



Advance directives for euthanasia in dementia: Do law-based opportunities lead to more euthanasia?

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ABSTRACT

Objective: To obtain insight into current practices regarding compliance with advance directives for euthanasia (ADEs) in cases of incompetent patients with dementia in Dutch nursing homes, in light of the legal possibility offered by the new euthanasia law to perform euthanasia in these cases.

Methods: A written questionnaire was completed by 434 elderly care physicians (ECPs).

Findings: Over the years 2005–2006, many ECPs took care of patients with dementia and an ADE, actual life termination of these patients took place very rarely and never in incompetent patients. ECPs reported practical difficulties in determining the ‘unbearableness’ of the suffering and choosing the right moment of carrying out the ADE.

Conclusions: Although the enactment of the Dutch euthanasia law in theory provided a window of opportunity for euthanasia in incompetent patients with dementia and an ADE, it has not led to obvious changes in compliance with ADEs of this patient group in practice. Crucial in the reticent attitudes of ECPs appears to be the impossibility of patient–physician communication. This raises questions on the feasibility of the law on this point. In our opinion, the role of ADEs in end-of-life care of patients with advanced dementia in the Netherlands deserves serious reconsideration.

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1. Introduction

The attention for the use of advance directives as a way of allowing people to give instructions for future care and medical decisions in case of incompetence has increased over time. From that perspective, several countries have already given legal recognition to non-treatment direc-

tives (living wills) [1]. Some countries also have legislation regarding euthanasia and/or assisted suicide (EAS). In this respect The Netherlands, Belgium and Luxembourg stand out as they have also decriminalized active euthanasia in cases of incompetent patients as long as certain criteria are met and an advance directive is present. In the Netherlands active euthanasia is defined as ‘the intentional termination of a person’s life at his/her request’. Assisted suicide refers to the act of helping people to terminate their own life at their own request. The Dutch Euthanasia Legislation (Wtl) dates from 2002 [2]. In this Act EAS still falls under the Penal Code, but physicians will not be punished if they follow the due care requirements (see Fig. 1) and report cases to a regional review committee.

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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, and
6. The physician has terminated the patient's life or provided assistance with suicide with due medical care and attention.

Fig. 1. Requirements of due care in the Dutch Euthanasia Legislation.

Until the introduction of the law the practice of euthanasia was restricted to competent people and based on the above mentioned due care criteria, that were developed through jurisprudence and prosecutorial policy. The new element of the law, laid down in Section 2, paragraph 2 of the WtI and not based on prior jurisprudence, was that oral requests for EAS (requirement 1) could be replaced by advance directives for euthanasia (ADEs) as long as the remaining requirements of due care (2–6) were met in a corresponding way. Hence, the euthanasia law gave formal legal status to ADEs, with the intention of making it possible to comply with the written request for euthanasia of incompetent people, for example people with dementia.¹

In practice, when drafting an advance directive, advance non-treatment directives and advance directives for euthanasia are regularly combined in one document (often provided by the NVVE, the Dutch Right to Die Society). These documents are formulated in such a way that the non-treatment directive automatically replaces the ADE in case the latter is not complied with.

From the outset, the euthanasia legislation caused debate about the validity of ADEs in cases of people with more advanced stages of dementia. This debate focuses on the ethical dilemma of how to appreciate the current wishes and interests of an incompetent, but not unconscious patient with dementia against the background of his advance directive which may hold opposite wishes. In case euthanasia is requested this adds for doctors the question whether it is justified to actually 'end' someone life based upon an ADE [3–5]. In the Netherlands, the doctors most likely to be confronted with requests to execute an ADE are elderly care physicians (ECPs), because 92% of all patients with dementia are admitted to a nursing home in the advanced stage of their disease and die there [6]. Formerly termed nursing home medicine, this specialty, which involves a 3-year specialist training programme, has its principal site of practice in the nursing home, with 1 full-

time ECP carrying medical responsibility for approximately 100 nursing home patients [7]. Before the enactment of the euthanasia law only 4% of elderly care physicians indicated they had complied with the ADE of a patient with dementia [8]. In a study conducted in 2005 none of the ECPs, general practitioners and specialists reported euthanasia in case of a patient with dementia who had an ADE [9], indicating that euthanasia occurs very rarely.

