CHAPTER 3

ADVANCE DIRECTIVES IN THE NETHERLANDS: AN EMPIRICAL CONTRIBUTION TO THE EXPLORATION OF A CROSS-CULTURAL PERSPECTIVE ON ADVANCE DIRECTIVES

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"I been in the right place, but it must have been the wrong time
I've said the right thing, but I must have used the wrong line"

Wright Place, Wrong Time,
by Dr. John

ABSTRACT

Research Objective

This study focuses on ADs in the Netherlands and introduces a cross-cultural perspective by comparing it with other countries.

Methods

A questionnaire was sent to a panel comprising 1621 people representative of the Dutch population. The response was 86%.

Results

95% of the respondents didn't have an AD, and 24% of these were not familiar with the idea of drawing up an AD. Most of those familiar with ADs knew about the Advanced Euthanasia Directive (AED, 64%). Both low education and the presence of a religious conviction that plays an important role in one's life increase the chance of not wanting to draw up an AD. Also not having experienced a request for euthanasia from someone else, and the inconceivability of asking for euthanasia yourself, increase the chance of not wanting to draw up an AD.

Discussion

This study shows that the subjects of palliative care and end-of-life- decision-making were very much dominated by the issue of euthanasia in the Netherlands. The AED was the best known AD; and factors that can be linked to euthanasia play an important role in whether or not people choose to draw up an AD. This differentiates the Netherlands from other countries and, when it comes to ADs, the global differences between countries and cultures are still so large that the highest possible goals, at this moment in time, are observing and possibly learning from other cultural settings.

INTRODUCTION

Quality of life is an important concern when it comes to care at the end of life. In palliative care it is even considered as one of the main goals. However, it is a highly subjective matter. Because of this, personal preferences about medical treatment at the end of life are very important when trying to guarantee the best possible care. One of the ways to make someone's wishes about end-of-life care known, so that they are taken into account and granted if possible, are advance directives (ADs). ADs are written statements about a person's preferences regarding possible future medical decisions. They are intended for situations where the person in question is not able to express his wishes because of incompetence or loss of consciousness.

There is still contradiction when it comes to the effectiveness of ADs. On the one hand it is said that ADs can enhance the quality of care [1]. On the other hand, a more sceptic sound is heard [2] when, for instance, it comes to the question of whether an AD can reflect the wishes of a person about a certain moment, when it is formulated at an earlier time under different circumstances [3].

Although ADs are becoming more widespread across the world [4], there are still a lot of differences globally. There are nations where ADs are not legally accepted [5], while at the other end of the spectrum there is the USA where the use of ADs is promoted by a law, the Patient Self Determination Act (PSDA) [6]. This leads to the question of the possibilities and limitations of considering ADs from a cross-cultural perspective. Can and should it, for instance, lead to universal statements about ADs that are more or less applicable across the world?
In trying to answer these questions, empirical data can be helpful. They can provide information on the way ADs function in practice. This can serve as a basis for discussions on policy and ethical issues. Therefore we aimed at gathering data that focus on the situation concerning ADs in a single country, the Netherlands, and take this as a starting point.

In the Netherlands there are several different types of ADs. They are commonly subdivided into two categories: a 'negative' AD, aimed at declining treatments or forms of care, and a 'positive' AD, intended to request certain treatments or to give consent for them to be carried out. An example of the last category is the advance euthanasia directive (AED), a written document requesting that one's life should be terminated in a specified situation. The refusal of treatment document (ROTD) belongs to the group of negative ADs. It states that a person does not want to receive treatment when there is no hope of returning to a specified state of quality of life that is of a reasonable standard to him. Furthermore, a person can appoint a representative to uphold his/her wishes and preferences, when he/she is no longer able to in a durable power of attorney for health care (DPOHC or healthcare proxy). Finally, the so-called will-to-live statement contains a declaration that a person wants to be guarded against either life terminating acts or excessive (medical) treatment at the end of his/her life and that he/she wants to receive committed care and can die in a dignified manner. Next to standard forms of ADs, which are issued by different organizations, there is also the opportunity to formulate a personal statement.

