

The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia

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ABSTRACT

Recent evaluation of the practice of euthanasia and related medical decisions at the end of life in the Netherlands has shown a slight decrease in the frequency of physician-assisted death since the enactment of the Euthanasia Law in 2002. This paper focuses on the absence of euthanasia cases concerning patients with dementia and a written advance euthanasia directive, despite the fact that the only real innovation of the Euthanasia Law consisted precisely in allowing physicians to act upon such directives. The author discusses two principal reasons for this absence. One relates to the uncertainty about whether patients with advanced dementia truly experience the suffering they formerly feared. There is reason to assume that they don't, as a consequence of psychological adaptation and progressive unawareness (anosognosia). The second, more fundamental reason touches upon the ethical relevance of shared understanding and reciprocity. The author argues that, next to autonomy and mercy, "reciprocity" is a condition sine qua non for euthanasia. The absence thereof in advanced dementia renders euthanasia morally inconceivable, even if there are signs of suffering and notwithstanding the presence of an advance euthanasia directive. This does not mean, however, that advance euthanasia directives of patients with dementia are worthless. They might very well have a role in the earlier stages of certain subtypes of the disease. To illustrate this point the author presents a case in which the advance directive helped to create a window of opportunity for reciprocity and shared decision-making.

Recently the Dutch Euthanasia Law that came into effect in 2002 was evaluated. The results of this evaluation were published together with the third nationwide study on the frequency and characteristics of euthanasia, physician-assisted suicide and related medical acts at the end of life, based on data from 2005.^{1,2} This third end-of-life study was the first one performed under the new law and showed, perhaps contrary to the expectations of critics of the Dutch policy, a moderate decrease in the rates of euthanasia and assisted suicide. This paper focuses on an until-now-neglected finding of this study, namely, the decrease in cases of euthanasia in patients with dementia and an advance euthanasia directive (AED). While in the second follow-up study, based on data collected just before the enactment of the Euthanasia Law, 3% of the respondents indicated that they had experience with euthanasia in dementia patients with an AED, no cases were reported in the 2005 study.^{1,3} This is all the more stupefying because the

only new element of the law—which is largely consistent with existing jurisprudence and already prevailing rules of prudent practice—was that it gave a formal legal status to AEDs, thereby raising the hope of many (mainly older) authors of AEDs to see their written request complied with in the case of dementia or a related disorder.

After a brief overview of the Euthanasia Law, this paper addresses the reasons for this gap between the formal possibility offered by the law and actual end-of-life care. This discrepancy raises the question of whether AEDs can have any role whatsoever in the practice of physician-assisted death related to patients with dementia. I believe they can, but only in restricted and circumscribed types of cases. This viewpoint will be exemplified by the case that is presented in the second part of this paper.

EUTHANASIA AND ASSISTED SUICIDE: CONCEPTS AND RULES

Under Dutch law, euthanasia is defined as "the intentional termination of a person's life at his/her explicit request". Assisted suicide refers to the act of helping people to terminate their own life at their own request. The essence of the Euthanasia Act is that a physician-assisted death (which has to be reported to a review committee) can go unpunished on condition that the physician follows these rules of due care:

- 1) the physician is satisfied that the patient's request was voluntary and well considered;
- 2) the physician is equally satisfied that the patient suffered "hopelessly" and "unbearably";
- 3) the physician has informed the patient thoroughly about the patient's situation and prospects;
- 4) the physician together with the patient arrived at the conclusion that there was no reasonable alternative to relieve the suffering;
- 5) at least one other independent physician has seen the patient and has given a written assessment of the previous requirements;
- 6) the life termination has been performed in a professional and careful way.

Within these six requirements, a distinction can be made between the more procedural and technical rules (5 and 6) and the more substantive ones that refer to (the quality of) the decision-making process (1–4). The latter constitute a coherent whole of mutually dependent requirements. Thus, the first requirement can be met only if the patients are well informed about their condition and prognosis (requirement 3), as well as about any alternative interventions that might

help to alleviate their situation (requirement 4). Likewise, the physician can only be persuaded that the patients perceive their situation as one of hopeless and unbearable suffering (requirement 2) on the basis of the joint conclusion that for these patients there is no other way to stop the suffering than euthanasia or assisted suicide (requirement 4).

