

CHAPTER 5

CONTINUING OR FORGOING TREATMENT AT THE END OF LIFE? PREFERENCES OF THE GENERAL PUBLIC AND PEOPLE WITH AN ADVANCE DIRECTIVE

M.P.S. van Wijmen, H.R.W. Pasman, G.A.M. Widdershoven, B.D. Onwuteaka-Philipsen.

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*"Darling you got to let me know
Should I stay or should I go?"*

Should I Stay or Should I Go,
by The Clash

ABSTRACT

Background

We studied preferences on continuing or forgoing different types of treatments at the end of life in two groups: the general public and people with an advance directive (AD). Furthermore we studied factors associated with these preferences, and whether people's preferences concurred with the content of their AD.

Methods

A representative sample of the Dutch population (n=1402) and a cohort of people who own an advance directive (AD), consisting of members of Right to Die-NL (NVVE, n=5661) and the Christian orientated Nederlandse Patiënten Vereniging (NPV, n=1059), answered written questionnaires in 2005 or 2007. We used two hypothetical scenarios, about cancer and dementia, and asked questions about continuing or forgoing four medical treatments.

Results

A majority of the Dutch public (62-87%) and NVVE-members (88-99%) wanted to forgo the different treatments in both scenarios, while members of the NPV generally wanted to continue treatment (46-73%). In all three groups, in both scenarios, a substantial group (13%-38%) had different preferences for the different treatments. People were more explicit in their preferences in case of dementia than in case of cancer. Being female, over 55 years of age, having had a higher education and having no (significant) religion increased the odds to refuse treatment. ADs that gave the direction to refuse treatment generally concurred with the preference of their owners (85-98% wanting to refuse treatments).

Discussion

The fact that people with and without ADs have different preferences concerning different treatments and diseases, stresses the importance of communication surrounding decision-making at the end of life.

INTRODUCTION

Decisions to continue or forgo treatment at the end of life involve several ethical principles, like the autonomy of the individual, beneficence but also cost-effectiveness¹. In some cases the resulting dilemmas evoked heated discussions in society². And of late the problem of rising healthcare costs adds a different kind of urgency to the subject³. Insight in what people's preferences are concerning forgoing or continuing treatment at the end of life is a valuable contribution to this debate. When it comes to the general public in Japan and the U.S., studies showed that a majority was in favour of forgoing treatment when presented with certain hypothetical scenarios at the end of life⁴⁻⁶. A study among the Dutch public found that adding quality to life was favoured above adding length to life⁷. But are there specific characteristics that distinguish people who want to forgo from the ones that want to continue treatment at the end of life? And do people make a difference in their preferences when it comes to various treatments or diseases?

Due to the gravity of decisions at the end of life, the decision-making process and adjacent communication can be difficult for physicians, patients and their loved-ones⁸⁻¹⁰. More insight into people's preferences and reasons to either want to continue or forgo treatment may be helpful to improve communication and so ease the decision-making process. With our study we aimed to show what people would prefer regarding life sustaining treatments when it came to the end of their own life and to investigate which factors are associated with wanting to continue or forgo treatment.

An advance directive (AD) is a document stating a person's preferences about medical decisions at the end of life, and thus provides a guideline for physicians, when the person is not able to speak for him- or herself due to incompetence. It is an instrument to enhance patient autonomy. ADs and their usefulness are often criticized^{11,12}. Amongst other things, this criticism is based on studies about the communication surrounding ADs^{13,14} and the suggestion ADs fail to correspond with actual practice¹⁵. There is little known, however, about another basic question: do ADs correspond with the preferences of their owners? For the value of ADs, this is important to know and therefore one of the aims of our study was to answer this question. Besides the general public, we therefore focused on people who owned ADs and who chose to try to enhance their autonomy by means of these documents. By comparing them to the general public, you can see if you have to consider them as a different group when it comes to preferences about life sustaining treatment or that the only thing that sets them apart is the fact they possess an AD.

METHODS

Design & Population

We presented two hypothetical scenarios, one about cancer and the other about dementia,

to the general public and people with an AD in the Netherlands and asked questions about forgoing or continuing treatment by means of a written questionnaire. In the Netherlands these kinds of decisions are common as found in a study by van der Heide et al¹⁶: in 20% of all deaths a non-treatment decision was taken. We chose for scenarios about cancer and dementia, because these are among the most common progressive diseases in the Netherlands¹⁷.

The population consisted of a random sample of the Dutch population and people with an (intent to have an) AD. The people owning an AD were members of the Advance Directive Cohort (ADC). This cohort study 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 (AED). These respondents (n=5.561) had not all actually drawn up an AD. Nineteen percent had only requested one with the NVVE and had not completed it yet (n=1.064).

