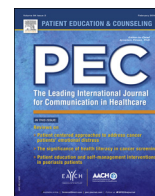


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Patient Perception, Preference and Participation

Motivations, aims and communication around advance directives A mixed-methods study into the perspective of their owners and the influence of a current illness



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ABSTRACT

Objective: What are motivations of owners of an advance directive (AD) to draft an AD, what do they aim for with their AD and do they communicate about their AD?

Methods: Written questionnaires were sent to a cohort of people owning different types of ADs ($n = 5768$). A purposive sample of people suffering from an illness was selected from the cohort for an in-depth interview ($n = 29$).

Results: About half of our population had no direct motivation to draft their AD. Most mentioned motivation for the other half was an illness of a family member or friend. Many different and specific aims for drafting an AD were mentioned. An often mentioned more general aim in people with different ADs was to prevent unnecessary lengthening of life or treatment (14–16%). Most respondents communicated about having an AD with close-ones (63–88%) and with their GP (65–79%). In the interviews people gave vivid examples of experiences of what they hoped to prevent at the end of life. Some mentioned difficulties foreseeing the future and gave examples of response shift.

Conclusion: ADs can give directions to caregivers about what people want at the end of life.

Practice implications: ADs have to be discussed in detail by their owners and caregivers, since owners often have specific aims with their AD.

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1. Introduction

Advance directives (ADs) are documents in which people put down their preferences about future medical care, in case they get in a situation where they are not able to express these preferences themselves. ADs are instruments with the purpose to improve end-of-life care, which from the patient's perspective should include a sense of control over what they are going through and clear decision-making [1,2]. The US government promotes the use of ADs by the Patient Self Determination Act of 1990 [3]. However, in practice the use of ADs appears to be more complicated than expected [3,4]. Problems regarding communication about them,

their completion and their effectiveness, even make some authors question their value [5,6].

In order to ADs to be useful in practice, the perspective of their owners is important. What do people hope to achieve or prevent with their AD? Studies showed that a majority of people who own an AD want to limit (over-)treatment at the end of life [7,8]. Although this gives a general insight into the aims of ADs, caregivers will want to know more about the meaning patients attach to their ADs and the way they handle them in practice. Lambert et al. showed with their study that long-term-care residents made little use of information from professionals while formulating their ADs [9] and Becker et al. unveiled some of the mechanisms underlying the lack of communication about ADs [10]. These findings are relevant in light of the growing notion that the success of ADs is greatly dependent on the communication surrounding them [4,11].

In this article, we focus on three subjects: what were the motivations to people who own an AD to formulate their AD? What do they hope to achieve or prevent with their AD? Do they

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communicate about their AD with others? While trying to answer these questions, we specifically wanted to explore the relationship between someone's (previously) recorded preferences and their current illness.

2. Methods

2.1. Design and population

For this article, we used a mixed-method approach to answer our research questions. We used data gathered through the Advance Directives Cohort (ADC), a longitudinal cohort study on people who own ADs. The study took place in the Netherlands, where the use of ADs is not promoted by any policy and only 7% of the general population owns such document [12,13]. The ADC started in 2005 and recruited its respondents via two associations. 'Right to Die-NL' (NVVE in Dutch) is an organization that aims to enhance the autonomy and control of an individual when it comes to the last phase of his or her life. They provide different standard ADs, which are the most common type of standard ADs in the Netherlands. Among these are a refusal of treatment document (ROTD), a do not resuscitate order (DNR), the appointment of a healthcare proxy and an advance euthanasia directive. These respondents ($n = 5561$) had not all actually drawn up an AD. A part had only requested one with the NVVE and had not completed it yet ($n = 1064$); they were left out for this paper.

The other association, the Dutch Patient Association (NPV in Dutch), a Christian orientated patient association, also provides a standard AD as an alternative to those of the NVVE, the 'wish-to-live statement', where a person declares that he or she wants to receive proper care, meaning no excessive, medically futile treatments at the end of his life, but also no actions with the purpose of actively terminating his or her life. The respondents of the NPV in the cohort ($n = 1263$) all possessed this document. The members of the ADC received written questionnaires each one and a half year, the first in 2005. For more information about the ADC see the design article on this study [14].