It follows from these rules that the practice of euthanasia is thoroughly rooted in the end-of-life care for competent patients. This, of course, is not surprising in view of its origin in the care for patients with cancer. Up until today, oncological diseases still constitute the majority of euthanasia cases as reported to the review committees. However, ever since the beginning of the 1990s a societal debate has been taking place in The Netherlands on the possibility of euthanasia in incompetent patients with an AED, with dementia being one of the most prominent and most feared conditions for which people in an ageing society have been seeking an end-of-life solution. The Euthanasia Law offered such a solution by stipulating (in article 2.2.) that a physician can comply with an AED of an incapacitated patient, provided that “the requirements of due care are met in a corresponding way”.

REASONS FOR THE ABSENCE OF EUTHANASIA IN ADVANCED DEMENTIA

Even before the advent of the law regulating the ending of life, active termination of the life of a patient with dementia and a euthanasia declaration was already extremely rare. On analysis, the low percentage (3%) reported in the second end-of-life study might still be an overestimate, since this study only asked physicians about their intention to hasten death, which is a rather broad formulation also covering interventions such as intensifying symptom relief. In addition, with regard to the choice of the appropriate drugs, to hasten death is far from being identical to intentionally terminating a patient's life. Although officially opioids have long since been advised against in performing euthanasia, it now appears in retrospect that physicians at the time of the second follow-up study might have had a relatively poor understanding of the life-shortening effect of these drugs and thus overestimated their lethal potential.² A change in attitude towards the use of opioids, together with an improved knowledge of palliative care, might in itself explain the difference between the second and the third end-of-life studies. But in my view these factors are not sufficient to explain the virtual absence of euthanasia in cases of advanced dementia, despite the existence of a law that formally allows for such a practice.

What seems to be more important here is the uncertainty about whether or not people in the advanced stage of dementia truly suffer from the perspective they feared at the time they drew up their AED. In recent years, several expert committees have addressed this issue and arrived at a similar conclusion, namely, that the condition of dementia as such does not meet the above-mentioned second requirement of lawful euthanasia, because of the declining disease-insight (asonognosia) and the lack of awareness of cognitive deficits that typically accompany the disease trajectory.⁴⁻⁷ The realisation of having dementia—once feared as a source of degrading suffering—is progressively lacking from the patients' subjective experience, rendering it impossible for them to evaluate the present situation as unbearable and/or hopeless. In addition, recent research focusing on the patient's perspective has demonstrated that psychological coping strategies also contribute to the fact that people with dementia often come to terms with the consequences of their disease and adapt to the situation of

dementia.⁸ In addition to neurologically based unawareness, this psychological response, too, might help to explain the clinical observation that people with dementia frequently act and behave differently from the values and preferences held in the past and laid down in the AED. And although there may be considerable doubt as to the decisional capacity of the now demented author of the AED, care givers will not disqualify the current person as a moral agent and will thus act in accordance with the person's present preferences as much as possible.⁹

Yet, the paradigm of unaware, demented patients affirming their present state does not typify the whole phenomenological spectrum of dementia. Even in the absence of insight, dementia can be accompanied by more or less severe suffering from several sources. For that reason, some protagonists of euthanasia have pleaded to expand the scope of unbearable suffering in dementia by including symptoms such as anxiety, depression, various forms of behavioural problems and the loss of control of one's environment. What speaks against such proposals is that some aspects of these problems are clearly related to failing palliative care, inadequate symptom control and a social environment that lacks understanding and exposes the person with dementia to the detrimental effects of what Tom Kitwood has coined “malignant social psychology”.^{9, 10} And insofar as failing care can never be a viable motive for euthanasia, there is an urgent need for improvement here. Nonetheless, without underestimating the promises of palliative and “person-centred care”, I feel we must acknowledge that even the most dedicated care givers regularly find themselves standing empty-handed in the face of insoluble suffering. This is an embarrassing and painful situation, but the question to be asked here is whether the insolubility of this suffering also makes it “unbearable and hopeless” in the sense of the Euthanasia Law. Put differently: if a patient with an AED referring to this situation suffers from such a form of insoluble suffering, would this be sufficient reason to perform euthanasia?

