

Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives

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OBJECTIVES: To gain insight into how advance directives for euthanasia affect resident care in Dutch nursing homes.

DESIGN: Survey of elderly care physicians and additional qualitative interviews with a selection of elderly care physicians and relatives of people with dementia who had an advance directive for euthanasia.

SETTING: Dutch nursing home practice.

PARTICIPANTS: Four hundred thirty-four elderly care physicians completed the general part of the questionnaire; 110 physicians provided case histories. Interviews were conducted with 11 physicians and eight relatives.

MEASUREMENTS: The questionnaire contained general questions about the incidence of advance directives for euthanasia in people with dementia. A second part involved questions about the most recent case of a person with dementia and an advance directive for euthanasia who had died. The interviews with elderly care physicians and relatives focused on further exploration of the decision-making process regarding adherence to the advance directive for euthanasia.

RESULTS: Despite law-based possibilities, advance directives for euthanasia of people with dementia were rarely adhered to, although they seem to have a supportive role in setting limitations on life-sustaining treatments. Elderly care physicians and relatives were found to be reluctant to adhere to advance directives for euthanasia. Not being able to engage in meaningful communication played a crucial role in this reluctance.

CONCLUSION: Advance directives for euthanasia are never adhered to in the Netherlands in the case of people with advanced dementia, and their role in advance care planning and end-of-life care of people with advanced dementia is limited. Communication with the patient is

essential for elderly care physicians to consider adherence to an advance directive for euthanasia of a person with dementia. *J Am Geriatr Soc* 59:989–996, 2011.

Key words: advance directives; dementia; euthanasia; nursing homes; advance care planning

Advance directives are developed as a way of allowing people to state their preferences for future care and how medical decisions are to be made should they become incompetent in the future. Several countries legally recognize the most common form of advance directive (nontreatment directives or living wills).¹ In the Netherlands, advance directives for euthanasia are also legally recognized as part of the euthanasia law enacted in 2002 (Termination of Life on Request and Assisted Suicide Act 2002).² According to this act, euthanasia and assisted suicide (EAS) still fall under the penal code, but physicians will not be prosecuted if they follow the specifically defined due care requirements (Table 1) and report cases to a regional review committee.

According to this euthanasia legislation, an advance directive can replace an oral request in case of incompetence (Table 1: Requirement 1), meaning that physicians may perform euthanasia following an advance directive as long as the remaining requirements (Requirements 2–6) of due care are met “in a corresponding way.” In principle, this new law opened the door for adherence to the advance directives for euthanasia of incompetent people, such as people with dementia, but euthanasia is not standard medical practice, and other than in cases of nontreatment directives, physicians are not obliged to adhere to advance directives for euthanasia, nor do they have a moral duty to facilitate the transfer of patients to another physician in case of nonadherence. Before the enactment of the law, advance directives for euthanasia were rarely adhered to,³ so the question is whether this new legislation has led to changes in practice.

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Table 1. Requirements of Due Care in Dutch Euthanasia Legislation

1. The physician is convinced that the patient has made a voluntary and well-considered request.
2. The physician is convinced that the patient's suffering is unbearable and that there is no prospect of improvement.
3. The physician has informed the patient about his or her situation and prospects.
4. The physician has come to the conclusion, together with the patient, that there is no reasonable alternative in light of the patient's situation.
5. The physician has consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above.
6. The physician has terminated the patient's life or provided assistance with suicide with due medical care and attention.

In the Netherlands, approximately 90% of all people with dementia are admitted to a nursing home in the advanced stages of their disease and die there.⁴ Having their principal site of practice in nursing homes, elderly care physicians, formerly called nursing home physicians, are the doctors most likely to be confronted with advance directives for euthanasia of people with dementia.

Data on the experiences of physicians with advance directives for euthanasia of people with dementia in nursing home practice is limited, and to the knowledge of the authors, no data exist on the experiences of relatives of these people and their involvement in the decision-making process regarding adherence to advance directives for euthanasia.

Therefore, this study aimed at gaining insight into the way advance directives for euthanasia of people with dementia affect resident care in nursing homes and at identifying any changes regarding this issue since the introduction of the new euthanasia law by comparing the results with data from previous research.³ The research highlights experiences of elderly care physicians and of relatives of people with dementia who had an advance directive for euthanasia.

