

CHAPTER 9

GENERAL DISCUSSION

This chapter provides an overview of the main findings of this thesis and puts the findings in perspective. It will start with a summary of the main findings, which will be followed by some methodological considerations. The findings will be put in perspective by using the three main themes presented in the introduction of this thesis: ‘The meaning of advance directives’, ‘Stability of preferences about care at the end of life’ and ‘Communication surrounding advance directives’.

The section ‘The meaning of advance directives’ will subsequently discuss the meaning of advance directives (ADs) in society, the meaning of ADs to their holders and the meaning of the content of ADs. In ‘Stability of preferences about care at the end of life’, besides the degree of stability of preferences, also the influence of life-events on this will be addressed. The stability of preferences about euthanasia and alterations made in ADs will be discussed separately in this section. In ‘Communication surrounding advance directives’ the findings about this subject will be addressed. This chapter ends with conclusions and recommendations.

SUMMARY OF THE MAIN FINDINGS

The meaning of ADs

ADs were not widespread in the Netherlands in 2005: only 7% of our sample of the Dutch population (n=1402) 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. Also experiences of holders of ADs with illnesses and deaths in their surroundings emerged as important motivations to draft an AD in the quantitative as well as the qualitative data from the Advance Directives Cohort (ADC).

When it came to what holders of ADs aimed at with the document, members of the NVVE (n=5561), an association focused on self-determination at the end of life, wanted to prevent suffering, physical and mental decline, being dependent or being a burden to others. The members of the Christian orientated NPV (n=1263) 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.

Turning to preferences of holders of ADs, 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. A majority of the NVVE-members would want euthanasia in case of both end-stage cancer as well as dementia.

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 respondents made less use of the 'probably'-options from the four possible answers to the question if they would prefer a specific treatment ('Yes', 'Probably yes', 'Probably no' or 'No'). 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.

The preferences of NVVE-members about forgoing treatment and wanting euthanasia on the whole concurred with their ADs. 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.

Stability of preferences

Our longitudinal data showed that preferences of holders of ADs generally stayed stable over time. With a minority of the respondents the preferences did change. When we asked respondents who had experienced a life-event, like a change in health or the experience of a change in health of a close-one, if their general preferences about care at the end of life had changed because of this, in both groups the minorities who indicated that this was the case were smaller than 2%. For specific preferences about continuing or forgoing treatments the quantities with instable preferences for NVVE-members 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. Preferences concerning continuing or forgoing treatment were more stable in case of dementia, while preferences concerning euthanasia (with NVVE-members) were more stable in case of cancer.

We mostly found no associations between a change in 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. The experience of a positive life-event gave larger odds to change to not wanting euthanasia in case of cancer, also with NVVE-members. We did find an association between instability of preferences and a

change in health or a change in quality of life in some instances. However we found changes in health or quality of life increased as well as decreased 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 the interviews, which were part of the qualitative part of our study, respondents suffering from an illness 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.

Only with members of the NVVE we 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 our study. A self-reported bad health and the experience of the death of loved-one were associated with making alterations among other factors, like increased age, having no children and having a higher education.

Communication surrounding ADs

In the interviews for the qualitative part of our study with respondents suffering from an illness, 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. The longitudinal 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. When it came to not discussing them with their partners (18% for NVVE-, 28% for NPV-members) and children (32% for NVVE-, 56% for NPV-members) these numbers were smaller. Health related factors, like suffering from an illness or the experience of 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 your AD.

METHODOLOGICAL CONSIDERATIONS

We used different methods for different purposes in our study. We used written questionnaires to collect quantitative data about background characteristics, the experience of life-events, preferences about care at the end of life and ADs. The answers respondents gave to questions about their health in the written questionnaires were used to create a purposive sample of people suffering from an illness, who were interviewed for the qualitative part of our study. The questionnaires were sent repeatedly over time in 5 consecutive waves in order to gather longitudinal data about preferences, alterations in ADs and communication about ADs.

Cross-sectional data

The use of questionnaires has limitations. An important aspect is validity: does a questionnaire measure what it aims to measure? ¹ With respect to the questionnaires we used, validity was not an issue when it came to most questions about background characteristics that were asked. For measuring health related quality of life we used a validated set of questions, the EQ-5D ². But when it came to ADs, there were no validated questionnaires available, so we had to develop the questions ourselves. For some subjects, like what respondents hoped to aim with their AD, we used open-ended questions. When using close-ended questions, where possible we gave respondents the possibility to add an answer with free text to our printed options. We tested our questionnaires in pilot studies and made adjustments accordingly.

