

COMMENTARY

Ageism and euthanasia in the Netherlands: questions and conjectures

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ABSTRACT *The authors question whether or not age plays a role in the honouring or rejection of euthanasia requests in The Netherlands, where euthanasia was legalised in 2002. They argue that qualitative case studies suggest that the current application of legal requirements of due care with regard to euthanasia (incurable and unbearable suffering, competence, and consistency of request) leads to discrimination against older people who ask for euthanasia. The authors plead for systematic research on this problem.*

Introduction

In an article that has gained some notoriety the American anthropologist Glascock investigated the treatment of older people (now and in the past) in 41 non-industrialised societies. According to Glascock in half of these societies 'death-hastening behaviour' occurred: the death of the elderly was systematically hastened by withholding care, refusing them food, leaving them behind to die, or by actively killing them (Glascock, 1983, 1990). The Netherlands, a country which has 'pioneered' the legalization of euthanasia, is sometimes criticised by foreign observers and suspected of ageist application of 'the gentle death' (Hendin, 1996, Krauss, 2000). Dutch society does not want to be characterised as 'death hastening', however. 'Ageism' (discrimination based on age) may occur, but to hasten people's death *because* they are old is generally looked upon with indignation. In a study about elder mistreatment (estimated to occur with about 6% of the non-demented elderly living at home) no connection has been made with the hastening of death (Comijs, 1999). In this paper we acknowledge that euthanasia for elderly people is indeed a highly sensitive topic in The Netherlands and argue that physicians generally want to prevent any suspicion that the lives of older people are shortened. This, we argue, may lead to an opposite form of ageism: the unjust rejection of euthanasia requests by older people.

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Do physicians in The Netherlands indeed discriminate against older people asking for euthanasia? To answer this question we first deal briefly with the rules of euthanasia. We then discuss three criteria for granting euthanasia and look at their consequences for the elderly. Our argument is not based on systematic research, instead it poses questions and makes conjectures on the basis of cases mentioned in the literature. There are very few 'hard' figures available about this matter but it is worth noting that some years ago almost half (43%) of out of 136 cases of euthanasia and assisted suicide concerned people younger than 65 (Van der Wal & Van der Maas, 1996). Reasons for the apparent 'under-representation' of older people could be their higher pain tolerance as a result of their life experiences and their different value system, particularly religious objections to euthanasia. Other figures suggest, however, that euthanasia is more often denied to older than to younger people. Haverkate *et al.* (2001), for example, report that out of 234 honoured requests for euthanasia only 9% involved cases of people aged 80 years or older and of the 148 rejected requests 24% concerned this age category.

Euthanasia and assisted suicide

Public discussion in The Netherlands about euthanasia since the 1970s has led to gradually increasing public support for the allowance of euthanasia in certain situations. In recent decades the policy of physicians and government has paralleled this development. Until recently euthanasia was prohibited by the Criminal Code, but it was institutionalised via regulations. Legislators decided to allow euthanasia in certain situations. In 2001 this practice was finally legalised. The law stipulates that in order to allow euthanasia there must be unbearable suffering without prospect of improvement and a voluntary and well-considered request from the patient who is competent to express his/her will. A second physician must be consulted and the euthanasia has to be carried out with due medical care and attention. According to the Ministry of Justice, euthanasia is a life-terminating action on the explicit request of the patient. These rules also apply to assisted suicide.

Ageism

Ageism differs in one important aspect from other forms of discrimination such as racism and sexism (Bytheway, 1995). The other -isms are usually based on unchangeable characteristics which deviate markedly from the characteristics of those who discriminate. This does not apply to ageism; all people grow older and those who discriminated against older people when they were young may themselves suffer from ageism in a later phase of their lives. A second point to notice is that discrimination against older people does not only imply restricting their rights but can also include overprotection. Could this also be the case with regard to euthanasia?

Decision-making with regard to euthanasia

A person who wants euthanasia conveys his/her request to a physician and the physician decides whether or not to honour it. It is exactly at this point in time that discrimination is likely to occur. There is a risk that the physician decides to grant euthanasia when this is not what the person in question wants, but the opposite is also possible: the request of the person in question is unjustly rejected. Robert Pool (2000), who studied euthanasia in a Dutch hospital, explains that decision-making with regard to euthanasia is an equivocal process. It consists of many individual, often implicit, decisions. Personal characteristics of the physician play an important role. According to Pool decisions with regard to euthanasia are taken independently for each case, and are not based on clear common rules. Just when he thought he had begun to understand the decision-making process, he was confronted with a case in which everything went totally differently than he had expected. The context in which the decision is made is determinative, especially the communication and interaction between those involved.

