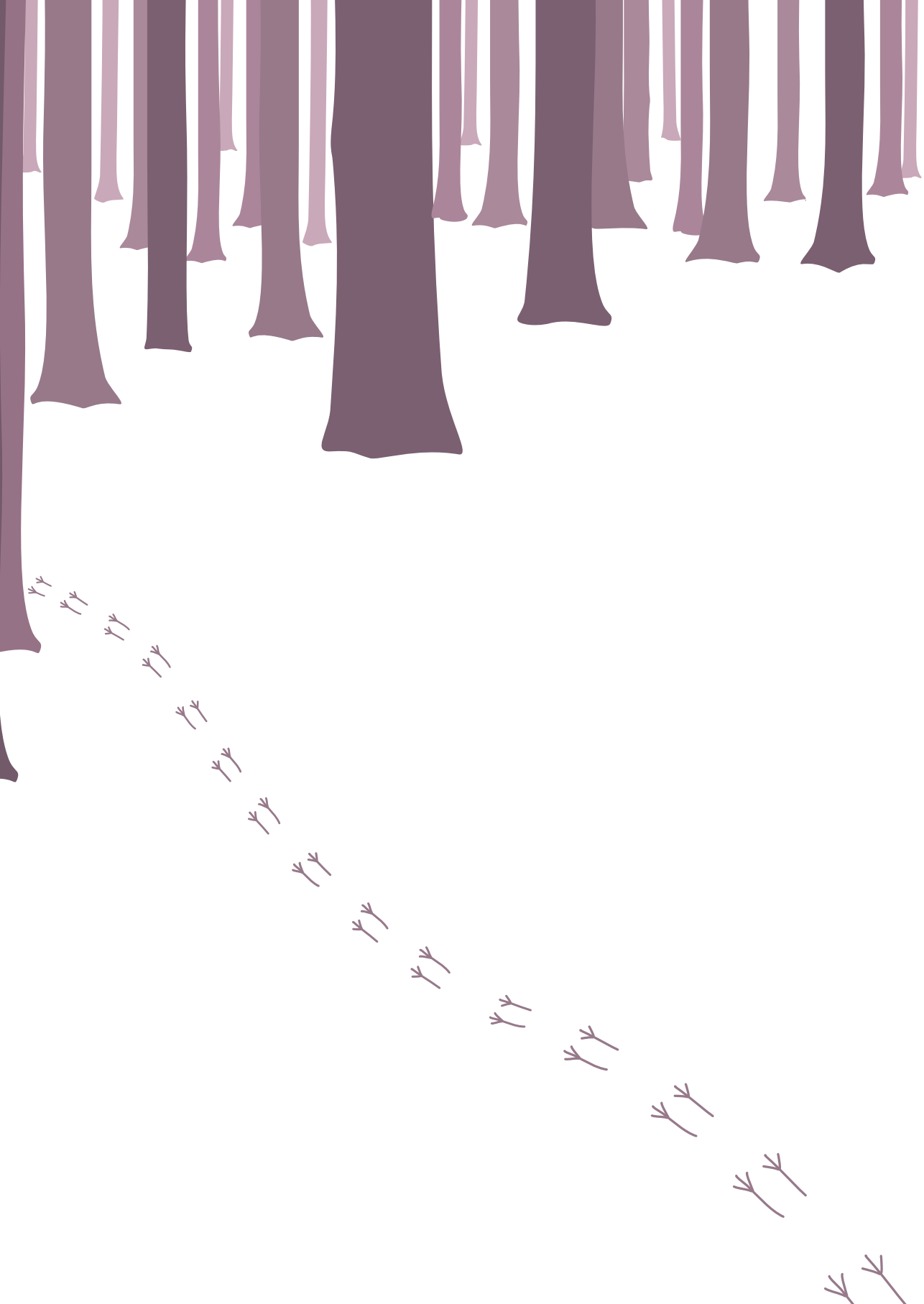

Chapter 4

From advance euthanasia directive to euthanasia; a stable preference in older people?

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Published in Journal of American Geriatrics Society 2016, Vol 64, Issue 8, pg 1628-1633

ABSTRACT

Background/Objectives

The most common advance directive in the Netherlands is the advance directive for euthanasia (ADE), which describes situations in which someone would wish euthanasia. The validity of ADEs is questioned because people might change their minds over time. This study aims to describe 1) whether older people with ADEs are stable in their advance euthanasia wish in the last years of life, 2) how frequently older people with an ADE eventually request euthanasia, and 3) what factors determine this.