ADs are legally accepted in the Netherlands, which is reflected in the Medical Treatments Contract Act (WGBO). AEDs are specifically mentioned in the Euthanasia Act, which allows a physician actively to end the life of a patient when certain demands are met. This last law puts the Netherlands in an exceptional position, because elsewhere euthanasia is only legally permitted in Belgium and Luxemburg. In the states of Oregon and Washington (USA) and in Switzerland, physician-assisted suicide is allowed.

Rurup et al. [7] found that in the Netherlands 10% of older people have an AD. However, it is not clear to what extent average Dutch people know of the existence of ADs. What are characteristics of people who do or don't draw up an AD? What are the reasons for a person to formulate an AD or choose not to?

We use the data from a survey among the Dutch general public to answer these questions, and subsequently discuss how these results are related to the circumstances surrounding ADs in other countries, exploring the potential of a cross-cultural perspective on ADs and its possible boundaries at the present moment.

METHODS

Design and population

In October 2005 a written questionnaire was sent to an established sample of the Dutch public: the Consumers' panel for Health services of the Netherlands Institute for Health Services Research (in Dutch: NIVEL). This sample is designed to be representative of the population of the Netherlands aged 20 years and older. When the sample was composed, possible members were recruited by mail and telephone. A survey done in 2005 and 2006 by the European Union showed that 100% of the Dutch population had telephone access (8). Consequently these methods of recruiting didn't create a selection bias. From the original sample of 1621 persons, 1402 people returned the questionnaire, which makes a response of 86%. The respondents were representative of the Dutch population for age, but women were somewhat overrepresented (56% versus 51%). First and second generation migrants were underrepresented in the sample (7% versus 19% in the general Dutch population in 2005 according to Statistics Netherlands). This also affects its representativeness regarding ethnicity and language. A possible explanation for this lies in the fact that it was a written questionnaire in the Dutch language. However, the sample did correspond to the religiosity of the Netherlands as shown by the following figures: 28% (95% CI 26–30) of the sample was Roman Catholic versus 30% in general Dutch population, 22% (CI 19–24) versus 20 % was Protestant and an equal percentage was people with no religion (41%). The misrepresentation regarding migratory background is seen in the amount of Islamic people in the sample (<1% versus 6%).

Questionnaire

The questionnaire covered a number of subjects such as ADs, end-of-life issues and background

characteristics of the respondents. The questions about ADs focused on possession of ADs, and, if this was the case, which kind a person had. The respondents, who indicated that they did not have an AD at the moment, were asked about their awareness of ADs and the different standard forms. They were also asked about the reasons why they did not have one and the likelihood of their drawing one up in the future.

The questions about end-of-life issues addressed preferences, experiences and expectations concerning dying and end-of-life care and decision-making. Next to standard demographics, people were also asked about their health and quality of life.

Statistical analyses

First a descriptive analysis concerning the possession and awareness of ADs was done. For further statistical analysis, the intention to have an AD in the future was taken as an outcome measure, because the number of people actually possessing an AD was too small to produce reliable results. Three groups were distinguished: respondents who *have* an AD or *certainly* want to draw up one in the future, respondents who *may* want to draw up an AD in the future and respondents who did *not* want to draw up an AD. The relationship between this variable on the intention to formulate an AD in the future and variables concerning background characteristics and end-of-life issues was first assessed using 95% confidence intervals; two percentages differ significantly when their confidence intervals do not overlap. After that, in a multivariate analysis, variables associated with *not* wanting to draw up an AD were identified. For this analysis the dependent variable was dichotomized into not wanting to draw up an AD versus the rest (having an AD, certainly or maybe wanting to draw up an AD in the future). All significant variables from the univariate analysis were included in a stepwise backward logistic regression. Variables were removed if $p > 0.05$.

