

SUMMARY

PART I: INTRODUCTION

This thesis is about advance directives (ADs), documents in which a person puts down his or her wishes concerning care at the end of life. An AD is meant for situations where the owner is not able to express his or her wishes by him- or herself.

The aim of ADs seems to be clear: to ensure that someone receives the care at the end of life he or she wants. However, questions arise about the status of ADs in practice. For instance, do these documents reflect the actual preferences of their owners? Did their owners understand the impact of the often complex medical procedures at the end of life when they put their preferences down in a document? And do these preferences stay stable over time?

Aim and design of this thesis

This thesis tries to clear up some of the issues surrounding ADs and takes the perspective of the people who have an AD.

Three important themes emerge throughout the thesis:

- *The meaning of ADs*
 - The meaning of ADs in society: how widespread are ADs and does the general public have the desire to draft an AD?
 - The meaning of ADs for the people who have one: what are the reasons to have an AD? What do people hope to reach or prevent with ADs?
 - The meaning of the content in ADs: do the preferences recorded in ADs reflect what people actually want? How do the views of people owning ADs on the end of life relate to actual practice?
- *The stability of preferences about care at the end of life*
 - Do preferences about care at the end of life stay stable over time? What is the influence of a change in health or other life-events on this? Do people make adjustments in their ADs?
- *The communication surrounding ADs*
 - How often are ADs discussed over time and with whom? What are reasons to discuss ADs?

Design

The data for this thesis was derived from two sources: the Consumers' panel for Health services (CoPa) and the Advance Directive Cohort (ADC).

The CoPa (n=1621) was a sample of the Dutch public established by the Netherlands Institute for Health Services Research (NIVEL in Dutch), representative of the population of the Netherlands aged 20 years and older. A questionnaire was sent to the members of the CoPa containing questions about background characteristics, end-of-life issues and ADs. 1402 respondents returned this questionnaire.

In **chapter 2** the design and origin of the ADC is described. The ADC was a cohort of people who had an AD. The cohort provided quantitative as well as qualitative data, so both methods could be used to investigate the subject of ADs. Two associations were used to reach people

who had an AD. The Right to Die-NL (NVVE in Dutch), from which 5661 members participated in the ADC, is an association that is committed to the possibilities of individuals to determine the end of their life. The Dutch Patient Organization (NPV in Dutch), from which 1261 members participated in the ADC, is a Christian orientated association. Both provide the most common types of standard ADs in the Netherlands.

Both groups were sent questionnaires each one and a half year from 2005 to 2011 containing questions about background characteristics, end-of-life issues and ADs. Using the data provided by this certain respondents were asked to participate in the interviews for the qualitative part of this study.

PART II: THE MEANING OF ADVANCE DIRECTIVES

In **chapter 3** data from the CoPa is presented about the dissemination of ADs in the Netherlands and the views of the general public on them. ADs were not widespread in the Netherlands in 2005: only 7% of the sample of the Dutch population indicated to have one. A majority of 86% indicated they (maybe) wanted to draft an AD in the future. Most mentioned reasons for not (yet) formulating an AD were that the respondents considered themselves too young and healthy or other reasons related to timing. 5% of the Dutch population indicated that they found the subject too confronting to think about. 2% did not have any thrust in the effectiveness of ADs. The advance euthanasia directive was the best-known AD. Factors linked to euthanasia, like a respondent imagining that he or she might ask to end his or her life in specific situations, were associated with the intention to draft an AD among the Dutch general public, so the subject of euthanasia played an important role when it came to ADs in the Netherlands.

Among the general public the experience of an unpleasant or unpeaceful death, but also euthanasia in one's social surroundings was associated with the intention to formulate an AD. As described in **chapter 4**, in the quantitative as well as the qualitative data from the ADC also experiences of holders of ADs with illnesses and deaths in their surroundings emerged as important motivations to draft an AD. For this chapter motivations, aims and communication surrounding ADs were investigated using mixed methods.

When it came to what holders of ADs aimed at with the document, members of the NVVE wanted to prevent suffering, physical and mental decline, being dependent or being a burden to others. The members of the NPV seemed to be less fearful of the effects of possible future illnesses, but worried more about shortening of life against their wishes. In both groups respondents deemed it important that their AD ensured that they would die in a dignified manner and would prevent unnecessary lengthening of life.

In the interviews with a purposeful selection of respondents suffering from an illness, interviewees indicated that they now endured situations of which they had thought they would not be able to before they got ill. On the other hand some limits about when life would not be worthwhile anymore remained, and seemed unchanged. Others indicated they found it hard to

foresee the future and where they would set limits.