Nevertheless the data produced by the questionnaires had to be interpreted with the shortcomings of written questionnaires in mind. A shortcoming can be that respondents do not understand the questions or the concepts used in them. As will be discussed more in detail later in this chapter, results about preferences concerning continuing or forgoing treatments showed signs that respondents possibly did not have full apprehension of what these treatments imply. The ADs of the respondents, like the refusal-of-treatment document (ROTD) and do-not-resuscitate order (DNR) from the NVVE, contain preferences about the same treatments. This shortcoming of written questionnaires, that respondents misunderstood concepts used in questions, made them paradoxically more suitable for investigating ADs in this regard, by revealing that their owners may not have full comprehension of the treatments their ADs cover. We made use of qualitative methods for this thesis to complement the quantitative data provided by the written questionnaires. The interviews done with members of the Advance Directive Cohort gave more insight than the quantitative data in the fears and motives of holders of ADs. The interviews also showed that seemingly clear-cut preferences about medical care in ADs could be based on complex views and difficulties foreseeing the future, findings that were not uncovered by the written questionnaires. The combination of both qualitative and quantitative data produced a more nuanced view on ADs, than a study with a single method would have.

Longitudinal data

The longitudinal design gave us the opportunity to investigate important issues surrounding

ADs, like stability of preferences and communication about them over time. Longitudinal research also has limitations, like the loss to follow-up of respondents which may lead to selection bias^{3,4}. We tried to keep this attrition to a minimum, for instance by sending two reminders after the first questionnaire each wave. By performing the interviews we could include respondents for the qualitative part who dropped out the ADC, because they were not able to complete a written questionnaire because of an illness like dementia.

Recall bias is essentially a problem that occurs with cross-sectional data, but in the case of the Advance Directive Cohort this was possibly amplified by the longitudinal design. Part of the questions enquired about events that happened in the 1,5 year before the sending of the questionnaire, like experienced life-events or adjustments in ADs. It is possible that respondents wrongfully remembered a certain event to have taken place in the previous 1,5 years, while it actually took place earlier during our period of follow-up or even before the start of the study. As a result potentially the same events might have been measured twice and others might have been wrongfully regarded as having occurred during the course of our study, both overestimating prevalence.

The mere fact that respondents participated in the study may have affected certain outcomes. Sending the questionnaires each 1,5 years could have acted as a reminder to discuss ADs or make alterations in them, both outcomes we studied.

Generalisability

Besides the sample of the Dutch general public, the population used for this thesis consisted of people who had an AD, a small group in the Netherlands at the time it took place. We found 7% of the general population owned an AD in 2005 and this was confirmed in another study⁵. With ADs being the main focus of this thesis, this population suited the subject of this study. However, if ADs are going to be promoted or become more widespread among the general public, the findings presented in this thesis should not straight away be extrapolated to the general population of the Netherlands. We did compare the members of the ADC to the Dutch public. It showed that NVVE-members were more often single, higher educated and non-religious. Their preferences concerning forgoing care at the end of life were similar to a majority of the Dutch public, although the percentages wanting to forgo treatments were higher among NVVE-members. They were also more outspoken, meaning there were less respondents indicating they would 'probably' refuse a certain treatment. NPV-members were much more religious, specifically of the Protestant Christian belief, as compared to the general population. Older respondents in this group had a lower education. NPV-members more preferred to continue treatment at the end of life as compared to the Dutch general public.

NVVE- and NPV-members can be placed at opposite ends of the spectrum when it comes to views on the end of life in the Netherlands. Both are interest groups, the NVVE is in the progressive front line when it comes to the extension of self-determination at the end of life, while the NPV represents conservative Christian values. Although this means the members of the ADC do not necessarily represent the Dutch general public, they cover a wide range

when it comes to views on the end of life and adequately represent people with an AD in the Netherlands. A group that falls outside of the scope of this thesis, but which is growing in the Netherlands and Europe, concerns non-Western immigrants⁶⁻⁸. This topic will be addressed more elaborately later in this chapter, in the section with the subheading ‘What do ADs mean in society?’

MAIN FINDINGS PUT IN PERSPECTIVE

The meaning of advance directives

What do ADs mean in society?

Our findings show that ADs were not widespread in the Netherlands (7% of the general population). More recent research showed that dissemination of standard ADs in the Netherlands has not increased (ranging from 1-3% for different types individually in 2016)⁹. At the same time a majority of the general public (86%) probably wanted to formulate one in the future. 5% of them indicated they found the subject too confronting and 2% had no thrust in the effectiveness of ADs. This contradicts the argument made by critics of ADs that low completion rates of ADs exist because people do not want to think about their death or have low thrust that ADs do what they are meant for^{10,11}. The reasons that members of the Dutch public did give for not formulating an AD (yet) mostly had to do with timing, for instance because they considered themselves still too young or healthy.

With the low rate of dissemination of ADs in the Netherlands in mind, the question can be raised: when is the right time to think and talk about the end of your life? The right timing of discussions about preferences concerning care at the end of life seems to be difficult, for patients as well as caregivers. Patients show different degrees of readiness to discuss these issues, also in more advanced stages of illness¹²⁻¹⁴. Also patients have different preferences to what extent they want to be involved in the decision-making process about their medical care at all^{14,15}. Caregivers are afraid to take away patients’ hope when discussing the end of life^{12,13}, but also lack of time and availability plays a role in not having these kinds of discussions^{14,16}.

