CHAPTER 9

General discussion
In this final chapter an overview and elaboration on the main research findings of this thesis is presented. Subsequently, some methodological considerations are discussed. In addition, implications and recommendations are suggested for practice, and recommendations for future research.

**MAIN FINDINGS**

**Part I - Measuring quality of end-of-life care and quality of dying in dementia**

In part I of this thesis, the following main findings were found on the three research questions:

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

   The qualitative content analysis showed that five of the eleven instruments measure quality of end-of-life care, and four other instruments measure quality of dying (Box 1). One instrument measures both quality of end-of-life care and quality of dying, and one instrument measures quality of dying, but includes also patient factors.

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

   Of the five instruments measuring quality of end-of-life 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 was highest in the Dutch study for the EOLD-CAD and MSSE. They were followed by the EOLD-SM. The POS was judged not to be 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 an average validity and internal consistency.


   In order to determine which is the best instrument to measure quality of end-of-life care and quality of dying in research and practice, an overview of the performance in terms of the validity, reliability and feasibility of the ten available instruments in the Netherlands and the United States was made. We recommend the EOLD-SWC

---

*We did not include the MDS-PC in our psychometric properties analyses*
as the instrument to measure quality of end-of-life care, because it showed the best overall performance in both countries. Of the instruments measuring quality of dying, the EOLD-CAD and the MSSE performed best on the mentioned 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.

**Box 1. Quality of end-of-life care and quality of dying constructs captured by the 11 available instruments**

<table>
<thead>
<tr>
<th>Construct</th>
<th>Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of end-of-life care</td>
<td>End-of-Life in Dementia Satisfaction With Care (EOLD-SWC)</td>
</tr>
<tr>
<td></td>
<td>Family Assessment of Treatment at the End-of-Life Short Version (FATE-S)</td>
</tr>
<tr>
<td></td>
<td>Family Perception of Care Scale (FPCS)</td>
</tr>
<tr>
<td></td>
<td>Family Perception of Physician-Family Caregiver Communication (FPPFC)</td>
</tr>
<tr>
<td></td>
<td>Nursing home version of the Toolkit of Instruments to Measure End-of-Life Care (TIME)</td>
</tr>
<tr>
<td>Quality of dying</td>
<td>End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD)</td>
</tr>
<tr>
<td></td>
<td>Mini-Suffering State Examination (MSSE)</td>
</tr>
<tr>
<td></td>
<td>End of Life in Dementia Symptom Management (EOLD-SM)</td>
</tr>
<tr>
<td>Quality of end-of-life care and quality of dying</td>
<td>Palliative Care Outcome Scale (POS)</td>
</tr>
<tr>
<td>Quality of dying and patient factors</td>
<td>Quality of Dying in Long-Term Care (QOD-LTC)</td>
</tr>
<tr>
<td>Quality of dying and patient factors</td>
<td>Minimum Data Set – Palliative Care (MDS-PC)</td>
</tr>
</tbody>
</table>

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

In part II of this thesis, the following main findings were found regarding the four research questions:

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?*

The literature review showed that the literature reported on a variety of factors related to initiating ACP regarding end-of-life issues in dementia. We defined initiation of ACP as starting a discussion, starting decision making, or having a documented patient-written advance directive. Family factors dominated in the
Discussion

included articles. Several studies described family’s (lack of) initiative and willingness and reluctance related to 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 initiating ACP.

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

A main care goal focused on comfort was established shortly after admission to a Dutch nursing home (i.e. within 8-weeks after admission) for just over half of the patients with dementia. 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 goal classified as ‘other’. No care goal had been determined shortly after admission for 19% of the patients with dementia. At death, the large majority of patients (89%) had a comfort care goal. For 4% of the patients no care goal has been determined.

Adjusted for the severity of the illness, patients who had 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, the interviewed family member of patients with a comfort care goal shortly after admission was higher educated.

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?

The quality of end-of-life care was higher when a comfort care goal was established shortly after admission than when no such goal was established shortly after admission. We found this association only for patients who died within 6 months after admission. We found no association between quality of dying and establishing a comfort care goal shortly after admission.
Chapter 9

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 advance care planning?

The interviews with family members, physicians and nurses showed that admission to the nursing home is the starting point for ACP of patients with dementia. Based on the interviews, elderly care physicians appeared to take the initiative for ACP discussions. The interviews showed that elderly care physicians almost always had advance cardiopulmonary resuscitation (CPR) and hospitalization discussions with family shortly after admission. These discussions mostly resulted in a do-not-resuscitate and do-not-hospitalize order. Discussed and established care goals varied during nursing home stay and the terminology to describe the care goals varied between nursing homes.

The timing and content of discussions on other treatment decisions and on general goals of care depended upon a variety of factors. We found two underlying strategies that guided elderly care physicians in initiating ACP 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 for discussions (proactive, including describing scenarios). Within this second strategy, the level of detail in which physicians discussed and made other treatment decisions varied. For example, some used scenarios to arrive at a number of advanced decisions, while others used scenarios to convince family that prolonging life is not preferred, but would specify treatments only when a specific health problem developed.

In addition to the two strategies that guided elderly care physicians in initiating care planning discussions in nursing homes, we also identified other factors that are related to 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.

REFLECTIONS

Part I - Measuring quality of end-of-life care and quality of dying in dementia

Properties of available instruments

We did not include the MDS-PC in our psychometric properties analyses (Chapter 3 and 4) because no specific quality indicators or scales were available. In the field there were ongoing efforts to develop these scales. After publication of our psychometric properties analyses, eight MDS-PC Clinical Assessment Protocols (CAPs) are developed to trigger clinicians to evaluate and adapt the plan of care of
Discussion

These CAPs evaluate individual symptoms. Still no scales are available to evaluate symptom burden or quality of dying overall. The MDS-PC is a checklist rather than an evaluation instrument. If we were to repeat our study, we would not include the MDS-PC in our psychometric properties analysis.

The recommended instruments to measure the quality of end-of-life care (EOLD-SWC) and quality of dying (EOLD-CAD and MSSE) are all developed for people with dementia, are short instruments with short items and are instruments with the same response options for all items. Further, our findings showed that the recommended quality of end-of-life care instruments had a longer recall period than the recommended quality of dying instruments. Quality of dying instruments measure symptom burden. The presence of symptoms can vary over time and when the recall period is longer it could be harder to answer whether a symptom was present. The symptom could be present at the beginning of the recall period and not at the end or vice versa. When the recall period is shorter, there is lower probability that the symptom was only present part of the time. Despite the shorter recall period, last week of life, it is recommended to investigate whether an even shorter recall period for the EOLD-CAD would be more suitable.