Interviewees indicated they talked about their ADs with close-ones and caregivers mostly thoroughly and realistically. Some mentioned difficulties in the communication about this subject with their physician, stemming from their side or from the side of the caregiver. The quantitative data showed that almost all respondents from both groups (98-99%) had discussed their AD with someone at least once at some point.

For **chapter 5** specific preferences about continuing or forgoing treatments at the end of life of holders of ADs and the general public were investigated, by presenting them hypothetical scenarios. A majority of the members of the NVVE was inclined to forgo treatment when it came to continuing or forgoing treatment in case of end-stage cancer or dementia. This made them similar to the Dutch public, although the majority preferring to forgo treatment was smaller among the general public. Among members of the NPV a majority wanted to continue treatment, but there was also a significant part that wanted to forgo treatment. ADs from the NVVE, that gave the direction to refuse treatment, generally concurred with the preference of their owners (85-98% wanting to refuse treatments).

When looking more closely at the preferences, differences were found between cancer and dementia in all groups. Preferences were more outspoken in case of dementia, meaning that from the four possible answers to the question if they would prefer a specific treatment ('Yes', 'Probably yes', 'Probably no' or 'No') respondents made less use of the 'probably'-options. There were also differences between treatments. For instance with NVVE-members and the general public, the percentage of people that preferred to forgo resuscitation was larger than the percentage of people that preferred to forgo artificial ventilation.

PART III: OVER TIME

For **Chapter 6** longitudinal data from the ADC about changes in preferences, adjustments in ADs en communication about ADs were analysed. Respondents who had experienced a life-event, like a change in health or the experience of a change in health of a close-one, were asked if their general preferences about care at the end of life had changed because of this. In both groups, NVVE- and NPV-members, the minorities who indicated that this was the case were smaller than 2%.

Only with members of the NVVE there was enquired whether they had made adjustments in their existing ADs or had formulated new ones. The number of respondents, who indicated they did, ranged from 6 to 10% over the different waves of the study. A self-reported bad health and the experience of the death of a loved-one were associated with making alterations among other factors, like increased age, having no children and having a higher education.

The data showed that not everyone discussed their AD repeatedly over time. 58% of NVVE-members and 72% of NPV-members did not discuss their AD with their GP during our 6-year follow-up period. These numbers were smaller when it came to the ones that did not discuss

their AD with their partners (18% for NVVE-, 28% for NPV-members) and children (32% for NVVE-, 56% for NPV-members). Health related factors, like suffering from an illness or the experience of a decrease in quality of life, but also the experience of a change in health or death of a close one, were associated with communication about ADs over time. The background characteristics being male and having a lower education reduced odds to discuss an AD.

In **chapter 7** stability over time of specific preferences about continuing or forgoing treatments was investigated with the use of hypothetical scenarios. The percentage of NVVE-members with instable preferences ranged from 2% for resuscitation in case of dementia to 24% for artificial ventilation in case of cancer. For NPV-members it ranged from 24% for resuscitation in case of dementia to 33% for artificial ventilation in case of cancer. This shows that also concerning stability of preferences there were differences between treatments and illnesses. There was mostly no association between instability of preferences and the experience of life-events, also not for a change in a respondent's health or quality of life. There were some exceptions, like with NVVE-members the experience of the death of a loved-one gave smaller odds to change from forgoing to wanting resuscitation in case of cancer. In some instances there was an association between instability of preferences and a change in health or in quality of life. However, they could increase as well as decrease odds to change preferences. The results were also inconclusive about in which direction a change in health or quality of life made preferences change: towards lengthening or shortening life.

In **chapter 8** the preferences about euthanasia and their stability over time were investigated using hypothetical scenarios. A large majority of holders of an advance euthanasia directive would want euthanasia in case of both end-stage cancer as well as dementia. A large majority of these preferences (90% in case of dementia, 94% in case of cancer) stayed stable over time. Only the experience of a positive life-event, like the birth of a (grand)child, was associated with instability of preferences.

PART IV: DISCUSSION

The meaning of ADs

Data from this study showed that ADs were not widespread in the Netherlands in 2005 with 7% of the general population having an AD. More recent data showed similar results. At the same time a majority of 86% of the general public indicated they (possibly) wanted to formulate an AD in the future. This raises the question: when is the right time to think and talk about the end of your life? Timing of these kinds of discussions seems to be difficult, for patients as well as caregivers. It seems warranted that caregivers take initiative in this matter, but they need proper training on this subject.