It seems warranted that caregivers take the initiative in this matter, as they are trained professionals. They should be supported by the knowledge that most people are not against discussing the end of life per se. Of course they will need proper training on this subject, as a lack training can be a potential barrier for having these discussions¹⁶⁻¹⁸. Some have suggested behaviour change models, as used with for instance smoking cessation¹⁹, can be applied to the different stages of readiness to talk about the end of life^{14,20}. Patients can be in different stages (pre-contemplation, contemplation, preparation, action and maintenance) and caregivers have to assess the stage the patient is in and adjust their approach accordingly.

Another subject linked to patients’ readiness or willingness to discuss the end of their lives, concerns cultural differences. Studies have shown differences in medical-decision making at the end of life and in communication about this between countries²¹, but also between

population groups within countries²². In Europe and the Netherlands, the population of non-western immigrants, especially from the Middle East and Africa⁶⁻⁸, is growing. Studies on palliative care amongst people of Moroccan and Turkish decent in the Netherlands, show that differences in views on the end of life between them and their caregivers can cause problems in communication and care^{23,24}. In the population of our study on ADs people with an immigration background are, unfortunately, strongly underrepresented.

The Netherlands has been one of the first countries to legalize euthanasia. The finding that ADs are linked to the subject of euthanasia is an indication that this subject seems to dominate the public debate about the end of life in the Netherlands. Yet euthanasia is an exception at the end of life with a prevalence of less than 5% of all deaths in the Netherlands in 2016⁹. Although euthanasia is important, it should not overshadow other subjects that are just as vital when it comes to the end of life, like continuing or forgoing treatment and preferred place of death.

Our data shows that a majority of the Dutch general public prefers to forgo treatment at the end of life in case of cancer and dementia. Data from practice shows patients suffering from these illnesses are receiving aggressive medical treatment in a significant number of cases²⁵⁻²⁷. Also in the Netherlands 62% of the physicians think that there is overtreatment at the end of life²⁸. The reasons can be sought in the complexities of medical decision-making and difficulties of communicating about this at the end of life^{29,30}. Bridging the gap between what people want and what care they actually receive, is one of the main goals of ADs. In the next sections these documents, their owners, their content and the communication about them will be discussed, in order to give more clarity about if ADs do what they intent to.

What do ADs mean to the holders of advance directives?

When asked what they hoped to prevent with their AD in the interviews done for chapter 4, people mentioned fears about the end of life based on experiences concerning illnesses and deaths of close-ones. Others talked about experiences, but then as a positive example of how they would want to die. Throughout this whole study we found associations 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. Others found associations between ADs and personal experiences with illness or death of close-ones as well^{20,31,32}. 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.

NVVE-members often seemed to want to prevent the consequences of illness with their AD, like suffering, deterioration, to be dependent from others or to be a burden to others. Studies on the views of patients or elderly people about the end of their lives found similar things people worried about³²⁻³⁴. NPV-members on the other hand, seemed to be less afraid of the effects of an illness, but with their ADs hoped to prevent specific actions of caregivers. NVVE-members wanted to prevent actions of caregivers as well, especially unwanted treatment, but still there

was a difference between both groups in what they feared most and hoped to prevent.

Preferences concerning dementia were expressed with more certainty than those concerning cancer. This was the case for both NVVE- and NPV-members and applied to preferences about continuing or forgoing treatment as well as euthanasia. An explanation may be that NVVE-members dreaded more the prospect of mental decay in case of dementia than the suffering of physical nature that is more often associated with cancer, also because there may be more options to treat or palliate in case of the latter. Evans et al. found that older people in general more often preferred to forgo treatment in case of dementia than in case of cancer³⁵. This may have the same underlying reason.

Interestingly, we found that among holders of advance euthanasia directives (AEDs) more people would not want euthanasia in case of dementia than in case of cancer, although this was a small difference. These findings could be a reflection of actual practice in the Netherlands, where performing euthanasia in case of dementia is considered much more problematic than in case of cancer³⁶⁻³⁸.

Part of the NPV-members expressed preferences about wanting life-sustaining treatment with more certainty in case of dementia than in case of cancer. This could stem from the fear that caregivers would hasten their death while they were less able to speak against this when suffering from dementia.

What does the content of ADs mean?

