SUMMARY

GENERAL INTRODUCTION

End-of-life care
When patients and their families face a life-threatening illness improving the quality of life of patients and their families becomes an important care goal. End-of-life care is of particular societal importance for older people, as they are usually affected by multiple medical problems. As a result of the ageing population people are living longer with chronic diseases. Consequently, there is an increased need for care over a longer period of time, and in particular there is a need for more complex care closer to death.

Preferences for (non)treatment decisions
The discussion about decision-making at the end of life particularly focuses on people with chronic disease(s), who generally receive care for a longer period of time. The associated longer period of care enhances the possibilities for advance care planning and communication about preferences in (non)treatment decisions. People may already have ideas about their end-of-life preferences before being ill, or develop them later. Important decisions at the end of life concern the type of medical care and the extent of care that a person prefers to receive, e.g. concerning artificial respiration, resuscitation, administration of antibiotics, or artificial administration of nutrition and hydration.

Advance directives (ADs)
In order to make their preferences known, people may write down these preferences in an advance directive (AD), a written statement in which they can specify preferences in end-of-life decisions or appoint a health care proxy. It either can make statements about receiving or refusing treatments at the end of life, or appoint a person who will take decisions for the patient at issue. In the Netherlands, two associations provide the most common types of ADs: ‘Right to Die-NL’ (NVVE in Dutch) and Dutch Patient Association (with a Christian background; NPV in Dutch). As the patients’ quality of life and preferences are a primary focus in end-of-life care, ADs can be important in the process of decision-making at the end of life.

AIM OF THIS THESIS

The main aim of this thesis was to investigate end-of-life care and preferences for (non) treatment decisions that potentially affect the life of older people during their last three months of life. Special emphasis was put on the role of advance directives (ADs). Several
data sources were used. The results in chapter 2, 4, 5 and 6 are based on retrospective after-death proxy reports about deceased cohort members. These data consists of a sample representative for Dutch older people (Longitudinal Aging Study Amsterdam (LASA), n=168) and a sample representative for older people who had formulated an AD (Advance Directives Cohort (ADC), n=184), who died in 2005-2009. In addition, chapter 2 includes a comparison of retrospective after-death proxy reports of a sample of Dutch older people ten years ago, who died in 1995-1999, and a sample of Dutch older people who died in 2005-2009 (both from LASA, termed samples 2000 and 2010; 2000-sample, n=270). The results in chapter 3 are based on a cross-sectional sample of the Dutch general population (Consumers Panel, NIVEL, all ages, n=1402) and of people who had formulated an AD (all ages; NVVE (‘Right to Die-NL’) n=5561, and NPV (Dutch Patient Association with a Christian background) n=1037).

MAIN FINDINGS

END-OF-LIFE CARE

Chapter 2. End-of-life care: are there changes over a decade in the end-of-life care and transfers of older people in their last three months of life

In the last decade (2000-2010), the care received by older people during the last three months of life changed into constituting more formal home care, or a combination of formal and informal home care.

In both the 2000 and 2010 sample, half of the Dutch older people moved one or more times to another care setting in the last three months of life. Place of death and the percentage of home deaths did not change during the ten-year period; only a small but statistically significant decrease in hospital deaths was found (2000 sample 35%, 2010 sample 29%). Regardless of the study year, older people receiving informal home care were more likely to be hospitalized until death (OR 2.3), than people living in an institution (i.e. nursing or residential home).

Chapter 3. End-of-life care: what do people consider important for a ‘good’ death

With respect to what people hoped for during the dying process (all ages; Dutch general population and people who had formulated an AD of the NVVE and NPV), a majority of all three samples said that they hope to die with dignity (Dutch general population 94%, NVVE 97%, NPV 92%), to say goodbye to loved ones (Dutch general population 94%, NVVE 89%, NPV 94%), and to decide on the treatments they do or do not want to receive (Dutch general population 92%, NVVE 99%, NPV 91%). However, preferences varied between the three groups predominantly with respect to the importance of being able to decide for themselves about the exact moment of death: for the NVVE members this was very important and for the NPV members this was the least important (Dutch general population 50%, NVVE 85%, NPV 5%).
Age and religion were found to be associated with preferences in multivariate analyses. Notably, the experience of a good or bad death of a loved one was not associated with preferences regarding a good death. Of the general population 73% had experienced a good death of a loved one, while 31% had experienced a bad death of a loved one.

Chapter 3 showed that in experiencing a death of a loved one, a good death was predominantly related to mental or psychosocial factors (e.g. dying peacefully, having said goodbye to loved ones). A bad experience was predominantly influenced by physical and communicational factors (e.g. poor decision-making and coordination of care by health care professionals).