Design

A mortality follow-back study nested in a cohort study

Setting

Older adults in the Netherlands.

Participants

Relatives of deceased members of a cohort representative of Dutch older people (n=168) and a cohort of people with advance directives (n=154). Response was 65%.

Measurements

Data from cohort members (possession of ADE) combined with after-death proxy information on cohort members' last three months of life. We performed multiple logistic regression analysis on determinants of a euthanasia request among those with an ADE.

Results

142 cohort members possessed an ADE at baseline. Three months before death, 87% remained stable in their advance euthanasia wish; eventually 47% requested euthanasia (compared to 6% without an ADE) and 16% died after euthanasia. People with an ADE were more likely to request euthanasia if they worried about loss of dignity.

Conclusion

The majority of older adults who complete an ADE will have a stable preference over time. However, an advance euthanasia wish does not necessarily result in a euthanasia request. Writing an ADE may reflect a person's need for reassurance that they can request euthanasia in the future.

4.1 INTRODUCTION

In advance directives people describe their future preferences for end-of-life care. In the Netherlands, advance directives for euthanasia (ADEs) are the most popular advance directives; 6% of older adults owns an ADE.(1, 2) In ADEs people describe an advance euthanasia wish; in certain situations they would want euthanasia. Most people discuss their ADE with their family physician at the time of writing.(3) If they later develop an active euthanasia wish because of unbearable suffering, they can request euthanasia. However, an ADE is not required for euthanasia, and people without an ADE can also request euthanasia. After a request, the physician assesses whether euthanasia would fall within the legal criteria, and consults a second physician. However, in cases which fall within the legal criteria a physician can always refuse to perform euthanasia for personal reasons.

Since the enactment of the 2002 Law on Euthanasia and Assisted Suicide, physicians are permitted to perform euthanasia if they adhere to strict criteria. One of these criteria is the presence of an explicit request by the patient. If a patient is able to request euthanasia, an ADE is not required. If a patient can no longer express his or her wishes, a previously written ADE can replace the request.(4) In case of severe dementia, the meaning of a previously written ADE is often discussed between relatives and physician.(5) However, the value of an ADE in this case seems limited, because very few physicians would consider executing an ADE.(6)

In the Netherlands, 6.7% of people request euthanasia before their death and euthanasia is performed in 2.9% of deaths.(7) It is unknown how often people with ADEs eventually request euthanasia and whether advance euthanasia wishes remain stable over time. Two studies showed that most patients with advanced disease who develop an active euthanasia wish remained stable in their wish.(8, 9) It is unknown whether this is the same for advance euthanasia wishes. An advance euthanasia wish in people whose health slowly declines may disappear over time, because they adapt to a changing situation. A shift in end-of-life care preferences over time is often assumed,(10, 11) but was not observed in most longitudinal studies on preferences on continuing or forgoing treatment.(12, 13)

Longitudinal studies on advance euthanasia wishes, and ADEs in particular, are lacking. Therefore, we performed this study with the following research questions:

1. Are older people with an ADE stable in their advance desire for euthanasia in the last years before death?
2. How frequently does an ADE result in (a request for) euthanasia?

3. What factors determine whether older people with an ADE eventually request euthanasia?

4.2 METHODS

Design

To follow advance euthanasia wishes over time, we combined data from two cohort studies with a nested retrospective study among relatives of cohort members. Information on the last months of life was collected from relatives, while information on possession of ADEs was collected some years earlier from the cohort members (self-reports). In order to study both people with and without an ADE, the older people were extracted from two cohort studies; the Longitudinal Aging Study Amsterdam (LASA) and the Advance Directive Cohort Study (ADC). LASA was set up in 1992 and is nationally representative of older people in the Netherlands. It consists of 2165 members aged 55 and over at recruitment. The ADC study was set up in 2005 and consists of people who requested a standard advance directive form from Right to Die-NL (n=5561). The design of both cohort studies is described elsewhere.(14, 15) The Medical Ethics Review Committee of the VU University medical center approved the study.

Participants

Cohort members who died between 2005 and 2009 above the age of 55 and had given permission to contact their relative after death were included in this study. Figure 1 shows the selection process and response. Of 498 relatives, 324 participated (65%). Two participants were excluded because of missing answers.