The refusal-of-treatment document (ROTD) of the NVVE refuses all medical treatment, with exception of purely palliative treatment, if the owner should be in a situation where he or she suffers without chance of recovery, or there is no reasonable prospect of returning to a dignified state of living, or continued deterioration is to be expected. The do-not-resuscitate order (DNR) and advance euthanasia directive (AED) have similar descriptions of the situations where they should apply to. These ADs also have space where the owner could write a personal addition, but these are outside the scope of this study. The pre-printed content of these ADs seemed to correspond to the preferences of a large majority of their owners, who refused (or 'probably' would refuse) treatment in the two hypothetical cases about advanced cancer and dementia. What are the considerations of the minorities of NVVE-members that did want to continue treatment (ranging from 1% of the owners of a DNR who wanted to be resuscitated to 15% of owners of a ROTD who wanted to receive mechanical ventilation, both in case of advanced cancer)? From our pilot studies on the questionnaires, we know some of these considerations. Respondents mentioned a fear for a death by suffocation as a reason to want mechanical ventilation. This could explain the large difference between the preferences concerning resuscitation and artificial ventilation from respondents. In practice artificial ventilation has no place in the palliative treatment of shortness of breath^{39,40}. Moreover, artificial ventilation or admission to an ICU, where artificial ventilation is administered, are associated with diminished quality of life with cancer patients^{41,42}. An explanation of what artificial ventilation implies might influence the preferences of NVVE-members concerning this treatment and thus seems

warranted. Tang et al. for instance found an association between inaccurate prognostic awareness of respondents and the preference for continuing treatment at the end of life ⁴³.

The wish-to-live-statement from the NPV states that its owner wants to receive proper care, meaning no excessive, medically futile treatments at the end of his or her life, but also no actions with the purpose of actively terminating his or her life. When it comes to translating the wish-to-live statement into preferences concerning continuing or forgoing treatment in case of advanced cancer and dementia, it is difficult to interpret its content. This is shown by the preferences of the owners of this AD in the two hypothetical cases: they were divided between forgoing (27-54%) and continuing (47-73%) treatment, with a majority for the latter. The data about what NPV-members hope to accomplish with their AD shows two aims that are among the most frequently mentioned: prevent euthanasia or hastening of death (44%) and prevent unnecessary lengthening of life (16%). This could make this AD difficult to interpret for caregivers, at least when it comes to decisions about continuing or forgoing treatment.

The preferences of the majority of NPV-members deserve further consideration. They preferred to continue treatment in both the hypothetical cases about advanced cancer and dementia. In the Netherlands it is left to physicians to decide if a treatment is medically futile and has to be stopped ⁴⁴. Most physicians would probably consider the treatments in both hypothetical cases as futile, except possibly for antibiotics in case of a pneumonia, which is also seen as palliative measure ⁴⁴⁻⁴⁷. This will not automatically mean that physicians would always refuse these treatments, because they would want to take into account the wishes of the patient and his or her family members ^{44,45,48}. NPV-members do take a less common position in Dutch society when it comes to preferences concerning the end of life, as is underlined by the fact that a majority of the general public would want to forgo treatment. Communication could help to clarify preferences and the practice of care and bring the views of physicians and patients closer together.

As came forward in the motivations to draft ADs and aims of ADs, a part of NPV-members seemed to fear to receive euthanasia against their wishes. This fear seems to be ungrounded, because physicians are not likely to perform euthanasia without an explicit request. Legally this would not be considered euthanasia, because it fails to meet the requirements as prescribed by the Euthanasia Act. To kill someone against his or her wishes is in fact murder or manslaughter and it is doubtful if the presence of an AD would be able to prevent such an act. Nevertheless it is unfortunate that people have these kinds of fears. They could be addressed by explanation of the legislation and procedures concerning euthanasia in the Netherlands.

It can be concluded that some of our findings suggest a lack of comprehension of the complexities of care and decision-making at the end of life by people who have an AD, which was one of the arguments sceptics had against the use of ADs ^{10,11,49}. These sceptics also argued that the content of ADs was often formulated in a manner that was too general to be a clear guideline for caregivers in practice.

Our findings about the preferences in the two hypothetical cases show that the wish-to-live statement of the NPV is too vague to be an adequate guideline for physicians in practice. For the ADs of the NVVE this seemed less so, at least if one looks at the mostly homogeneous results concerning preferences about forgoing treatments at the end of life by their owners. Of course we did not investigate the experiences of caregivers with the use of ADs from the NVVE, or from the NPV.

Three studies based partly on data from the same cohort, the ADC, two by Kaspers et al.^{50,51} and one by Pasman et al.⁴⁸, do provide a perspective on the use of ADs of NPV- and NVVE-members in practice. All three studies used relatives of deceased cohort members (from the ADC and LASA, a cohort of elderly people), to investigate medical decision-making and care at the end of life. Kaspers et al. found that while relatives were generally satisfied about the communication process about ADs, 50-58% of them indicated that ADs had little or no influence on the administered care. 15-17% of the relatives specified that this was because the AD did not relate to the situation the patient had been in⁵⁰. In another study⁵¹ Kaspers et al. found that the presence of an AD increased the chance of discussions about whether to forgo treatments at the end life. Pasman et al.⁴⁸ found that while making one's preferences known was associated with receiving care in concordance with one's wishes, having an AD was not. They also found that if no preference was known, treatment was more often started than forgone.

