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## Involvement of the Dutch General Population in Advance Care Planning: A Cross-Sectional Survey

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### ABSTRACT

**Background and Objective:** Advance care planning (ACP) is a process of communication among patients, health care providers, and relatives regarding end-of-life care. The aim of our study was to determine if a representative sample of the Dutch general public is currently involved or is inclined to be engaged in ACP, and to delineate the factors associated with greater engagement. **Methods:** An online questionnaire was completed by a representative sample of the Dutch general public, derived from an established Internet panel (CentERdata, University of Tilburg, the Netherlands). **Results and Conclusions:** Although the majority of the Dutch population seems open to discussions about end-of-life care, our study revealed that discussions with physicians are exceedingly rare. To improve ACP as a joint process among patients, relatives, and physicians, the general public's awareness of the importance of end-of-life discussions with their physicians needs to be increased and physicians need to play a more active role by initiating conversations and dialogue regarding end-of-life care. **Introduction**

Advance care planning (ACP) is a process of communication among patients, health care providers, and relatives regarding end-of-life care. ACP aims to ensure that patients' values remain central in decision making when patients can no longer make decisions and that this care remains consistent with patients' preferences.<sup>1</sup> ACP encompasses various components, including the consideration of treatment goals and communication with relatives and physicians.<sup>2</sup> ACP may also involve the designation of a surrogate decision maker, or an advance directive (AD) in which treatment

preferences are recorded. ADs can contain a refusal of treatments (negative directive) or preferences for care and treatments to be applied (positive directive) under specified conditions. In the Netherlands, the Dutch Medical Treatment Act states that patients have the right to refuse medical treatment and can do this in writing through an AD. In principle, a physician has to follow such a negative AD when it is clear and sufficiently detailed. In contrast, a positive AD only serves to support a physician in understanding the preferences of the patient.<sup>3,4</sup> In the Netherlands, a positive AD might include a specific request for euthanasia, which is a relatively common type of AD in the Netherlands.<sup>5</sup> Although ACP comprises more than drafting an AD, most research has focused on ADs that have been subject to increasing criticism.<sup>6</sup> Important limitations of ADs are related to its drafting (e.g., it is difficult to foresee future wishes; people may change their preferences) and its interpretation (e.g., it is difficult to interpret the content; ADs may involve incomplete or conflicting information). Furthermore, research on the impact of ADs has shown disappointing results. Over recent decades, the prevalence of having an AD ranged from 3% to 36% among the general public<sup>5,7-12</sup> and from 5% to 19% among (deceased) patients.<sup>10, 13,14</sup> Various efforts to improve patients' completion rate of an AD have not been very successful<sup>15, 16</sup> and minimal effects of ADs on directing end-of-life care and its quality have been reported.<sup>13,17,18</sup> Currently, the focus of research on ACP has shifted toward ACP as a process of communication, and aims to approach ACP as a concept that is wider than solely drafting an AD.<sup>19,20</sup> One study showed that ACP, as a process, improves end-of-life care for elderly patients, as well as patients' and families' satisfaction with care; also, among surviving relatives, ACP leads to stress reduction, less anxiety, and less depression.<sup>21</sup> Because of these potential benefits of ACP, it might be seen as a healthy and useful behavior to promote among the general public.<sup>22</sup> Although qualitative studies have assessed the patient's perspective on ACP<sup>2,19,23,24</sup> and the barriers they define for ACP,<sup>25-27</sup> little information is available on the involvement of the general public in ACP. Therefore, the aim of the present study is to determine if people are currently involved or are inclined to be engaged in ACP, and to delineate the factors associated with greater engagement.

## METHODS

### Design and population

This cross-sectional survey was conducted in the Netherlands. An online questionnaire was completed by a representative sample of the Dutch general public, derived from an established Internet panel (CentERdata, University of Tilburg, the Netherlands). This panel was constituted from a random sample of national postal codes. Multiple measures were in place to avoid selection bias of this Internet panel, such as guaranteeing accessibility for all selected households without Internet access at the time of study recruitment by providing them with a free tool, the so-called Net.Box (KPN Telecom, the Hague, the Netherlands). This tool enabled those without Internet access to respond via a telephone line and a television set. During the survey period 2503 persons were active members of the total panel.

## **Questionnaire**

The structured questionnaire addressed actual and preferred involvement in ACP, as well as factors associated with engagement. The questionnaire was developed by the KOPPEL research group, comprising physicians, ethicists, researchers, and a methodologist. Questions were based on literature,<sup>28</sup> previous research,<sup>29,30</sup> and expert opinion. The questionnaire was pretested for length, comprehensibility, and feasibility for online use by 14 members of the Dutch general public. The pretest population varied in educational level, age, and gender. The questionnaire and two reminders were sent between December 2009 and February 2010.