RESULTS

Possession and awareness of ADs

Of the respondents 7% possessed an AD (Figure 1). Of these people 35% had formulated an AD themselves, 60% had one or more standard ADs and 5% had both. From the 65% that had a standard AD, the majority had an AED (67%). After this the ROTD (40%), the DPAHC (30%) and the DNR (28%) were the most owned ADs. All other standard forms were possessed by 9% or less from this group. Most respondents did not have an AD (93%).

The main reason for not having an AD was that people had never thought about it, often because they indicated they were still young and healthy (60%). Some quotes within this group were ‘I’m only 26 years old’ or ‘I’m only 65 years old’ and ‘I don’t plan on dying any time soon’. Other reasons were ‘I plan to formulate an AD, but not right now’ (10%), ‘Not necessary now, I plan to do so later’ (5%), ‘I’ll leave it to my family, they’ll know what I want’ (10%), ‘I don’t know what I want’ (5%). Some people didn’t have any faith in the effectiveness of ADs (2%), some

didn't think an AD would be necessary at all (4%) and 5% indicated that they didn't want to think about the matter because it was too confronting (data not shown in figure).

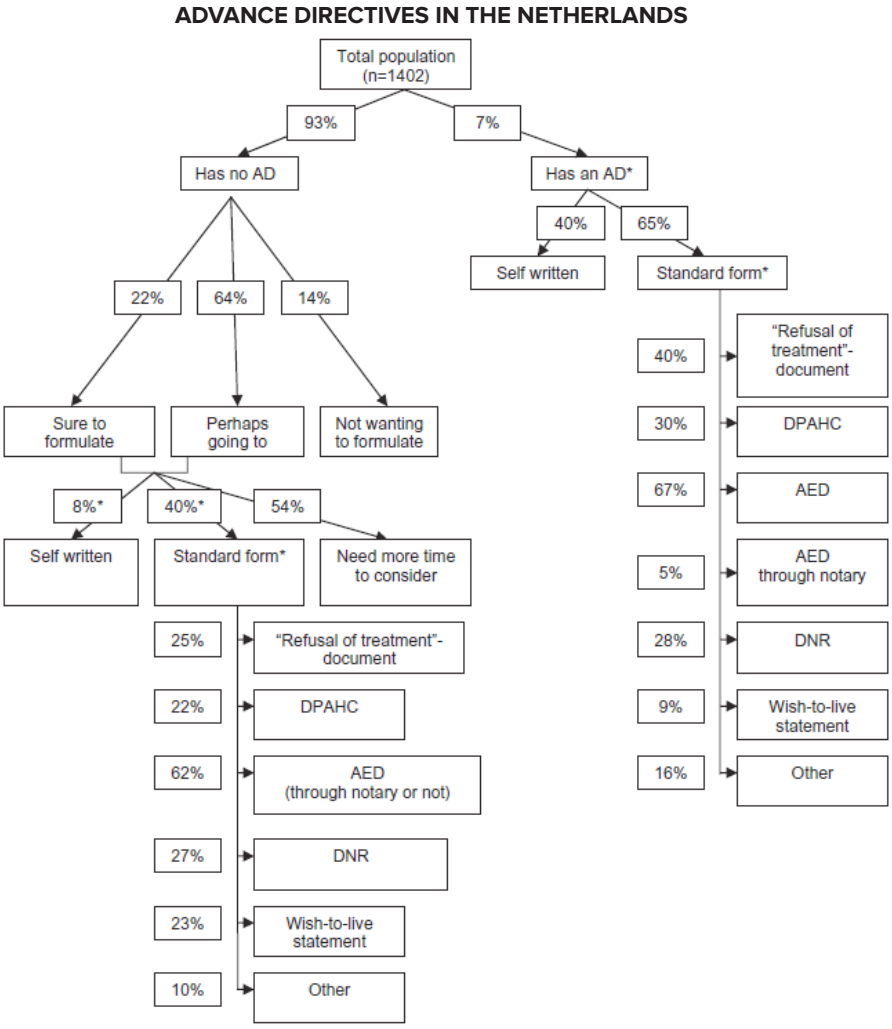

Figure 1. Possession of ADs, tendency towards formulating ADs and awareness of AD's (rounded percentages)