The other association, the Dutch Patient Association (NPV in Dutch), a Christian orientated patient association, provides the second most common type standard AD in the Netherlands after 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=1.263) all possessed this document.

The members of the ADC received written questionnaires each one and a half year, the first in 2005. The NPV-respondents received the hypothetical cases in the first questionnaire in the autumn of 2005. The NVVE-respondents received the hypothetical cases in the spring of 2007. This is the reason for the decreased number of NVVE-respondents in this study (n=4.575) as compared to the start of the cohort (n=5.561): 16% of the respondents did not participate in the second round due to different reasons (n=896, for example deceased, moved or end of membership from the NVVE) and 2% was not used because of missing data on background characteristics (n=90).

In 2005 an excerpt of the questionnaires for the ADC was also sent to the Consumers' panel for Health services of the Netherlands Institute for Health Services Research (in Dutch: NIVEL), an established sample of the Dutch public representative of the population of the Netherlands of 20 years and older (n=1.402, response rate 86%). This third group completed our research population for this study.

As compared to the Dutch population, NVVE-members are on average more often single, higher educated and non-religious. The younger segment has more often health problems. NPV-members mostly are adherents of the protestant Christian religion (about 90%), while in the Dutch population this is only approximately a quarter. The older segment of NPV-respondents has a lower education compared to the Dutch population. Both groups are older as compared to the Dutch population. From the sample of the Dutch population, only a small part possessed

some sort of AD (7%). A more elaborate description of the realization and characteristics of the ADC and Consumers' panel for Health services can be found in a study protocol.¹⁸

Ethical approval and confidentiality

The Medical Ethics Review Committee of the VU University Medical Center approved the study under registration number 2005/82.

The data of the Consumers' panel for Health services was provided by the NIVEL completely anonymized. The questionnaires were sent to the ADC by the two associations involved using their membership files. They were returned to the researchers using only the respondent number. That way the researchers did not get to know the respondent's name and address. All respondents got extensive information on the study before they agreed to participate and received the first questionnaire.

Questionnaires

In the questionnaires several background characteristics, like age, gender, marital status, education and life stance, as well as experiences and preferences concerning the end of life were asked. Several pilot studies were performed on the subsequent questionnaires. For this study the main focus is on two hypothetical cases.

The hypothetical cases outline situations where the respondents have to imagine themselves in an advanced stage of cancer or dementia and answer questions on preferences about receiving or forgoing four treatments (see box 1).

Box 1. The two hypothetical cases

Case on cancer:

'You are diagnosed with cancer, which has widely disseminated over your body. The disease is incurable. For some days you have not been responsive anymore to any form of communication. You clearly show signs of severe pain and agitation.'

Case on dementia:

'You suffer from dementia and no longer recognize your family or friends. You refuse to eat and drink and you retreat more and more into yourself. To communicate with you about medical treatments is not possible anymore.'

In both cases the respondents had to give their preferences about four treatments:

- artificial feeding and hydration
- antibiotics in case of a possible pneumonia
- resuscitation in case of a cardiac arrest
- artificial respiration.

They could make a choice between wanting ('Yes' or 'Probably yes') and forgoing ('No' or 'Probably no') these treatments.

Statistical Analyses

First descriptive analysis of the treatment preferences in the hypothetical cases was done dividing the population into the three groups: the sample of the Dutch public, NPV- and

NVVE-members.

We analysed whether refusing treatment was associated with having certain background characteristics, such as age, gender, marital status, education but also the possession of an AD, opinions and experiences. We performed logistic regression for this purpose for the cancer as well as for the dementia scenario. We looked at two of the four treatments, artificial feeding and hydration and resuscitation, because these were the most unambiguous treatment decisions both in medical practice and when it came to comprehension of the respondents as found in a pilot study concerning the questionnaire.

First, we combined the data of the three groups ($n=7238$). As a check we also performed the logistic regression in the 3 groups (general public, NVVE and NPV) separately. This led to similar results (not shown in this paper).

We looked at the independent variables univariately and analysed them multivariately with only significant variables ($p \leq 0.05$) remaining in the final model. We added membership of the NVVE as an independent variable in this model in all analyses, because not all NVVE-members necessarily owned one of the ADs. Correction for membership of the NPV was not necessary, because this coincided with the possession of a wish-to-live statement and was as such already an independent variable in the model.

Finally we looked at the congruence between preferences for (non-) treatment decisions and having an AD about forgoing treatment (people who own a ROTD ($n=2556$) for artificial feeding and hydration, treatment with antibiotics and artificial respiration; people who own DNR ($n=1109$) for resuscitation).

RESULTS

Preferences about (non-)treatment decisions

Table 1 shows that for both the scenario concerning advanced cancer and the one about dementia, a majority of the sample of the general public (probably) want to forgo all four presented treatments (ranging 62-87%). This is confirmed when looking at the preferences for all the treatments together. The majority to forgo stands out the most in case of resuscitation in both scenarios (87% and 86%).