Definitions

Euthanasia was defined as intentional hastening of death by a physician, either by administration of lethal drugs on the patient's request, or by provision of lethal drugs which are ingested by the patient himself (physician-assisted suicide). An advance euthanasia wish is a preference for euthanasia in certain future circumstances; an ADE is a document in which an advance euthanasia wish is written down. The evolution of an advance euthanasia wish was studied in four steps, starting with possession of an ADE at baseline (cohort questionnaire). Data on the consecutive steps was gathered from relatives: having an advance euthanasia wish three months (step 2) and three days before death (step 3); and requesting euthanasia (step 4). The relative was appointed by the cohort member and could also be a friend.

Measurements

Data gathered before death (self-reports) and after death (through relatives) was combined using unique identifying numbers. At baseline (2005) members of both cohorts received a questionnaire on possession of ADE and other advance directives and discussion of their wishes (with relatives/physician). Furthermore, the questionnaire included questions on socio-demographic characteristics.

If a cohort member died between 2005 and 2009, their appointed proxy was invited to participate six months to two years after death. If they agreed, they received the proxy questionnaire which focussed on the last three months before death. Relatives were asked about the presence of an advance euthanasia wish at three months and three days before death ('My relative wanted his or her life to be terminated in certain situations: yes/undecided/no/don't know)'. They could indicate by yes/no/don't know whether the cohort member had discussed this advance wish (with relatives/physician), whether the situation described in an ADE was reached and whether the cohort member requested and received euthanasia. Other questions included time of death, place of residence, diagnoses, presence of different symptoms (fatigue, pain, dyspnoea, impaired in daily activities, self-care and mobility, memory loss, mood problems, loneliness, inability to accept things as they are, feeling of being a burden, loss of interest in others) at three months before death (no-somewhat/severe) and worries (worries about having pain or dyspnoea, loss of consciousness, confusion, loss of dignity, fear of dying or death, becoming unable to communicate, being dependent on or a burden for others, going to a residential home, missing out on a life-event) during the last three months before death (yes/no).

Analyses

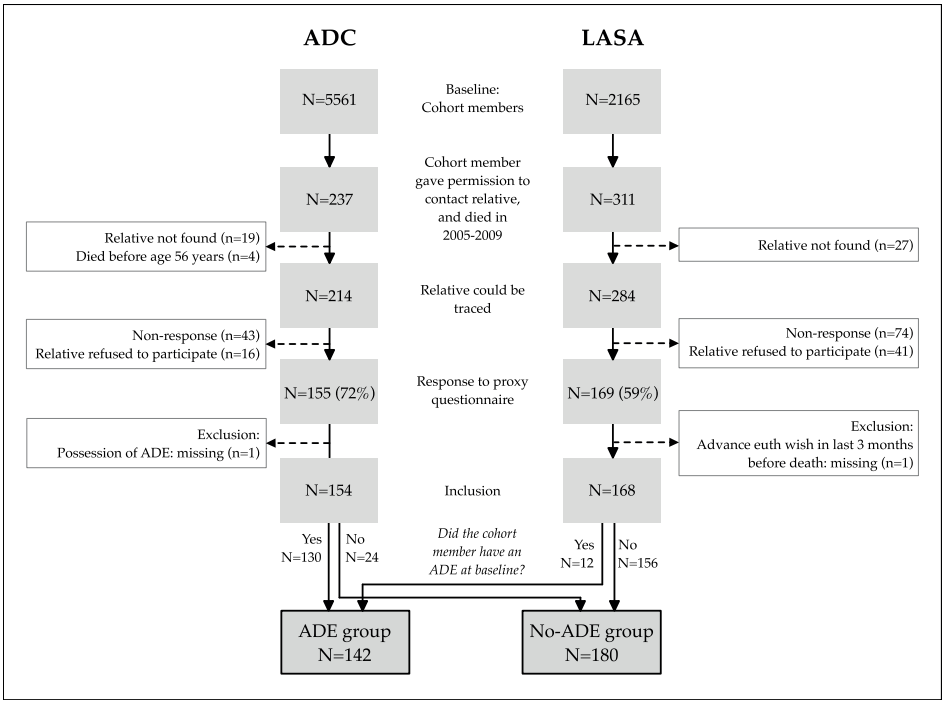
Unless otherwise described, missing values did not exceed 5.0%. Logistic regression analysis was performed to identify determinants of evolution of an ADE into a euthanasia request. Only cohort members with an ADE at baseline were included, the dependent variable was 'euthanasia request'. The included determinants for bivariate analysis were age at death (three categories), gender, partner status and presence of children, educational level (moderate/high versus low), place of residence (home versus other), presence of three disease groups (cancer, chronic lung or heart disease and central neurologic disease), symptoms and worries. To avoid overlap, the specific worries were categorized by principal component analysis. Only determinants that were bivariately associated with the dependent variable with a probability of <0.10 were entered into backward multiple regression analysis. Determinants were removed stepwise until all remaining determinants were significantly associated with the dependent variable ($p<0.05$).