METHODS

The data described in this article are part of a large-scale study that took place in 2007 to 2008 and consisted of a written questionnaire for elderly care physicians followed by additional interviews with physicians and relatives of people with dementia and an advance directive for euthanasia who had died. The Medical Ethics Committee of the VU University Medical Center approved the study.

Survey

All elderly care physicians with medical responsibility for people with dementia were eligible for participation. In Dutch nursing homes, approximately 42% of the beds are reserved for people with physical disabilities (long-stay wards and rehabilitation wards) and 58% for psychogeriatric patients, including people with dementia (dementia special care units).⁵ Elderly care physicians may work on one or multiple wards, which means that a proportion of the physicians is likely not to be responsible for people with dementia. Because the type of people physicians were re-

sponsible for could not be determined on the basis of the available address files, the questionnaire was distributed to all members of the Dutch Association for Elderly Care Physicians (N = 1,124), which includes approximately 90% of the total population of elderly care physicians. The physicians who had no medical responsibility for people with dementia (physicians not eligible for the study) were asked to indicate this and return the survey.

Questionnaire Content and Administration

The questionnaire, accompanied by a letter of recommendation from the Dutch Association for Elderly Care Physicians, was sent by mail to the elderly care physicians' home addresses, followed by a reminder after 6 weeks. The questions were partly derived from previous research on this topic³ to allow for comparison of data. The questionnaire was in Dutch and consisted of two parts. The first part contained general questions about the incidence of advance directives for euthanasia in their patients with dementia and the content of the nursing home's policy regarding euthanasia.⁶ The second part, completed only by physicians who had experiences treating people with dementia and an advance directive for euthanasia, involved questions about the most recent case of a person with dementia and an advance directive for euthanasia who had died. Topics were discussion of the directive and discussion of nursing home policy, the wishes of patients and relatives, the personal opinion of the physician, and the decision-making process. Physicians were asked whether they would participate in an additional interview about the case(s) they described.

Analysis

The quantitative data were analyzed with descriptive statistics using SPSS 11.0 (SPSS, Inc., Chicago, IL). Only valid percentages are presented in the results. (Missing values did not exceed 10% of potential responders in any of the results.) The results on the wishes of the resident and the wishes of relatives focus mainly on cases in which resident or relatives confirmed, orally and clearly, the resident's wishes for euthanasia during his or her stay in the nursing home.

Interviews

Participants

Based on the cases that elderly care physicians in the survey described, additional qualitative interviews were conducted with a selection of physicians and relatives of people with dementia and an advance directive for euthanasia who had died. Eligible elderly care physicians were all physicians whose case histories met the following selection criteria: people with Alzheimer's disease or a mixed type of dementia (the most common forms of dementia), year of death of the resident between 2004 (2 years after the euthanasia law came into force) and 2007 (year of data collection), and no stated refusal by the physician to participate in an additional interview (n = 13). Data collection continued until data saturation was reached, which resulted in 11 interviews.

The interviewed elderly care physicians were asked to approach the relatives involved in their cases and ask them to participate in an interview. Because of the sensitivity of the subject, some physicians were hesitant to approach the

family. In other cases, relatives refused to be interviewed. Hence, relatives were also approached through elderly care physicians who were not interviewed but whose case histories involved a person with Alzheimer's disease or a mixed type of dementia who died between 2004 and 2007. Eight relatives were interviewed face to face.

The Interviews

The structure of the interviews with elderly care physicians was based on the topics of the questionnaire and focused on the further exploration of the decision-making process regarding the advance directive for euthanasia of the person with dementia involved (e.g., what end-of-life decisions were made and what the influence of the advance directive for euthanasia was). The interviews, conducted by the first author of this article, lasted approximately 1 hour; cases were discussed anonymously with the physicians.

The interviews with relatives focused on the way the advance directive for euthanasia affected resident care in the nursing home and on the relatives' personal opinions and experiences regarding advance directives for euthanasia. The first author of this article conducted all interviews, which lasted 1 to 1.5 hours, in the relatives' homes.