For the NVVE-members a similar trend towards a majority for (probably) forgoing all four treatments in both scenarios was seen, and these majorities were overall larger than for the sample of the general public (ranging 88-99%); moreover, among the people who wanted to forgo treatment the group who answered 'probably no' instead of 'no' was smaller as compared to the public. From the NPV-members a majority generally would want to continue treatment in both scenarios (ranging 53-73%). Nevertheless, a significant group preferred to forgo treatment, which for resuscitation in case of advanced cancer even led to a small majority of those who (probably) wouldn't want this treatment (54%).

Table 1. Preferences about (non-)treatment decisions in case of advanced cancer and dementia of the general public and people who own an AD (NVVE- and NPV-members). (Rounded percentages, 95%-confidence intervals).

	Sample of the Dutch population (n=1402*)		NVVE-members (n=4575*)		NPV-members (holders of Wish-to-live statement) (n=1261*)	
	In case of advanced cancer	In case of advanced dementia	In case of advanced cancer	In case of advanced dementia	In case of advanced cancer	In case of advanced dementia
Artificial feeding & hydration						
Yes	5 (4-7)	9 (7-10)	1 (1-2)	1 (0-1)	40 (37-43)	51 (48-53)
Probably yes	25 (22-27)	18 (16-20)	6 (5-7)	2 (1-2)	27 (24-29)	20 (18-22)
Probably no	33 (31-36)	27 (24-29)	19 (18-20)	9 (8-10)	16 (14-18)	12 (11-14)
No	37 (34-39)	47 (44-50)	74 (72-75)	89 (88-90)	17 (15-19)	17 (15-19)
Antibiotics for possible pneumonia						
Yes	10 (9-12)	13 (11-15)	3 (2-3)	1 (0-1)	40 (37-43)	52 (49-55)
Probably yes	22 (20-24)	18 (16-20)	6 (5-6)	2 (2-3)	27 (25-30)	21 (19-23)
Probably no	29 (27-32)	23 (20-25)	15 (14-16)	7 (6-8)	16 (14-18)	10 (8-21)
No	39 (36-42)	46 (44-49)	77 (76-78)	90 (89-91)	17 (15-20)	17 (15-19)
Artificial respiration						
Yes	14 (12-16)	13 (12-15)	5 (4-6)	3 (3-4)	36 (33-39)	43 (40-46)
Probably yes	24 (22-27)	19 (17-21)	12 (11-13)	8 (7-9)	23 (21-26)	19 (17-22)
Probably no	22 (20-24)	19 (17-21)	14 (13-15)	10 (9-11)	17 (15-20)	12 (11-14)
No	40 (37-43)	49 (46-51)	69 (68-71)	78 (77-79)	24 (21-26)	25 (23-28)
Resuscitation						
Yes	6 (5-8)	6 (5-7)	1 (1-2)	0 (0-1)	31 (28-33)	38 (35-41)
Probably yes	7 (6-9)	8 (6-9)	2 (1-2)	1 (0-1)	16 (14-18)	15 (13-17)
Probably no	22 (20-24)	19 (17-21)	6 (5-6)	4 (3-4)	19 (17-21)	14 (13-16)
No	65 (62-67)	67 (65-70)	91 (91-92)	95 (95-96)	35 (32-37)	33 (30-35)
Continuing treatment in general**						
(Probably) yes	11 (9-13)	12 (10-13)	1 (1-2)	0 (0-1)	44 (41-47)	51 (48-54)
Not consistent for all treatments	38 (36-41)	30 (28-33)	21 (20-22)	13 (12-14)	32 (30-34)	27 (25-30)
(Probably) no	51 (48-54)	58 (56-61)	78 (76-79)	87 (86-88)	24 (22-27)	22 (20-25)

*Missing values below 4%, except for NPV-members below 8%

** Percentages of people answering (probably) yes or (probably) no consistently for all four treatments

Table 1 shows that people were more explicit in their preferences in the dementia case as compared to the cancer case. We therefore analysed the preferences for the dementia case as compared to the cancer case on respondent-level (table 2). It turned out that for all treatments a majority wants the same in both scenarios. This majority is the largest when it comes to resuscitation. However, it also confirmed that preferences in case of dementia were more often more explicit than less explicit as compared to cancer.

Table 2. Preferences of participants for different treatments in case of dementia as compared to cancer.

(Rounded percentages, 95%-confidence intervals).