Additional background characteristics were provided by CentERdata, based on self-reported data. For comparison purposes, background characteristics of the whole Dutch population were obtained from Statistics Netherlands (CBS).<sup>31</sup>

## **Statistical analyses**

Descriptive statistics were computed on background characteristics, involvement in ACP, need for information, health, experiences, attitudes, and knowledge. Univariate analyses, followed by multivariate logistic regression analyses, were used to calculate odds ratios with 95% confidence intervals for the relationships between involvement in ACP and demographic characteristics, health, experiences, attitudes, and knowledge. Involvement in ACP was analyzed based on three items: “having thought about end-of-life decisions,” “having discussed end-of-life decision making with relatives or physicians,” and “having a written AD.” Having discussed end-of-life decision making was scored on a 4-point Likert scale and dichotomized (seldom, sometimes, and often were recoded as “yes” and never as “no”). The variables of trust, attitudes toward decision making, knowledge of palliative care, and need for more information were also dichotomized.

Respondents were defined as having “substantial knowledge of the Euthanasia Act” if they answered all of four related questions correctly.

Four indicators concerning attitude toward euthanasia were used to compose an index measuring acceptance of euthanasia of the respondent, based on the outcome of factor analysis (1 factor with eigenvalue > 1.0, 78% explained variance) and reliability analysis (Cronbach’s alpha = 0.79). Using the median score of the sum scores, we distinguished respondents who generally accept or reject euthanasia.

## **Ethical considerations**

The Dutch Medical Research Involving Human Subjects Act does not apply to this research proposal. Therefore, no ethical approval of the Medical Ethical Committee was needed.

## **RESULTS**

### **Sample characteristics**

Of the 2503 questionnaires, 2004 were returned, and 1960 were complete and eligible for analyses (response 78%). The age of the respondents ranged from 18 to 95 years. Reasons for exclusion of 44 questionnaires were incompleteness (n = 17) and age of the respondent < 18 years (n = 27). Compared with the Dutch general public, respondents in the sample were older, more often male, more highly educated, more often living with a partner, and more often native Dutch (Table 1). Furthermore, nonrespondents were younger, more often female, more often living without a partner, and more often had a lower education level (data not shown).

Of the 1960 respondents, 85% reported good general health, and 11% reported to have (had) a life-threatening disease, 14% had had experience with a relative requesting euthanasia and 16% with a relative receiving palliative sedation (Table 2). In addition, 77% expressed trust that physicians would comply with their wishes about medical care/treatment in the last days of life. Most respondents favored shared decision making (67%), 31% preferred making their own decisions, and 2% preferred the physician to make the decisions.

Respondents expressing little trust that physicians would comply with their wishes about medical care/treatment in the last days of life more often preferred to make their own decisions ( $p < 0.001$ ). Of all respondents, 18% believed that a physician's current judgment about a patient's situation/ treatment is better than the patient's judgment in an earlier stage. Almost all respondents were aware of the existence of the Dutch Euthanasia Act (95%), 37% correctly answered all four questions regarding this Act and 53% were familiar with the term "palliative care."

### **Involvement and preferences to be involved in ACP**

#### **[TABLE 1] [TABLE 2]**

Of all 1960 respondents, 70% indicated to have thought about issues related to medical decision making at the end of their life (Table 3). Of all eligible respondents, 64% had discussed at least one of these issues with their relatives (6% often, 35% sometimes, and 24% seldom), and 13% had discussed these issues with a physician (0.3% often, 3% sometimes, and 9% seldom). In total, 33% had thought about end-of-life decision making and had discussed it with their relatives, but had not discussed it with a physician and had not written an AD. Of all respondents, 7% had documented their wishes in a written AD. Of all respondents with an AD ( $n = 139$ ), 24% had discussed the AD with their physician, and 81% had discussed it with their relatives. Overall, 21% of the respondents wanted more information on end-of-life decision making, for example, medical care and treatments at the end of life, ADs, or euthanasia. These respondents would look for information on the Internet (54%) or ask their general practitioner (GP) (69%). Older persons, people who had thought about or discussed end-of-life issues with a relative or a physician, or who had an AD more often wanted information than did others.