Analysis

All interviews were recorded on tape, transcribed verbatim, and subjected to qualitative analysis by the first author. A constant comparative method was used, and the analysis incorporated an iterative process of reading and re-reading the transcripts to code the transcripts and identify emergent themes.^{7,8} Atlas.ti 5.2 qualitative data software was used to facilitate this process (Scientific Software Development, GmbH, Berlin, Germany). All analyses were performed in Dutch and subsequently translated into English by a native speaker. An initial categorization system was established for the interviews with elderly care physicians and relatives based on the topics of the interview. All noncoded text segments were checked for other information that might be relevant to the research subject, and additional codes were introduced. The first author analyzed and coded the interviews, and all results were discussed within the research group involved in this project, in which the disciplines of elderly care medicine, psychology, and (behavioral) neurology were represented. Discrepancies in opinions were discussed, and consensus was reached on all themes and coded text segments.

RESULTS

Survey

Five hundred thirty-three (47.4%) questionnaires were returned; 434 were completed, and 99 elderly care physicians who indicated they had no medical responsibility for people with dementia also returned the questionnaire. Because the data collection by means of the survey was anonymous, no information was available on the nonresponders. Of the 434 physicians who completed the questionnaire, 110 indicated having treated a person with dementia who had an advance directive for euthanasia and provided us with a case history. In 75% the cases, treatment had taken place no more than 2 years before completion of the questionnaire.

Table 2. Patient Characteristics (N = 110)

Characteristic	n (%)
Sex, n (%) (1 missing)	
Male	42 (38.2)
Female	67 (60.9)
Diagnosis, n (%)	
Alzheimer's disease	48 (43.6)
Vascular dementia	18 (16.4)
Lewy body dementia	4 (3.6)
Parkinson's dementia	1 (.9)
Mixed dementia	26 (23.6)
Huntington's disease	2 (1.8)
Other dementia type	2 (1.8)
Unknown	9 (8.2)
Type of advance directive for euthanasia, n (%) (1 missing)	
Dutch Right to Die Society directive	78 (71.6)
Personal directive	25 (22.9)
Notarized directive	3 (2.9)
Other type of directive	3 (2.9)
Age, mean \pm standard deviation (7 missing)	81.9 \pm 6.7

Adherence to Advance Directives for Euthanasia

Five of the 434 elderly care physicians involved in the study reported that they had performed euthanasia on a person with dementia and an advance directive for euthanasia, but these people were all competent and able to express their wishes actively. (The directive was not really necessary in those cases.) None of the elderly care physicians reported having adhered to the advance directive for euthanasia of an incompetent person with dementia, but 35% indicated having treated (before or after the new euthanasia law) one or more people with an advance directive for euthanasia that they had not adhered to; 110 physicians described their most recent case, which dated from after the introduction of the new law. (See Table 2 for resident characteristics.) The most common type of advance directive for euthanasia is the directive that the Dutch Right to Die Society (Nederlandse Vereniging voor een Vrijwillig Levenseinde (NVVE)) provides and is formulated in such a way that advance refusal of treatment automatically replaces the advance directive for euthanasia in case the latter is not adhered to. In 43.1% of the cases, the resident had another directive in addition to their advance directive for euthanasia; these were mostly separate nontreatment directives (84.8%) and do-not-resuscitate orders (15.2%).

Discussion of the Advance Directive for Euthanasia and the Nursing Home Policy

Overall, adherence to the advance directive for euthanasia was discussed at various and sometimes multiple moments: before admission (7.3%), at admission to the nursing home (during intake) (24.7%), after admission (77.1%), or shortly before death (31.1%). In 59% of the cases, elderly care physicians indicated that the resident himself or herself was not involved in these discussions. Only five residents were found to have initiated the discussion about the

advance directive for euthanasia themselves. More often, others, such as the elderly care physician (28.6%), the resident's representative (28.6%), other relatives (27.6%) or healthcare professionals other than the elderly care physician (7.6%) (2.9% unknown), took the initiative.

The policy of the nursing home with regard to euthanasia was almost always (95.5%), according to the physicians, discussed with relative(s) or representative(s). In 54% of the cases, the nursing home policy involved nonadherence to advance directives for euthanasia, but these directives are taken into account (through a so-called "limited treatment policy," which sets limitations on life-sustaining treatments). Other policies were adherence only when all requirements of due care (Table 1) were met (27%) or if the resident had a serious physical illness in addition to the dementia (4%), no adherence ever (10%), or another policy not specified (5%). Residents were informed about the policy in 30% of the cases, 24.5% were not informed, and in the remaining cases the physicians could not remember informing the resident. Elderly care physicians indicated that, during these conversations, 85.5% of the residents did not mention their personal advance directive for euthanasia or express their wishes regarding euthanasia; according to the physicians, most residents were incapable of doing so.