When answering this question, one must bear in mind that the designations “hopeless” and “unbearable” in the second requirement of due care do not primarily refer to the intensity or severity of the suffering, but to the shared conclusion of doctor and patient that—all things considered—for this particular person there is no way to alleviate the person's situation other than euthanasia. It is clear that the state of severe dementia precludes communication at this level. There can be no intersubjectivity here in assessing the patient's condition, because of the loss of a common shared world of meaning that typifies the situation of advanced dementia.¹¹ It is often said that in advanced dementia “the suffering cannot be verified”, but this is an inaccurate formulation that overlooks the essence of the second due-care requirement. For we are dealing here not with hypotheses that have to be tested but with an intensive interpersonal interaction. Every physician who has ever had to deal with euthanasia will agree that this ultimate form of relief of suffering is possible only in the context of a relation of trust and mutual understanding. An AED can never replace this.

Thus, even in the face of obvious suffering, ending a demented patient's life out of respect for the AED is still morally inconceivable. All we can do here is to give our utmost in trying to relieve the hardship of the patient's condition, although in the end we will have to acknowledge that some suffering remains indeed insoluble.

To summarise, there are two main reasons why AEDs are not complied with. The first is that many patients—through a combination of loss of insight into what is happening to them

and psychological adaptation—don't appear to suffer in the way they feared at the time they drew up their advance directive; this is the most frequently formulated argument against AEDs encountered in the debate on this subject and in official policy-papers. The second reason, however, is more fundamental and relates to the above-quoted section of the euthanasia act stating that a written advance euthanasia request can be complied with, provided that the due care criteria are met "in a corresponding way". It is this cryptic formulation that precisely obscures what is essentially lacking in advanced dementia: the possibility of a shared understanding.

Put in more abstract terms, the problem of the discrepancy between the formal possibility the legal system offers and current end-of-life care in dementia touches upon the ethical foundation of euthanasia. This practice is generally conceived as an exceptional kind of assistance, entrusted to physicians, based on the values of autonomy (of the patient) and beneficence or mercifulness (as moral justification of the involvement of the physician). Take away one of these pillars and the whole of the euthanasia edifice collapses: it is not possible without a sustained autonomous request and it is not possible without a (bilateral) assessment of suffering, either. The problem of the AED bears upon this foundation in a specific way, because it clarifies the relevance of yet another moral value that is essential to euthanasia, namely, the value of reciprocity. For mercifulness cannot exist without receptiveness (or responsiveness, to borrow Joan Tronto's wording of this essential value in the practice of care-giving).¹² The Samaritan can be helpful only if the wounded and robbed traveller to Jericho is ready to accept his assistance, not if he rejects him, feels threatened by him or does not understand him. This is all the more relevant when the help that is offered consists not in saving life, but in assisting someone to die. Only the receptiveness of the other makes the Samaritan into a merciful giver and this receptiveness cannot be replaced by a distant request on a piece of paper. What this assistance needs is assenting reciprocity up until the moment it is given. Thus, the significance of reciprocity as an additional moral condition that supports the structure of the euthanasia practice clearly shows the limited role of AEDs. However, this conclusion does not imply that they have no function whatsoever in the practice of euthanasia. Instead, recognition of the crucial role of reciprocity does help to specify the circumstances under which an AED might be of assistance. This argument is illustrated by the following case.

CASE

Ten years after her husband died from dementia, Mrs Brown (aged 85) had a stroke. After a few days in hospital she was transferred to our geriatric rehabilitation centre. On admission she had a mild right-sided hemiplegia, combined with transcortical sensory aphasia and alexia. She was disoriented in time and place and had memory problems consisting in impaired recall of recent events with relatively intact recognition. Neuropsychological testing 2 and 6 weeks later also showed some perseveration, a lack of initiative and slightly impaired executive function.

Initially she had a varying awareness of her difficulties, and on confrontation she could become very angry with herself and her environment. What frustrated her specifically were her memory problems and her difficulties in making herself understood. Her outbursts often interfered negatively with the treatment programme. Regularly she refused to attend her speech therapy and at times she also refused her medication. Her children—who visited her daily—did their utmost to

motivate their mother. When she refused her meals, her daughter prepared her favourite dish; when she said no to her therapy, her son accompanied her and tried to motivate his mother to continue the rehabilitation programme. Several attempts were made to find out the reasons for her seemingly dissenting behaviour, but partly due to her impaired memory and speech, partly due to her children's embarrassment, these were inconclusive. During such talks she tended to look her daughter in the eye as if asking her for help but always uttered herself in terms and signs that seemed to indicate a consenting attitude. So she was held on the rehabilitation programme and in order to rule out possible depression, she also received a treatment with an SSRI (selective serotonin reuptake inhibitor) anti-depressant. Gradually she became more resigned and apathetic. She took her medication and meals and attended her therapy sessions but showed no further initiative.