### **Factors associated with involvement in ACP**

The probability of having thought about end-of-life decision making was higher for persons aged  $\geq 55$  years, as well as for females, for persons without religious beliefs, persons with a poor health status, persons who had experienced a euthanasia request of a relative, persons who generally accept euthanasia, persons who expressed little trust that physicians would comply with their wishes, persons not preferring physicians to make decisions for them, and persons who knew the term "palliative care" and were familiar with the Dutch Euthanasia Act (Table 4). Similar patterns were found for discussing and having a written AD. Persons living with a partner less often had a written AD than persons living without a partner.

### **DISCUSSION**

This study shows that the majority of the Dutch population has thought about end-of-life care and decision making, and a substantial part of the population has actively discussed their preferences with relatives. Furthermore, it shows that one-fifth of the

general public indicated a need for information on end-of-life care, and would use the GP as the major source of information. However, discussions with physicians about end-of-life care are rare among the general public, even among people who have an AD.

Several findings deserve particular attention. First, although many people think about end-of-life care and decision making, only 13% had discussed these issues with their physician.

**[TABLE 3]**

This is less compared with a recent study that found that Dutch and Belgian GPs had discussed medical treatment in the last phase of life in advance with 34% of their patients who had died nonsuddenly.<sup>32</sup> The higher percentage in this study might be explained by differences in the population studied, that is, the general population versus deceased patients, and by the respondents' perspective, that is, physicians' versus patients' perspective.

Second, in the present study, 7% of the members of the general public reported to have an AD. This finding supports previous research on the prevalence of ADs in the general population with percentages ranging from 3% to 36%.<sup>5,7,9,11,33,34</sup> Compared with the United States where the estimated prevalence of ADs in the general population varies from 18% to 36%,<sup>7,12,34</sup> the prevalence of ADs in the Netherlands seems lower. It has to be noted that the U.S. Patient Self-Determination Act (PSDA), requiring health care institutions to provide information about ADs to adult patients upon their admission,<sup>35</sup> came into effect earlier than the Dutch Medical Treatment Act. However, the SUPPORT study showed no effect of the PSDA on completion rates of ADs.<sup>36</sup> As said, the effects of ADs have been subject to major criticism, such as that they are not able to direct end-of-life care<sup>13</sup> and that they even involve a false promise, that is, that the AD concept itself is fundamentally flawed.<sup>6</sup> The limited effects of ADs have been suggested to be partly due to little involvement of physicians in the completion of ADs, to physicians often being unaware of the availability of ADs, and to nonspecific wording of preferences in ADs.<sup>13,18,37</sup> Our study confirms that physicians are rarely involved in completing an AD as only 24% of all respondents with an AD had discussed it with their physician.

Third, most demographic factors associated with engagement in ACP are consistent with earlier studies on the drafting of ADs. Patients who have completed an AD were found to be older, more highly educated, more often female, and to have increased dependency,<sup>5,7,11,33,38</sup> and older age has also been reported to be positively associated with ACP as a process.<sup>25</sup> Furthermore, a predictor of being interested in AD is the wish of having control.<sup>39</sup> Our results support this idea of control.

Those respondents in favor of physicians making decisions and expressing trust that physicians would comply with their wishes were significantly less inclined to be involved in ACP.

Persons who accept euthanasia, also associated with the wish for control,<sup>29</sup> were also more inclined to be involved in ACP.

Besides individual factors, societal and legal factors can influence the level of involvement in ACP. In the Netherlands, an accessible health system is present with compulsory social health insurance and a special role for GPs as gatekeepers. Dutch people often have a long-lasting relationship with their GP, which might contribute to the high level of trust in physicians in the Netherlands. This trust might

diminish the perceived need for ADs. Furthermore, the Dutch societal and public debate on euthanasia (which resulted in the Euthanasia Act in 2002) might influence the prevalence of ACP in the Netherlands and limit international comparability of the Netherlands. The Dutch general public is highly familiar with the advanced euthanasia directive,<sup>5</sup> indicating the dominance of the issue of euthanasia in the Netherlands regarding end-of-life decision making.<sup>8</sup> This context hampers the generalizability of our results to other settings. Also, some other methodological considerations of the study need to be addressed.