Difference in preferences	Total population (n=7238)	Sample of the Dutch population (n=1402)	NVVE-members (n=4575)	NPV-members (n=1261)
Artificial feeding & hydration				
<i>No Difference</i>	71 (70-72)	56 (53-58)	78 (77-80)	60 (57-63)
<i>More explicit</i>	14 (13-15)	16 (14-18)	13 (12-14)	15 (13-18)
<i>Less explicit</i>	4 (3-4)	6 (5-8)	2 (1-2)	6 (5-8)
Antibiotics for possible pneumonia				
<i>No Difference</i>	74 (73-75)	58 (55-61)	82 (80-83)	61 (58-64)
<i>More explicit</i>	12 (11-12)	14 (12-16)	10 (9-11)	14 (12-16)
<i>Less explicit</i>	3 (3-4)	6 (5-8)	2 (1-2)	6 (4-7)
Artificial respiration				
<i>No Difference</i>	76 (75-77)	64 (62-67)	82 (81-83)	69 (67-72)
<i>More explicit</i>	9 (8-9)	10 (8-12)	7 (6-8)	12 (10-14)
<i>Less explicit</i>	4 (3-4)	6 (5-8)	3 (2-3)	5 (4-6)
Resuscitation				
<i>No Difference</i>	86 (85-86)	75 (72-77)	93 (92-94)	70 (67-72)
<i>More explicit</i>	5 (5-6)	8 (6-9)	4 (3-4)	9 (7-11)
<i>Less explicit</i>	3 (2-3)	6 (5-7)	1 (1-2)	5 (4-7)

Factors related to refusal of artificial feeding, hydration and resuscitation

Being female, having an age over 55 years and having a higher education all increase the odds of having a preference to refuse artificial feeding and hydration and resuscitation in both the cancer and dementia scenario (tables 3 & 4). Having no religious belief or having one that is not important to you increased the odds of preferring to refuse artificial nutrition in case of cancer and resuscitation in case of dementia. On the other hand, the presence of a Christian belief, be it Protestant or Roman Catholic, decreased the odds of wanting to refuse both treatments in case of dementia and resuscitation in case of cancer.

Having a wish-to-live statement decreased the odds to refuse both treatments, i.e. refusal of artificial feeding and hydration, in both scenarios. The possession of a ROTD increased the odds to refuse both treatments in case of cancer and dementia. The possession of a DNR increased the odds of wanting to refuse resuscitation in case of cancer.

The experience with a close one's death that was not peaceful increased the odds of forgoing both treatments in both scenarios. Experience with a close one's death that was peaceful also increased the odds, but solely of wanting to forgo resuscitation in case of dementia. The experience of a close one requesting euthanasia increased the odds of preferring to forgo treatment as well, except for artificial feeding and hydration in case of dementia where no such association was found.

Agreement with the statements 'When I die I hope that I can make my own decisions about medical treatments' and 'When I die I hope I can determine the moment of dying myself' increased the odds of preferring to refuse both treatments in both cases. Agreement with

'When I die I hope I am not too much of a burden for my family' increased odds of refusing both treatments in case of dementia and resuscitation in case of cancer.

Agreement with the statements 'When I die I hope I'll stay conscious till the end' or 'When I die I hope that I will have been able to have said goodbye to my close-ones' decreased the odds of wanting to forgo both treatments in both scenarios.

Table 3. Factors related to the preference for **refusal of artificial feeding & hydration** in case of advanced cancer and dementia (n=7238, OR's, 95%-CI's)**