Patient Wishes

Fifteen of the 110 people with dementia (on their own or someone else's initiative) talked about the advance directive for euthanasia or their wishes for euthanasia during their stay in the nursing home; five of them wanted euthanasia in the short term, three wanted euthanasia in the future, and in the remaining seven cases the wishes of the person regarding euthanasia were less clear (e.g., longing for death without clearly asking for euthanasia). Elderly care physicians indicated that the remaining 95 people had never talked about euthanasia or their advance directive for euthanasia because they were not capable of expressing their wishes ($n = 80$) or for other reasons not specified ($n = 15$).

Further analysis of the cases in which the residents during admission had actively (orally) and clearly expressed their wishes for euthanasia at some point ($n = 8$) showed that people can change their minds during their stay in the nursing home and that the opinions of residents and relatives do not always match. (Relatives often asked for limitation on life-sustaining treatments in the situations in which the patient had expressed a wish for euthanasia.) Although physicians often felt that these residents were in the situation for which the advance directive for euthanasia was drafted, in nearly every case, they thought that the person was not capable or was not fully capable of judging his or her situation and making adequate decisions. Elderly care physicians mentioned various reasons for not adhering to the advance directives for euthanasia of those residents.

Wishes of Relatives

In 16 of the 110 cases, relatives of the residents involved wanted adherence to the advance directive for euthanasia; a similar number wanted the elderly care physician not to comply with the advance directive for euthanasia. Sometimes there was disagreement between relatives (6.4%), or the relative had no opinion at all (1.8%), but in the majority

of cases (62.7%), relatives wanted a limitation on life-sustaining treatments.

Further analysis of the cases in which the relatives wanted the elderly care physician to comply with the advance directive for euthanasia of their loved one showed that often the wishes of the person could no longer be identified; some physicians indicated that this was also their reason for not adhering to the directive, although the main reasons for not adhering to the advance directives for euthanasia in these cases were the impossibility of determining the extent of suffering of the person, the restrictions of the nursing home policy with regard to euthanasia, and the personal opinion of the elderly care physician.

Opinions of Elderly Care Physicians

Despite the nonadherence to advance directives for euthanasia, in 63.6% of all cases elderly care physicians were of the opinion that the advance directive for euthanasia applied to the person's current medical condition, although the wish of the person was clear only in 21.8% of the cases; in 14 cases, the physician believed that the person did not want euthanasia, and in six cases, physicians indicated that the person would have wanted euthanasia (in 4 cases, residents had other, less-clear wishes). In 78.2% of cases, physicians were unable to determine the wishes of the person. In addition, physicians were of the opinion that 97.2% of residents were not capable or were not fully capable of judging their situation and making adequate decisions about this. Reasons for elderly care physicians not adhering to the advance directives for euthanasia of people with dementia are summarized in Table 3.

Interviews with Elderly Care Physicians

Elderly care physicians considered euthanasia to be drastic, not to be looked at lightly, and a subject that requires information (Table 4, Quotation 1). Because of the restrictions of nursing home policies, some elderly care physicians had limited discussion about euthanasia with residents or relatives. Although euthanasia was sometimes not an

Table 3. Main Reasons for Not Adhering to Advance Directive for Euthanasia (Multiple Answers Possible)

Reason	n (%)
In my opinion there was no unbearable suffering of the patient.	42 (38.2)
Nursing home policy does not allow euthanasia.	17 (15.5)
My personal beliefs do not allow it.	17 (15.5)
The patient was not in situation the advance directive for euthanasia was intended for.	17 (15.5)
In my opinion there was no hopeless suffering of the patient.	14 (12.7)
Other*	
Opinion of patient was impossible to determine or no communication was possible.	11 (10.0)
Patient currently has no wishes.	6 (5.5)
Patient does not want euthanasia or does not want to die.	5 (4.5)
Patient is incompetent.	5 (4.5)
Relatives do not want euthanasia.	5 (4.5)
Not specified.	11 (10.0)

* These answers were not prestructured but were categorized during the process of analysis.