These results, concerning the lack of comprehension of medical care at the end of life by owners of ADs, and the content of ADs being too vague or not relevant, do not imply that ADs are useless. They do show that ADs by themselves often don't seem to be effective in improving care at the end of life. Communication about ADs and their content seems to be essential for success.

THE STABILITY OF PREFERENCES ABOUT CARE AT THE END OF LIFE

Preferences stay stable over time

Clear majorities of both NVVE- and NPV-members had stable preferences about care at the end of life. Other studies found similar results among several groups, like patients and elderly people, as is shown by the review of Auriemma et al.⁵². We found higher stability of preferences, which was confirmed in other studies that found higher stability of preferences among people who have ADs as compared to those who don't⁵³⁻⁵⁶. Auriemma et al. did find that preferences were more stable among sicker populations. This may lead to the hypothesis that preferences are more stable for people who reflected on them more carefully, either because they drafted an AD or because they were confronted with an illness.

We investigated stability of preferences in different ways, asking about general preferences concerning the end of life in relation to the experience of a life-event and about specific preferences concerning continuing or forgoing treatments. The minorities with instable

preferences were larger when it came to specific preferences. The NPV-members had more instable preferences about continuing or forgoing treatment as compared to NVVE-members. This may be explained by the fact that their AD, the wish-to-live statement, is not clear on this subject, which may have led to them not putting as much thought in their preferences on this issue as their counterparts of the NVVE might have done.

The most instable preferences we found concerned artificial ventilation in both groups. As discussed earlier the results concerning preferences about this treatment suggest people might not have had a clear understanding of what it implied. This might also have influenced the stability of these preferences. We know from a study by Evans et al. that specific treatment preferences from elderly people do not always concur with their general end-of-life goals³⁵. MacPherson et al. found that patients are more comfortable with formulating general preferences and have difficulty formulating specific ones⁵⁷. Our qualitative data showed that people with an AD suffering from an illness sometimes found it hard to foresee the future and be specific about their preferences. Some could formulate distinct, specific preferences that remained unchanged, while others had made alterations in their ADs in order to specify their adjusted preferences.

A parallel was seen between the differences in preferences concerning cancer and dementia on the one hand, and the differences in *stability* of preferences between these two illnesses on the other hand. Preferences concerning dementia were more often stable than those concerning cancer. The possible larger fear of people for the hardships of dementia, which made the preferences about this illness more outspoken, also could have made them more stable. Several other studies found higher stability of preferences when the conditions presented to the respondents to query their preferences were more severe⁵⁸⁻⁶⁰. Again preferences concerning euthanasia were an exception, because in this case we found more stable preferences in case of cancer than in case of dementia. The stability of preferences concerning euthanasia will be discussed more in-depth in a separate section.

The relation between stability of preferences and the experience of life-events

We didn't 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 we also mostly found no associations between life-events and stability of preferences. When we did find an association, the experience of a life-event or decrease in quality of life could either enlarge or reduce odds to change preferences. Some of these results were hard to interpret, like the findings concerning the influence of an experienced change in health by NVVE-members on the stability of their preferences. A change in health reduced odds to change from refusing to wanting artificial feeding in case of cancer. At the same time it enlarged odds to change from refusing to wanting to be resuscitated in case of dementia. With NPV-members, who had more instable preferences, we only found two associations: a decrease in quality of life and a change in health both reduced odds to change preferences. Overall it can be concluded that, in the minority of cases in which instability of preferences

occurred, the experience of life-events could be associated with changes in preferences, but also might strengthen existing preferences.

The review of Auriemma et al. provided an oversight of all studies that in some way investigated if changes in health status influenced stability of preferences⁵². Some studies found an association and some did not. One study found an association between stability of preferences and the death of a loved-one, as we also found⁶¹. As mentioned before, throughout our study we found the experiences with the illnesses or deaths of loved-ones were associated with preferences concerning the end of life and several aspects of ADs. These kinds of experiences, if present, deserve attention in the conversations about the end of life between patients and caregivers.

Besides our quantitative data our qualitative data also gave information about stability of preferences. Our findings suggested that 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 shift⁶². While their general view on the end of life seemed to remain unchanged, for instance favouring quality above quantity of life, within that scope specific preferences could change. The preferences of NVVE-members about refusing life-sustaining treatment in situations where they were not able to express their wishes anymore, which are the situations to which their ROTD or DNR applied, seemed to stay stable. However, when it came to preferences about euthanasia this was less clear. This issue will be addressed in the next section.