Variable	In case of advanced cancer		In case of advance dementia		
	Univariate	Multivariate	Univariate	Multivariate	
<i>Background characteristics</i>	%*				
Gender					
Female	62	1.5 (1.3-1.6)	1.4 (1.2-1.6)	1.4 (1.2-1.6)	1.4 (1.2-1.7)
Age					
- Below 56 yrs.	26	1.0	1.0	1.0	1.0
- 56-65 yrs.	21	2.4 (2.1-2.9)	1.6 (1.3-2.0)	3.1 (2.6-3.7)	2.1 (1.7-2.7)
- 66-75 yrs.	26	2.2 (1.9-2.5)	1.6 (1.3-1.9)	3.1 (2.7-3.7)	2.4 (1.9-3.1)
- Above 75 yrs.	26	2.9 (2.5-3.4)	1.8 (1.4-2.3)	4.5 (3.8-5.4)	3.0 (2.2-4.0)
Education					
-Elementary or basic vocational	20	1.0	1.0	1.0	1.0
- Secondary	32	1.7 (1.5-2.0)	1.3 (1.1-1.6)	1.7 (1.5-2.0)	1.5 (1.2-1.9)
- Higher	48	2.2 (1.9-2.6)	1.2 (1.0-1.4)	2.7 (2.3-3.2)	1.6 (1.2-2.0)
Life stance					
- No belief	49			1.0	1.0
- Roman Catholic	14			0.3 (0.2-0.4)	0.8 (0.6-1.0)
- Protestant	27			0.1 (0.1-0.1)	0.5 (0.4-0.7)
- Humanistic	7			3.1 (1.6-6.2)	1.4 (0.7-2.8)
- Other	4			0.8 (0.5-1.3)	1.0 (0.6-1.8)
Belief and its importance in someone's life					
- Important belief	36	1.0	1.0		
- Not important belief or no belief	64	5.9 (5.2-6.7)	1.6 (1.3-1.9)		
<i>Preferences and experiences</i>					
Possession of a Wish-to-live statement	17	0.7 (0.6-0.8)	0.4 (0.3-0.5)	0.4 (0.3-0.4)	0.3 (0.2-0.3)
Possession of a ROTD	36	6.7 (5.7-8.0)	1.6 (1.3-2.0)	21.0 (15.6-28.3)	1.8 (1.2-2.7)
Experience with a close-one asking for euthanasia[†]	37	2.8 (2.5-3.3)	1.3 (1.1-1.5)	3.8 (3.3-4.5)	1.4 (1.2-1.8)
Experience with a death that was not peaceful[‡]	35	2.0 (1.8-2.3)	1.4 (1.2-1.6)		
Not much or no confidence that physicians will deliver good care at the end of life[§]	27			1.2 (1.1-1.4)	0.8 (0.6-0.9)
'When I die I hope I am not too much of a burden for my family' (Agree)^{††}	85			3.2 (2.7-3.6)	1.4 (1.1-1.7)
'When I die I hope I'll stay conscious till the end' (Agree)^{††}	64	0.6 (0.5-0.6)	0.6 (0.5-0.8)	0.6 (0.5-0.7)	0.8 (0.6-0.9)
'When I die I hope that I will have been able to have said goodbye to my close-ones' (Agree)^{††}	91	0.5 (0.4-0.6)	0.6 (0.5-0.7)	0.4 (0.3-0.6)	0.5 (0.4-0.8)

Table 3 continued. Factors related to the preference for **refusal of artificial feeding & hydration** in case of advanced cancer and dementia (n=7238, OR's, 95%-CI's)**

Variable		In case of advanced cancer		In case of advance dementia	
		Univariate	Multivariate	Univariate	Multivariate
Background characteristics		%*			
'When I die I hope that I can make my own decisions about medical treatments' (Agree)**	96	4.0 (3.1-5.1)	1.5 (1.1-2.0)	4.9 (3.8-6.3)	1.5 (1.0-2.1)
'When I die I hope I can determine the moment of dying myself' (Agree)**	64	7.9 (6.9-9.0)	2.3 (1.9-2.8)	13.8 (11.8-16.0)	2.2 (1.8-2.8)

ROTD=Refusal of Treatment Document, DNR=Do Not Resuscitate Order

**Multivariate (backwards) logistic regression analyses with dependent variable (probably) not wanting artificial feeding and hydration and as reference variable (probably) wanting artificial feeding and hydration. This table only shows variables that were significant in the multivariate analysis.

Checked, but not significant multivariately: marital status, offspring (in case of cancer), health status, experienced quality of life, possession of a DNR or healthcare proxy, experience with euthanasia from a close-one, level of confidence that physicians will deliver good care at the end of life and level of agreement with the following statements: 'When I die I hope that I have no pain'; 'When I die I hope I can do so with dignity'; 'When I die I hope I am not dependant on others'; 'When I die I hope that I can make my own decisions about medical treatments'; 'When I die I hope that I will have been able to have said goodbye to my close-ones'

Checked, but not significant univariately: offspring (in case of dementia), experience with a death that was peaceful.

*Rounded percentage of total population.

‡ Reference group: no experience.

† Reference group: (Quite) a lot of confidence.

**Reference group: do not agree or neutral.

Table 4. Factors related to the preference for **refusal of resuscitation** in case of advanced cancer and dementia (n=7238, OR's, 95%-CI's)**