For the quality of end-of-life care and quality of dying instruments, the maximum score is most optimal. An important point of discussion is whether it is possible to score the maximum score for every patient on the quality of dying instruments. Quality of dying possibly cannot be optimal for every patient, because perhaps not all symptoms can be relieved despite optimal treatment and monitoring of symptoms. It is recommended to investigate for which items of the quality of dying instruments it is feasible to score the maximum score for all patients with dementia. We expect it is easier for professional caregivers to influence quality of end-of-life care and an maximum score is more easily realized here than for quality of dying. In addition, actions of professionals caregivers to improve the quality of end-of-life care might have a reverse effect on the reported quality of dying. For example, better physician-family communication about possible symptoms might lead to higher quality of end-of-life care. On the other hand more knowledge of symptoms through better physician-family communication could make the family more alert, leading to more symptoms being reported and resulting in lower comfort scores on quality of dying instrument.

Use of recommended instruments

The recommended instruments are intended for use in retrospective monitoring and evaluation of the quality of end-of-life care and quality of dying in LTC facilities. These evaluations can help identify and address shortcomings in quality of dying and quality of end-of-life care. Continuous monitoring is preferred to follow trends in
the quality of end-of-life care and quality of dying over time and to evaluate the effect of initiated improvement actions.

To compare the quality of end-of-life care and quality of dying between LTC facilities measured with one of the instruments, it is important to include demographic information about patients and their families. This is necessary to correct for differences in patient populations between facilities and differences in responders (families). Also some system level factors such as type of leadership and culture can be included.② No correction is necessary for these factors, but variation in quality can potentially be explained by differences in how the care is delivered.

The recommended instruments can be used for retrospective evaluation of the quality of end-of-life care and dying of people with and without dementia. We compared the instruments’ performance among American patients with and without dementia. The performance of the SWC was similar on all criteria. For the EOLD-CAD and MSSE, performance was similar on most criteria; when it was not similar, performance was not necessarily better for residents without dementia. However, in the literature, additional items are mentioned to provide a more comprehensive picture of the dying among people dying without dementia.③ The mentioned additional items are preparation for death, the opportunity to achieve a sense of completion and the presence of social connection.③,④,⑤ The QOD-LTC also had a version for cognitively intact patients, the QOD-LTC C. The QOD-LTC C consists of 23 items instead of 11 items. Two examples of items only included in the QOD-LTC C are ‘[resident] participated as much as [he/she] wanted in the decisions about [his/her] care’ and ‘[resident] had regrets about the way [he/she] lived [his/her] life’. As our focus was on patients with dementia, we did not investigate whether instruments developed only for LTC patients without dementia had better psychometric properties than instruments we tested.

CQ-index - Palliative Care

The CQ index - Palliative care was also developed for Dutch nursing homes and residential homes.⑥ During my doctoral research, I was frequently asked in which way the EOLD-instruments differ from the CQ index - Palliative care. The CQ index - Palliative care is an instrument developed for all palliative patients and unlike the EOLD-instruments, not specifically developed for patients with dementia and not specific for LTC facilities. The CQ index - Palliative care is intended to determine the quality of palliative care for people with an incurable disorder and for their informal caregivers. The content of the CQ-index Palliative care was based on existing questionnaires, literature, and interviews and focus group discussions with family, patients, and professional caregivers. The questionnaire was tested in 31
care facilities providing palliative care, including 5 nursing homes and 11 residential care homes. The questionnaire consists of questions about care related to the psychosocial and spiritual well-being of the patient, the relative’s own psychosocial and spiritual well-being, attitude to the relatives, autonomy, information for the relative in the last week before death and expertise. Most of the questions relate to the last week of life. The CQ index-Palliative care can be compared with the EOLD-SWC. The CQ index-Palliative care was not developed and validated especially for patients with dementia. To be able to conclude which instrument is most suitable for LTC patients with dementia the psychometric properties of the CQ index – Palliative care and the EOLD-SWC should be compared in a population of LTC patients with dementia. As our research shows that instruments specifically developed for dementia have the best psychometric features. We would for now recommend the EOLD-SWC over the CQ index – Palliative Care for use of evaluation of the quality of end-of-life care of LTC patients with dementia.

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

**Initiation of ACP in dementia**

The aim of ACP is careful anticipatory decision-making on the future care of a patient with all stakeholders. A short life expectancy for a patient caused by a progressive life-limiting disease can be a reason to start ACP, but is not the only reason. The current and expected needs and existing concerns of a patient – if the patient is able to express concerns - or his family are also reasons to start ACP. Starting early with ACP has the advantage that there is more time for conversations, more time for making decisions and more time to accept the approaching death. An early start is even more salient in dementia, to give patients the opportunity to participate in the discussions before they lose the mental capacity to do so. The patient’s ability to imagine, for example the ability to imagine future scenarios, decreases and they take the initiative to discuss and make decisions less often. This thesis revealed that the starting point of ACP is generally admission of the patient to a nursing home. However, to involve patients in ACP and give them the opportunity to express their wishes about care at the end of life an earlier start is preferable. Research has shown that only a small percentage of patients with cognitive impairment and dementia have the capacity to participate in ACP during nursing home stay and family is used as a proxy. It is important to involve patients in ACP because research has shown that there is a discrepancy between the patient’s vision of care and treatments he or she patient wants at the end of life and family realizing this vision.
Starting with ACP before admission to the nursing home will become more important. In the future, more patients with dementia will have to live at home longer. This development will enhance the role of general practitioners regarding ACP in dementia.

Initiators of ACP in dementia

The research findings showed that professional caregivers initiate ACP discussions. A characteristic feature of the organization of LTC in the Netherlands is that nursing homes are staffed by specially trained elderly care physicians who are experienced in the field of chronic diseases, including (advanced) dementia, and who have their principal site of practice in the nursing home.\textsuperscript{19,20} Because of this, it was expected that ACP discussions would be initiated more often by professional caregivers. The trajectory of admission of a patient with dementia until death is not new to them. Patients and family do not know what to expect, which makes it harder to plan ahead. Professional caregivers should realize it is important to take initiative for ACP discussions, as patients—if able— and family probably will not. However, it is also important that there is more attention in society for the timely discussion of the end of life and that it becomes more common. This is also one of the recommendation of the report ‘Not everything that could, needs to. Adequate care in the last phase of life’.\textsuperscript{21} In this perspective, the Royal Dutch Medical Association (KNMG) earlier published the patient booklet ‘Discussing about your end of life on time’.\textsuperscript{22}

Our study showed that Dutch elderly care physicians not always initiate ACP shortly after the patient’s admission to a nursing home. This may be explained by the fact that family first needs to adjust to the situation and to handing over their caregiving role to the nursing home. It can also be explained by the fact that the terminal nature of dementia is not clear to every family and every professional caregiver. In 2013 a palliative care in dementia course was added to the elderly care physician training in Amsterdam and Groningen, and this course also deals with ACP in dementia. Education about palliative care and ACP in dementia can help elderly care physicians realize the benefits of early initiation of ACP.