4.3 RESULTS

Description of the sample

Figure 1 describes the sample and response. At baseline, 142 of 322 cohort members had drafted an ADE, mostly members from the ADC cohort. In the LASA cohort (representative for the Dutch older population), 7% had an ADE. Participating relatives were mostly child (69%) or partner (23%) of the cohort member. Mean age was 60 years, 66% was female, and 65% had daily contact with the cohort member; 33% had weekly contact and 2% monthly. Table 1 compares baseline characteristics of the cohort members who reported to have an ADE at baseline ('ADE group') with those who did not ('no ADE group'). Almost all cohort members with an ADE had discussed the ADE with their relative(s) (97%) and physician (84%) before baseline. In the last three months of life, 69% discussed their advance euthanasia wish again with their relatives and 61% discussed it with their physician. According to the relatives, 78% of cohort members with an ADE reached the situation described in their ADE.

Figure 1. Flowchart



ADC: Advance Directives Cohort; LASA: Longitudinal Aging Study Amsterdam; ADE: Advance directive for euthanasia

Table 1. Characteristics of cohort members at baseline (information from cohort member)

	ADE group	No ADE group
	n=142	n=180
	%	%
Cohort*		
LASA	8	87
Right-to-Die-NL *	92	13
Gender: female	56	48
Female		
Partner status		
Married/cohabiting partners	49	55
Single	13	12
Widow/widower	35	33
Has children	91	90
Religious:*		
Yes	36	70
Education*		
Elementary school only	13	34
Low (lower level secondary school)	13	36
Middle (higher level secondary school)	42	24
High (college or higher)	32	6
Chronic disease†‡§		
None*	14	30
Arthritis	36	39
Heart disease	31	35
Cancer	32	33
Diabetes*	9	16
Chronic obstructive lung disease	15	15
(post) CVA†	11	15
Other neurological disorder	6	4
Psychiatric disorder*	8	1
Other	32	32
ADE:		
Age when drafting an ADE§ ‖		n.a.
Mean (±SD)	70 (±10)	
Type of ADE		n.a.
Standard Right to Die-NL form¶	99	
Other	1	
Possession of advance directives other than ADE*	76	8

Table 1. Characteristics of cohort members at baseline (information from cohort member) (continued)

	ADE group	No ADE group
Discussed contents of ADE before baseline‡		n.a.
With relative(s)	97	
With physician	84	
Information from relatives:		
Age at death		
Mean (±SD)	80 (±10)	82(±10)
Time between drafting ADE and death (calculated) ‖ §		
Mean (range) in years	11 (1-27)	n.a.
Discussed advance euthanasia wishes in last three months of life **		
With relative(s)*§	69	16
With physician *§	61	15
Situation described in ADE was reached:		n.a.
Yes	78	
No	16	
Don't know	6	
Unconscious or incompetent for more than one week before death:		
Yes*	81	70

Ninety-two LASA cohort members did not participate in 2005; in these cases we used their answers from 2002.

* Significant difference between ADE group and no ADE group ($p<0.05$, independent T-test for continuous variables, two-tailed Chi-square test for dichotomous and categorical variables).

† All chronic diseases were included, except for incontinence and asymptomatic diseases such as hypertension and hypercholesterolemia.‡ More than one answer possible.

§ Missing >5.0% (5.3%-14.6%).

‖ Question only asked to members of the Right-to-Die cohort (n=130).