Nevertheless, 4 months after her admission Mrs Brown had made a reasonable functional recovery. She could walk with a walking aid under supervision and her speech had somewhat improved. On repeated neuropsychological testing, however, her multiple cognitive impairments (of memory, language, attention, initiative and executive function) were confirmed, with no significant improvement except for her linguistic performance. It was concluded now that Mrs Brown had subcortical vascular dementia, based on lacunar infarctions and white matter disease.

When these findings were discussed with her and her children, Mrs Brown's reaction was heartbroken and desperate. It was at this time that the children presented the living will that their mother had drawn up 7 years earlier, containing an AED in case of dementia. During the past months this document—and the promise they had made to their mother to see to it that its content was respected—had weighed heavily upon them. But the prospect of possible recovery, reinforced by her referral to the rehabilitation department, made them decide to support their mother in the best possible way and hence not to discuss the advance directive as long as she was on the rehabilitation programme. However, now that the outcome of this process and their mother's prospects were becoming clear, they felt it their duty to present her earlier documented opinions on a life with dementia. And although Mrs Brown had forgotten all about her living will—and had never brought up the subject herself—she recognised it as her own, grasped it with both hands and made a very clear statement that if this was what the future had in store for her, life wasn't worth living anymore.

From this moment on she remained very consistent in her request, also in the absence of her children, and each time the advance directive was brought up she repeated her wish. We started the euthanasia protocol and went through several discussions, always with the living will as a basic document for our talks. With this document in her hands, Mrs Brown convincingly argued her case, notwithstanding her handicapped speech. In the next stage she was interviewed by a geriatrician, an old-age psychiatrist and a consultant in palliative care. They all agreed that Mrs Brown's request was voluntary and well-considered and that she experienced her situation as hopeless and unbearable. Nine months after her admission to the geriatric rehabilitation centre, she was given the requested assistance and died peacefully in the presence of her family.

ANALYSIS AND CONCLUSIONS

It should be emphasised that the case presented here is very exceptional and must be interpreted with caution. It does,

however, illustrate under what circumstances an AED can be useful for both patient and physician. Because Mrs Brown's recognition memory was spared, her previously drawn up AED helped her to tap into her formerly held values. As a sort of reminiscence work, the presentation and discussion of the advance directive allowed her to get access to her past self, which she could still identify with. Also, the advance directive compensated, as it were, for her lack of initiative. The combination of these features—relatively intact recognition performance and lack of initiative—is rather typical of vascular cognitive impairment and vascular dementia and not so much of Alzheimer disease, the type of dementia that is far more common at this age.¹³ In addition, the patient's executive functioning ability, though slightly impaired, still allowed her to evaluate her current situation in the light of her advance directive, which is a relevant criterion for decisional capacity. But most importantly, the AED in this case provided the common ground that allowed patient and physician to engage in a process of shared decision-making and reciprocity that ultimately resulted in a medically assisted suicide.

Although, in general, advance directives are meant to represent a demented patient's competent beliefs *after* the patient has lost the ability to participate in decisions regarding care and (medical) treatment, requests for euthanasia in advance directives are clearly unfeasible at this stage. In my view, however, there might be a window of opportunity, a restricted period of time in closely defined circumstances, during which AEDs can offer an opportunity to be acted on. As can be inferred from the case presented here, early dementia, especially with intact recognition and relatively spared executive functioning, can provide such an occasion. Consequently, AEDs, as a specific type of advance directive, derive their value from the possibility they offer to create and support a shared understanding between doctor and patient *before* competence is lost. It would therefore be advisable to adjust the Euthanasia Law in this direction in order to avoid misunderstandings and false expectations from people with AEDs and their healthcare proxies.

Finally, as AEDs do not execute themselves, a huge responsibility is placed on others, especially family members, because it is up to them to take the initiative of presenting the

directive, thus initiating the deliberation process. This responsibility often causes moral distress, as is illustrated by the hesitation of Mrs Brown's children to raise the subject of her AED in their contacts with the healthcare professionals. Research and clinical experience affirm that healthcare proxies often underestimate the gravity of the moral obligation they engage in, when accepting the responsibility of seeing an AED complied with.⁷ Many of them eventually shy away from this responsibility, which might be an additional reason for the absence of euthanasia in patients with dementia and an advance directive. In this respect, also, the case presented here is exceptional.

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