The role of general practitioners in ACP in dementia will increase because more patients with dementia will continue to live at home for a longer time. However, our interview findings show that, so far, general practitioners pass on little to no information about patient wishes and advance treatment decisions when a patient is admitted to a nursing home (Chapter 8). The general practitioner is the preferred person to gather information about the patient's wishes and values in the phase before admission to a nursing home as part of ACP. The general practitioner knows and treats vulnerable elderly in his practice (first-line health care) and talks
with them when they are still in good cognitive health. Conveying information about wishes regarding care is part of a good transfer to another physician. Research has shown that general practitioners initiate ACP discussions more frequently for cancer patients than for dementia patients.\textsuperscript{23} Important barriers to the initiation of ACP discussions for general practitioners are lack of time for ACP discussion and ambivalence about discussing a ‘bad prognosis’.\textsuperscript{24}

Current research is investigating how general practitioners and elderly care physicians can work together in the field of ACP in the future. In practice, we already see that professionals from the nursing home take responsibility for care of patients with dementia in first-line health care. The Government encourages this development, including ACP becoming more available in the first-line health care. Also, the role of dementia case managers in identifying needs and values could be expanded in the next years. A dementia case manager guides the patient with dementia and his relatives through the disease process in the home situation and monitors the needs and wishes of the patient and his relatives.\textsuperscript{25}

**Process of ACP in dementia**

Based on the findings presented in part II of this thesis, we developed a practical guide ‘Planning of care in the last phase of life with dementia’ (in Dutch). This guide describes six steps to plan end-of-life care in dementia (Box 2).\textsuperscript{26} We recommend that professional caregivers together with patients and family go through these steps in the process of ACP in order to plan the best possible end-of-life care.

**Box 2. Steps to plan end-of-life care in dementia**\textsuperscript{26}

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Anticipate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 2</td>
<td>Inform</td>
</tr>
<tr>
<td>Step 3</td>
<td>Gather information on wishes and values</td>
</tr>
<tr>
<td>Step 4</td>
<td>Decide</td>
</tr>
<tr>
<td>Step 5</td>
<td>Document and transfer</td>
</tr>
<tr>
<td>Step 6</td>
<td>Evaluate</td>
</tr>
</tbody>
</table>

The first step in planning end-of-life care is anticipate. By anticipation we mean: look ahead to what care and treatments a patient may need and prevent making decisions under pressure of a crisis. To prevent crisis decisions expected needs should be addressed. Addressing expected needs in the process of ACP is, however, often limited because the future is uncertain. Research among inpatient populations with cancer and heart failure has also shown this limited focus on the
The lack of focus on the future leads to forced decisions in crisis situations. In crisis situations patients—if able—and family do not always make the best decisions. The qualitative interviews revealed that in the physicians’ experience life-prolonging treatments are more frequently chosen in crisis situations, while this is not always the best decision (Chapter 7). In addition, there is often not enough time to discuss and think about preferred treatment in crisis situations. The results of Chapter 7 showed that some elderly care physicians only started discussions about treatment needs when there is a reason such as a change in patient’s health condition or initiative of family (except for CPR and hospitalization), as in the strategy ‘wait for a reason to initiate discussions’. By waiting for a reason, the patient—if able—and family may not have the opportunity to get information and think about future care and treatment options. In my opinion it is important that a professional caregivers initiate the discussion about future treatment needs as soon as possible to prevent forced decisions in crisis situations. However, if the patient or family does not want to discuss future treatment needs, this must be respected.

To inform is the second step. It entails professional caregivers providing information to the patient—if able—and family about for example the patient’s condition and possible treatments. Information about what to expect at the end of life with dementia is important, because the common picture in society of the end of life with dementia is not realistic. Adequate communication is needed between the professional caregivers, patient—if able—and family to keep them informed. Preferably at least one of the professional caregivers is involved throughout the disease trajectory, which has great advantages with regard to knowing the patient and family, and facilitating continuity of communication. Having one professional caregivers throughout the disease trajectory is not possible for most Dutch people with dementia. Many people with dementia will be admitted to an LTC facility at some point during the disease trajectory, but admission generally takes place years after the dementia first manifests itself. While the patient lives at home, the general practitioner is responsible for the care, which is taken over by the elderly care physician at admission to a nursing home. The effective transfer of information about ACP discussions is therefore important. In the LTC facility the elderly care physician, but also the nurse could play a role throughout the LTC stay. Nurses provide care according to the care plan, have a monitoring role in relation to the patient, their family and the responsible physician, and also play an important role in communication. High staff turnover may challenge the aspiration to involve the same professional caregiver throughout the whole LTC stay, but it is important to continue to pursue it.

Professional caregivers should inform the patient—if able—and family, but it is also important that the patient—if able—and family inform professional caregivers.
Knowing the wishes and values of a patient (step 3) makes it easier to take decisions about care goals and possible treatments according to the qualitative interviews (Chapter 8). Talking about wishes concerning preferred care and possible directions for end-of-life care can be the content of the first ACP discussion. Talking with patients about wishes and values during the nursing home stay is often not possible. This increases the importance of talking about wishes and values before the patient loses mental capacity to do so. Communication with patients with dementia in the early stages of dementia is quite possible and essential for adjusted advance care planning to their actual wishes and needs. When everyone is ready, decisions can be made about care goals and specific treatments (step 4) These decisions must be noted in the medical record and transferred when a patient is to be treated by another professional caregiver (step 5). Care should be continuous. With good transfer of earlier decisions, every professional caregiver can anticipate changes in the health situation of the patient. In addition, ACP-decisions are never final, but should be evaluated regularly (step 6) and reconfirmed when necessary. The health condition of the patient can change over time, as can the wishes of the patient or family. When changes occur it is important to initiate an ACP discussion and talk about these changes. Reconfirming or modifying decisions requires less time than having to start discussing (im)possible treatments in crisis situations.

