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Alzheimer's disease and life termination: the Dutch debate

_Viewpoint

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Introduction

Many people fear dementia and some would prefer an earlier death over having to progress into the final stages of Alzheimer's disease. One way to avoid this is to stop eating and drinking or to commit suicide. One may also wait for a life-threatening illness and then refuse treatment. Or one may ask for assisted suicide or euthanasia, as in the case of the Flemish writer Hugo Claus, whose life was terminated on his request by a physician in March 2008. Assisted suicide and euthanasia are legal only in a few countries worldwide; in the Netherlands, euthanasia (the intentional ending of the life of a person on his or her request) and physician assisted suicide (PAS) can be legally acceptable if 'due care criteria' are met: the request is voluntarily made and well considered and expresses an enduring wish; the suffering is unbearable and without prospect of improvement; the patient is informed about the situation and prospects; no reasonable alternative means exist to make life bearable; another, independent physician is consulted, and the termination of life is performed with due medical care and attention.

Internationally, much controversy exists over the legitimacy of assistance in dying if this involves actively and deliberately shortening the life of the patient. In the Netherlands there is debate over life termination when patients do not (or not only) suffer from somatic conditions, but (also) from mental disturbances such as in case of chronic mental illness, Alzheimer's disease or other neurological disorders. Currently, there is controversy over the legitimacy of PAS and euthanasia in cases of dementia (2, 3, 6). Debates center on two possible scenarios:

1. assistance in life termination on the request of a patient in the early phase of Alzheimer's disease, and
2. life termination based on an advance directive in cases where the patient has become incompetent.

Both raise common, but also different and specific ethical issues. Common is that 'unbearable suffering' is difficult to assess. A crucial difference between the two scenarios involves the voluntary and enduring request; in the first scenario it is the *current* request of the patient (which may be reconfirmed until the life terminating action takes place); in the second scenario it is the *past* request which cannot be reconfirmed because of incapacity. These issues are further explored below.

Physician-assisted suicide in the early stage of Alzheimer's disease

After a diagnosis of Alzheimer's disease, a person may request PAS. In cases of dementia, it commonly is the prospect of future decline of (cognitive) capabilities and the accompanying loss of dignity and increase of dependency which motivates requests for assisted suicide or euthanasia. Can such a request be a well-considered wish of a competent person? In the early stages of Alzheimer's, and after the first confusion following the diagnosis is over, patients may very well be able to validly request PAS, as much as they can be able to validly decide about (life saving) medical treatments and other life decisions.

And can the motive for requesting assistance in suicide be qualified as 'unbearable suffering'? Some argue that this cannot be the case, because such suffering should be in the present and actually experienced. As Den Hartogh (2) argues: 'For the person's request in his own sincere view is not motivated by his present suffering at all, but by his expectations for the future.' Nevertheless, in the Netherlands there have recently been a number of cases involving Alzheimer's patients in which the regional euthanasia review committee retrospectively concluded that the prospect of further decline of cognitive and other capabilities of the currently competent person could be qualified as 'unbearable suffering'. In these cases the patients sometimes had experience with the illness course of a loved one. The fearful prospect of personal mental decline (as the fear of suffocation in patients suffering from lung conditions) may thus imply actual (unbearable) suffering.

Termination of life and dementia advance directives

The Dutch Euthanasia Act a.o. addresses the legal status of a dementia advance directive requesting active life termination for a time when the person will be incompetent. The Act recognizes both written directives (living wills) and oral requests as legitimate. The recognition of written directives is especially important where a doctor decides to comply with a request for euthanasia in circumstances where the patient is no longer able to express his wishes. In such circumstances, a written directive counts as a well-considered request for euthanasia. However, an advance directive can never discharge the physician from his duty to reach his own decision on this request in the light of the statutory due care criteria. For dementia advance directives this implies that an assess-

ment must be made of the unbearable of the actual suffering of the patient who has become incompetent and unable to reconfirm the euthanasia request.

In the opinion of the Dutch government, the presence of dementia or some other such condition is not in itself a reason to comply with a request for aid in life termination. «For some people, however, the very prospect of one day suffering from dementia and the eventual associated loss of personality and dignity is sufficient reason to make an advance directive covering this possibility. Each case will have to be individually assessed to decide whether, in the light of prevailing medical opinion, it can be viewed as entailing unbearable suffering for the patient with no prospect of improvement.»

Some argue that it is difficult for physicians to act in such cases of euthanasia advance directives in accord with the rules of due care (1, 4). Previously, the Dutch Medical Association took the view that in cases of comorbid somatic illness it could be conceivable that an incompetent dementia patient was suffering unbearably (5). Nursing home physicians have pointed out that they consider it unimaginable that they would actively terminate the life of a demented patient who is unable to reconfirm his euthanasia request, and who may find no dissatisfaction in his demented existence.

No cases of euthanasia based on a dementia advance directive have yet been reported to the regional review committees or the public prosecutor. However, with an estimated notification rate of 80.2% in 2007, this does not mean that such cases have never occurred. Research shows that in the experience and opinion of interviewed nursing home physicians «the patient's suffering was unbearable to a very high degree in four of 39 cases [of euthanasia advance directives of demented patients, RB, BM, GW], to a high degree in six cases, and to a lesser degree in 14 cases.» In the other 15 cases they did not think that the patient's suffering was unbearable. This means that according to physicians, it is not hypothetical that a patient in a progressed state of Alzheimer's disease may experience unbearable suffering. Reasons for considering the suffering unbearable included: dementia itself (from the progressive deterioration or because the patient did not understand things anymore and was afraid), increasing dependence, agitation or confusion, anxiety, pain, cramps or contractures, difficulty breathing, pressure ulcers, vomiting, and depressed mood (7). The degree of suffering was particularly associated with breathing difficulty, cramps or contractures, agitation or confusion, pain, and anxiety. So although Alzheimer's disease *per se* may not involve unbearable suffering, a case can be made for arguing that accompanying symptoms, as well as comorbid conditions, may lead to the conclusion that a person suffers unbearably.

Conclusion

Life termination in Alzheimer's disease raises complex ethical questions. It cannot be ruled out that in particular circumstances physician-assisted suicide in the early stage of the illness may be justified on the basis of the consideration that the person suffers unbearably from the prospect of further progression of his condition. Neither do we think that it is defensible to categorically rule out euthanasia in advanced stages of dementia on the basis of a previously formulated euthanasia wish in an advance directive, when the patient actually suffers.

More debate is needed about the issue of suffering in dementia, both with regard to the prospect of progressive deterioration in case a person is diagnosed with Alzheimer's disease, as well as regarding the possibility of suffering during the process of dementia, particularly in the stages when the patient has lost decisional capacity. Also, more debate is necessary about the moral justification of life terminating acts in dementia. Is it exclusively the prevention of unbearable suffering? And what, if anything, counts (or does not count) as unbearable suffering? Only rational debate, together with empirical research, may clarify these issues and foster careful and responsible practices at the end of life.

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