The objective of this study was to obtain insight into current practices regarding ADEs and euthanasia in cases of incompetent patients with dementia in nursing homes, in light of the legal possibility offered by the euthanasia law to perform euthanasia in these cases.

2. Methods

This study was performed in 2007–2008 as part of a larger-scale study on advance care planning in dementia, and it consisted of a written questionnaire which was distributed among all elderly care physicians in the Netherlands who are members of the Dutch Association for Elderly Care Physicians (Verenso). The questionnaire consisted of questions about the incidence of ADEs among their patients with dementia (focussing on 2005–2006), cases of performed euthanasia based upon an ADE, and the policy of the nursing home regarding euthanasia. In addition, we used statements related to advance directives and patients with dementia, to explore the personal opinions of ECPs (with a five point scale). Data were analysed with descriptive statistics using the Statistical Package for Social Science 11.0 (SPSS Inc., Chicago, IL, USA). To explore relationships between the statements and different background variables (age, sex, working experience, religion, thoughts on performing euthanasia in the future) we used *t*-tests, Mann–Whitney *U*-tests and Pearson's correlation coefficients. In addition, Chi-square tests and *t*-tests were used to check for a relationships between background variables (age, sex, working experience, religion, nursing home policy) and the thoughts of ECPs about performing euthanasia in case of a patient with dementia and an ADE in the future. Only statistical significant relationships are presented in the text. The study was approved by the Medical Ethics Committee of the VU University Medical Center.

¹ The legislation in both Belgium and Luxembourg differs on this point, as euthanasia in cases of incompetent patients and based on an ADE is limited to unconscious people, hereby ruling out patients with dementia who might be incompetent but not unconscious and possibly still actively involved in their lives.

3. Results

The questionnaire was completed by 434 ECPs (42%).² The ECPs in our sample had an average age of 45 years (SD 8.1), had on average 13 years of working experience as a physician (varying from less than 1 year to 35 years) and two-thirds were women. On average the physicians were responsible for 57 patients, although this number varied between ECPs. These patients had somatic, psycho-geriatric and mixed problems. Not all ECPs answered all questions, which has resulted in different denominators in the calculation of percentages.

3.1. Incidence of advance (euthanasia) directives

Of all ECPs in our sample 89% (388/434) indicated having treated a patient with dementia who had an advance directive; 45 ECPs (10%) had never treated such a patient. Almost half of the physicians who ever treated patients with dementia and an advance directive (50%; 208/417) also reported having such patients ($n = 541$) among their current patients, on average 1 or 2 patients per physician. In almost half (49%; 264/541) of the cases reported, an ADE was part of the advance directive.

Over the years 2005 and 2006, 48% of all physicians (185/384) treated one or more patients with dementia who had an advance directive until death; 50 ECPs did not answer this question, mostly because of difficulties in retrieving exact numbers. In the same period 30% (118/388) of the physicians treated (until death) a patient with dementia who also had an ADE as part of the advance directive; 46 ECPs did not answer this question. Part of the ECPs ($n = 385$) provided information about the condition of these patients ($n = 188$): 65% only had a diagnosis of dementia and 35% (65/188) in addition to the dementia suffered from a serious illness, for example cancer.

In most cases (80% in 2005, $n = 58$; 76% in 2006, $n = 88$) compliance with the ADE was discussed. Over the years 2005–2006 the ADE was discussed most with relatives of the patient (90%); other parties with whom compliance was discussed were: the patient him/herself (34%), nursing staff (51%), another physician (29%) or the multidisciplinary team (26%).

Three of the 434 physicians indicated they had given medication with the intention of ending the patient's life to one or more patients with dementia who had an ADE. Two physicians did this in the year 2000, well before the law came into effect. One of these physicians assisted with the suicide of a patient with vascular dementia and a stroke, who was provided with an oral 'barbiturate'; the other physician performed euthanasia on a patient who suffered from Parkinson's disease and sub-cortical dementia by giving an intravenous injection of 'sodium thiopental and pancuronium bromide'. The third physician complied

with the ADEs of three patients with Huntington's disease (with considerable physical impairments and mild (signs of) dementia) in 2005 and 2006 by administering 'barbiturates followed by muscle-relaxants' to end their lives.