Content of ACP decisions

Estimating the life expectancy of nursing home patients with dementia for longer than one or a few weeks is difficult, so as recommended before, it is preferred to start ACP discussions about the care in the last phase of life as soon as possible. Within these ACP discussions, it is important to establish a main care goal, because prioritizing main care goals can help guiding care decisions. A main care goal is not the same as the actual delivered care, but can guide to this care. Unfortunately, the quantitative study showed that for 19% of patients no goal was established two months after admission, and the majority of these patients without a care goal had no ACP discussions in the first two months after admission in which care goals were discussed (Chapter 6).

Prioritizing the main care goals can only help guide care decisions, when the care goals provide clarity to everyone about the direction the care should take. In the Dutch LTC sector a total of four care goals can be distinguished, namely curative, rehabilitative, palliative and symptomatic. These care goals are described in the report ‘Concepts and accuracy demands as regards decision making at the end of life’. For the population of patients in the LTC facilities, the focus is on a palliative and symptomatic care goal. Both are aimed at comfort and when we refer to a
comfort care goal in this theses, both a palliative care goal and a symptomatic care goal are meant.

The following definitions are used for palliative and symptomatic care goal:

A **palliative care goal**: 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**: 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.

For patients and families these definitions are not very clear, but elderly care physicians and nurses also do not agree on what is meant by a palliative care goal and a symptomatic care goal. The qualitative interviews showed that professional caregivers have various definitions for a palliative or symptomatic care goal (Chapter 8). Some physicians and nurses thought a palliative care goal was relevant as dementia is a life-limiting disease, while some physicians and nurses thought a palliative care goal is relevant to all nursing home patients. On the other hand, other physicians and nurses thought a palliative care goal was only relevant when the patient’s condition was life-threatening or the patient lost the ability to find meaning in his current life. Some physicians indicated that a symptomatic care goal is the same as a palliative care goal, while others indicated that with a symptomatic care goal treatments intended to prolong life are undesirable and this is not contraindicated with a palliative care goal. In addition, the qualitative interviews showed that in practice not only the care goals as described in the above-mentioned report were used, but that several other terminologies were also used. The question is whether it is clear to professional caregivers what the direction of care is for the patient. Uniform terminology regarding care goals is preferable. This can be achieved by only using the definitions of care goals as described in the report ‘Concepts and accuracy demands as regards decision making at the end of life’, but clarification of the care goals in medical records and ACP discussions is also needed.

Two months after admission to a nursing home slightly more than half (57%) of the patients with dementia had a care goal focused on comfort (palliative or symptomatic goal), and at death the vast majority (89%) of the patients with dementia had a care goal focused on comfort (Chapter 6). The question is whether more patients should have a comfort care goal two months after admission. With the progression of the dementia, a main care goal aimed at comfort or quality of life—as in palliative care—may become more appropriate. Patients with
Discussion
dementia who are admitted to the nursing home, almost all have moderate or severe dementia, so a focus on comfort is more appropriate. In ACP discussions for nursing home patients with dementia the shift from cure to comfort care goal should be discussed upon admission. When everyone is ready, a care goal focusing on comfort should be the shared result of the ACP discussions.

Establishing a main care goal is most important, but in addition specific decisions can be made about what care and treatments are or are not preferred. This may include advance decisions about hospitalization, cardiopulmonary resuscitation, use of antibiotics or hydration. Advance decisions about hospitalization and cardiopulmonary resuscitation are necessary as there is no time for discussions at the critical moment. The qualitative interview study (Chapter 8) showed that the physician almost always discussed these treatments with family shortly after admission. The timing of care planning discussions about other specific treatments or conditions and the content of treatment decisions varied. It is important that professional caregivers also talk about other treatments with patients –if able– and family, especially about life-prolonging treatments, because treatments mainly intended to prolong life may not be compatible with a comfort care goal. Discussing possible treatments allows professional caregivers to prevent situations that no one wanted for the patient’s last phase of life.

Outcomes of care focused on comfort

The positive relation found between quality of end-of-life care and establishment of a comfort care goal shortly after admission is important to inspire professional caregivers to establish a comfort care goal for patients who are admitted to a nursing home. However, ACP is more than establishing of a care goal and establishing of a comfort care goal in itself does not guarantee optimal palliative care (comfort care). A care goal can help guide care decisions, but care and treatment should be provided to realize maximization of comfort. A care goal can be established long before it is translated into actual care. The presence of physicians in Dutch nursing homes perhaps makes it easier to elaborate specific treatments focused on comfort in case of concrete calamities, which may make an early comfort care goal less essential for the patient. The WHO definition of palliative care refers to treatment of symptoms to improve comfort. Treatments may focus disproportionally on limiting therapeutic treatments rather than on what non-therapeutic treatments can be given to improve comfort. These issues may explain why we have not found a relationship between the comfort care goal shortly after admission and quality of dying; a relationship between quality of end-of-life care and a comfort care goal shortly after admission was found, but only for patients who died within 6 months after admission (Chapter 7).
Chapter 9

METHODOLOGICAL CONSIDERATIONS

In this section the strengths and limitations of the study design used to answer the research questions in parts I and II of this thesis are discussed.

Part I - Measuring quality of end-of-life care and quality of dying in dementia

Search strategy to find available instruments

We used different strategies to search the field for measurement instruments to assess quality of end-of-life care and quality of dying for patients dying in LTC: 1) we identified all available instruments that were in use at our own institutes (the EMGO institute for Health and Care Research or at the University of North Carolina) and in use or known by our international network of researchers in end-of-life care and care for elderly people; and 2) we performed a PubMed search on the international literature for additional instruments, using a broad spectrum of search terms. The limitation of every search strategy is that studies and in our case (studies about) measurement instruments may be missed. To minimize this possibility, we used these two search strategies, and for the PubMed search we included search terms that were used in the articles about measurement instruments we identified with the first search strategy. Even so, it is possible that measurement instruments were missed. We did not identify the FPCS at the start of the study (2007), because the instrument was indexed in PubMed as a questionnaire, not an instrument. In the summer of 2008 an international colleague drew our attention to the FPCS. The FATE-S was also not identified in the first search of the study (September 2007) as the first publication on the FATE-S appeared in 2008.

We had the opportunity to compare our search findings with a systematic review of palliative care outcome measures published by Parker in 2009 and 2011.\(^38,39\) Parker et al. aimed at outcome measures used to assess the quality of palliative care provided in residential aged-care facilities. They found 9 of the 11 measurement instruments that we evaluated. The MSSE was perhaps not found, because this instrument was developed specifically for patients with dementia and was tested in an Alzheimer Research and Treatment Center. The review of Parker et al. was focused on long term care and not especially on dementia. Parker also did not identified the FPPFC; it is unclear why. Three additional measurement instruments that were identified in the review of Parker et al., were not included in our study. Those instruments were the Quality of Dying and Death, the Quality-of-Life Concerns in the End of Life Questionnaire and the modified Quality-of-Life Concerns in the End of Life Questionnaire.\(^40-42\) These instruments did not fit our
criteria for inclusion, because they were not tested in a cognitively impaired population.