** People had the possibility to choose more than one option*

Abbreviations used:

AD = Advance Directive

DPAHC = Durable power of attorney for health care

AED = Advance Euthansia Directive

DNR = Do-not-resuscitate order

Figure 1 shows that of the 93% that did not possess an AD, 14% did not want to formulate one, 22% was sure to draw one up in the future and the largest part (64%) indicated they maybe wanted to formulate an AD. These last two groups were asked which kind of AD they (possibly) wanted to formulate in the future. They didn't have to choose just one type of AD, but had the opportunity to select several different ADs. The majority (54%) stated that they first wanted to consider the matter further, 8% wanted to formulate an AD themselves and 40% chose one or more of the standard forms. Of these standard forms, the AED was by far the most opted for, with 62% against 27% or less for the others.

The people who indicated that they did not have an AD were also asked if they knew of the existence of ADs before filling in this questionnaire. Almost a quarter of them (24%) had never heard of the possibility of formulating an AD. Most of the people who had heard of ADs knew specifically about the AED (64%) and the DNR (37%). Other standard ADs, like the ROTD, DPAHC and care statements, were less known (<15%) (data not shown in figure).

Background characteristics in relation to intentions to formulate an AD

In Table 1, there are only three background characteristics that produce a statistically significant difference when it comes to the intention *not* to formulate an AD. Of the people who had children and also had a good relation with them, a statistically significant *larger* part did not intend to formulate an AD compared to people who did not have children (15% versus 8%).

The same applies for people who had an elementary or basic vocational training compared to those who had secondary or higher education (24% versus 12% and 8%). Finally, a larger part of the people who had a (religious) belief did not want to draw up an AD compared to those that had no belief (16% versus 10%). This difference becomes larger when the importance of the belief in someone's life is taken into account (22% versus 9%).

Education and belief were also the only variables to create significant differences when it came to people who definitely intended to formulate an AD or already had one. A significant larger portion of persons with a higher education possessed an AD or wanted to in the future compared to people with elementary or basic vocational education (32% versus 21%), while people without belief more often had an AD or definitely wanted to formulate one in future compared to people with a belief (32% versus 24%).

The data provided some results concerning religion that justify a small side-step at this point. It's noteworthy that of the people who were Christian (Roman Catholic or Protestant) and whose belief played an important role in their lives (n = 396), 60 % could imagine they would ask to end their lives in certain circumstances and 9% stated they would possibly draw up an AED in the future. Within this group, five persons actually possessed an AED (data not shown in Table).

Table 1. Background characteristics of people in the Netherlands by possession of an AD or tendency to draw one up in the future (n = 1385, rounded percentages with 95% confidence intervals)