Table 4. Experiences and Opinions of Elderly Care Physicians with Advance Directives for Euthanasia of Patients with Dementia**Physician's responsibility**

1. I think there should be information anyway, but I also think it is also the case that we should not look at euthanasia so lightly, it is a very drastic thing, for the client as well as for the physician who has to carry it out.
2. We always feel an advance directive for euthanasia is a very clear statement by someone who is coming in . . . and we basically go along with everything except with the active euthanasia.

Patient's actual behavior

3. I can't imagine carrying out euthanasia on her. Because, had I told her I am now going to kill you, she would have screamed. . . . At least that's what I think. . . . And when she was enjoying herself, she didn't want to die at all. . . . But when she wasn't having a good time, she did want to die. But even then, I still think that, even if she wanted to die then, that if I had—that just wouldn't have been possible—I could never have done it.
4. A dementia patient who has an advance directive for euthanasia and does not ask for it, termination of life, you know, or does not very explicitly utter all kinds of wishes to die and does so consistently, then I wouldn't even consider it, so to speak.

Ascertaining unbearableness

5. Someone suffers unbearably when he says he is suffering unbearably. . . . I lack the tools to ascertain it. I'm not saying it is not true, but I also can't say that it is.

Role of relatives in nonadherence to advance directive for euthanasia

6. She would have been a candidate, it was possible, only her husband prevented it really.
7. He really wanted to keep her alive. . . . I was unable to explain, medically speaking, treatment restrictions would be appropriate.

Effect on policy

8. Sometimes you are even more reticent in your medical actions because of an advance directive for euthanasia.
9. The fact that a person has thought about it, has put in writing, is well—can guide the policy, so it can . . . In the sense that you can agree on a limited, a symptomatic policy.

Expectations

10. It sometimes seems like the idea is, I write something down, and then it will be arranged as if it is my right.
11. They raise false expectations with those advance directives for euthanasia. . . . People really think it fixes everything, but that is not the case at all.

option, this did not automatically mean an advance directive for euthanasia was ignored altogether (Table 4, Quotation 2). Some physicians had personal (religious) beliefs that prevented them from considering euthanasia, or they experienced other personal dilemmas (Table 4, Quotation 3). Several physicians explained that an active request for euthanasia by the person himself or herself was essential for them to consider euthanasia (Table 4, Quotation 4). This requires communication with the patient, which physicians also indicated as being essential to be able to determine the suffering of the person (Table 4, Quotation 5). Different situations were described in which the family of the person with dementia was reluctant to consider euthanasia (Table 4, Quotation 6) or even restrictions in treatment, notwithstanding the presence of the advance directive for euthanasia (Table 4, Quotation 7). Although advance directives for euthanasia were not adhered to, physicians considered them to have a (minor) effect on their treatment decisions (Table 4, Quotations 8 and 9). Some physicians were of the opinion that advance directives for euthanasia gave people false hope (Table 4, Quotations 10 and 11).

Interviews with Relatives

Overall, acting on advance directives for euthanasia appeared to be a difficult task for relatives. Relatives indicated that advance directives for euthanasia were often drafted well before the first symptoms of dementia emerged, sometimes at the request of children but mostly on the person's own initiative. According to one relative, the patient experienced the presence of the directive as a relief, which made it easier to continue and enjoy life (Table 5, Quotation 1). After it was drawn up, the advance directive for euthanasia was not discussed or evaluated again (Table 5, Quotation 2)

until it was no longer possible to discuss the subject with the patient. Some relatives appeared to have limited general knowledge about the possibilities of euthanasia (Table 5, Quotation 3); others had a clear opinion (Table 5, Quotation 4). Euthanasia was not performed in any of the cases. There were relatives who indicated they were not ready for euthanasia (Table 5, Quotation 5) or (when the interviewed representative was a child of the patient) they felt that the patient's spouse would not have wanted euthanasia (Table 5, Quotation 6). Others never considered asking for adherence to the advance directive for euthanasia, because they did not feel that the person was "suffering" (Table 5, Quotation 7), which for one relative would have made euthanasia an act of "murder" (Table 5, Quotation 8). In some cases, the person died before adherence to the advance directive for euthanasia became a real issue. Relatives were convinced that the elderly care physicians had a positive attitude toward euthanasia, even though the advance directive for euthanasia of their loved one was not adhered to (Table 5, Quotation 9). Relatives felt that it was relatively easy to arrange to forgo life-prolonging treatment (Table 5, Quotation 10) and often chose this option, including the option of palliative sedation, instead of adherence to the advance directive for euthanasia, although looking back, relatives were not always content with this decision, because the process of palliative sedation took longer than anticipated (Table 5, Quotation 11).