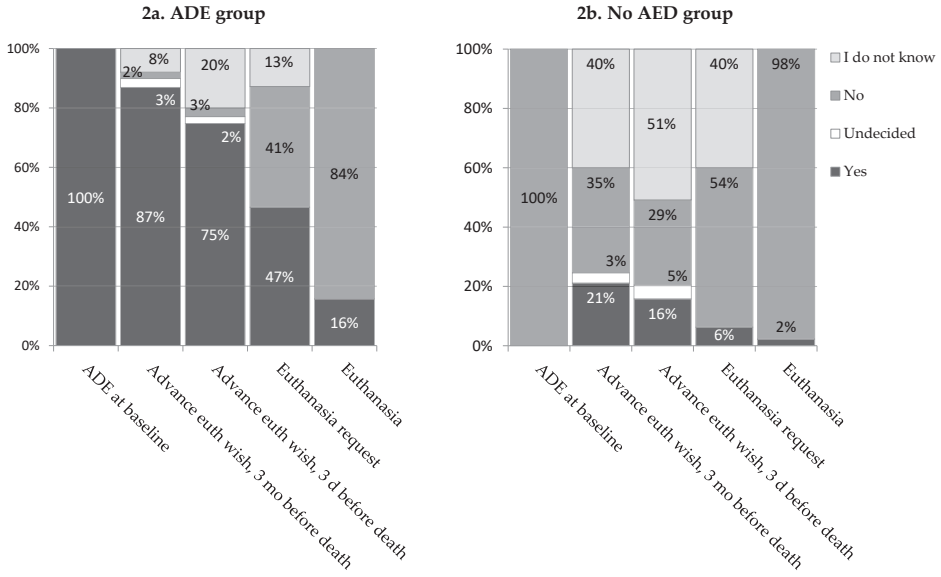
¶ The standard ADE provided by Right-to-Die NL consists of a future request for euthanasia in case of unbearable suffering without a probable chance of recovery. There is the option to add information on what people consider unbearable.

** Some relatives described they did not know whether the cohort member had discussed their wish in the last three months. In the ADE group 2% did not know whether it was discussed with a relative and 21% did not know whether it was discussed with the general physician, In the no ADE group, these percentages were 10% and 53%. These answers were not seen as missing.

From ADE to euthanasia

Figure 2 shows the evolution of an advance euthanasia wish until the end of life in older people, according to relatives. This wish was mostly stable in the ADE group; 87% persisted in their advance euthanasia wish at three months before death and 75% had an advance euthanasia wish at three days before death. Eventually, 47% requested euthanasia and one-third of these requests was granted. For the no ADE group these percentages were lower; 21% had an advance euthanasia wish at three months before death (p-value compared to ADE group <0.001), 16% at three days before death (p-value compared to ADE group <0.001) and 6% requested euthanasia (p-value compared to ADE group <0.001). The odds of requesting euthanasia in the ADE group was 12.7 times higher than in the no ADE group (OR, 95% CI 6.5-26.2).

Figure 2: Evolution of an advance euthanasia wish in cohort members with (2a) and without (2b) an ADE at baseline.



Information from relatives, with the exception of the first column ('has an ADE'). Significant difference for all items between ADE group and no ADE group (p<0.001 for all items, two-tailed Chi-square test).
First column: Information from baseline measurement, cohort member.
Third column: Missing >5.0% (5.3%).

Factors influencing the evolution of an ADE into a euthanasia request

Finally, we studied what factors determined whether older people with an ADE at baseline would later request euthanasia. Bivariate regression analysis showed that cohort members with an ADE were more likely to request euthanasia if they were unable to accept things as they are, had the feeling of being a burden to others, were worried in general and were specifically worried about loss of dignity, pain or dyspnoea, becoming dependent on medical equipment or becoming unable to communicate ($p<0.05$, missing values 3.5-9.9%). In multiple regression analysis, the likeliness of a euthanasia request was higher in people who worried about loss of dignity (OR4.5, 95% CI 2.1-9.5), and lower in people with a heart disease or chronic lung disease (OR0.40, 95% CI 0.18-0.90). Other factors were not associated with requesting euthanasia in older people with an ADE.

4.4 DISCUSSION

Stability of advance euthanasia wishes

In this study, older people with an ADE rarely withdrew their advance euthanasia wish. In line with a review on end-of-life treatment preferences, advance euthanasia wishes seem quite stable over time, despite physical decline and approaching death.(12) This finding supports the validity of ADEs as representation of someone's advance wishes.

From advance wish to request

Forty-seven percent of people with an ADE at baseline requested euthanasia at the end of life. Although possession of an ADE increased the likelihood of actually requesting euthanasia, not all people did. People can decide not to act in accordance with their ADE for different reasons. People may 'push their limits' and tolerate a health condition that seemed unbearable in the past,(3, 11) postpone a euthanasia request for practical or social reasons,(16) or perceive a barrier to ask their physician for euthanasia. Moreover, an advance euthanasia wish can become irrelevant if a person loses consciousness, symptoms are relieved by palliative care,(16) or death is hastened by forgoing treatment. Finally, in a minority of cases in this study, the person never reached the situation described in their ADE.