For the quantitative part of this article we used data gathered by means of three questions in the questionnaire of 2005:

1. Was there a direct motivation to draft your AD?
2. What do you mainly hope to achieve or prevent with your AD?
3. Did you talk about the document with others?

For the first and the third question, we gave options respondents could choose from. Respondents also had the possibility to give their own answer that was not amongst the given options. The second question was an open question: the answers of the respondents were coded in categories based on the most frequently occurring themes. The analyses only took into account the respondents that answered the question, so missings, meaning people who left it open or gave a meaningless answer were left out.

We performed descriptive analyses on the answers to these three questions.

2.2. Qualitative substudy

The data gathered for the qualitative part of this article was part of an ongoing qualitative substudy of the ADC that focussed on two subjects: ADs and dignity. We selected 29 respondents from the ADC who had declared in the questionnaire they would want to participate in an oral interview. They were selected purposively using the answers from their written questionnaires. Furthermore we selected people having different illnesses or health problems,

since we expected that these people would have different motivations and aims for drafting an AD. Respondents could be interviewed more than once, but for this article the 29 interviews in which the subject of ADs was discussed for the first time were used. Six were NPV-member, 23 member of the NVVE. Ages ranged from 44 till 91 years; 16 were female and 13 male.

2.2.1. Qualitative data collection

In-depth interviews were held with the respondents in the period from 2008 until 2012. They were performed by two trained interviewers. A topic list was used as a guide for the open-ended questions of the interviewer. It was based on three main subjects: the motivations to draw up the AD, the aim of the AD and communication about the AD. The interviewer did not give the preconceived answer options that were used in the written questionnaire, respondents came up with themes themselves whereupon the interviewer would let them elaborate. The interviewer could draw information from previously completed written questionnaires by the respondents for the ADC and use this in the interviews to probe the respondent. The interviews were audiotaped and transcribed verbatim. The interviewer also made field-notes directly after the interview. During the process of gathering the data, the first author of this article already read several transcripts, gave feedback about his findings to the interviewers and subsequently changes were made to the topic list to improve the interviews.

2.2.2. Qualitative analysis

The interviews were read and themes (or codes) were identified linked to the three main subjects by the first author (MvW) with the use of Atlas/ti software. Another author (RP) also coded part of the interviews simultaneously. As new themes emerged, there was a constant process of comparing and reviewing earlier read interviews with these new insights. During key moments in the analysis meeting were held with the project group. Only at the end of the analyses, the connection was made to the questions on the same subject in the written questionnaires.

2.3. Ethical approval and confidentiality

The Medical Ethics Review Committee of the VU University Medical Center approved the study. The participants were anonymous to the researchers for the quantitative study. From the people who gave consent to be asked for an interview and were selected for the qualitative study, their name and address was asked for from the NVVE or NPV.

3. Results

Next to themes closely connected to the three research questions (motivations to draft ADs, aims of ADs and communication about ADs), another theme emerged from the qualitative data: difficulties foreseeing the future and setting limits. This subject is however linked to the relationship between (previously) recorded preferences and a current illness we wanted to explore as well. As this links closest to things one hopes to achieve or prevent with an AD, this theme is discussed after the section on aims.

3.1. Motivations to draft an AD

Table 1 shows data from the questionnaires (right two columns) and narratives from the interviews (left). Half of the NVVE-members and 63% of NPV-members, stated there was no direct motivation. The motivation that was mentioned most frequently in the NVVE-group was a serious illness of someone close by (31%), followed by dementia in the direct environment (15%), a serious

Table 1
Motivations to draft an advance directive (AD).