We limited our search to LTC facilities, because we had a special interest in people with dementia. A large number of people dying with dementia die in an LTC facility. Because of our focus on dementia, we excluded other settings, such as community settings and residential aged-care facilities. Structures and processes of care in LTC facilities are different from those in other settings, so we do not know whether our instruments are applicable to these other settings. Our intention was to give an overview of available instruments to assess quality of end-of-life care and quality of dying for patient with dementia living in LTC facilities. We expect that quality of end-of-life care will vary more between settings than quality of dying.

**Qualitative content analyses**

To evaluate the content of the available instruments, we used the classification system of Stewart et al. In 2010, we chose this model over other models, because it captures and separates quality of end-of-life care and quality of dying. In addition, the model of Stewart et al. distinguishes and defines (sub)categories and is based on the widely used Donabedian structure, process and outcome model of health care. We are not aware of new models that would be better to use in the qualitative content analyses.

The overarching categories of the model of Stewart et al. ‘structure of care’, ‘process of care’ and ‘satisfaction with health care’ represent the construct ‘quality of care’ and the overarching category ‘quality of length of life’ represents the construct ‘quality of dying’. Because the coding of the items of the measurement instruments is rather subjective, our procedure of content analyses was strict. Each individual item of all measurement instruments was independently coded and categorized by three Dutch researchers and three U.S. researchers. Afterwards, differences in coding and categorization were reviewed and discussed until full agreement was reached within-country, followed by between-countries discussions. Any disagreement was generally not related to whether an item was about quality of end-of-life care or quality of dying; disagreement mostly concerned the subcategories within the constructs.

The strength of our content analyses and results is that the content of the included measurement instruments is clear in regard to quality of end-of-life care and quality of dying. Future users can, depending on their intentions, consciously choose a measurement instrument that measures quality of end-of-life care, and the same applies to quality of dying. Some instruments seem to measure other aspects than...
suggested by the name of the instrument (see Figure 2, Chapter 2). The name of the QOD-LTC, Quality of Dying in Long-Term Care, suggests that the instrument measures quality of dying. In fact the instrument does include items about quality of dying but it includes more items about quality of end-of-life care.

**Twelve criteria for the performance of measurement instruments**

Our overview of the performance of ten measurement instruments is unique in two respects. No other overview is available of the validity, reliability and feasibility of end-of-life instruments in LTC facilities. In addition, this overview allows for comparison of instruments, as all instruments were tested simultaneously in the same population. We were able to recommend the best instruments to measure quality of end-of-life care and quality of dying based on the measurement properties. The overview also provides the opportunity for users to select a measurement instrument by themselves.

The 12 criteria and cut points we used to test the performance of the ten measurement instruments were based on consensus between the researchers involved. Other researchers or users of the instruments, may miss important criteria or recommend other cut points. We are not aware of any other applicable set of criteria with cut points and good, intermediate and poor ratings for validity, reliability and feasibility. Our 12 criteria partly followed the quality criteria for measurement properties of health status questionnaires and the COSMIN guideline to describe the quality of measurement instruments based on validity and reliability. The criteria of Terwee et al. and the COSMIN guideline also include the domain Responsiveness, which is the ability of an instrument to detect change over time in the construct to be measured. Responsiveness could not be investigated in this study because we did not conduct two measurements over time. However, 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 measured with the EOLD-SWC.

Except for two criteria (concurrent validity with different respondents and inter-rater reliability), we weighed all our criteria equally, because doing otherwise was considered arbitrary. With regard to concurrent validity and inter-rater reliability we compared assessments of different respondents (family and professional caregivers). These assessments do not necessarily correspond as they are based on different perspectives. We only considered which of the 10 equally weighed criteria were more important than others when the performance of measurement instruments was shown to be equal. We prefer good performance on content
validity for research and on feasibility for practice. Future users may make their own decision on the weight of our criteria and on which is the best instrument for their purpose.

The measurement properties were generally consistent across the United States and the Netherlands, and across U.S. patients with and without dementia. Therefore, the results likely apply to other Western countries as well, and to patients with and without dementia in LTC facilities. As indicated before, it is mentioned in the literature, that additional items are needed to fully measure quality of end-of-life care or quality of dying for patients without dementia (see also Use of recommended instruments).

Data collection with the measurement instruments

Our study presented in the first part of the thesis has several strength regarding the data collection: the data collection was performed in two countries, with prospective observations, with two types of retrospective administration (i.e. written questionnaires and telephone interviews), with family and professional caregivers, and with patients with and without dementia. However, there were also some limitations. One limitation is the fact that the FATE-S and FPCS were identified midway through our study and so were included only in the last part of the data-collection. However, when we performed analyses in the subpopulation in which the FATE-S and FPCS were tested, these instruments did not perform better than the EOLD-SWC.

Family had to complete many measurement instruments. The instruments were compiled in order of timeframe of reference, beginning with instruments referring to the last month of life, and ending with instruments focusing on the last 3 days of life. To avoid possible bias due to the order of instruments within each timeframe, the order within timeframes was reversed for half of the population.

The response rate of families was somewhat low in the Netherlands. The response rate might have been higher if family had been asked to complete the instruments to provide insight into the quality of end of life in the nursing home instead of for the research purpose of selecting the best instrument. However, for both countries the response rates fall within earlier reported response rates (50-80%). The sample size of the Dutch study was smaller than the U.S. study. However, in the Dutch study professional caregivers also completed a retrospective questionnaire with the quality of dying instruments and two elderly care physicians performed observations when death was expected within one week. In the United States all data were collected in a telephone interview and most Dutch data were collected with a written questionnaire. In an effort to identify bias due to administration
modality, EOLD-SWC was administered to a subsample (n =20) of Dutch study participants in the form of a telephone interview and a written questionnaire. We found that the EOLD-SWC scores did not differ significantly between telephone and written questionnaire administration.\textsuperscript{58} When we asked family for their preference, they mostly said it makes no difference to them.