**Chapter 4. End-of-life care: how many older people experience limitations in decision-making capacity (DMC) during their last three months of life and how does DMC affect satisfaction with and communication about care**

*Limited DMC before death*

A month before death 27% of the LASA sample had limited DMC. This increased to 67% of older people developing limited DMC in the last week of life. Limited DMC that developed a week or less before death was mostly due to reduced consciousness or coma, limited DMC more than a week before death was predominantly due to dementia. Older people who remained lucid until death died significantly more often of heart disease than of other diagnoses.

*DMC and communication about care*

According to the relatives, the care received was overall in accordance with the patient’s preferences for the majority of older people although less often for people who had limited DMC for more than a week before death. The majority of relatives were satisfied with the communication between the physician and the patient and themselves, regardless of the DMC of the patient. Even if patients had limited DMC, the physician often communicated about the treatment choices with the patient and also with relatives (communication with both patient with limited DMC and relative 58%). Furthermore, even if a patient had full DMC, the physician also frequently communicated about treatment choices with their relatives (communication with both patient with full DMC and relatives 56%).

*DMC and the role of ADs*

Most relatives of older people with an AD and with limited DMC before death experienced communication about ADs as good, regardless of the duration of limited DMC. Of people with an AD, a small majority indicated that the AD had been of additional value in the decision-making. Finally, no differences were found in the role of the relative and the satisfaction about this role between people with and without a proxy AD.
(NON)TREATMENT DECISIONS

Chapter 5. (Non)treatment decisions: what preferences do older people have for forgoing treatment and are these preferences discussed during their last three months of life
While only 16% of the LASA sample had an AD, a substantial part of this sample had specific preferences on whether or not to forgo resuscitation (42%), artificial administration of fluids and nutrition (26%), antibiotics (41%) and artificial respiration (30%).

(Discussing) preferences and the role of ADs
Of the Dutch older population who had a preference for resuscitation or life prolonging treatments (artificial fluids and nutrition, antibiotics and/or artificial respiration), less than half had discussed these preferences with their physician (41% for resuscitation, 36% for one or more life prolonging treatments). This also holds for relatives discussing the patient’s preferences with the physician. In general, for people without an AD, the preferences on the four treatments at three months before death were more frequently unknown to the relatives (46-60%), than for older people with an AD (14-29%). Having an AD was the most important factor associated with not wanting the four treatments studied. Both older people with and without an AD more frequently wanted antibiotics than other potential life-prolonging treatments. Together with preferring no treatment, the most important factor associated with discussing preferences with their physician was having an AD.

Changes in preferences during the last three months
The potential change in preference, e.g. through a change in health status, has been discussed as a threat to the validity of ADs. However, for 82-90% of the older people, with and without AD, preferences did not change during the last three months of life, according to their relative. If preferences changed, they generally changed from wanting the treatment into neutral or not wanting the treatment.

Chapter 6. (Non)treatment decisions: what are preferences for (non)treatment of older people and which actual treatment decisions are made for older people during their last three months of life
Decision-making in (non)treatment
For a majority of older people who came in the situation an actual treatment decision had to be taken and who preferred to receive treatment, this preference was followed (88% - 100% for the different situations, i.e. resuscitation (n=2/2), artificial administration of nutrition and hydration (n=23/26), antibiotica (n=33/38), artificial respiration (n=23/24)). In only about half of the older people who preferred that a treatment should be forgone, this preference was followed (i.e. resuscitation (n=6/13), artificial administration of nutrition and hydration (n=11/18), antibiotica (n= 3/5)), except for artificial respiration (n= 1/8, 12% preference followed).
Making preferences for (non)treatment known
Older people who had a known preference for forgoing treatment had a six times higher chance that treatment indeed would be forgone (OR 6.3), compared to older people for whom no preference was known. Older people who had a known preference for starting treatment had a much lower chance that treatment would be forgone (OR 0.28), compared to older people for whom no preference was known.

GENERAL DISCUSSION

Finally, in chapter 7 the main findings and conclusions with regard to the contributing insight of this study into end-of-life care during the last three months of life are summarized. Furthermore, reflections on the methodological aspects of the study and suggestions for further development of practice and research are discussed. For instance, the following six general key points arise from the findings, and could be taken into account in the policy and practice regarding the trajectory of end-of-life care:

1. For a substantial group of older people, their preferences in end-of-life care and (non) treatment decisions are unknown to the relatives.
2. Moreover, the majority of these older people did not discuss end-of-life preferences with their physician in the last three months of their life.
3. Making preferences known to physicians can have effect on actual decision-making and, therefore, discussing preferences is useful as it increases the odds of an actual (non) treatment being in accordance with preferences.
4. In practice, physicians, patients and their relatives could stimulate each other to initiate an active discussion about preferences concerning end-of-life care and decision-making.
5. ADs seem to stimulate awareness and discussion of preferences, and, therefore, ADs can influence actual decision-making.
6. The physician, patient and their relatives all have their individual role in the advance care planning; performing this role could be encouraged; in chapter 7, suggestions for the implementation of each role are made.