At the time of the request and performance of the euthanasia or assisted suicide, all of these patients ($n = 5$) were competent and able to actively express their wishes. In each case the drugs used to perform EAS were in accordance with the pharmaceutical guidelines.

3.2. Policy of the nursing homes

Many of the Dutch nursing homes have some guidelines for dealing with euthanasia requests. Only 6% (24/429) of the ECPs indicated the nursing home they worked in did not have a policy with regard to euthanasia. The vast majority ($n = 405$) indicated that their nursing home had an explicit policy either in writing (92%) or in the form of oral agreements (8%).

Almost half (46%) of these 405 ECPs indicated the policy included specific information with regard to euthanasia in cases of patients with dementia. In most cases (119/188; 63%) the policy entailed that advance directives for euthanasia in cases of dementia are not complied with, but are taken into account in the form of a restricted treatment policy; 16% (30/188) indicated the policy stated that requests for euthanasia in cases of dementia are never complied with, and 14% (27/188) answered that the policy articulates that requests for euthanasia in cases of dementia are only complied with if the requirements of due care are met. The majority of ECPs (88%; 165/188) who worked in a nursing home that had a policy regarding euthanasia in cases of dementia ($n = 188$) indicated they agreed with this policy. In case of disagreement, the most reported argument was that the ECP in question was not an advocate of euthanasia in cases of dementia.

3.3. Policy in practice

Two-thirds (289/434) of the ECPs indicated that it is standard practice in their nursing home to inform patients along with relatives/representatives of the policy of the nursing home regarding euthanasia. The most common moment to provide this information was during a meeting on advance care and treatment planning following admittance to the nursing home (53%; 154/289). About a quarter of all ECPs (24%; 105/434) reported that patients and/or relatives were only informed in case they actively asked for the policy statements. According to the majority of ECPs (72.6%; 315/434) after admittance of a new patient it is standard practice to inquire whether he or she has an advance directive (either a treatment directive and/or a directive for euthanasia).

According to 90% (392/434) of the ECPs, if an advance directive is present its content is also discussed with one or multiple others, like relatives and/or representatives of the patient (96%; 416/434) the demented patient him- or herself (75%; 324/434), colleagues (44%; 191/434) or a multidisciplinary team (24%; 103/434).

² 1124 questionnaires were distributed; 533 ECPs returned the questionnaire of which 99 indicated they had no responsibility for patients with dementia. Therefore these 99 were deducted from the original 1124 approached ECPs which results in a response of 42% (434/1124-99).

3.4. Attitudes/opinions of elderly care physicians

The attitudes and opinions of ECPs towards euthanasia in cases of patients with dementia and an ADE were investigated by presenting the respondents with a number of statements relevant to this context. ECPs were asked to what extent they agreed or disagreed with these statements. The results are presented in Table 1. The majority of ECPs (87%) were of the opinion that it is important for people who think about drawing up an advance directive to

Table 1
Attitudes of elderly care physicians towards euthanasia in cases of dementia ($n=434$).

	%
1. It is important that people who think about drawing up an advance directive discuss this with their physician	
Fully agree	56.5
Agree more than disagree	30.5
Neither agree nor disagree	8.6
Disagree more than agree	2.5
Fully disagree	1.9
2. All institutions should make their position on physician-assisted death known	
Fully agree	74.6
Agree more than disagree	21.9
Neither agree nor disagree	1.9
Disagree more than agree	1.3
Fully disagree	.3
3. A physician can better judge what is best for the patient in the actual situation than the patient can beforehand in an advance directive	
Fully agree	7.9
Agree more than disagree	26.7
Neither agree nor disagree	35.2
Disagree more than agree	23.5
Fully disagree	6.0
4. The presence of dementia can be a valid reason for life-terminating actions, provided that a written advance directive for euthanasia is present	
Fully agree	2.2
Agree more than disagree	14.9
Neither agree nor disagree	10.2
Disagree more than agree	36.2
Fully disagree	36.5
5. It is impossible to determine at what moment an advance directive for euthanasia of a person with dementia is to be carried out	
Fully agree	41.6
Agree more than disagree	34.6
Neither agree nor disagree	7.6
Disagree more than agree	11.7
Fully disagree	4.1
6. It is impossible to determine whether an incompetent person experiences his/her 'dementia' as unbearable and hopeless suffering	
Fully agree	17.5
Agree more than disagree	36.8
Neither agree nor disagree	14.0
Disagree more than agree	27.3
Fully disagree	4.4
7. If, in case of a person with severe dementia, there is severe suffering, this is at all times the consequence of additional illnesses or non-treatable complications of the dementia	
Fully agree	8.6
Agree more than disagree	27.6
Neither agree nor disagree	18.7
Disagree more than agree	35.2
Fully disagree	9.8