	NVVE (n = 4497) [*]	NPV (n = 1271) [*]
Quotes from the interviews (R = respondent, I = interviewer)		
No direct cause	50%	62%
Serious illness in environment	31%	8%
'... I think he [father in law, spent the end of his life in hospital being treated against his will] died about that time [...] and that I said at that moment: now I am going to complete that thing [AD].' (Male, 65–85 yrs, NVVE, myelofibrosis)		
Dementia in environment	15%	2%
'Also that my father was on a psychogeriatric ward, that is also a nightmare to me. And that he blamed my mother that it was her fault. That made such an impression... [...] That all has contributed [to draw up an AD].' (Female, 65–85 yrs, NVVE, dementia)		
Serious illness from myself	8%	2%
'... at the time of the stroke, that frightened me severely. I also got several attacks of epilepsy during a period of time. [...] And at that time I requested the AD [from the NVVE]' (Male, 45–64 yrs, NVVE, multiple myeloma)		
Experiences in my job	6%	4%
'I did a lot of terminal care and also saw a lot of people dying of cancer. ... And, then I got cancer myself and I was quite scared of that... Well, and then I drew up a euthanasia directive.' (Female, 45–64 yrs, NVVE, breast cancer)		
Hereditary illness in my family	3%	1%
I: '... what was really the motivation to say: I have to do it [drafting an AD] immediately?' R: 'Well, because I saw with my brothers and sisters [suffering from a hereditary form of M. Alzheimer] how fast you are not able to speak anymore for instance. And if you can't speak anymore or you have lost your memory completely, then you also don't have the right anymore to do it.' (Male, 45–64 yrs, hereditary form of Alzheimer's disease)		
Fear that physicians will hasten death against my wishes	–	18%
Fear that physicians will prolong life against my wishes	–	8%
'Look, I have children that go to church, but I also have some that do not. And then I think, yes, I do not want to be on a plug in the hospital if it's not going well. If it's your time, it's your time. And then don't keep on prolonging and prolonging and again prolonging. And also no euthanasia, that's also something I don't want.' (Female, 65–85 yrs, NPV, heart condition, diabetes, M. Parkinson)		
Stories in the media and/or developments in society	0%	3%
R: '... but I have little trust in the doctors in the hospital. It's no fear, it's based on facts. They treat you according to their own standards and to put it bluntly: they think it is a waste of money to continue treatment.' I: 'Do you have an example of this in your environment?' R: 'No, I don't have an example but I read the magazine of the NPV' (Male, 65–85 yrs, among other things diabetes and incontinence)		
Otherwise	3%	4%
Being alone or single is a cause mentioned by respondents in interviews as well as in the written questionnaire 'And that's the advantage, on the one hand, of being divorced. I can write it all down as I want it and see if it can be arranged. As far as that goes, I don't need to take into account anybody. [...] In the past we always talked about being an organ donor and in case of brain damage, coma: guys, no! At that time you still could expect that your partner could do something. But if you don't have a partner anymore, then it becomes more difficult. That's when I decided to turn to this [AD].' (Female, 45–64 yrs, NVVE, hereditary fronto-temporal dementia)		
Respondents were able to choose more than one motivation.		

^{*} Rounded percentages, missings: ≤5%.

illness of oneself (8%), experience in one's job (6%) and the presence of a hereditary illness (3%). NPV-members most often indicated the fear that physicians might hasten their death against their wishes (18%), the fear that physicians would prolong their life against their wishes (8%), a serious illness in the direct environment (8%) and experiences in their job (4%).

As Table 1 shows, themes found in the interviews were similar to those in the written questionnaires. Almost all respondents that were interviewed had specific examples: a situation at the end of life they feared most, as is illustrated in the quotes belonging to a serious illness and dementia in the direct environment. Very often these situations were things they actually had experienced in their

Table 2
'With my advance directive (AD) I aim to'.

	NVVE (n = 3889) [*]	NPV (n = 1055) [*]
Quotes from interviews (R = respondent, I = interviewer)		
Prevent suffering (unnecessary or without hope of recovery)	27%	2%
'I had another friend who got breast cancer. Oh my, did they mutilate her! [...] She didn't die in a dignified manner as far as I am concerned. I wasn't there at the final moment, but I visited her. She was just like a Michelin doll in a wheelchair, just awful. You know, I sometimes I get really angry about that. Then I think: you wouldn't even treat your pet like that.' Later in the interview answering the question what she hoped to achieve or prevent with her AD: 'Unbearable suffering.' (Female, 45–64 yrs, NVVE, laryngeal, oesophageal and thyroid cancer)		
Realize self-determination/to be treated according to wishes	21%	22%
'Well, at this time we ourselves are still able to work at how we would want it.' (Male, 65–85 yrs, NPV, dementia)		
Prevent unnecessary lengthening of life/treatment	14%	16%
'Not dignified is in a hospital with all kinds of bells and whistles. So that's also why I have a ROTD, because I think that's the most terrible thing there is... that your family, who loves you very much, sees you lying like that.' (Female, 45–64 yrs, NVVE, spastic quadriplegia from birth)		
Have a dignified or peaceful death	14%	10%