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

In the second part of this thesis, we used different research methods to contribute to a better understanding of ACP for patients with dementia; a review of the literature, qualitative data collection and quantitative data collection. The use of different research methods provides a broad view on ACP in nursing homes. Based on the findings obtained with all three research methods, the practical guide ‘Planning of care in the last phase of life with dementia’ was developed.\textsuperscript{26} It is a practical guide for professional caregivers, to guide shared planning of care in the last phase of life of patients with dementia. With the development of this practical guide, we contributed to the transfer of our research results to practice. The limitations and strengths of each of three methods are discussed below.

**Review**

The review reports on barriers and facilitators for initiation of ACP regarding end-of-life issues in dementia. We excluded articles about the contents of ACP or the treatment decisions taken. These issues are also essential parts of planning end-of-life care, but it was our goal to present a synoptic overview of factors we decided to limit our inclusion to the initiation of ACP. There will be overlap with factors that influence the contents of ACP or treatment decisions and care delivered, yet our identified factors are different. In addition, we decided to exclude studies performed in acute care and in hospitals. Initiation of ACP in these settings may be related to future decisions, but might be too late.\textsuperscript{59,60}

Sometimes it was difficult to extract factors related to initiation of ACP from the articles. We therefore decided to have multiple researchers extract the factors independently. For example, some studies were not limited to end-of-life care, but also include financial or legal issues.\textsuperscript{61-63} In some qualitative studies, there was no clear distinction between the initiation of ACP and content of ACP (e.g. 64; 65). For example, in the article of Gessert the aim was to identify areas in which better communication between health professionals and patients/families might be expected.\textsuperscript{64} These areas can concern initiation of ACP as well as content of ACP. One of the factors identified in the article was ‘Health professionals have been unaware of family’s needs for information’. The article does not stated clearly
whether this relates to the timing of contact moment, the number of contacts or to the decisions made for patients.

We reported a comprehensive list of factors related to ACP initiation. We tabulated only the factors that were found in at least two studies, in order to reduce the amount of information and in view of the generalizability of the findings. We found no other overview of factors related to initiation of ACP in dementia. We did not systematically judge the quality of the articles. Quality seems more important when the strengths of relations are reported, but is perhaps less important in a review aimed at providing a comprehensive list of factors.

**Quantitative data collection using questionnaires**

A quantitative approach was most suitable for answering research questions 5 and 6: ‘What care goals are established for nursing home patients with dementia and which factors are associated with establishing a comfort care goal?’ and ‘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?’.

Results were obtained by prospective data collection with questionnaires in the Dutch End of Life in Dementia (DEOLD) study. The prospective nature of data collection is a strength of the DEOLD study. To our knowledge, this is the only fully prospective, nationwide end-of-life study that followed nursing home patients in varying stages of dementia from admission to the nursing home throughout their stay. This enabled us to follow the change of care goals over time.

Another strength of the data collection is that questionnaires were completed by both families and physicians. As a result, we were able to test whether similar factors from different perspectives were related to establishing a comfort care goal. Earlier studies have found the same factors as identified in our review, but most of these studies only examined one factor, or different factors from only one perspective. In addition, we could investigate whether the care goal shortly after admission according to the physician questionnaire was associated with the quality of end-of-life care and quality of dying according to the family questionnaires after death.

Physicians reported the main care goal, the single goal that took priority, in all the assessments (questionnaires). The six response options were: (1) palliative care goal, aimed at well-being and quality of life, irrespective of shortening or prolonging of life; (2) symptomatic care goal, aimed at well-being and quality of life, additional prolonging of life undesirable; (3) maintaining or improving function; (4) life prolongation; (5) other; and (6) global care goal has not been established yet. These response options reflect the three care goals of the adapted model of Lynn.
and Adamson as published in the EAPC white paper Palliative Care: prolongation of life, maintenance of function and maximization of comfort.\textsuperscript{3} The response option palliative care goal and symptomatic care goal, both focus on well-being and quality of life or in other words maximization of comfort.\textsuperscript{33} A distinction is made between a palliative care goal and a symptomatic care goal, because in the Netherlands this is a distinction commonly made in the palliative care for nursing home patients with dementia.\textsuperscript{34} The qualitative interviews showed that in actual practice the terminology to describe the care goals varied between nursing homes; also, not all respondents used terminologies used in our answer options and various definitions of a palliative and symptomatic care goal were given by physicians. Despite this lack of uniformity, the number of missing answers to the question about the main care goal was not high (2-3\% per assessment), perhaps thanks to the short description of a palliative and symptomatic care goal that was provided with the answer options.

The causality of the associations of factors with the establishment a comfort care goal shortly after admission should be interpreted with caution. For example, a comfort care goal may have been the result of a good communication process between family and the physician and it is the communication that the family is satisfied with, not the comfort care goal. It is also possible that families may have been satisfied with the communication because it resulted in a comfort care goal. In this study we were only interested in the formulation of care goals. A care goal can help guide care decisions, but care and treatment should be provided to realize maximization of comfort.\textsuperscript{33} A care goal can be established long before it is translated into actual care. We have not identified which treatments were given based on established care goals. It would be interesting to get more insight into 1) the relation between provided treatments and established care goals, and 2) the relation between provided care including treatments and the quality of end-of-life care and quality of dying.

Further, because of the small number, we were not able to compare patients with each separate care goal with each other. Therefore we dichotomized in ‘comfort care goal’ and ‘no comfort care goal’. It would have been interesting to also split no comfort care goal in ‘maintain function or life prolongation’, ‘life prolongation’, ‘other’ and ‘no main care goal’. Especially ‘no main care goal’ is interesting, as ‘no main care goal’ suggests it is unclear what care should be provided.

We asked family the following question in the family questionnaires: ‘How did you feel about the timing of ACP discussions in relation to your loved one’s health?’ In retrospect, we would rephrase this question. It would have been better to ask the family how they felt about the timing of ACP discussions without the reference to
the patient’s health condition. The patient’s health condition can be a reason to initiate ACP discussion, but other reasons for initiating ACP can also be important to family. An additional question could then be why they feel the timing was too early, just in time or too late. In addition, the questionnaires did not ask families who did not discuss ACP with a professional whether they would have wanted such discussions. Therefore, it was not possible to provide firm conclusions on the family view about the timing of ACP discussions.

In the after-death questionnaires, family was asked about quality of end-of-life care and quality of dying. Retrospective assessments of the quality of end-of-life care and quality of dying are most frequently used. These assessments may be most suitable for studies with limited resources or when there is a clear time frame (e.g. last month, last week) or a specific study population (e.g. patients in the last days of life).

Finally, the Netherlands is a country with a high presence of specialized physicians in nursing homes compared to, for example, the United States. Therefore, our results may not be representative for countries with other health care systems. However, our identified associations can be used to verify these associations in countries with other care systems.