We found that people with an ADE who worry about loss of dignity were more likely to request euthanasia. Previous studies also described loss of dignity as an important factor for a desire to hasten death.(17, 18) Other causes for suffering, such as pain or loneliness, were not associated with euthanasia requests in our study. This

resonates with a study which found no association between unbearable suffering and euthanasia requests.(19) Factors not related to suffering may be more important motives to request euthanasia, such as a desire to control the circumstances of one's death,(19, 20) a low perceived level of mastery,(21) experiencing a sudden decline in health status,(16) or the prospect of losing the ability to hasten death.(16)

Interpretation of ADEs

Although ADEs are not required for euthanasia and often do not result in euthanasia, they are the most popular advance directives in the Netherlands. Possibly, people draft ADEs to feel reassured that euthanasia is an option in case of future suffering. Drafting an ADE may be an attempt to gain a sense of control over the future.(22) This desire for control is also described in people who seek information about euthanasia or non-medicalised suicide.(22, 23) In many cases reassurance is enough, which is illustrated by the fact that Dutch physicians yearly receive a threefold higher number of euthanasia requests in due course (to be carried out in the future) than explicit euthanasia requests.(24)

ADEs as part of advance care planning

In this study, drafting an ADE was rarely an isolated act. Most cohort members drafted an advance directive concerning other end-of-life decisions at the same time, and most discussed their advance wishes with relatives and their physician. Because ADEs are well-known in the Netherlands, drafting an ADE could be the first step in advance care planning for many people. Also, people with ADEs often discussed their wishes again at the end of life. Possibly, ADEs are valuable facilitators for reflections on and conversations about end of life, just as other advance directives.(10, 13)

Strengths and limitations

Although only 7% of the Dutch population possesses an ADE, we were able to collect information on 142 deceased people with an ADE. By combining information from cohort members and relatives, the evolution of advance euthanasia wishes until death could be studied. To include both people with and without ADEs, we needed to extract participants from two cohort studies. In interpreting the data we have to take this into account; the sample cannot be used to assess frequencies for all older Dutch people, but only for people with or without AD separately. Moreover, some years have passed between data gathering and publication, and the findings may be less relevant for the current situation. However, the euthanasia law has not changed since 2002. Another limitation of this study is the use of relatives as source of information. They might not always be fully informed about the cohort members' preferences on euthanasia. Especially in the no ADE group, many relatives did not

know whether their relative had an advance euthanasia wish. Still, it seems unlikely that a cohort member develops or withdraws a euthanasia wish without discussing it with their relative. Secondly, recall bias could have played a role. However, 94% of the relatives in the ADE group knew the cohort member possessed an ADE and studies show that relatives are a reliable source for this type of information.(25, 26) Thirdly, we do not know the exact motives of cohort members with an advance euthanasia wish to request or not to request euthanasia. Finally, most cohort members remained competent until at least one week before death (75%). Therefore, these results cannot be extrapolated to people with advanced dementia.

4.5 CONCLUSION

In this study, most older people with an ADE had a stable advance euthanasia wish in the last years of life. However, a stable advance euthanasia wish does not necessarily result in a euthanasia request. People who visit their physician to discuss an ADE may be in need of reassurance, so physicians should pay attention to the patient's concerns and fears. At the same time, this moment could serve as a starting point for a conversation about end-of-life care in general.

DECLARATIONS

Acknowledgments

We thank all the participants for sharing their experiences with us.

This study was funded by the Netherlands Ministry of Health, Welfare and Sport (LASA cohort) and a grant from Right to Die-NL and the Pieter van Foreest Foundation (ADC cohort). The proxy study was supported by a career award to BD Onwuteaka-Philipsen by the Netherlands Organization for Scientific Research (The Hague; VICI 916.96.628).

Conflict of interest

The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper.

Author contributions

Pasman, Onwuteaka-Philipsen, Deeg: study concept, design, and data collection. Bolt, Pasman, Onwuteaka-Philipsen, Deeg: analysis and interpretation of data, review and revision of manuscript. Bolt: manuscript preparation.

