



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

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