Variable		In case of advanced cancer		In case of advance dementia	
		Univariate	Multivariate	Univariate	Multivariate
Background characteristics		%*			
Gender					
Female	62	1.9 (1.6-2.1)	2.1 (1.8-2.6)	1.6 (1.4-1.8)	1.8 (1.4-2.2)
Age					
- Below 56 yrs.	26	1.0	1.0	1.0	1.0
- 56-65 yrs.	21	2.3 (1.9-2.9)	1.8 (1.4-2.4)	3.3 (2.7-4.1)	2.6 (1.9-3.6)
- 66-75 yrs.	26	1.7 (1.4-2.0)	1.4 (1.1-1.8)	2.8 (2.3-3.4)	2.6 (1.8-3.5)
- Above 75 yrs.	26	1.8 (1.5-2.2)	1.1 (0.9-1.5)	3.6 (2.9-4.4)	2.4 (1.8-3.3)
Education					
- Elementary or basic vocational	20	1.0	1.0	1.0	1.0
- Secondary	32	2.6 (2.2-3.1)	2.4 (1.9-3.1)	2.2 (1.8-2.6)	1.8 (1.4-2.4)
- Higher	48	4.4 (3.7-5.2)	3.0 (2.3-3.8)	3.5 (3.0-4.2)	2.1 (1.6-2.7)
Life stance					
- No belief	49	1.0	1.0	1.0	1.0
- Roman Catholic	14	0.2 (0.2-0.3)	0.4 (0.3-0.6)	0.2 (0.2-0.3)	0.8 (0.5-1.2)
- Protestant	27	0.1 (0.1-0.1)	0.4 (0.3-0.5)	0.04 (0.03-0.05)	0.5 (0.3-0.9)
- Humanistic	7	1.0 (0.6-1.6)	0.8 (0.4-1.4)	5.4 (1.3-22.0)	2.6(0.6-10.9)
- Other	4	1.1 (0.6-2.4)	1.3 (0.5-3.1)	0.8 (0.4-1.6)	1.5 (0.6-4.1)

Table 4 continued. Factors related to the preference for **refusal of resuscitation** in case of advanced cancer and dementia (n=7238, OR's, 95%-CI's)**

Variable	%*	In case of advanced cancer		In case of advance dementia	
		Univariate	Multivariate	Univariate	Multivariate
Background characteristics					
Belief and its importance in someone's life					
- Important belief	36			1.0	1.0
- Not important belief or no belief	64			13.7 (11.3-16.7)	1.7 (1.1-2.5)
<i>Preferences and experiences</i>					
Possession of a Wish-to-live statement	17	0.7 (0.6-0.8)	0.4 (0.3-0.5)	0.3 (0.2-0.4)	0.3 (0.2-0.4)
Possession of a ROTD	36	15.4 (11.0-21.5)	1.7 (1.0-3.0)	52.9 (29.1-96.1)	3.2 (1.5-6.6)
Possession of a DNR	16	15.5 (8.7-27.5)	3.1 (1.5-6.5)		
Possession of a healthcare proxy	34	14.2 (10.2-19.8)	2.5 (1.4-4.5)		
Experience with a close-one asking for euthanasia[‡]	37	4.6 (3.7-5.6)	1.4 (1.1-1.8)	5.9 (4.7-7.3)	1.6 (1.2-2.1)
Experience with a death that was peaceful[‡]	65	1.2 (1.0-1.3)	1.3 (1.1-1.6)		
Experience with a death that was not peaceful[‡]	35	2.6 (2.2-3.1)	1.5 (1.2-1.9)	2.6 (2.2-3.2)	1.4 (1.1-1.8)
Not much or no confidence that physicians will deliver good care at the end of life[‡]	27	1.1 (1.0-1.4)	0.7 (0.6-0.9)	1.2 (1.0-1.4)	0.7 (0.5-0.9)
'When I die I hope that I have no pain' (Agree)^{††}	90	2.8 (2.3-3.4)	1.6 (1.3-2.1)		
'When I die I hope I am not too much of a burden for my family'^{††}	85	2.5 (2.1-3.0)	1.5 (1.1-1.9)	3.2 (2.7-3.8)	1.5 (1.2-1.9)
'When I die I hope I am not dependant on others' (Agree)^{††}	77	2.5 (2.2-2.9)	0.8 (0.6-1.0)		
'When I die I hope I'll stay conscious till the end' (Agree)^{††}	64	0.4 (0.4-0.5)	0.6 (0.5-0.8)	0.4 (0.4-0.5)	0.5 (0.4-0.7)
'When I die I hope that I will have been able to have said goodbye to my close-ones' (Agree)^{††}	91	0.4 (0.3-0.5)	0.5 (0.3-0.8)	0.3 (0.2-0.5)	0.5 (0.3-0.9)
'When I die I hope that I can make my own decisions about medical treatments' (Agree)^{††}	96	4.0 (3.1-5.2)	1.5 (1.1-2.2)	4.9 (3.8-6.3)	1.6 (1.1-2.3)
'When I die I hope I can determine the moment of dying myself' (Agree)^{††}	64	8.8 (7.4-10.4)	1.9 (1.5-2.5)	16.9 (13.8-20.8)	1.9 (1.4-2.6)

ROTD=Refusal of Treatment Document, DNR=Do Not Resuscitate Order

**Multivariate (backwards) logistic regression analyses with dependent variable (probably) not wanting artificial feeding and hydration and as reference variable (probably) wanting artificial feeding and hydration. This table only shows variables that were significant in the multivariate analysis.

Checked, but not significant multivariately: marital status, health status, experienced quality of life (in case of dementia) and level of agreement with the following statements: 'When I die I hope I can do so with dignity', 'When I die I hope I am not dependant on others', 'When I die I hope that I can make my own decisions about medical treatments', 'When I die I hope that I will have been able to have said goodbye to my close-ones'

Checked, but not significant univariately: offspring, experienced quality of life (in case of cancer) and experience with a death that was peaceful.