Table 2 (Continued)

	NVVE (n = 3889) ^a	NPV (n = 1055) ^a
R: 'Because I came to the conclusion that I wanted to die like that [like brother-in-law who got euthanasia]. That if I asked, I wanted to die like that.'		
I: 'Yes, that you yourself could determine the moment...'		
R: 'I put my cat to sleep as well, why can't I ask to be put to sleep? One cat was put to sleep, the other just died from old age. He sought his spot, [...], and just passed away. [...]. I wouldn't mind either if I would die in my sleep. That's also dignified to me.'		
(Female, 65–85 yrs, NVVE, skin and breast cancer, M. Crohn, severe cardiac failure)		
Prevent to be dependent	11%	0%
I: 'Is there another reason why you say: being able to wash myself is important because...?'		
R: 'That I want privacy and also that I hate when other people are touching me or have to do something. I just want to take part in life independently. I often also have the feeling I'm at the sidelines.'		
I: '[...] Is it therefore so much more important for you to hold on to that piece of independence?'		
R: 'Yes, because that is the only piece you have left. I won't allow it beyond this. This I just about tolerate, but much further it should not go. No, then nothing of the actual person is left. And I think that you don't contribute to other people at that point; that you don't mean anything for them any longer. That may not be true, but that's how I feel.'		
(Female, 45–64 yrs, NVVE, laryngeal, oesophageal and thyroid cancer)		
Prevent to be a burden to close-ones or others	10%	0%
'Yes, look, I don't know it anymore, I'm not there anymore. [...] But an empty shell of a human, that's of use to nobody. And this sounds really strange: it costs tons of money, for what? I take the place of someone else, who's still a bit better and still does enjoy the care and everything.'		
(Female, 45–64 yrs, NVVE, hereditary fronto-temporal dementia)		
Prevent a undignified existence and/or deterioration	10%	0%
'My father was not manageable anymore. So, at one point he got this adjusted wheelchair, but he was even tied down with his upper body. He was not able to raise that himself. I find that so undignified. And that clearly made me decide: I don't want that.'		
(Female, 45–64 yrs., NVVE, hereditary fronto-temporal dementia)		
Prevent dementia or cognitive decline	8%	0%
'If you really don't know anymore... like a kind of zombie, that is a real vision of terror for me. [...] when you're not able to live consciously anymore, well in that case there really isn't much sense.'		
(Female, 65–85 yrs., NVVE, dementia)		
– Prevent euthanasia/hastening of death (NPV)		44%
See quote in Table 1.		
– Have euthanasia/determine moment of dying oneself (NVVE)	7%	
R: '... if I am so drowsy that I'm not able to react to what happens around me, or that I'm so deranged because of the cognitive deterioration that I don't recognize people anymore, let alone talk about intimate things. ... It's more in the direction of euthanasia that I now...'		
I: 'That doesn't matter, because indeed my question would be if you would want euthanasia in the situation described above?'		
R: 'Yes, that would be the idea.'		
(Male, 45–64 yrs, NVVE, multiple myeloma)		
Prevent pain	7%	0%
'Constant pain is not dignified. I will not have that. If nothing helps against the pain and you have it constantly. That you can't even briefly – pffff – catch your breath.'		
(Female, <44 yrs, NVVE, HIV and hepatitis C)		
Prevent a vegetative state/lengthy coma	6%	0%
'And the reason [to draw up the AD] was because I had this nightmare, that you would get into this kind of vegetative state, where to live on is only possible on machines and lots of help without any prospect of recovery. That doesn't seem right to me.'		
(Male, 45–64 yrs., NVVE, multiple myeloma)		
Prevent that family has to make choices	3%	3%
'I would want to prevent that I will get into a situation where my children would have to pull the plug. [...] You can be on a ventilator for a year, for instance. And that has to stop at some point. Look, I focus on the children. You can't do that to your children.'		
(Male, ≥86 yrs, NPV, history of colon cancer and pulmonary embolisms, osteoporotic fractures of the vertebrae)		
Die according to God's will/in a natural way	0%	9%
'...my confession is that life is a gift from God and I should not meddle with that, even if it may be undignified in the eyes of another person.'		
(Male, ≥86 yrs, NPV, history of colon cancer and pulmonary embolisms, osteoporotic fractures of the vertebrae)		
Receive all possible medical treatments	0%	6%
'Well I say it is dignified, if I... [long silence] ... can get myself to finish the path till the end. That is dignified, with that I would fulfill that what is asked from me. It will not be, even if it will be very difficult, that I would think at some point: I wish the end was here. As long as it is treatable, than I say: that is the way to go; that is my dignity.'		
(Male, 65–85 yrs, NPV, diabetes and incontinence)		
Receive meticulous/good care	0%	5%
No suitable quote in interviews.		
Otherwise	13%	12%