Sponsor's role

The researchers were independent from the funders. The funders were not involved in the collection, analysis, or interpretation of data; writing the manuscript; or the decision to submit the article for publication.

Appendix

Logistic regression analysis: Factors associated with an advance euthanasia directive resulting in a euthanasia request (n=137)*

			Univariate regression analysis		Multiple regression analysis	
	Request (%) N=63	**No request (%) N=74**	**OR**	**(95% CI)**	**OR**	**(95% CI)**
Patient characteristics: (Information from cohort member)						
Age at death†						
56-74	39	33	1			
75-84	42	36	1.00	(0.45-2.2)	‖	
85 and up	19	30	0.52	(0.21-1.3)	‖	
Gender						
Female	56	57	0.95	(0.48-1.9)	‖	
Social situation						
Has a partner	49	48	1.1	(0.54-2.1)	‖	
Has children	92	91	1.2	(0.37-4.0)	‖	
Educational level						
Low	71	66	1			
Moderate to high	29	34	0.77	(0.37-1.6)	‖	
Circumstances: (Information from proxy)						
Diagnosis: ‡						
Cancer	46	41	1.3	(0.64-2.5)	‖	
Heart disease or chronic lung disease	25	41	0.50	(0.24-1.04)	0.40	(0.18-0.90)
Disease of the central nervous system	16	15	1.1	(0.43-2.7)	‖	
Presence of severe symptoms:‡						
Fatigue	56	49	1.3	(0.67-2.6)	‖	
Impaired in daily activities	36	33	1.1	(0.54-2.2)	‖	
Pain†	32	24	1.5	(0.7-3.2)	‖	
Incontinence	32	41	0.67	(0.3-1.4)	‖	
Impaired in self-care†	31	26	1.2	(0.58-2.7)	‖	
Inability to accept things as they are	31	16	**2.4**	**(1.0-5.6)**	- ¶	

Logistic regression analysis: Factors associated with an advance euthanasia directive resulting in a euthanasia request (n=137)* (continued)

			Univariate regression analysis		Multiple regression analysis	
	Request (%) N=63	No request (%) N=74	OR	(95% CI)	OR	(95% CI)
Dyspnoea	27	14	2.3	(0.98-5.6)	- ¶	
Impaired mobility	28	15	2.2	(0.93-5.1)	- ¶|	
Feeling of being a burden†	30	10	**3.7**	**(1.4-9.6)**	- ¶	
Loss of interest in others	21	15	1.5	(0.6-3.8)	||	
Mood problems	16	7	2.5	(0.79-7.6)	||	
Loneliness	13	10	1.4	(0.46-4.0)	||	
Memory loss	11	10	1.1	(0.38-3.5)	||	
Worries††						
Being worried	97	78	**8.4**	**(1.9-38.2)**	- ¶||	
Subject of worries‡:						
Depending on or burdening others	65	55	1.5	(0.75-3.0)	||	
Loss of dignity	70	36	**4.0**	**(2.0-8.3)**	**4.5**	**(2.1-9.5)**
Pain or dyspnoea	56	38	**2.1**	**(1.0-4.0)**	- ¶	
Becoming dependent on medical equipment/ unable to communicate	44	20	**3.1**	**(1.5-6.7)**	- ¶	
Going to a residential home	37	32	1.2	(0.59-2.4)	||	
Fear of dying or death	29	23	1.3	(0.62-2.9)	||	
Confusion	16	14	1.2	(0.47-3.1)	||	
Missing an event	11	8	1.4	(0.45-4.5)	||	
Loss of consciousness	6	1	4.9	(0.54-45)	||	
Other factors:						
Incompetence > 1 week before death	14	24	0.54	(0.22-1.3)	||	
Last place of residence:						
Not home	32	32	1.0	(0.49-2.1)	||	
Treatment options were clearly described to patient†	78	67	1.7	(0.77-3.8)	||	

* 23 of 158 were excluded from regression analysis, reasons for exclusion were: unknown whether cohort member requested for euthanasia (n=6), missing answer on presence of euthanasia request (n=3), unable to request for euthanasia due to incompetence (n=6), reduced consciousness (n=4), aphasia (n=1), rapid decline and death (n=1) or sudden death (n=2).
† Missings 5.1-8.9%.
‡ More than one answer possible.
|| P>0.20 in univariate logistic regression; not entered in multiple logistic regression.
¶ Entered in multiple logistic regression, but did not remain significant (p>0.05).

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