather than a one-off event, as the condition of the patient changes and wishes can also change over time.
To avoid any misunderstandings, it is important that there is more uniformity in the terminology regarding care goals used in practice. By consistently reporting main care goals for the last phase of life in the medical record with a brief explanation, it is clear for all professional caregivers what the direction of care for a patient is. A care goal focused on comfort should at least be considered in ACP discussion from admission, because patients with dementia who are admitted to the nursing home almost all have moderate or severe dementia.

Several tools are available to assist professional caregivers with ACP in dementia. One of these is the practical guide ‘Planning of care in the last phase of life with dementia’ (in Dutch), which was developed based on the finding presented in part II of this thesis. Future research can focus on determining the effects of this practical guide and other tools like the family booklet ‘Comfort care in dementia’ and a video based on this family booklet.

Additional research is also needed to better understand the relationship between the establishment of care goal, the treatments that are given and having a comfortable death. In addition, it would be interesting to not only conduct qualitative interviews after death, but also during the stay of patients in the nursing home. In this study, we interviewed respondents who look back on the stay in the nursing home and did not have to make difficult decisions anymore. Also, a participatory observational study in Dutch nursing homes, could help to better understand the process of ACP.

Improved understanding enables better planning of future care and hopefully this will result in better quality of end-of-life care and quality of dying with dementia. To ensure that our results are generalizable to other countries with other care systems additional research is needed. It would also be interesting to interview family and professional caregivers of home-dwelling patients with dementia as the coming years will see increasing numbers of patients with dementia continuing to live at home for a longer period of time.