ROTD = Refusal of treatment document.

^a People who answered the open question: 'What do you hope to achieve or prevent with you AD?'

direct environment. They used them to indicate what they surely would not want and hoped to prevent with their AD.

3.2. Aims of an AD

When asked in the questionnaire what they aimed for with their ADs, NVVE-members most often hoped to prevent unnecessary suffering without chance of recovery with their AD (27%, 2% for the NPV, Table 2). The aim mentioned most in both groups was to realize self-determination or be treated according to their wishes (NVVE 21%, NPV 22%), followed by the aim to prevent unnecessary lengthening of life or to prevent treatment in a certain situation (NVVE 14%, NPV 16%) and having a dignified or peaceful death (14% and 10%).

Then there were a number of aims only mentioned by the NVVE-members: prevent to be dependent (11%), to be a burden to close-ones or others (10%), an undignified existence or deterioration (10%), dementia or cognitive decline (8%), pain (7%) and a vegetative state or lengthy coma (6%). Preventing that your family has to make choices for you again was mentioned by both groups (both 3%).

Members from the NPV most frequently stated they hoped to prevent euthanasia or hastening death (44%), while on the other hand 7% of NVVE-members hoped to have euthanasia or determine the moment of dying themselves. Other aims were only mentioned by NPV-members: to die according to God's will or in a natural way (9%), to receive all possible medical treatments (6%) and to receive meticulous or good care (5%). Except for the last one all these aims

frequently came up in the interviews as well. As the quotes in Table 2 show, there is overlap between aims. Some quotes could easily be placed under other aims in the table as well. The quote under the aim to prevent suffering for instance could also be placed under hoping to prevent unnecessary lengthening of life or treatment. This particular quote is also another illustration of a personal experience used as an example of what a person hopes to prevent at the end of life.

3.3. Difficulty foreseeing the future and setting limits

In several interviews people said it was difficult to anticipate the future and determine where they would draw the limit as from where their lives would be not worthwhile living anymore because of their progressing illness. A 68 year-old woman with dementia, member of the NVVE and in the possession of an AD stating she would want to have euthanasia in case of cognitive decline, and her partner talk about this:

Interviewer: 'Where do you set the limit? When would you say with this Alzheimer's disease that has been diagnosed: till that point and no further? Can you try and put in words how that situation looks like for you?'

Respondent: 'That's extremely difficult. [...] I think that if you look at it realistically, you can't answer that. If you're that far gone that you will not perceive it anymore, maybe you'll like life again at that point. But...'

Partner of respondent: 'Yes, but you've always said, that's what you've always said to me: if I am not able to wash and dress myself independently, if I become dependent, if I have to leave my home, that's when I want to step out [of life]. That is very clear, what she's always said.'

Elsewhere in the interview, when the respondent was not in the room for a short while, her partner said that there was a great difference between the firmness with which she used to ventilate her views on the end of life and now at the time of the interview.

A man in his fifties and suffering from multiple myeloma, in hindsight concludes he adjusted his views:

'Yes, several years ago I thought: if I have to sit in a wheelchair, I don't want that. But meanwhile that has happened a couple of times and I didn't mind it as much. It wasn't all that bad. So that has changed.'

And:

'Yes, I changed it [AD] once; I have to dig deep... I believe it was about the restriction in the ability to move around. That I have a lot less aversion to this as compared to several years ago.'