DISCUSSION

This article aimed at gaining insight into how advance directives for euthanasia of people with dementia affect resident care in Dutch nursing home practice since the enactment of the euthanasia law in 2002.

Table 5. Experiences and Opinions of Relatives of People with Dementia with an Advance Directive for Euthanasia

Effect of having an advance directive for euthanasia
1. That [the presence of the advance directive for euthanasia] was well, a relief, he started living very differently after that, he became more cheerful again, he really saw a relief, he really saw a way out.
Discussion about advance directive for euthanasia
2. No. Actually we did not talk about it ever again between times. No. That [advance directive for euthanasia] was there, and it was OK.
Knowledge about advance directive for euthanasia
3. And I have no idea under what circumstances you would use an advance directive for euthanasia.
Euthanasia as a right
4. I feel that people who have indicated it in advance, absolutely have a right to euthanasia.
Role of relatives in nonadherence to advance directive for euthanasia
5. Well, maybe I wasn't ready for it myself.
6. I think that if my brother and I had told my father, "like God, Dad, think about it, don't you think it would be wise, to let Mum go to sleep, so to speak," then I don't think he would have agreed to it.
Patient's actual behavior
7. No, but there was, no, that thought never entered our minds, because, . . . Because we actually—because we actually felt that despite the fact that her dementia progressed, she still enjoyed lots and lots of things. She wasn't someone who suffered.
8. As long as he still had these moments he enjoyed, I actually saw it as murder. I couldn't find it in my heart to ask for euthanasia.
Physician's responsibility
9. If she [physician] had had the option, if it had been possible for her to do it [give an injection], I think she would have done it. But she didn't have the option.
Alternatives (for euthanasia)
10. That we didn't want any more hospitalization, no more life-prolonging treatments, the nursing home—the nursing home immediately agreed with that.
11. If you simply look at it instinctively, we would have much preferred an active euthanasia, instead of having to go through this too . . . We also assumed that it would be much quicker with this palliative sedation.

This research showed that, in practice, euthanasia in dementia based on advance directives for euthanasia had not changed from before the introduction of the euthanasia law.³ Despite the law-based possibilities, advance directives for euthanasia were rarely complied with and never in people with advanced dementia. This finding was consistent with the reports of the review committees to which cases of euthanasia must be reported.^{9–16} None of these reports described a case of euthanasia based on an advance directive for euthanasia of a person with dementia who had become incompetent. The few reported cases of euthanasia or assisted suicide involving people with dementia who had an advance directive for euthanasia in this study all proved to involve competent people who were able to express their wishes actively. The advance directive for euthanasia had no significant role other than perhaps supporting the person's oral request. Looking from the perspectives of elderly care physicians and relatives of people with dementia, this study found various explanations for this high nonadherence to advance directives for euthanasia of people with dementia.

From the perspective of elderly care physicians and based on the quantitative data, difficulty determining the unbearableness of the suffering of people with dementia was found to be one of the important elements in not adhering to advance directives for euthanasia. In other research, elderly care physicians have reported high percentages of unbearable suffering of people with dementia and an advance directive for euthanasia, without this resulting in adherence to the directive.³ Differences in interpretation due to the lack of a generally accepted definition of unbearable suffering may explain these varying numbers of reported cases of unbearable suffering.¹⁷

Less obvious from the questionnaire (possibly because it was not included as a prestructured answer), but prom-

inently present in the interviews as an important element for not adhering to the advance directive for euthanasia, was the absence of a wish of the person involved. Because advance directives for euthanasia are specifically meant for incompetent people who are unable to express their current wishes, this argument was not included in the questions on the reasons for nonadherence, although the interviews revealed that adherence to the advance directive for euthanasia was inconceivable to the elderly care physician if the resident could not confirm his or her earlier wishes for euthanasia as recorded in the advance directive. Furthermore, cases were found in which the residents' wishes had changed during their stay in the nursing home. This is to be expected in view of the fact that people with dementia do not undergo their illness passively but are constantly adapting to their changing situation.^{18,19} By examining the arguments that elderly care physicians provided in the quantitative and qualitative data, it may be concluded that (meaningful) communication with the person is essential for them to consider adherence to the advance directive for euthanasia.

