SUMMARY

Chapter 1
To improve their quality of life people with dementia need adequate palliative care, and there are still many questions to answer about providing adequate palliative care. One of these questions concerns the optimal starting point of palliative care across dementia stages. The identification of the palliative phase and palliative care needs in dementia is a point of discussion, and opinions vary among health care professionals.

Understanding the clinical course of dementia forms the foundation of physician prognostication and supports palliative care actions, decision-making, and advance care planning. Although the majority of people with dementia are eventually admitted to and die in long-term care facilities, we lack a thorough understanding of the clinical course of dementia, palliative care needs and decision-making in long-term care settings. Available knowledge is mostly based on retrospectively collected data, limited to the dying-phase, or limited to nursing home residents with advanced dementia.

Therefore, the overarching goal of this thesis is to achieve a better understanding of the clinical course of dementia in people in various stages of dementia in Dutch nursing homes, to help optimize palliative care for nursing home residents across the dementia stages. To address the objectives of this thesis, data from the Dutch End of Life in Dementia (DEOLD) study were used.

Chapter 2
In chapter 2, Mokken models were fitted to the Bedford Alzheimer Nursing-Severity Scale (BANS-S) to study its psychometric properties. Since Alzheimer is a progressive disease, studying the hierarchy of the items in the scale can be useful to evaluate the progression of the disease. We found that the BANS-S met the criteria for an ordinal scale. The probability of having problems with an item with a higher mean score (higher in the hierarchy) was higher for residents with more severe dementia than for residents with less severe dementia. This result is relevant because many scales do not discriminate between residents with more severe dementia. Furthermore, it should also be taken into account that the data were from baseline measurements and that the population at this point did not always have severe dementia. Further research should be done to determine whether the dementia patterns found for this population apply to the course of the dementia for individuals and to evaluate the responsiveness of the scale to individual changes.
Chapter 3
Chapter 3 describes the incidence of pneumonia and intake problems and how these health problems affect survival. Further, this chapter shows whether pneumonia and intake problems mediated the relationship between dementia severity and death. Using longitudinal data is important to characterize the disease dynamics. We found that pneumonia and intake problems were not limited to, or typical of, advanced dementia. Moreover, these health problems were important risk factors for mortality in nursing home residents in all stages of dementia. Developing pneumonia and intake problems are important signals to consider palliative care actions. The high risk of developing pneumonia and intake problems, and the poor survival of residents with dementia in a long-term care facility even shortly after admission, call for a palliative care approach and an active focus on advance care planning upon nursing home admission, or preferably earlier.

Chapter 4
Chapter 4 describes the longitudinal changes in symptoms and provided treatment during nursing home stay. There is a lack of knowledge about how specific symptoms are managed over time in a nursing home population with dementia in variable stages. We found that burdensome symptoms frequently developed during the disease trajectory. Agitation was persistent and the most common symptom, yet it decreased at the end of life. Pain was also common and persistent and increased in the last week of life. Shortness of breath was less common, but it often persisted and increased at the end of life. No significant longitudinal association was found between pain and agitation. A positive significant longitudinal association was found between advanced dementia and pain, but not at the end of life and there was no association with other symptoms. Parenteral opioids, morphine, and anxiolytics were prescribed substantially more frequently at the end of life. Symptom control may be suboptimal from admission, and a stronger focus on symptom control is needed at an earlier stage than the end of life.

Chapter 5
Chapter 5 describes the last week of life of nursing home residents, focusing in detail on treatment provided for the most important burdensome symptoms. Pain was the most common symptom (52%), followed by agitation (35%), and shortness of breath (35%). Opioids were the most commonly provided treatment for residents in pain and residents with shortness of breath. Agitation was mainly treated with anxiolytics. Death from respiratory infections was associated with the largest symptom burden, in comparison with death from cardiovascular disorders or dehydration/cachexia. Furthermore, quality of life in the last week was worse in residents with pain or agitation. The large majority of all residents (77%) received opioids and one-fifth (21%) received palliative sedation until death. Symptom management at the end of life may be improved, with regard to weighing of effects and side effects.
Chapter 6
Chapter 6 describes the changes in care goals and treatment orders around the occurrence of pneumonia and intake problems, and whether hospitalization was in line with earlier agreed upon do-not-hospitalize orders. Overarching care goals were drawn up soon after admission and were reassessed and discussed in more detail when the condition of the resident worsens. The proportion of residents with palliative care goals and do-not-treat orders rose during follow-up, especially before death. The proportion of people with palliative care goals was similar after pneumonia, and increased after intake problems and in the period shortly before death (last six months of life). The most frequently reported reason for hospitalization was a fracture, especially in the group of residents with a do-not-hospitalize order. Overarching care goals that anticipate expected health problems in the trajectory of dementia and that anticipate the most acute decisions may help prevent burdensome, unnecessary treatment and avoidable transfers to the hospital.

Chapter 7
Chapter 7 describes end-of-life treatment decisions for residents in the last phase of life. We found that only a minority of the residents had a written advance directive upon admission. Potentially burdensome life-prolonging treatments were rare in residents with advanced dementia and less advanced dementia. Decisions not to start or to withdraw treatment shortly before death mainly related to artificial nutrition and hydration, and medication. Physicians and families often establish a palliative care goal, because they may feel that a palliative care approach is more appropriate at the end of life in nursing home residents with dementia.

Chapter 8
The general discussion in this chapter provides a summary of the study’s most important results, and it addresses a number of methodological considerations about the design of the study and issues related to measurements. Reflections on the study’s findings highlight that 1) Although dementia stages were heterogeneous in long-term care, people with dementia who were admitted to a nursing home have in common that they are vulnerable with a short survival time after admission. Especially incident pneumonia and intake problems are prognostically unfavorable. 2) Residents frequently have burdensome symptoms that persist over the disease trajectory. Because treatments are frequently continued and changed only at the end of life, the question is raised whether symptom management is adequately evaluated during nursing home stay. 3) Establishing overarching care goals is well embedded in long-term care in the Netherlands, and this way of advance care planning seems to suit actual practice and fits with the clinical course of the disease. Further, residents with dementia rarely undergo potentially burdensome life-prolonging treatment in the last phase of life, but decisions to withdraw oral (preventive) drugs are made shortly before death.
Implications of the study's results for care practice include: 1) More rigorous and timely evaluation is needed to provide comfort and adequate symptom management. 2) The usefulness and benefits of (preventive) medication should be reviewed regularly and discussed with residents and their families. 3) Awareness should be created among people with dementia and their families, as well as among health care professionals and policy makers that admission to a nursing home is a sufficiently important signal to start a palliative care approach. Informing residents and families about the course of dementia may help formulate realistic overarching care goals. 4) Explicit discussions about the desirability of prolongation of life and the life-extending side-effect of medical treatment may also be helpful to formulate care goals.

Suggestions for further research focus on the evaluation of symptom management, and on uniform use of the terminology for care goals. Further, future research should focus on the clinical course of the disease and the palliative care needs of people with dementia in primary care.

Establishing overarching care goals, timely evaluations of symptom management, and conversations about the (un)desirability of life prolongation and the usefulness of (preventive) medication will hopefully become routine practice, in order to optimize palliative care in nursing home residents with dementia.