First, despite a good response rate, the respondents were not fully representative of the Dutch general population; the respondents were older, more often male, more highly educated, and more often sharing a household. This may have led to an overestimation of the involvement in ACP of the Dutch general public. Moreover, nonnative Dutch people were underrepresented and cultural factors are known to impact health care use<sup>40</sup> and health communication,<sup>41</sup> thus influencing end-of-life care and decision making.<sup>42</sup> In studies from the United States, ADs are more common among the white population.<sup>7,11,43</sup> Additionally, an Internet panel used for surveys may involve selection bias. To minimize this bias, we made use of an existing panel consisting of a randomized sample of people (thus not self-selected) and this enabled all selected members to participate (no restriction to Internet users only). Finally, because this study only examines the respondents' report of their involvement, without triangulation, the results may be subject to recall bias. Although until now only one study has shown positive effects of ACP as a process<sup>21</sup> and more research is needed to confirm these results, ACP may be a potential contributor to better end-of-life care. Our study shows that most people are open to discussions about end-of-life care, and that a need for more information is present.

#### [TABLE 4]

Because only a very small percentage of our study population has discussed end-of-life issues with their physician, our findings suggest that a more active role of physicians in initiating end-of-life discussions would be useful. In line, it has been suggested earlier, that physicians have a responsibility to start end-of-life discussions in a timely way,<sup>44-47</sup> by informing and educating their patients. Therefore, to facilitate ACP, we suggest a dual approach to inform both the public and health care professionals.

First, to increase the awareness of the general public regarding the need to take the next step in ACP, that is, to have timely discussions with physicians about their preferences at the end-of-life, such as the Dying Matters initiative in United Kingdom.<sup>48</sup> This will contribute to overcoming known barriers related to end-of-life discussions at the patient level, such as patients' ambivalent attitudes toward their prognosis, and a general reluctance to (spontaneously) talk about their problems and needs.<sup>46</sup> Second, physicians need to be educated and supported in how to initiate and have end-of-life discussions, because physicians are reluctant to discuss end-of-life issues and wait until the patient raises the topic.<sup>49</sup> This training and support should reach beyond technical aspects of communication and involve reflection of the physician's own emotions and values.<sup>50</sup> In conclusion, the majority of the Dutch population has thought about their ideas and preferences regarding end-of-life decision making or has actively discussed these ideas with relatives, and a need for information on end-of-life care is present. Despite the fact that the majority of Dutch

population seems open to discussions about end-of-life care, our study reveals that discussions with physicians are exceedingly rare. To improve ACP as a joint process among patients, relatives, and physicians, the general public's awareness of the importance of end-of-life discussions with their physicians needs to be increased and physicians need to play a more active role by initiating conversations and dialogue regarding end-of-life care.

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### **Author Disclosure Statement**

No competing financial interests exist.

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TABLES AND FIGURES

TABLE 1. BACKGROUND CHARACTERISTICS OF THE RESPONDENTS OF THE ONLINE SURVEY COMPARED WITH THE DUTCH GENERAL POPULATION

	<i>Respondents (n=1960)</i>	<i>Dutch adults<sup>a</sup></i>
Age in years (Mean ± SD)	53.4 ± 15.1 (%)	48 (%)
Gender		
Male	54	50
Education <sup>b</sup>		
Low	32	32
Middle	29	40
High	39	29
Composition of household		
Living with partner	76	64
Religious beliefs		
Yes	58	59
Urbanization living area		
Low/middle	61	57
High	39	43
Nationality		
Native	96	80
Immigrants <sup>c</sup>	4	20

<sup>a</sup>Based on 2009 data of Statistics Netherlands (CBS); <http://statline.cbs.nl/statweb>

<sup>b</sup>Low=level 1-3 according to the ISCED guidance (primary school, lower secondary general education, lower vocational education), middle=level 4 according to the ISCED guidance (intermediate vocational or higher secondary general education), high=level 5-7 according to the ISCED guidance (higher vocational education or university).

<sup>c</sup>Immigrants are defined as being born in a country other than the Netherlands, or having a mother or father who was born in a country other than the Netherlands.

SD, standard deviation.

TABLE 2. OTHER CHARACTERISTICS OF THE RESPONDENTS OF THE ONLINE SURVEY: EXPERIENCES, ATTITUDES, AND KNOWLEDGE RELATED TO END-OF-LIFE ISSUES

	<i>Respondents (n=1960) (%)</i>
Good self-reported general health <sup>a</sup>	85
Having (had) a life-threatening disease	11
Experience with euthanasia request of a relative	14
Experience with palliative sedation for a relative	16
Trusting physicians to comply with patient's wishes at the end of life <sup>b</sup>	77
Believing that physician's current judgment is better than the patient's in an earlier stage <sup>c</sup>	18
Preference for end-of-life decision-making style:	
Physicians should make decisions, based on what is best for me.	2
Physician and I should make decisions together.	67
I should make decisions, based on what is best for me.	31
Substantial knowledge of the Dutch Euthanasia Act <sup>d</sup>	37
Familiar with the term "palliative care"	53

<sup>a</sup>Missing values on self-reported health were >10%. Valid percentage was based on 1403 respondents.