discuss this with their physician. Almost all ECPs agreed with the statement that institutions should make their position on physician-assisted death known; older ECPs (Pearson's $r=-.131$; $p=.007$) and ECPs with more working experience ($t=.132$; $p=.006$) agreed more strongly with this statement. The opinions of ECPs with regard to who can better judge what is best for the patient in the actual situation (the physician or the patient in his/her advance directive) varied, however men agreed more than women ($t=-3.081$; $p=.003$). Almost three-quarters of ECPs (73%) disagreed to a certain extent with the statement that the presence of dementia can be a valid reason for life-terminating actions, provided that a written directive for euthanasia is present; disagreement with this statement was more present in ECPs with a religious background ($t=-2.076$; $p=.039$). A similar number of ECPs (76%) found it impossible to determine at what moment an ADE of a patient with dementia is to be carried out. More than half of the ECPs (54%) were of the opinion that it is impossible to determine whether an incompetent person experiences his/her 'dementia' as unbearable or hopeless suffering (the 2nd due care requirement); older ECPs agreed less with this statement (Pearson's $r=.119$; $p=.013$). Slightly more than one-third (36%) of ECPs were of the opinion that severe suffering in the case of a person with severe dementia is at all times the consequence of additional illnesses or non-treatable complications of the dementia; 45% of ECPs disagreed with this statement.

Of those ECPs who to date had not performed euthanasia in the case of a patient with dementia and an ADE, 40% considered it conceivable that they might do so in the future; another 40% considered it inconceivable and 20% did not know. Most of the ECPs who thought they might in the future perform euthanasia in the case of a patient with dementia and an ADE added to this statement that the patient with dementia would have to be competent (75%). ECPs considering euthanasia conceivable in the future were found to be slightly older ($t=2.693$; $p=.007$) and they worked more often in nursing homes whose policy, under conditions, allows for compliance with ADEs ($X^2=6.033$; $p=.049$). ECPs considering it inconceivable to perform euthanasia in case of a patient with dementia and an ADE in the future were found to have more often a religious background ($X^2=11.1$; $p=.001$). The majority of ECPs (81%; 2 missing) claimed they had not changed their views with regard to euthanasia in cases of dementia after the euthanasia legislation came into force in 2002; 11% of ECPs claimed to have become more tolerant in their views, while 7% indicated their views had become more restrictive. In comparison to ECPs who considered it conceivable to perform euthanasia in case of a patient with dementia and an ADE in the future, ECPs considering this inconceivable agreed more strongly on statements 5 ($U=8770$; $p=.000$), 6 ($U=10.117$; $p=.000$) and 7 ($t=2.663$; $p=.008$) (see Table 1 for statements) and less with statement 4 ($U=7537$; $p=.000$).

4. Discussion and conclusions

This article aimed to provide insight into the current practice regarding ADEs and euthanasia in cases of patients

with dementia in nursing homes, in light of the introduction of the euthanasia law. To our knowledge this study is the first to focus specifically on Elderly Care Physicians (ECPs), as they are most likely to be confronted with ADEs of people with (advanced) dementia. Despite the legal recognition of ADEs of incompetent patients with dementia, our results lead us to conclude that this new element of the euthanasia law has not resulted in an increase in euthanasia among this group of patients in nursing homes. Although in the period 2005–2006 many ECPs took care of one or more patients with dementia and an ADE, actual life termination of these patients occurred very rarely and only in patients deemed competent and able to communicate their wishes.