	People who posses an AD or certainly want to draw up one in the future. (n=377)	People who maybe want to draw up an AD in the future. (n=825)	People who don't want to draw up an AD. (n=181)
Gender			
- Male (n=610)	25 (21-28)	61 (57-65)	14 (12-17)
- Female (n=769)	29 (26-33)	59 (55-62)	12 (10-15)
Age (mean with 95% confidence intervals)	52,4 yr. (50,8-53,9)	49,4 yr. (48,4-50,4)	54,7 yr. (52,3-57,1)
Marital status			
- Partner (n=1124)	26 (24-29)	60 (57-63)	14 (12-16)
- Single (n=255)	33 (27-39)	58 (52-64)	9 (6-14)
Children			
- Children, good relation (n=1013)	26 (23-29)	60 (57-63)	15 (12-17)
- Children, bad relation (with some or all) (n=90)	32 (23-42)	56 (45-66)	13 (7-20)
- No children (n=276)	30 (25-36)	62 (56-67)	8 (5-12)
Education			
- Elementary of basic vocational (n=297)	21 (16-25)	56 (50-61)	24 (19-29)
- Secondary (n=512)	26 (22-30)	62 (58-66)	12 (10-15)
- Higher (n=557)	32 (28-36)	60 (56-64)	8 (6-11)
Ethnical background*			
- Native (n=1273)	27 (24-29)	60 (58-63)	13 (11-15)
- Not native (n=101)	33 (24-42)	52 (42-61)	16 (10-24)
Life stance			
(Religious) Belief (n=756)	24 (21-27)	61 (57-64)	16 (13-18)
- Roman Catholic (n=391)	24 (20-28)	62 (57-67)	14 (11-18)
- Protestant (n=302)	18 (14-23)	62 (56-67)	21 (16-25)
- Other (n=72)	49 (37-60)	49 (37-60)	3 (1-9)
No Belief (n=567)	32 (28-36)	58 (54-62)	10 (8-13)
Belief and its importance in someone's life			
- Important belief (n=458)	23 (19-27)	56 (51-60)	22 (18-26)
- Not important belief or no belief (n=912)	29 (26-32)	62 (59-65)	9 (7-11)
Experienced health			
- Very good (n=270)	27 (22-33)	61 (55-60)	12 (9-17)
- Good (n=926)	27 (24-30)	60 (57-63)	13 (11-15)
- Less than good (n=183)	31 (24-38)	55 (47-62)	15 (10-20)
Suffering from a disease			
- No (n=834)	26 (23-29)	60 (57-64)	14 (12-16)
- Yes (n=529)	29 (26-33)	59 (54-63)	12 (10-15)
Experienced quality of life			
- Very good (n=347)	30 (25-35)	57 (52-63)	13 (9-16)
- Good (n=972)	26 (23-28)	61 (58-64)	13 (11-16)
- Less than good (n=61)	39 (28-52)	49 (37-62)	12 (5-21)

** Not native, being a person with at least one parent not born in the Netherlands*

End-of-life issues in relation to intentions to formulate an AD

Table 2 focuses on experiences with, and views on, end-of-life issues. People statistically significantly more often had an AD or certainly wanted one in the future if they had an experience with a request for euthanasia compared to those who had not had such an experience (39% versus 21%).

The same applies to persons with the experience of a 'bad' death of another person, people who hoped they could determine their moment of death themselves, those who were able to imagine situations in which they would not want to live on anymore, who were able to imagine asking to end their lives in certain circumstances, or would not want artificial hydration and nutrition in case of an advanced stage of dementia. Of people who had confidence in physicians, when it comes to delivering good care and following their wishes at the end of life, a larger part did not want to formulate an AD compared to people who had no confidence in this (respectively 20% versus 9% and 18% versus 7%). Other variables that were analysed but didn't come up with significant differences were: experience with a 'good' death of another person, the attitude towards the statements 'I hope I can prepare for death before I die', and 'I hope I'm not dependent on others when I die'.

Table 2. Experience with and views on end-of-life issues by possession of an AD or tendency to draw one up in the future (n = 1385, rounded percentages with 95% confidence intervals)

	People who posses an AD or certainly want to draw up one in the future. (n=377)	People who may want to draw up an AD in the future. (n=825)	People who don't want to draw up an AD. (n=181)
Experience with a request for euthanasia of another person			
- Yes (n=467)	39 (34-43)	55 (50-59)	6 (5-9)
- No (n=910)	21 (19-24)	62 (59-65)	17 (14-19)
Experience with a 'good' death of another person*			
- Yes (n=1011)	28 (26-31)	59 (56-62)	13 (11-15)
- No (n=362)	24 (20-29)	63 (58-68)	13 (10-17)
Experience with a 'bad' death of another person**			
- Yes (n=426)	35 (31-40)	58 (53-62)	8 (5-10)
- No (n=944)	24 (21-27)	61 (58-64)	15 (13-18)
'I hope I can prepare for death before I die'			
- Disagree (totally) or neutral (n=506)	25 (21-29)	61 (56-65)	14 (12-18)
- Agree (totally) (n=859)	29 (26-32)	59 (56-62)	12 (10-15)
'I hope I'm not dependant on others when I die'			
- Disagree (totally) or neutral (n=369)	25 (21-30)	62 (46-66)	14 (10-17)
- Agree (totally) (n=995)	28 (26-31)	59 (56-62)	12 (11-15)
'I hope I can determine the moment of death myself when I die'			
- Disagree (totally) or neutral (n=681)	17 (14-20)	65 (61-68)	18 (16-21)
- Agree (totally) (n=684)	38 (34-41)	55 (51-59)	8 (6-10