The requirements of due care of the euthanasia law presume good communication between patients and their physicians;^{20,21} the fourth requirement (no reasonable alternative) directly asks for joint decision-making of patient and physician.

Relatives also experienced difficulties in acting on the advance directive for euthanasia of the person with dementia. Although some relatives insisted on adherence, others were hesitant to ask the elderly care physician to adhere to the advance directive for euthanasia of their loved one. Sometimes relatives were not ready for (discussing) euthanasia or avoided discussing the directive because of their own limited knowledge of the possibilities of euthanasia in

cases of dementia. Asking for adherence sometimes simply did not seem relevant; in several cases, relatives felt that the person was not suffering, so adherence to the advance directive for euthanasia was not a concern for them; in other cases, the person died before they had a chance to discuss the matter. Whenever the issue of adherence or nonadherence to the advance directive for euthanasia had been discussed, the decision to forgo life-prolonging treatment(s) proved easier than adherence to the advance directive for euthanasia. Relatives and elderly care physicians felt that the presence of the advance directive for euthanasia supported such a decision. Furthermore, these choices are consistent with most nursing home policies, which hold that advance directives for euthanasia are not adhered to but are taken into account in the form of limitations on life-sustaining treatments.⁵

In practice, advance directives for euthanasia do not seem to have an effect other than perhaps a supportive role in setting limitations on life-sustaining treatments, but this is not what these directives were primarily developed for. Moreover, as one of the physicians in the study pointed out, advance directives for euthanasia may raise false expectations among those who compose them and, in addition, perhaps place too much responsibility on elderly care physicians and relatives.

Some comments are in order with regard to the response rates in this study. The seemingly low response rate (47.4%) on the general part of the survey is an underestimation. The questionnaire was sent out to 1,124 (approximately 90%) of all elderly care physicians in the Netherlands, including an unknown number of physicians with no medical responsibility for patients with dementia (see Methods) and who were therefore not eligible for the study. Based on the fact that 42% of all available nursing home beds in the Netherlands are reserved for people with physical disabilities only, it was expected that this ineligible group of elderly care physicians would be larger than the 99 individuals who returned their questionnaire as requested. In all likelihood, this negatively influenced the response rate. The case histories that the 110 elderly care physicians provided are a fair representation of actual practice, and sufficient interviews with physicians were conducted to reach saturation of data, but the response on the qualitative interviews with relatives lagged behind. The sensitivity of the subject caused elderly care physicians to be hesitant in approaching families and caused relatives to refuse to participate. Nevertheless, the data provide a valuable insight into the general experiences, which allows conclusions to be drawn. Because it was decided to collect data anonymously to increase the reliability of the data and increase the response, a full description of the nonresponse group could not be provided. The anonymous data collection also meant that it was not possible to perform analyses at the nursing home level.

A possible limitation of this study is found in the method used (asking physicians about the last case) because it may have negatively influenced the reliability of the data, but this design was chosen to optimize comparability of the data with data from a previous study that used a similar design.³ Possible recall bias in the responses of physicians is another potential limitation of the study design. Difficulty recollecting events may have played a role in the description of the case

histories by elderly care physicians, although 75% of cases occurred recently (between 2004 and 2007 (year of data collection)). By selecting only those recent cases, recall bias was limited in the interviews with physicians and relatives.

The overall conclusion is that, despite the possibilities the law seems to offer, the role of advance directives for euthanasia in advance care planning and end-of-life care of people with dementia in the Netherlands is limited. Although advance directives are intended for situations in which communication with the person is no longer possible because of incompetence, the fact that people with advanced dementia are unable to communicate meaningfully about their advance directive for euthanasia seems to be the main reason for the nonadherence to advance directives for euthanasia in current practice. Because elderly care physicians have no legal obligation to adhere to advance directives for euthanasia, this indicates that euthanasia in dementia seems to be reserved for people in the early stages of the disease who are still able to communicate their wishes.

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