We also found that many ECPs worked in nursing homes which had a general policy on euthanasia, but that policy rules on euthanasia in the specific case of patients with dementia was less common. The importance of institutions making their policy known was stressed by ECPs, especially the older and more experienced physicians. The most reported policy was one of non-compliance with ADEs in cases of dementia, but these directives are taken into account in the form of a restricted treatment policy. In the majority of cases patients and relatives were informed about the policy of the nursing home. The standard in many nursing homes is to actively inquire about the presence of advance directives and to discuss their contents.

The special focus of our study on the opinions of ECPs towards euthanasia and their compliance with ADEs of patients with dementia, provides possible explanations for the reticent attitudes of ECPs with regard to these issues. The majority of ECPs in our study did not consider the presence of dementia as such to be a valid reason for life-terminating actions, even if a written ADE requesting it was present. Also, ECPs reported difficulties determining the 'unbearableness' of the suffering (2nd requirement of due care) and choosing the proper moment to carry out the ADE. An additional explanation for the reticent attitudes of ECPs with regard to euthanasia might be found in the policy statements of nursing homes. The majority of ECPs reported working in a nursing home with policy statements of non-compliance with ADEs. As most physicians agreed with the policy statements of their nursing home, this is likely to have an effect on the prevalence of euthanasia among their patients with dementia. However, the limited use of the law-based opportunities for complying with ADEs of people with dementia does not mean that ECPs attach no value to ADEs at all, for it seems to be common practice in Dutch nursing homes to take ADEs in account by applying a restricted treatment policy. Commonly, such policy holds a focus on palliative care and specific restrictions on certain interventions, such as hospital admittance, cardio pulmonary resuscitation, artificial tube-feedings and/or the use of antibiotics [10]. By doing so, ECPs try to meet the ethical challenges and establish medical goals in conjunction with patients, relatives and other health care personnel. Also, ECPs do not exclude the possibility of performing euthanasia based upon an ADE of a patient with dementia in the future, although this seemed less likely for ECPs with a religious background, who more often disregard dementia as a valid reason for life-terminating actions. However, regardless their reli-

gious background, ECPs added that in order to consider euthanasia the patient would have to be competent.

In order to place our results into context we compared our data with somewhat similar studies performed before and after the Dutch euthanasia law came into effect in 2002 [8,11,12]. Comparison with these other data shows that life termination in cases of patients with dementia and an ADE has remained consistently low over the years: just before the enactment of the euthanasia law, 4% of the responding elderly care physicians indicated they had complied with the ADE of a patient with dementia [8] in 2005 no cases were reported among a wider population of physicians [9] and in our study we found only five cases of euthanasia or assisted suicide by ECPs. Notably, these five cases did not involve situations for which an ADE is intended, as all five patients were competent and able to confirm their ADE at the time of the request and the performance of AES. Compared to data from 2000 to 2001 [8,11] we found lower numbers of ECPs who took care of patients with dementia whose advance directive includes an ADE (50% and 31% respectively). However, in common parlance the terms 'advance directive' and 'euthanasia directive' are often used as synonyms in the Netherlands and this may have led to an over-reporting of ADEs in the 2000–2001 study, because the questionnaire used in this study did not distinguish between advance directives in general and ADEs. The probability of over-reporting in 2000–2001 is enhanced by the fact that there are no indications that less people have been drafting advance directives for euthanasia in 2006–2007, which is after the enactment of the law on euthanasia [13,14].

When comparing data with regard to the attitudes of ECPs, we noticed an increase between 2002 [11] and 2007 (our data) in the percentage of ECPs who think it conceivable that they might comply with an ADE of a patient with dementia in the future (22% and 40% respectively). This suggests a trend in the direction of a more tolerant attitude of physicians towards euthanasia in cases of patients with dementia and an ADE since the introduction of the euthanasia law, while this attitude was not reflected in actual end-of-life practice. However, as stated above, the majority of ECPs specifically emphasized that the patient with dementia had to be competent in order to consider compliance with an ADE. In addition, most ECPs claimed they had not changed their views with regard to euthanasia in cases of dementia since the euthanasia legislation came into force. This leads us to conclude that the more tolerant attitude of ECPs does not account for euthanasia in *incompetent* patients with advanced dementia and an ADE. In other words: there does not seem to be a trend amongst ECPs to make use of the specific opportunity for euthanasia for this patient group, which was provided by giving legal status to ADEs within the Dutch euthanasia law of 2002.