Table 2 continued. Experience with and views on end-of-life issues by possession of an AD or tendency to draw one up in the future (n = 1385, rounded percentages with 95% confidence intervals)

	People who posses an AD or certainly want to draw up one in the future. (n=377)	People who may want to draw up an AD in the future. (n=825)	People who don't want to draw up an AD. (n=181)
Confidence in physicians when it comes to good care at the end of life			
- Great (n=217)	25 (20-31)	55 (48-61)	20 (15-26)
- Moderate (n=949)	26 (24-29)	61 (58-64)	12 (10-15)
- Little or none (n=207)	33 (27-40)	58 (51-65)	9 (5=13)
Confidence in physicians when it comes to following wishes about end-of-life decisions			
- Great (n=163)	26 (20-34)	55 (48-63)	18 (13-15)
- Moderate (n=916)	25 (22-28)	61 (58-64)	14 (12-17)
- Little or more (n=296)	35 (29-40)	48,45 (53-64)	7 (5=10)
Being able to imagine situations in which one wouldn't want to live on			
- Yes (n=1217)	29 (27-32)	61 (58-63)	10 (9-12)
- No (n=157)	12 (8-18)	53 (45-61)	35 (28-43)
Being able to imagine that one would ask to end his/her life in certain circumstances			
- Yes (n=1117)	30 (28-33)	61 (58-63)	9 (8-11)
- No (n=257)	14 (10-19)	56 (50-62)	30 (25-36)
Artificial hydration and nutrition in case of advanced stage of dementia			
- (Probably) Yes (n=364)	19 (15-24)	59 (53-64)	22 (18-17)
- (Probably) Not (n=1004)	31 (28-33)	60 (57-63)	9 (8-11)

** The question was if the person had experienced a death, in their social surroundings, that occured peacefully*

*** The question was if the person had experienced a death, in their social surroundings, that was unpleasant or unpeacefull*

Factors associated with not wanting to draw up an AD

Table 3 shows the results of the multiple logistic regression, showing factors associated with not wanting to formulate an AD. People who had an elementary or basic vocational education had 2.9 times higher odds of not wanting to draw up an AD as compared to people with a higher education.

People who had a belief that was important in their life had two times higher odds of not wanting to formulate an AD. (OR 2.0) Experiences and views on end-of-life issues that about double the odds of not wanting to formulate an AD were: having great confidence in physicians when it comes to following one's wishes at the end of life (OR 2.2), not being able to imagine there are situations in which one wouldn't want to live on (OR 2.1), no experience with a request for euthanasia of another person (OR 2.1), and not being able to imagine that one would ask to end one's life in certain circumstances (OR 1.8).

Table 3. Factors associated with not wanting to draw up an AD (n = 1385, odds ratio's and 95% confidence intervals)*

	Odds ratio	95% CI
Background characteristics		
Eduction		
- Elementary or basic vocational	2.9	1.9-4.4
- Secondary	1.6	1.0-2.4
- Higher	1.0	
Having a belief that is important in one's life	2.0	1.4-2.8
Experiences with and views on end-of-life issues		
Confidence in physicians when it comes to following wishes about end-of-life decisions		
- Very much	2.2	1.2-4.2
- Fairly much	1.9	1.2-3.3
- Not much or no	1.0	
Not being able to imagine there are situations in which one wouldn't want to live on	2.1	1.3-3.6
No experience with a request for euthanasia of another person	2.1	1.3-3.2
Not being able to imagine that one would ask to end his/her life in certain circumstances	1.8	1.1-2.9

** Stepwise backward mutiple regression, reference group 'having an AD or (maybe) wanting to draw up one in the future'. Variables that were included in the multivariate analyses were the ones that were significant in the univariate analyses in tables 1 and 2.*

Variables included in the mutivariate analyses that were excluded in the final model: 'Children', 'I hope I can determine the moment of death myself when I die'. 'Confidence in physicians when it comes to good care at the end of life', 'Artificial hydration and nutrition in case of advanced stage of dementia' and 'Experience with a "bad" death'.