Qualitative data collection using interviews

We investigated the experiences and factors related to ACP with qualitative in-depth interviews. The strength of our design was that we included various perspectives in the interviews; family, elderly care physicians and responsible nurses. This allowed us to identify more factors and compare experiences and perceptions for the same patient.

Selection of patient cases from the quantitative data of the DEOLD study should enabled for selecting patient cases with variability in the ACP for the family and professional caregiver interviews. Unfortunately, sampling among the patients who died near the end of the DEOLD study yielded few families who thought planning was too early or too late. We did not sample among the patients who died earlier in the DEOLD study, because the period between the qualitative interview and the period of the patient’s stay in the nursing home would be too long to remember everything. Simultaneous collection of quantitative and qualitative data would have been a better option.

Our study was performed among nursing home patients with dementia. Many identified factors will be comparable for patients with dementia in other settings. However, it would be interesting to interview family and professional caregivers of
home-dwelling patients with dementia, because more and more patients with dementia will continue to live at home for a longer period of time. In addition, Dutch nursing homes have specialized physicians who care for nursing home patients (elderly care physicians). In settings with less presence of specialized physicians, other factors may possibly play a role in planning of end-of-life care. However, many of the identified factors will probably also play a role in these settings.

Most of the interviews were carried out by telephone. We chose this way of data collection, due to time constraints. Face-to-face interviews are more commonly performed than telephone interviews, but there is little evidence that missing the visual cues results in bias. We held eight face-to-face interviews, to rule out that face-to-face interviews would have yielded additional information that could not be collected in telephone interviews. The face-to-face interviews inspired the exploration of new issues, which were subsequently examined in telephone interviews. However, they did no yield information that could not be collected in telephone interviews. The context of the DEOLD study in which families had been involved for some time may also have facilitated recall during the telephone interviews. Further, the discussions with professional caregivers, either face-to-face or by telephone, were more detailed when the patient’s chart was available during the interview.

**IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE**

**Part I Measuring quality of end-of-life care and quality of dying in dementia**

**Feedback on quality**

For a good impression and the opportunity to improve, the quality of end-of-life care and quality of dying need to be measured. In Dutch nursing homes and residential homes, the quality of end-of-life care and quality of dying are not structurally evaluated. We recommend that nursing homes and residential homes start structurally evaluating the quality of end-of-life care and quality of dying in dementia. The EOLD-SWC and EOLD-CAD or MSSE are recommended for this evaluation, because of their good psychometric properties. Overall the psychometric properties of the EOLD-CAD were slightly better than of the MSSE, but the MSSE performed better on feasibility than the EOLD-CAD. However, users can independently select most suitable instrument from the overview of all instruments.

When implementing the EOLD-instruments or MSSE in practice, we prefer completion by family members. The EOLD-SWC is only suitable to be answered by family members, but the EOLD-CAD and MSSE can also be completed by
professional caregivers. We prefer the family as respondents for both instruments, because professional caregivers may learn most from the perception of family members about the quality of end-of-life care. Furthermore, many family members like to tell or write their story, and it saves professional caregivers work. Moreover, the caregiver may get bored filling out the same questionnaire for each resident. However, it is informative to ask the physician and/or responsible nurse to complete the EOLD-CAD in addition to family completion of the EOLD instruments for short periods of time. This provides the opportunity to compare answers on the EOLD-CAD items between family and professional caregivers. Discrepancies are especially important to reflect on. For example, lower scores by family than professional caregivers may indicate a need for better communication between professional caregivers and family.

For users of the instruments, it is important to take note that simply measuring quality of end-of-life care and dying is not enough to improve quality. Structural assessments of care performance that are compared to professional targets or standards –audit and feedback– is widely used as a strategy to improve professional care practice. In the nursing home setting, there are indications that audit and feedback may improve nursing home care in general, including nursing home care for patients with dementia. The literature also suggests that audit and feedback is more effective when accompanied by a clear plan about what to do with this feedback on the quality. An example of what to do with feedback on the quality are the improvement suggestions developed for the FOLlow-up project (see also recommendation for Future research). The improvement suggestions were developed based on the latest national and international literature and care guidelines in the field of end-of-life care. The improvement suggestions were reviewed by professionals in the field for their practical applicability to improve care quality.

**Using the EOLD-instruments and MSSE to provide aftercare**

Good communication and guidance of the family after the death of a patient is very important. Also, this aftercare is part of providing good palliative care. Asking family to complete the EOLD-SWC and EOLD-CAD or MSSE provides families with the opportunity to give feedback. In addition, the completed questionnaire can 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. For the family the contact with professionals often ended abruptly with the death of their relative, while contact with the professionals frequently took place over a longer period of time. Research with quality indicators for palliative care (CQ index - Palliative care), showed that 53% of the families of a patient who died not suddenly six weeks to six
months earlier indicated that they had no final conversation or discussion to evaluate the care and treatment after the death of their family member. Almost half of the family members who completed the CQ index – Palliative care indicated their family members died in a nursing home or residential care home. The family has to live on with the memories after a patient’s death, so it is good to conclude this period with a final conversation or discussion for which the completed questionnaire with EOLD-SWC and EOLD-CAD or MSSE may provide input.

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

For professional caregivers in dementia, i.e. elderly care physicians, but also general practitioners and dementia case managers, it is important to take note of the identified factors that play a role in ACP and in establishing comfort care goals. To address these factors, communication is essential. It is important for professional caregivers to realize that they should take the initiative regarding ACP, as the patient or family frequently will not. We concluded that acute decisions are discussed in advance by elderly care physicians, but regarding other treatment decisions we see both a proactive and responsive style. Education about the benefit of ACP and palliative care in dementia in the training to become an elderly care physician, but also in the general practice training, is important. It supports professional caregivers in initiating ACP and provides guidelines on how and what to plan in advance and how to overcome potential barriers. For example, attention needs to be given to what to do if family is not ready yet to talk about the end of life. However, it is also important to ensure that talking about the end of life becomes more common in society. Herewith, the media can play an important role.

Estimating the life expectancy of patients with dementia is difficult, so it is good to start with discussions about the care in the last phase of life as soon as possible. If the patient or family is not ready to plan care for the last phase of life, information can be provided on why it is important to plan, and perhaps, it can be discussed why it is difficult to talk about the end of life. A first step in the process may be talking to patient –if able– and family about their feelings on dementia or about the admission to the nursing home. 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.