The underlying arguments for the overall reticent attitudes of ECPs towards compliance with ADEs of incompetent patients with dementia have remained nearly the same when comparing data from just before [8,9] and three years after the enactment of the euthanasia law (our study). All these studies found difficulty determining the suffering of the patient and determining the exact moment of exe-

cuting the ADE by performing euthanasia to be key issues in the reticence of ECPs.

These – persistent – arguments in our opinion point to a more fundamental problem. Both physicians and ethicists have reported repeatedly on the morally and emotionally challenging experience of euthanasia, in which a reciprocal relation of trust and mutual understanding are of crucial importance [5,15–17]. In fact, the whole structure of the due care criteria rests upon communication and shared decision-making. This is expressed in the fourth requirement which states that the physician ‘together with the patient’ has to arrive at the conclusion that there is no reasonable alternative in view of the patient’s situation. Communication is crucial in determining the circumstances as well as the exact moment of performing euthanasia. This is precisely what seems to cause the fundamental problem of complying with ADEs in cases of advanced dementia and incompetence. Without the possibility of discussing this with the person him/herself, execution of an ADE places a huge responsibility on others, including ECPs. Although general attitudes of ECPs towards euthanasia were found to be positive, this attitude seems limited to the situation of *competent* patients. In those cases the patient is often able to express his/her own wishes, which makes the presence of an ADE less relevant, although it might be supportive of the patients’ wishes and helpful in the communication.

In short: patient–physician communication in cases of requests for euthanasia is essential and this cannot be captured in or replaced by an ADE. The paradoxical nature of this situation raises questions about the feasibility of ADEs in advanced dementia and the enforcement of the law on this point: ADEs were developed for situations in which the patient is no longer able to actively communicate a request for euthanasia, but exactly this lack of in-depth communication seems to be the crucial factor in the non-compliance with ADEs.

A possible limitation of our study lies in the representativeness of our study group. Our study involved a questionnaire returned by part of the population of ECPs. Part of the non-response can be explained by the fact that of the approached ECPs a certain amount had no medical responsibility for patients with dementia, which made responding irrelevant (42% of the 65.000 nursing home beds are meant for geriatric rehabilitation and long term care for patients with non-dementing chronic conditions [18]). A significant characteristic of our responders was that they all had considerable working experience, which gave them the advantage of having experienced the situation around ADEs in dementia both before and after the introduction of the euthanasia law. Another limitation was that not all ECPs answered the questions on the number of patients with and advance (euthanasia) directive they (had) treated. This was probably caused by the time-lag between the moment of data collection and the time-period focussed upon. Difficulties in remembering or retrieving exact numbers on the amount of patients with an advance (euthanasia) directive resulted in relatively small numbers of responders for those questions. However, in view of the sensitivity of the research subject, the overall response was fairly high and the conclusions of our article

are based upon reliable answers from a acceptable number of ECPs. Part of the results are based on questions about attitudes, which may have led to socially desirable answers. Additional research into the actual behaviour of ECPs in practice is therefore recommended, but in light of the research topic this could be difficult to set up and carry out.

Overall we can conclude that while the enactment of the Dutch euthanasia law (WtI) intended to provide the opportunity for euthanasia in cases of patients with advanced dementia, incompetency and an ADE, it has not led to obvious changes in the end-of-life care of ECPs, who – when it comes to complying with ADEs of demented patients – form the most relevant group of physicians. Our findings raise questions about the feasibility of the law on this point. It has been suggested that the development of guidelines or other tools to enhance knowledge among physicians and relatives would facilitate implementation of the law [19]. Similarly, there might be a case for re(de)fining nursing home policies on euthanasia, which are often perhaps too restrictive when it comes to the possibilities of lawful euthanasia. However, it is uncertain whether such initiatives will bring about a real change in practice, as they will not affect the fundamental problem. For crucial in the reticent attitudes of ECPs appears to be the patient–physician communication and its lacking in patients with advanced dementia. As a consequence, determining the (unbearable-ness of) suffering of the patient and planning the moment of executing the ADE becomes very difficult, making it virtually impossible for ECPs to perform euthanasia. Hence, the role of ADEs in end-of-life care for people with the advanced stages of dementia remains morally problematic. ADEs might fulfil a complementary role, in the sense of initiating or supporting discussions between patient, physician, family and other health care professionals, in the earlier stages of dementia, but where the possibility for communication and joint decision-making is lost, they offer no viable approach towards a good death. In those cases an ADE would have to be interpreted as a directive for optimal palliative care and/or as a directive to forego life-sustaining treatments.