DISCUSSION

Only 7% of the adult Dutch population had an AD. Of these, the majority had an AD about situations in which they would want their life to be ended through euthanasia.

A similar result is seen when it comes to which AD is best known, and which AD people indicated most frequently that they might draw up in the future. Of the people without an AD, almost a quarter had never heard of the existence of ADs, while 86% stated they (maybe) wanted to formulate one in the future. While most background characteristics of people were not associated with their not wanting to draw up an AD, lower education and having a belief that is important in one's life respectively tripled and doubled the odds of not wanting to formulate an AD. Furthermore, several attitudes towards and experiences with end-of-life issues, such as having or not having experience with a request for euthanasia from another person, were related to intention to formulate an AD.

A strength of this study is the high response rate of 86%, making selection bias unlikely. Although migrants were underrepresented in the sample, the results were representative for the native Dutch population. This study also has limitations, however. As only a small part of the Dutch public has an AD, this study, in spite of the large sample, could not provide a sufficient amount of respondents with an AD to make it possible to study factors associated with having an AD. That would have provided clearer results. However, taking the intention to formulate an

AD as an outcome measure was a good alternative. A limitation of studying the general public is that it is only possible to investigate the first relevant steps necessary for ADs to be a useful tool. This population cannot shed light on other steps relevant to the use of ADs, such as the acceptance of them among physicians and the extent to which they are taken into account and followed when the owner has become incompetent and is in the situation indicated in the AD. The data show that variables related to attitudes and experiences with end-of-life issues are more frequently related to not wanting to formulate an AD than are the personal characteristics of the individuals. It should be noted, however, that the variable most strongly related to not having an AD is level of education. People who had confidence in physicians when it comes to following their wishes at the end of life were less likely to want to draw up an AD. This result is consistent with the result of a previous study, which showed that people who had less confidence that physicians would follow their end of- life wishes were more likely to have engaged in some form of advance care planning [9]. It is arguable whether this should be seen as an attitude towards an end-of-life issue or as a more general attitude towards health care. The percentage of respondents who actually possessed an AD is fairly low at 7%. However, 86% of the people that did not have an AD might consider drawing one up in the future. This shows a potential for successful promotion of ADs. On the other hand, it is debatable whether one should put forward an argument to promote the drawing-up of ADs and knowledge about them, in the Netherlands, because much is still unclear about the effectiveness of ADs when it comes to enhancing quality of care at the end of life. Only limited studies have been done on this, both in the Netherlands and in the rest of the world [10]. It could be rather premature to promote something that is potentially difficult and confrontational for people, when it is not yet proven to be beneficial.

Another point that is striking is that euthanasia seems to be a returning factor of significance throughout the results. The AED was the AD that was most owned, best known and most likely to be wanted in the future. In addition, variables related to euthanasia were associated with the intention to have an AD. You could argue that experience with a request for euthanasia by another person is actually a personal experience of a terminal illness, which was associated with ADs in other studies[11]. This, however, is contradicted by the fact that experience with a 'bad' death, which certainly represents experience with terminal illness in general, did not make it to the final regression model. One can conclude from all of this that in the Netherlands the issue of ADs is strongly connected to the subject of euthanasia.