For patients, some things are difficult to foresee and limits might change, while other preferences seemed to be more distinct and therefore less subject to instability. This is illustrated in the following two quotes of a middle-aged woman with terminal breast cancer:

'You keep on pushing your limits. [...] Yes, still I used to think: that's just very awful [being in pain, being dependent, having wounds]. And yes, now you're in the middle of that, but yes... you postpone it [asking for euthanasia] for a little while again. Although the pain is clear: yes, if I will be in too much pain than it'll all be over.'

And:

'No. I don't want to go to the hospital anymore. [...] Yes, if I should not be able to eat anymore, then I also would not want an IV or something, or fluid nutrition or something. [...] No, that is the limit really, it has been enough.'

Table 3

Did you inform people about drawing up an AD?

	NVVE (n = 4497) [*]	NPV (n = 1271) [*]
Nobody	1%	2%
Partner [†]	88%	83%
Children [†]	85%	63%
GP or other physician ^{††}	79%	65%
(Other) family members	19%	18%
Friends/acquaintances	13%	4%
Others	6%	4%

Respondents were able to choose more than one option.

^{*} Rounded percentages, missings ≤4%.

[†] Percentages are given for the part of the population that indicated they had a partner (NVVE n = 2775; NPV n = 881) or children (NVVE n = 3449; NPV n = 951).

^{††} From the people who informed a physician, 100% informed their general practitioner (GP). Besides that 9% of NVVE-members and 6% of NPV-members also informed a medical specialist. Not all respondents were under treatment of a specialist, probably the majority was not.

Only NVVE-members mentioned difficulties foreseeing future situations or talked about pushing limits; NPV-members did not. They seemed to be more at peace with and less in fear of the natural course of the disease.

3.4. Communication about ADs

Only a very small part of the respondents did not discuss the fact that they had drawn up an AD with anybody (1% of NVVE-members, 2% of NPV-members, Table 3). Many talked to close-ones, especially their partner (NVVE 88%, NPV 83%) and children (NVVE 85%, NPV 63%). A majority also talked with their general practitioner (GP) (NVVE 79%, NPV 65%).

The interviews were in line with the results shown by Table 3: most people talk about their ADs with their physicians and people in their environment, often thoroughly and realistically. The interviews added information about why some people did not talk about their ADs with physicians. The reason most often heard in the interviews was the quitting or retirement of the GP. Respondents often had discussed it with their former GP, but not yet with his successor. Sometimes the reason not to discuss the subject with physicians seemed to come from the side of the patient. This man in his fifties suffering from multiple myeloma says the following:

'Yes, we [respondent and his GP] never... That isn't necessary for me. We never went through the scenario, like we are doing now actually... [...]

I sometimes have the impression that if... if my end is near, that will happen. Then I want to do that, if, at least, he will be involved. There is a chance that it will happen in the hospital. But my treating specialist doesn't possess a copy [of the AD]. I keep on forgetting that.

That must have something... and this is also the psychiatrist speaking [respondent's profession was psychiatrist], unconsciously there must be something behind this. Maybe I don't dare to do that, because it doesn't concur with the idea that I still have the hope that he is able to cure me.'

In other cases people discussed their AD and preferences with their physician, but the latter was not able to bring his views on the subject across to his patient. An elderly woman with dementia and her partner tried to talk about euthanasia with their GP:

Respondent: 'Yes, we've been to him once, right?'

Partner: 'Yes, the papers [ADs] are also in his possession. But that's a long while ago already, not in the last year. But he doesn't give a clear answer anyway.'

[...]

Interviewer: 'Will he or she agree to do that [euthanasia] potentially?'

Respondent: 'Well, we don't know. He doesn't answer. . . We asked, but he doesn't answer that.'

4. Discussion and conclusion

4.1. Discussion

Whereas about half of our respondents had no direct motivation to draw up their AD, the motivations most seen were illnesses of a family member or friend. In the qualitative interviews many respondents gave examples, often situations they had seen in the past, of what they definitively wished to prevent at the end of their lives. Aims of ADs heard most were to assure to be treated according to one's wishes, to prevent unnecessary suffering or lengthening of life and to achieve a peaceful or dignified death. Next to unnecessary lengthening of life, NPV-members also hoped to prevent intentional shortening of life and some of them wanted all treatment possible till the end.