In addition, it is important to increase uniformity in the terminology of care goals. Consistently reporting main care goals for the last phase of life in the medical record with a brief explanation, makes it clear for all professional caregivers what the main care goal of a patient is and what it means. When establishing a main
care goal together with family it is also important to discuss how the care goal will be reported in the medical record. A care goal focused on comfort should at least be considered from admission, because patients with dementia who are admitted to the nursing home are almost all in the moderate or severe stages of dementia. However, establishing a comfort care goal is not enough, a care goal only gives direction to future care decisions.

Materials are available to support professional caregivers when planning care in the last life stage. First, there is the practical guide developed in this project ‘Planning of care in the last phase of life with dementia’\(^{26}\) There is also a family booklet ‘Comfort care in dementia’ which can be provided to relatives (available through ACA VUmc).\(^{82}\) This contribution describes how dementia in general develops towards the end, and provides information about palliative treatment options. A video based on this family booklet is also available. In addition, the KNMG published the physician guideline ‘Timely discussion of death’.\(^{83}\) This guideline contains discussion points that can be used by the physician as a tool to organize their thoughts in advance, structure ACP discussions and discuss possibilities with the patient and their family.

**RECOMMENDATIONS FOR FUTURE RESEARCH**

**Part I Measuring quality of end-of-life care and quality of dying in dementia**

**Implementation of the EOLD-instruments**

With regard to the best instruments to measure quality of end-of-life care and quality of dying, it is a logical step to consider the optimal manner of implementing these instruments in actual practice. Determining the best instruments does not guarantee their use in practice. Therefore an implementation project has been developed after determining which are the best instruments; the FOLlow up project.\(^{81}\) 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. A total of 18 nursing homes, three groups of six homes were randomly assigned to an intervention group or the control group. The effect of the two audit- and feedback strategies on quality of end-of-life care and quality of dying will be tested with a quantitative effect evaluation and the implementation process will be evaluated using a mixed-method design. 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 where necessary improve the quality of end-of-life care and quality of dying. Afterwards, the quality can be continuously monitored and it
can determined how the quality of end-of-life care and quality of dying in dementia can be improved.

**Trends in quality of end-of-life care and dying over time and comparison between countries**

Over the period 2005-2010, analyses based on three Dutch studies showed a positive trend of increasing quality of end-of-life care and indications were found that patients also had a more comfortable death according to their family. It would be interesting to investigate whether these trends have continued over more recent years and will continue in the years to come, especially because the burden of care of patients with dementia admitted to the nursing homes will increase and health care is under pressure due to cutbacks. In addition, it would be interesting to compare our scores on the EOLD-instruments with other countries. In the current study, we compared the Dutch scores on the EOLD-instruments and other instruments with the scores on the instruments in the United States, and demonstrated that family of patients with dementia dying in nursing homes, residential care homes and assisted living facilities in the United States generally reported higher quality end-of-life care and dying than Dutch family caregivers. Van Uden et al. compared scores on the EOLD-instruments between Dutch and Belgian nursing homes. Like in the United Stated, in Belgium the general practitioner also remains the treating physician for patients admitted to a nursing home. The general practitioner visits the patient on a regular basis in the nursing home. Despite this difference between Belgium and the Netherlands, the quality of end-of-life care for patients with dementia is similar according to their family members. However, family of Dutch patients reported lower quality of dying. It would also be interesting to compare our scores with other European countries.

**Aftercare for families of patient with dementia who died in a nursing home**

The provision of aftercare is important, but no practical guide on how to provide this aftercare is available. In some nursing homes professional caregivers contact the family after death, for example by telephone, and other nursing homes organize a memorial service one or two times a year. In addition, it is also unclear what the family needs are for aftercare from the nursing home. These needs are expected to vary between family members. Future research should investigate what are family needs regarding aftercare and what are the existing possibilities and experiences with aftercare. Based on such a research project a practical guide can be formulated with concrete recommendations for LTC facilities for providing customized aftercare.
Part II Advance care planning and establishing a comfort care goal for patients with dementia

The strength of the second part of this thesis is the prospective design of the quantitative data collection. However, regarding factors related to establishing a comfort care goal and the relation between a comfort care goal and outcomes of care causality cannot be inferred from observational data. In our study, we lacked a full account of all treatments provided and we could not identify the effectiveness of treatment to improve comfort in our observational study. In additional research the relation between care goals, treatments provided and comfort after death should be investigated.

In future 'mixed method' research, it is recommended to start the qualitative research simultaneously with the quantitative research when possible. This will enable the purposeful selection of a variety of patient cases in terms of ACP from the quantitative research part for the qualitative research part. 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 advance care planning.

Further research in countries with other models of care is needed to generalize our findings regarding factors related to establishing a comfort care goal and the relation between a comfort care goal and outcomes of care. Our study was conducted in a country with on-staff specialized elderly care physicians. A qualitative interview study in the Netherlands and the United States concluded that differences in physician training and care delivery can influence the physician-perceived care role regarding treatment decisions. The researchers found that Dutch families may have less influence on the decision making process as compared to in the United States.

In addition, patients with dementia will be living at home longer and ACP in dementia will become increasingly relevant for general practitioners. Further research is needed to develop and evaluate tools to help physicians plan end-of-life care in advance across different settings. This may also include an intervention study to examine the effect of practical guide developed in this research ‘Planning of care in the last phase of life with dementia’ and other tools for ACP such as the family booklet ‘Comfort care in dementia’ and the video based on this family booklet. Little evidence is available that ACP interventions (e.g. a framework for the discussion of ACP with patients –if able– or family) benefit patients with
dementia. Evidence of benefit for patients will motivate professional caregivers to initiate ACP for patients with dementia in a timely manner.

CLOSING REMARKS

The overall aim of the research presented in this thesis was to contribute to ‘good’ end-of-life with ‘good’ end-of-life care for patients with dementia who die in an LTC facility. ACP, the subject of the second part of this thesis, can facilitate ‘good’ end of life with ‘good’ end-of-life care. The first part of this thesis provided information on the best way to evaluate the quality of end of life and quality of end-of-life care. We hope that this thesis will be a source of inspiration for professional caregivers to find the best way to plan end-of-life care in advance for patients with dementia and to evaluate their end-of-life care afterwards to be able to optimize it step by step.

REFERENCE LIST

29. de Kwant L. [De echte problemen van de langdurige zorg]. Medisch contact 2015;8:334-337.
37. van der Steen JT, Helton MR, Ribbe MW. Prognosis is important in decisionmaking in Dutch nursing home patients with dementia and pneumonia. Int J Geriatr Psychiatry 2009;24(9):933-936.

214
78. Teigland C, Pulungan Z. Quality measures for Alzheimer’s Dementia residents lead to improved outcomes and quality of life [abstract].