*Rounded percentage of total population.

[‡] Reference group: no experience.

[†] Reference group: very much or quite much confidence

^{††}Reference group: do not agree or neutral.

Concurrence of ADs and the preferences of their owners

Looking at ROTDs and the treatments these documents refer to (artificial feeding and hydration, treatment with antibiotics and artificial respiration) a majority in the group of people who owned such document would want to forgo the treatments in case of advanced cancer and dementia (ranging 85-98%, table 5). A part of this majority is not certain and probably wants to forgo these treatments (ranging 5-17%). In the population without ROTD there was also a majority for forgoing, but this was not as outspoken (ranging 64-72%).

For resuscitation we looked at people with or without a DNR. Of these people 99% and 100% (probably) would not want resuscitation in case of cancer and dementia (of which 3% and 2% 'probably'). In the rest of the population there was also a majority that (probably) didn't want to be resuscitated (85 and 86%), but there were also people who did want this treatment (14% in both cases).

Table 5. Preferences of people with and without ADs covering forgoing treatment and resuscitation. (Rounded percentages, 95%-confidence intervals).

	In case of advanced cancer		In case of advanced dementia	
	Holders of a specific AD*	Rest of population*	Holders of a specific AD*	Rest of population*
Artificial feeding & hydration	ROTD (n=2556)	No ROTD (n=4478)	ROTD (n=2530)	No ROTD (n=4487)
Yes	1 (1-2)	13 (12-14)	1 (0-1)	16 (15-17)
Probably yes	5 (4-6)	18 (17-19)	1 (1-2)	12 (11-13)
Probably no	17 (15-18)	24 (22-25)	6 (5-7)	17 (16-18)
No	77 (76-79)	45 (44-47)	92 (91-93)	55 (54-57)
Antibiotics for possible pneumonia	ROTD (n=2518)	No ROTD (n=4465)	ROTD (n=2531)	No ROTD (n=4492)
Yes	2 (1-2)	15 (14-16)	1 (0-1)	18 (17-19)
Probably yes	4 (4-5)	17 (16-18)	1 (1-2)	12 (12-13)
Probably no	12 (11-13)	21 (20-22)	5 (4-6)	14 (13-15)
No	82 (80-83)	47 (46-48)	93 (92-94)	56 (54-57)
Artificial respiration	ROTD (n=2506)	No ROTD (n=4463)	ROTD (n=2490)	No ROTD (n=4435)
Yes	4 (4-5)	16 (15-17)	3 (3-4)	17 (16-18)
Probably yes	11 (10-12)	19 (18-21)	8 (7-9)	15 (14-16)
Probably no	12 (11-13)	18 (17-19)	9 (8-10)	14 (13-15)
No	73 (71-75)	46 (45-48)	80 (79-82)	54 (52-55)
Resuscitation	DNR (n=1102)	No DNR (n=5921)	DNR (n=1109)	No DNR (n=5914)
Yes	1 (0-1)	8 (8-9)	0 (0-1)	9 (8-10)
Probably yes	0 (0-1)	6 (6-7)	0 (0-1)	5 (5-6)
Probably no	3 (2-5)	12 (12-13)	2 (1-3)	10 (9-10)
No	96 (94-97)	73 (72-74)	98 (97-99)	76 (75-77)

AD=Advance Directive, ROTD=Refusal of Treatment Document, DNR=Do Not Resuscitate Order.

*Composition of these groups:

ROTD: 99% NVVE, 1% sample Dutch population

No ROTD: 43% NVVE, 27% NPV, 29% sample Dutch population

DNR: 99% NVVE, 1% sample Dutch population

No DNR: 57% NVVE, 21% NPV, 22% sample Dutch population

DISCUSSION

We found that a majority of the sample of the Dutch public prefers to forgo treatment at the end of life when asked to picture themselves in two hypothetical scenarios, one concerning cancer, the other dementia. This majority is even more outspoken for people who are members of the association the NVVE and either own an AD or have the intention to formulate one. Another group of people who possess ADs, the members of the Christian patient association the NPV, showed a majority for continuing treatment. In all three groups, respondents were more explicit in their preferences in case of dementia as compared to cancer. While the majority in all three groups had similar preferences for the 4 different treatments, a substantial part in each group preferred to forgo some of the treatments while wanting to continue others. Being female, over 55 years of age, having had a higher education and not being a religious person increased the odds to refuse treatment. We found that a large majority of the owners of ROTDs and DNRs indeed wanted to forgo treatment. When it came to the AD from the NPV, there was a majority of its owners that preferred to continue to be treated, but also a considerable part that wanted the opposite.