Conflict of interest

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References

- [1] Vezzone C. The legal status and social practice of treatment directives in the Netherlands. Groningen: RUG; 2005.
- [2] Termination of life on request and assisted suicide act. [In Dutch: Wet toetsing levensbeëindigend handelen op verzoek en hulp bij zelfdoding]; April 2002.

- [3] De Boer ME, Hertogh CPM, Dröes RM, Jonker C, Eefsting JA. Advance directives in dementia: issues of validity and effectiveness. *International Psychogeriatrics* 2009;1–8. Epub August 10.
- [4] Hertogh CPM, de Boer ME, Dröes RM, Eefsting JA. Would we rather lose our life than lose ourselves. Lessons from the Dutch debate on euthanasia for patients with dementia. *The American Journal of Bioethics* 2007;7:48–56.
- [5] Van Delden JJM. The unfeasibility of requests for euthanasia in advance directives. *Journal of Medical Ethics* 2004;30:447–52.
- [6] Houttekier DMA, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. *Journal of the American Geriatrics Society* 2010;58:751–6.
- [7] Hoek JF, Ribbe MW, Hertogh CPM, Van Vleuten CPM. The role of the specialist physician in nursing homes: the Netherlands' experience. *International Journal of Geriatric Psychiatry* 2003;18:244–9.
- [8] Van der Wal G, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ. Medical decision-making at the end of life. [In Dutch: Medische besluitvorming aan het einde van het leven]. Utrecht: De Tijdstroom; 2003.
- [9] Onwuteaka-Philipsen BD, Gevers JKM, van der Heide A. Evaluation. termination of life on request and assisted suicide act. [In Dutch: Evaluatie. Wet toetsing levensbeëindigend handelen op verzoek en hulp bij zelfdoding]. Den Haag: ZonMw; May 2007.
- [10] Hertogh CPM. Advance care planning and palliative care in dementia: a view from the Netherlands. In: Hughes JC, Lloyd-Williams M, Sachs GA, editors. *Supportive care for the person with dementia*. Oxford: Oxford University Press; 2010. p. 271–81 (ISBN 978-0-19-955413).
- [11] Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, van der Maas PJ. Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands. *Journal of the American Geriatrics Society* 2005;53:1138–44.
- [12] Rurup ML, Onwuteaka-Philipsen BD, Pasman HRW, Ribbe MW, van der Wal G. Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. *Patient Education and Counseling* 2006;61:372–80.
- [13] Dutch Right-to-Die Society (NVVE). Annual reports 2001 [In Dutch: Jaarrapporten 2001]. Amsterdam: Jubels; 2001.
- [14] Dutch Right-to-Die Society (NVVE). Annual reports 2007 [In Dutch: Jaarrapporten 2007]. Amsterdam: Jubels; 2007.
- [15] Hertogh CPM. The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia. *Journal of Medical Ethics* 2009;35:100–3.
- [16] Clark CC, Kimsma GK. 'Medical Friendships' in assisted dying. *Cambridge Quarterly of Healthcare Ethics* 2004;13:61–7.
- [17] Obstein KL, Kimsma G, Chambers T. Practicing euthanasia: the perspective of the physician. *The Journal of Clinical Ethics* 2004;15:223–31.
- [18] Actiz. The branch in numbers [In Dutch: De branche in cijfers]. Utrecht: Actiz; 2006.
- [19] Rurup ML, Pasman HRW, Onwuteaka-Philipsen BD. Advance directives for euthanasia in dementia. Qualitative research among physicians and patients. [In Dutch: Euthanasieverklaringen bij dementie. Kwalitatief onderzoek onder artsen en patienten]. *Nederlands Tijdschrift voor Geneeskunde* 2010;154:A1273.