Stability of preferences concerning euthanasia

A request for Euthanasia doesn't have to be granted by a physician in the Netherlands⁶³. This is one of the things that sets it apart from decisions about forgoing treatment at the end of life, where a physician is legally obliged, with few exceptions, to follow the wishes of the patient, including the ones on paper^{64,65}. Our results concerning preferences about euthanasia have to be considered with this in mind. Preferences about euthanasia in general stayed stable and we only found the experience of a positive life-event was associated with instability of preferences concerning euthanasia in case of cancer. Bolt et al., who questioned family-members of deceased NVVE-respondents from the same cohort, the ADC, about their euthanasia preferences in the last three months before they had died, also found preferences concerning euthanasia overall stayed stable, while this not always resulted in an actual request let alone that the euthanasia request was granted and euthanasia was performed⁶⁶.

However, our qualitative data showed that people had difficulty to foresee the future and, more specifically, found it problematic to determine when their limits would be reached concerning a life not worth living anymore. In one interview for example, a woman with dementia found it difficult to foresee the moment when she would want euthanasia. Her partner pointed out that she used to be much more ardent in her wishes concerning euthanasia, but that this had changed during the course of her disease.

With euthanasia a decision about an irreversible action has to be taken actively. The moment

when to perform euthanasia has to be determined, while with decisions to forgo treatments it is often in reaction to a change in the situation of the patient, for instance when a person stops eating and drinking. If a patient is competent and able to express his or her wishes, the patient and the physician can determine the preferred moment for euthanasia in conversations about the subject. This can also be the case in early stages of dementia for instance. When the process of cognitive decline progresses, it can become harder or even impossible to have these conversations. Then the moment when to perform euthanasia has to be determined on the basis of a written request, an AED. The patient writes this document in an earlier stage and at that point determines the moment of euthanasia in a possible future situation. Our qualitative data showed this could be difficult to do. The physician then has to determine whether the situation described in the AED corresponds with the situation the patient is in. He or she may have the possibility to consult close-ones from the patient on the subject and always is legally obliged to consult an independent physician⁶³. However, it is harder, and might feel virtually impossible to many physicians, to determine the right time for euthanasia in this way than together with the patient in a conversation.

The difficulties surrounding euthanasia in case of dementia resulted in a debate in the Netherlands about whether it is possible or desirable to perform euthanasia based on a written request⁶⁷⁻⁷⁰. While our findings underlined the difficulties when it comes to this subject, they did not provide decisive proof to settle the debate about euthanasia on the basis of an AED in case of dementia. On the one hand findings of our study do show that people especially fear the hardships of dementia and would consider euthanasia an option when suffering from it. On the other hand a majority of physicians doesn't find it is conceivable to perform euthanasia in these cases³⁶. Probably, communicating about each other's views and empathy on both sides, trying to imagine being in the position of the other, could help make difficult situations less hard.

Adjustments in advance directives

Most NVVE-members did not make alterations in their ADs, meaning no changes in an existing AD or the signing of a new one. Of the respondents from the NVVE 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. Another explanation may be that the NVVE published new versions of their ADs during the course of our study, which urged respondents to sign a new AD. The experience of the death of a loved-one, a self-reported bad health and increase of age were all associated with alterations in ADs. These factors could either make someone sharpen existing preferences or adjust previous preferences. Such changes should be a reason to discuss ADs with family members and caregivers. When it comes to increase of age, it may be good to discuss an AD every 3 to 5 years.

Overall the claim of critics of ADs that instability of preferences undermines their validity^{10,49}, does not seem to hold, since preferences of people who have an AD generally stay stable

over time. Changes in health status, quality of life and other life-events, like the death of loved-one, are associated with stability of preferences concerning care at the end of life. When such events occur, it is important to discuss the person's preferences and AD.

Communication surrounding advance directives

The subject of communication was already addressed in this chapter several times. Our data showed that communication about ADs and their content seems to be warranted, for instance to explain treatments or procedures at the end of life, or to discuss a possible change of preferences or the conformation and specification of preferences. The importance of communication for the success of ADs was confirmed by studies that used the same population^{48,50,51}, as well as by other studies^{71,72}. Moreover, communication in itself seems to improve quality of care at the end of life^{25,73,74}.

What does our data show concerning communication about ADs by their owners? The cross-sectional data showed that a vast majority of our respondents (98-99%) had discussed their AD at least at some point. The qualitative data confirmed this, with interviewees often indicating that they had discussed their AD thoroughly and realistically with both physicians and people in their social surroundings. However, we also found reasons for not discussing ADs with physicians. One reason concerned continuity of care: patients were confronted with quitting or retirement of their general practitioner (GP). Other reasons could be on the side of the owner of the AD or on the side of the physician. The hesitation to talk on the side of the owner of the AD showed similarities to the different degrees of readiness of patients to talk about the end of life found by other studies^{12,13}.