Methodological considerations

We think the composition of the research population is a strength of our study, providing both data representative for the Dutch public and specific information on people with an AD. The latter provides valuable data on the value of ADs. It is possible that some respondents did not have a clear understanding of the sketched scenarios, the different treatment decisions and their possible outcomes. It struck us for instance, that when it came to the decision of artificial respiration, the results were not as clear as with for instance resuscitation. In interviews, taken for the pilot studies on the questionnaires, people had mentioned that they would not want to suffocate and therefore preferred artificial respiration in case of the hypothetical scenarios. This may be an explanation for the results we found: people may see the treatment of artificial respiration mainly as a comfort measure to prevent suffocation, while in reality this decision has much more to it. This seems to reflect what actually happens in practice: people have difficulty grasping modern day medicine in all its complexity. Therefore these results themselves are not questionable; however, one should take this into consideration in interpreting the results. It for instance stresses the importance of good communication between physician and patient when it comes to medical decision-making.

Preferences about forgoing or continuing treatment

Looking at the preferences of the general public concerning forgoing or continuing treatment at the end of life, we found similar results as previous studies did in Japan and the U.S: a trend towards forgoing treatment.⁴⁻⁶ At the same time there still was a significant minority of the sample that wanted to continue treatment.

It is interesting that studies that not only looked at the public, but also at patients showed

a trend towards continuing treatment^{19,20}. Whether this difference is caused by instability in preferences, by other underlying conditions, or differences in study design, cannot be concluded on the basis of these data.

Our study showed that people can have diverse preferences concerning various types of treatments and in case of different diseases. People seem to be more explicit in their preferences at the end of life when comes to dementia as compared to cancer. The fact that dementia is a disease that affects the mind, while cancer is generally more an illness of the body, may be part of the explanation. Losing one's mind and the coinciding loss of dignity may be a bigger horror than physical pain and suffering and may make people more sure about a preference for forgoing treatment. In the study of Ikegami et al. also a larger majority in favour of forgoing treatment was found in case of dementia as compared to cancer⁴. On the other end of the spectrum, the fear that your death is hastened against your wishes, while you are mentally impaired and not able to advocate for yourself, could make people also more certain about wishing continuation of treatment in case of dementia as compared to cancer. In the case of artificial feeding and hydration however, following the principle of non-maleficence physicians have the responsibility carefully explain that this treatment may not only increase suffering, but also may prevent a peaceful death²¹⁻²³.

Advance directives

In the Netherlands people obtain standard ADs through associations with specific backgrounds and explicit views on the end of life. The content of these ADs is obviously tightly associated with the associations' preferences about continuing or forgoing treatment. A distinct majority of the members of the NVVE, an association stressing the importance of autonomy and control at the end of life, had the preference to forgo treatment. While a majority of the members of the Christian patient association NPV was in favour of continuing treatment.

This is a different situation as compared to for instance the U.S., where standard ADs can be customized to either forgoing or continuing treatment and are often distributed through health care organisations. Studies about ADs in the U.S. showed that the majority of their owners preferred to forgo treatment²⁴⁻²⁶.

When comparing the Dutch public with the owners of ADs in the Netherlands, the former are more akin to the NVVE-members, who are inclined to want to forgo treatment at the end of life, than to the NVP members. While many people of the public have clear preferences, only 7% of the public has an AD.

Favourable for ADs is the result we found concerning the value of DNRs and ROTDs: in general these seem to concur with the preferences of their owners, thus giving information to caregivers about treatment decisions at the end of life. On the other hand, part of the owners of these documents still had some reservations, using the 'probably no' option of our questionnaire. A very small minority of them even did want to be treated in both scenarios.

We found the members of the NPV were divided when presented with our hypothetical scenarios, while all of them possessed documents stating the same preferences. We think this

is a result of the ambiguity of the content of the will-to-life AD, which refuses both excessive medically futile treatments at the end of life, and actions actively terminating life. Thus, these ADs do not give clear direction to physicians.

Conclusion and implications for practice

When it comes to their preferences, people can make distinctions, between both treatments and diseases. This shows that good communication between caregivers and patients about what a person really wants and the possible consequences should be one of the hallmarks of end-of-life decision-making, especially because the principles of respecting patient autonomy and beneficence can in some instances be in conflict with each other. This also suggests that ADs that are formulated in a general manner are probably not sufficient to inform caregivers. While we did find that ROTDs and DNRs generally reflected people's preferences, our results also suggest that there are limitations in grasping all nuances of preferences and actual practice in a written document. Instead of using an AD as a legal document containing someone's preferences, this suggests that elucidating preferences is a process involving more communication, a form of advance care planning. The completion of an AD can be a guideline in discussions about preferences between patients and their caregivers, which has already been proved to improve end-of-life care^{27,28}.

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