While people often had vivid images of what they did not want at the end of life given aforementioned examples, respondents indicated having difficulty where exactly to set limits in the future. Looking back some also concluded formerly drawn limits had been crossed and had turned out not to be definite. Not all preferences of the same respondents seemed to be subject to change. These issues with setting future limits did not occur with NPV-members. Most respondents communicated about having an AD with close-ones and a large majority did this with their GP. The reason most heard in the interviews not to discuss this subject with their GP was a change in GPs.

4.1.1. Motivations and aims of ADs

Often interviewees had vivid examples in their direct environment of how they did not want their lives to end. These examples add extra insight in reasons and motivations to formulate an AD. The relevance of examples in the environment was also described in qualitative studies among long-term-care residents and elderly patients [9,15]. Aims found in the written questionnaires, like wanting to prevent suffering, realize self-determination or a dignified death give an indication of what people want with their ADs, but tend to be quite general. The concrete examples and fears that mostly seem to underlie these aims might be more suitable as a starting point for a conversation about preferences between patient and caregiver and thus more meaningful for practice. Part of the members of the NVVE and NPV, two groups with very different backgrounds and views on the end of life, mention the same aims to possess an AD. Especially the fear of over-treatment and unnecessary prolonging life seems to be a general concern in both groups. This was found in other studies in different settings as well [1,7,9].

4.1.2. Difficulty foreseeing the future and setting limits

Several respondents mentioned difficulties foreseeing the future, a phenomenon seen in studies that took place in specific patient groups as well [16,17]. As opposed to these specific patient groups however, all of our respondents chose to record preferences

about possible future medical decisions in an AD. Some of them also mentioned that they had already pushed their limits during their illness. A question that is raised frequently when it comes to ADs is whether the recorded preferences are stable. Some quantitative studies found associations between a change in health status and a change in preferences [18,19], while others did not [20,21]. Our results suggest that people can change their preferences as a result of adaptation to the situation in which their illness brought them, also known as response shift [22]. To conclude from this that ADs are useless due to instability in preferences would be too rash, because we found as well that this was not applicable to all preferences or all people. Besides this, ADs can be adapted if necessary. A conversation with caregivers on a regular basis about the (possible change in) preferences in the AD would further ensure the validity of the document.

4.1.3. Communication

The importance of communication at the end of life and specifically surrounding ADs has been emphasized before [2,4,11]. Our findings that holders of specific ADs in the Netherlands talk about their AD and a large majority talk to their GP about it, are favorable in this light. It was found elsewhere that the presence of an AD increases the likelihood of communication between patients and physicians on this subject [23]. Besides the question if there was communication, it is as important how the quality of this communication was. Our data suggest that this quality was often good. This contradicts the findings of a qualitative study on the use of ADs in case of dementia in the Netherlands where patients and physicians were interviewed, where was found that the conversations about ADs were mostly short and GPs often had no recollection that they had taken place [24]. As for the reasons not to discuss ADs, the barriers we saw from the side of patients as well as physicians, were found by others as well [25,26]. Becker et al. also found issues concerning trust, finance and time in connection to a lack of communication about ADs, which we did not. However, they focused more on assistance when formulating an AD [10]. The reason we most often found, a change in GPs, stresses the importance of continuity of care, especially at the end of life [27].

4.1.4. Methodological considerations

The mixed-methods approach of this article is a strength: the qualitative results reveal motivations and considerations on the level of the individual having an AD, and the quantitative data put them in a broader perspective.

A limitation may be that our data about foreseeing the future and crossing limits came from cross-sectional interviews. We could compare what respondents said in their interviews to the answers they had given earlier in the written questionnaires, but the results on these subjects are for a large part dependent upon the memory of our respondents.

4.2. Conclusion

ADs can give directions to caregivers of what people want at the end of their lives. There is a clear distinction between someone who doesn't want to be committed to a hospital anymore and someone who wants all possible treatments till the end. There is also a gray area: besides the difficulty of condensing end-of-life preferences in a written document, it is hard to exactly foresee what will happen in the future and if current limits will be under pressure to change.

4.3. Practice implications

We found that people can have specific aims for drafting an AD. Therefore the usefulness of ADs strongly depends on the process of

communication around them. It is not only advised to talk regularly about situations aimed for in an AD, but also to discuss them in detail to really understand the wishes of people. In this way ADs could improve the communication about end-of-life preferences and decision-making between physicians and patients. An AD could be an incentive to think and talk about preferences for future care.

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