Our longitudinal data showed that the possession of an AD does not necessarily guarantee frequent, repeated discussions about ADs. 58-72% of our respondents did not discuss their AD with their GP during the 6 years of our follow-up, with percentages for medical specialists being much higher. For partners (18-28%) and children (32- 56%) these percentages are lower. We did find that factors related to a (change in) health were associated with communication about ADs, as were the experience of a change in health or the death of a loved-one. These associations may seem obvious, but nevertheless are favourable for the use of ADs in the sense that their owners seem to discuss them on relevant moments.

While respondents discussed their AD with family-members more often than with physicians, still a considerable amount did not. Both NPV- and NVVE-members had the option to designate a healthcare proxy in their ADs. People who have a partner or children often choose these to be their proxy³¹. Discussing their preferences with them is thus important. A review by Shalowitz et al. showed that about one third of surrogates wrongly predict patients' treatment preferences⁷⁵. Other studies show that making decisions about medical care for an incapacitated loved-one may cause distress with surrogates^{76,77}. While some critics of ADs see this as arguments against ADs¹¹, it can also be regarded as an argument in favour of communication. While discussing ADs or preferences may not solve everything, it is likely to help healthcare proxies in their difficult task.

Our findings concerning communication about ADs seem to indicate that a more structured approach is needed when it comes to discussing these documents and the preferences they contain. Advance care planning (ACP), which has become more emphasized in recent years, implies a shift from the completion of ADs to communication about preferences⁷⁸. ACP is defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”⁷⁹ The positive effects of ACP on communication about preferences and quality of care at the end of life were shown by two reviews^{78,80} and tested in randomized controlled trials^{81,82}. ACP has different forms. There are more comprehensive programs resulting in documented preferences^{81,82}. However, there is also the view that ACP should prepare patients and surrogates for in-the-moment medical decisions and thus not necessarily has to lead to a completed AD⁸³. Some form of documentation of preferences might help patients, their close-ones and caregivers make decisions in moments of acute care or when the patient in question is incapacitated, whether this is in an AD or by a physician in medical records⁸⁴.

CONCLUSION

The results of our study on ADs are complex. While a majority of 86% of the Dutch population considered drafting an AD in the future, only 7% actually possessed one. The preferences of NVVE-members seemed to concur with their AD, while NPV-members showed more variability. Preferences of people with an AD generally stayed stable over time, which supports the validity of the content of ADs. Our findings suggest that people with ADs not always had a clear understanding of medical treatments and procedures at the end of life. Almost all people with an AD discussed this document at least at some point. Factors related to (changes in) health increased odds to talk about ADs over time, but having an AD proved to be no guarantee to frequently discuss this document with physicians.

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 ACP, the process of communication about preferences concerning the end of life.

RECOMMENDATIONS

Recommendations for practice

The main recommendation for practice is to discuss patients' views and preferences about the

end of their life before and repeatedly after they are recorded in an AD or medical records. Some of the main issues about conducting conversations and recording preferences are addressed below.

When should conversations start?

Obviously, conversations about the end of life should start if the patient brings up the subject, for instance with the completion of an AD. Conversations may also start at specific moments, for instance, when a person is diagnosed a serious illness (and has had some time to come to terms with this). Reaching a certain age can also be a moment to start such conversations, for instance the age of 70 or 75.

Because the right timing of conversations about the end of life is difficult, caregivers, who have more professional distance to the subject, should take the initiative in starting these discussions. They should be trained to do so and be able to explore in which stage of readiness someone is to talk about this subject.

Who should conduct conversations?

Programs have been developed in which trained health professionals (mostly nurses) conduct structured conversations following a specific model with patients about their views and preferences on the end of life and record these in ADs. These have proven to be successful^{81,82}. However, due to practical or financial objections these kinds of programs might not be easily implemented in every setting. In the absence of a trained nurse, physicians are the most likely candidates to conduct these conversations.

How to conduct conversations?

The Dutch Medical Association (Koninklijke Maatschappij ter Bevordering der Geneeskunst (KNMG) in Dutch) has published a guidance, which is helpful, but very extensive. Even the short checklist contains more than 40 example questions⁸⁵. An alternative is to have a conversation loosely based on the structure of a consultation used to train physician's communication skills^{86,87} and combine this with the idea that in each encounter between physicians and patients each has their own agenda and needs^{88,89}. This results in distinguishing three phases: exploration, clarification and determination (see box 1).

During the first phase, exploration, the patient should get the opportunity to talk freely. An already drafted AD, which may be the reason for the conversation, can be used as guidance. If not present, an opening question could address personal experiences of illnesses or deaths in the patients' social surroundings. If this question is considered to be too confronting, the Patient Dignity Question could be a good alternative: 'What do I need to know about you as a person to take the best care of you that I can?'⁹⁰

In the next phase, clarification, the patient's views and preferences can be specified and applied to the actual care situation. In this phase the physician can explain medical treatments and procedures at the end of life.