<sup>b</sup>Trusting=a lot of trust; quite a lot of trust.

<sup>c</sup>Agree=agree; completely agree. Not agree=neither agree nor disagree; don't know, disagree; completely disagree.

<sup>d</sup>Substantial knowledge includes those who gave a correct answer to all four questions about the Act.

TABLE 3. INVOLVEMENT IN ADVANCE CARE PLANNING (ACP) AMONG DUTCH ADULTS

	<i>Respondents</i> (n = 1960) %
Has thought about one of the following topics regarding end-of-life decision making:	70
Medical treatments that I would (not) want at the end of life	57
Whether and in which circumstances I would want resuscitation	48
Whether and in which circumstances I would want euthanasia	55
Who decides about medical treatments when I am no longer able to	53
Has discussed one of these topics with relatives <sup>a</sup>	64
Has discussed one of these topics with a physician <sup>a</sup>	13
Has a need for more information about these topics <sup>b</sup>	21
Possible sources for information on these topics:	
General practitioners	69
Internet	54
Relatives	44
Has a written advance directive, describing:	7
The circumstances in which I would not want certain medical treatments	4
The circumstances in which I would not want resuscitation	4
The circumstances in which I would want euthanasia	3
Who decides about my medical treatments when I am no longer able to	4
Other	1

<sup>a</sup>Responses measured on a 4-point Likert scale. "Yes" includes seldom, sometimes, and often. <sup>b</sup>Responses measured on a 4-point Likert scale. "Yes" includes sometimes and often.

TABLE 4. FACTORS ASSOCIATED WITH INVOLVEMENT IN ADVANCE CARE PLANNING (ACP) IN THE RESPONDENTS OF THE ONLINE SURVEY<sup>a</sup>

	Thought about end-of-life decision making OR (95% CI)	Discussed preferences with relatives or physicians OR (95% CI)	Has a written advance directive OR (95% CI)
<b>Demographic characteristics</b>			
Age ≥55 years	1.83 (1.37 – 2.45)	1.91 (1.45 – 2.51)	2.96 (1.76 – 5.00)
Male	0.59 (0.45 – 0.79)	0.60 (0.46 – 0.78)	1.37 (0.84 – 2.23)
High education	0.87 (0.65 – 1.17)	0.79 (0.59 – 1.04)	0.78 (0.47 – 1.27)
Living with partner	0.82 (0.58 – 1.16)	1.02 (0.74 – 1.41)	0.54 (0.33 – 0.90)
Having religious beliefs	0.64 (0.48 – 0.86)	0.71 (0.54 – 0.94)	0.98 (0.61 – 1.59)
<b>Health</b>			
Good health status	0.64 (0.42 – 0.98)	0.66 (0.45 – 0.98)	0.47 (0.28 – 0.80)
Having (had) life-threatening disease	1.17 (0.72 – 1.90)	1.33 (0.84 – 2.10)	1.30 (0.71 – 2.35)
<b>Experience with end-of-life decision making</b>			
Experience with euthanasia request of a relative	2.65 (1.50 – 4.70)	2.61 (1.55 – 4.38)	1.99 (1.08 – 3.67)
Experiences with palliative sedation for a relative	1.39 (0.88 – 2.20)	1.46 (0.95 – 2.25)	0.80 (0.42 – 1.53)
<b>Attitudes</b>			
Acceptance of euthanasia	1.58 (1.09 – 2.29)	1.67 (1.19 – 2.36)	2.71 (1.65 – 4.44)
Trusting physicians to comply with patient's wishes at the end of life	0.40 (0.28 – 0.59)	0.51 (0.37 – 0.72)	1.00 (0.59 – 1.70)
Preference for physician to make end-of-life decisions for me	0.19 (0.07 – 0.49)	0.24 (0.10 – 0.62)	-
<b>Knowledge</b>			
Familiar with the term "palliative care"	2.76 (2.05 – 3.70)	2.35 (1.78 – 3.09)	0.98 (0.59 – 1.63)
Knowledge of the Dutch Euthanasia Act	2.06 (1.51 – 2.82)	2.13 (1.59 – 2.85)	1.63 (1.02 – 2.63)

<sup>a</sup>Adjusted odds ratios (ORs) were estimated with multivariate logistic regression analyses. These analyses included 1231 respondents with complete information on all variables.  
CI, confidence interval.