Throughout this whole study associations were found between experiences with illnesses or deaths of close-ones: with the intention to draft ADs, the motivation to draft ADs, making changes in ADs, with stability of preferences and communication about ADs. In conversations

about the end of life, caregivers should ask patients about these experiences, because they can be a good starting point to learn what people fear or prefer at the end of life.

Holders of ADs expressed preferences concerning dementia with more certainty than those concerning cancer. Possibly the prospect of suffering from dementia is dreaded more than the prospect of suffering from cancer, which made them more outspoken in their preferences in case of the former.

The preferences of a large majority of NVVE-members seemed to concur with the content of their AD. The minorities where this did not seem to be the case, for instance the 15% of the owners of a refusal-of-treatment document preferring artificial ventilation in case of end-stage cancer, might not have had a clear understanding of what the treatment implied, which influenced their preferences. It is hard to draw a conclusion in this respect about NPV-members, because the content of their AD, the wish-to-live statement, is ambiguous about continuing or forgoing treatment. This was reflected by the more equal distribution of preferences to continue or forgo treatment among NPV-members.

The stability of preferences about care at the end of life

A majority of people who have an AD had stable preferences concerning care at the end of life and euthanasia. There were differences between general preferences and specific preferences about continuing or forgoing treatments: general preferences showed a higher stability.

Differences in stability of preferences were also found between different treatments. The most instable preferences found concerned artificial ventilation. As discussed earlier the results concerning this treatment suggest people might not have had a clear understanding of what it implied. This might also have influenced the stability.

Interviewees for the qualitative part of this study indicated they had difficulties foreseeing the future and where to set specific limits, especially surrounding euthanasia.

An overall conclusion could be that people find it easier to formulate general preferences than specific ones.

This study did not find a clear association between the experience of life-events and stability of general preferences in both groups. When it came to specific preferences about forgoing or continuing treatment also mostly no associations were found. When they were, the experience of a life-event could either enlarge or reduce odds to change preferences. The findings from the interviews did suggest that some people adjusted their preferences when they became ill. They seemed to lower their bar for what is acceptable in terms of quality of life, a phenomenon also known as response shift.

Most NVVE-members did not make alterations in their ADs. Of the respondents who experienced a life-event, the minorities who indicated they made alterations in their ADs were larger (ranging from 6 to 10%) than the minorities who indicated their preferences concerning the end of life had changed (all smaller than 2%). This may indicate changing an AD might entail not changing one's views, but sharpening the content of the AD.

The communication surrounding ADs

The findings of this study showed that communication about ADs and their content seems to be warranted, for instance to explain treatments or procedures at the end of life, to discuss a possible change of preferences or the conformation and specification of existing preferences. While a vast majority (98-99%) of the respondents had discussed their AD at some point, the longitudinal data showed that the possession of an AD did not necessarily guarantee frequent, repeated discussions about ADs.

Conclusion and recommendations

Do ADs improve care at the end of life or are they useless? The answer is not black and white, but has many shades of grey. It seems that ADs can have a place in improving quality of care at the end of life. However, communication is vital to their success. An AD is not an end in itself, but merely an instrument in Advance Care Planning (ACP), the process of communication about and determination of preferences concerning the end of life. Preferences about care at the end of life should be discussed before they are recorded and afterwards repeatedly over time. Besides specific ACP programs that are already being developed and tested, there should also be invested in a more generic approach to ACP, meaning a basic method how to conduct conversations about the end of life that can be used in the training of physicians and applied in every setting. Box 1 gives an example of what such a generic approach could look like.

Box 1. How to conduct a conversation about patient's preferences concerning care at the end of life.

Phase 1: Exploration	<ul style="list-style-type: none"> - To start the conversation, ask the patient about examples of people dying in his/her surroundings. - Give the patient room to talk freely.
Phase 2: Clarification	<ul style="list-style-type: none"> - Specify the patient's preferences by asking directed questions. - Clarify and explain medical practice and procedures where necessary.
Phase 3: Determination	<ul style="list-style-type: none"> - Summarize and record the patient's preferences.

The right timing of conversations about the end of life, how to record preferences and warrant continuity of care are subjects that need further research. Qualitative research about preferences, especially the relationship between general views and goals concerning the end of life and more specific preferences, ACP in different cultures and populations and ACP in case of dementia, could provide valuable information.