The last phase entails summarizing and recording the patients' preferences in the medical records. The patient of course has the possibility to draft an AD on the basis of the conversation or adjust an existing one (see below).

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.

What should be discussed in the conversations?

The topics to be addressed depend from what's relevant to the patient and situation he or she is in. As shown by our data, patients have personal fears and wishes concerning the end of life that should be addressed. Explanation of medical treatments and procedures may already relieve some of the worries of patients.

The situation of the patient is in may ask for a specific approach. The needs of a patient suffering from chronic obstructive pulmonary disease (COPD) ⁹¹ differ from a those of a patient who is diagnosed with cancer ⁹². Preferences of patients with illnesses like COPD and chronic heart failure are often not discussed ⁹³. The prognosis of these illnesses is less predictable, which may make timing of conversations hard. This pleads for an early start of ACP in these cases ⁹¹.

The physician also has to consider the level of education and literacy of the patient ⁹⁴ and take into account that views on care at the end of life in different cultures vary ^{22,24}.

Subjects to be addressed in general entail: preferences concerning preferred place of death (and hospitalization) ⁹⁵ and continuing or forgoing treatments (for instance resuscitation, treatment in an intensive care unit). The physician should explain that there are several possibilities to treat symptoms and relieve suffering at the end of life. Specific treatments or acts at the end of life may need more extensive explanation, for instance the use of opioids, palliative sedation and euthanasia.

Patients should be encouraged to have a conversation about their preferences with close-ones and think about the possibility to appoint a surrogate. It could be helpful that the physician is present at one of these conversations.

What should be recorded and in what form?

Depending from what is relevant to the patient's situation, preferences concerning hospitalization and the wish to forgo specific treatments should be recorded in medical records.

This information should be available to other caregivers, for instance in case of emergency or out-of-hours consultations.

The patient has the possibility to draft an AD, whether this is a standard AD or a document that is written by him- or herself. The more personal and specified the preferences in this document are, the more helpful the AD can be as a guidance for caregivers or surrogates in situations where the patient is not able to conduct conversations on this subject in the future. However, not everyone will be able to formulate his or her personal preferences, let alone in written form. A personal AD should therefore not be considered as obligatory, but as a possible addition to the preferences recorded in the medical records.

An exception is if there is a wish for euthanasia in case of dementia (or other forms of cognitive decline). In that case an AED is needed that specifies the situation in which euthanasia should be performed as much as possible. If the physician does not want to perform euthanasia in these kinds of situations, he or she should discuss this openly and still encourage the patient to draft an AED about this. They should together discuss possibilities how the wishes concerning euthanasia of the patient could be granted.

How often should conversations be conducted?

Conversations about preferences should be repeated over time, especially when relevant changes in the situation of the patient take place. In this way general views and preferences can be specified and adjusted to the new situation. Changes in health of the patient or events concerning the health of a loved-one should alert caregivers to revisit patient's preferences about the end of life.

RECOMMENDATIONS FOR FURTHER RESEARCH

This thesis contains mainly observational, descriptive research about ADs and their owners. The main conclusion about ADs is that they are not an end in themselves, but need to be embedded in ACP. The recommendations for further research will be made distinguishing between subjects that need further observational research, and subjects where interventions can be tested, needing interventional research.

Observational research

Our results showed that people might have difficulty understanding medical treatments and procedures at the end of life. We also found differences between general preferences and specific preferences. For instance a small part of our respondents with a ROTD or DNR preferred continuing treatment in the hypothetical scenarios. Specific preferences were less stable over time than general preferences. Although we found that preferences about the end of life overall stay stable, our results showed that response shift occurred, the adaption of patients to the effects of the progress of their illness.

All these findings ask for further research. Qualitative research about preferences, especially the relationship between general views and goals concerning the end of life and more specific preferences, for instance about continuing or forgoing treatments, could provide valuable information.

Specific attention should be paid to the views on care at the end of life and dying in different cultures and populations. Especially interesting for Europe and the Netherlands are those in the Middle East and Africa, because of growing migrant populations from these regions.

ACP in case of dementia has to be studied further, especially in relation to euthanasia. Qualitative methods, like observation of conversations between patients and physicians, in line with the study of Brom et al. on decision-making with cancer patients⁹⁷, might provide new insights in this subject.

Interventional research

Different ACP programs have been developed, tested and continue to be tested, also in the Netherlands⁹⁶. Besides these specific programs, which often take place in hospitals, 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, should be developed and tested.

Some aspects of ACP need specific attention. More research is needed concerning the timing of conversations about the end of life. Studies have been done on facilitators, barriers and different stages of readiness to discuss preferences. A next step could be developing different approaches and comparing these by evaluating the experiences of physicians and patients with them.

Another aspect that needs further research is how to record preferences and warrant continuity of care. Studies on different ways to record preferences, also electronically, and the collaboration between different disciplines in healthcare could be useful.

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