Of the studies on advance directives in other countries, the majority took place in the USA [12] and a smaller number in other Western countries like Canada and Japan [13].
When we tried to compare our results with other countries, to put our results in a cross-cultural perspective, a difficulty emerged because, to our best knowledge, very few studies similar to the one presented in this article have been carried out. Most studies concerning ADs are not representative of the general public, but based on specific populations, like the elderly, patients committed to hospitals or residents of nursing homes[14]. This especially limits comparison of the prevalence of ADs, since such a comparison is only relevant for studies that

are also representative for a general public. In the USA, data showed that the prevalence of ADs in the general public is higher compared to the Netherlands, with 18% [15]. This difference can probably be explained by the fact that the knowledge about ADs is promoted in the USA by the PSDA. In other countries, like Italy for instance, ADs are not even recognized as legally binding [16]. This will probably have implications for the prevalence of ADs.

When it comes to the background characteristics of holders of an AD, comparison with other studies with a more specific study population is more relevant. Some demographics, like age and gender, are associated with the possession of an AD in studies from the USA, [17] while we did not find this. Marital status is often combined with having children in American studies, so is therefore difficult to compare with our results [18]. Then there are several associations found in studies in the USA that did not apply to our population, like being African-American or the length of stay in an institution[19]. Higher education is found to be related to a higher rate of AD completion in the USA,[20] which is similar in our results. Having a religion is also associated with the possession of ADs in other countries[21] but there is a difference compared to the Netherlands. Religiosity is often positively associated with the formulating of an AD, while in the Netherlands the contrary seems to apply. Again, an explanation may be found in the fact that euthanasia plays a significant role concerning ADs in the Netherlands. AEDs are positive ADs aimed at requesting euthanasia. Religious people with strict beliefs in the Netherlands tend to be against euthanasia, but also not in favour of excessive medical treatment at the end of life. This is reflected by one of the standard ADs, the will-to-live statement, which is issued by a Christian organization, the Dutch Patient Association (NPV). This could lead to the assumption that religious people in general would most likely be expected to have an ROTD. Nonetheless, this is questionable as well, as is exemplified by some of the legal cases in the USA, where medical treatments that would be considered excessive in the Netherlands were sometimes promoted by Christian pro-life movements [22].

In most countries, people with religious beliefs would be expected to be against euthanasia. That religious people in the Netherlands can take a different position in this matter is also shown by our data. A majority of Christian people, whose belief played an important role in their lives, stated that they could imagine asking to end their life in certain situations; 9% of them would possibly draw up an AED in the future and five indicated they actually possessed one. This seems to contradict our findings discussed above, but it is merely a paradox. In relation to the acceptance of euthanasia, Cohen et al. [23] found that because of secularization, religious people in the Netherlands tend to be more liberal and progressive as compared to countries where there is still a more conservative religious climate, like for instance Italy. This makes that is possible for a Dutch Christian to possess an AED, as we found, but Christian people in the Netherlands are still more likely to be against euthanasia compared to their non-believing fellow-countrymen [24].

In conclusion, if you focus on experiences and views on end-of-life issues, the fact that euthanasia seems to play an important role, when it comes to ADs, sets the Netherlands apart from other countries, simply because euthanasia is not allowed and AEDs do not exist in most

other countries.

Now that we have put the situation in the Netherlands concerning ADs in a cross-cultural perspective, what can we conclude? Quality of life is very important when it comes to end-of-life care and it is enhanced by following someone's wishes regarding his treatment. You could say that this premise is universally accepted, although the paternalistic model is still present in medical decision making [25]. ADs are a way of trying to ensure that a person is treated according to his wishes. There is a lot that is unclear about ADs which means that they are far from universally accepted. There are different views on their effectiveness, different (cultural) backgrounds, in various countries, which result in different legislation and different factors playing a role regarding the possession of ADs. All this uncertainty creates limitations when it comes to putting ADs in a cross-cultural perspective. That does not mean that it is pointless to do this or even to strive for a universal point of view on ADs that would be accepted all across the world. At this moment in time, however, the (practical) possibilities of developing one global approach on ADs extend no further than comparing different cultures and in this way trying to nurture the debate and clarify the thinking about end-of-life decision-making. Doing more research, preferably in international studies, could take an important place in clarifying the uncertainties and putting the whole process on a more solid foundation. The effectiveness of ADs in practice and changes in personal preferences due to illness need special attention.

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