For an exploration of decision-making and ageism only the first two requirements of due care (see above) are relevant: (1) there must be unbearable suffering and (2) a carefully considered, consistent request. This supposes that (3) the patient is mentally able to make this request. A patient must, therefore, fulfill three conditions before a physician can honour his/her request for euthanasia. The consequences of these three demands for older patients will be discussed using examples mentioned in the literature.

Incurable and unbearable suffering

The law on euthanasia states that there can be no incurable and unbearable suffering when there is still a prospect of improvement or when the patient has voluntarily refused further treatment (according to Dutch law patients have the right to refuse treatment they do not want). It is the physician who must judge whether or not the patient's suffering is indeed unbearable and incurable. But what is suffering, what influences suffering and when does it become unbearable?

'Suffering' is a much broader concept than 'pain'. Van der Wal and Van der Maas (1996: 56) report that in 74% of the cases they examined 'unbearable and incurable suffering' was mentioned as a reason for an euthanasia request and 'pain' was cited in only 32% of the cases. Suffering becomes unbearable within the context of someone's total life situation. Kleinman *et al.* (1994) remark that besides the biological and psychological factors, socio-cultural factors also have an important influence on suffering. Physical, mental and socio-cultural well-being cannot be viewed as separate. For Kleinman and his co-authors the concepts of pain and suffering overlap. Additionally they argue:

Pain is an inner experience, and even those closest to a patient cannot truly observe its progress, or share in its suffering. Patients thus have no means to establish its validity as an 'objective' part of the world for health professionals or

society at large. Absolute private certainty to the sufferer, pain may become absolute public doubt to the observer. The upshot is often pervasive distrust that undermines family as well as clinical relationships (Kleinman *et al.*, 1994: 5).

Suffering, therefore, is a subjective experience. Yet according to the requirements of due care with regard to euthanasia the suffering has to be judged by another person, a physician. When does a physician consider a person's suffering to be unbearable?

Nursing home physician Bert Keizer writes about the most horrible deathbed scene he witnessed in his career: 'I can't get Jules out of my head, I still smell him . . . I have never seen someone suffering so much' (Keizer 1995: 115). One can wonder what made this dying so awful. The statement concerns a young man who had AIDS to whom the physician had granted the request for euthanasia. As a reason for his request Jules had indicated: ' . . . It is now all becoming too animal for me. I am having the runs day and night. And did you have a close look at me? I am looking dreadful, dreadful. I cannot lie or sit without pain. I can't go on . . . ' (p. 109). Not only is the pain mentioned, but also his looks and incontinence. It is significant that the physician labelled this suffering as unbearable. As a nursing home physician he had witnessed a lot of suffering, but this was the worst. His book provides several examples. Why was this case worse? We will suggest an answer in a moment.

Pool's study also mentions an AIDS patient, David, whose euthanasia request is also comparatively quickly and easily honoured for the same reasons. In both books several other examples of terrible suffering are mentioned, but their requests for euthanasia raised much more doubt in the physicians. In some of these cases the euthanasia request was in fact rejected. What distinguished those cases from others? Was it the disease? Was it the person? Or were there other factors involved? Besides the problem that suffering is a subjective experience which is difficult to assess by others, the assessment is also influenced by other factors. For Chabot (1996) suffering can originate from life experiences or psychiatric diseases. Suffering can be caused by physical constraints which are often the result of a disease such as being no longer able to walk and being dependent upon others for daily activities such as eating and washing oneself. Suffering can also stem from anxiety about the disintegration of personality (degradation) and loss of human dignity.

In the cases of both AIDS patients their suffering was sufficient for physicians to grant their requests for euthanasia. Let us compare this with another case which Pool (2000: 135–156) describes. Mr. Oosten was an elderly chronic lung patient who frequently requested euthanasia in direct terms. In his case, however, the attending physicians rejected the request for euthanasia. Instead, the ward physician gave him more active morphine treatment to suppress the tightness in his chest which eventually would lead to his death. The physicians remarked repeatedly that in their opinion this was not yet a case of unbearable suffering. For instance: ' . . . Mr. Oosten is not really in *such* a bad shape. . . . When you look at him lying there in bed, you get the impression that his situation is bearable. His real problem is that he doesn't want to go to a nursing home' (p. 137).

Comparing Mr. Oosten's situation with Jules' or David's condition, one wonders why the request for euthanasia was not honoured in all these cases. Was David's suffering worse than Mr. Oosten's? It seems an entirely different element plays a role here: a social view of when suffering is 'normal' and 'acceptable' and when it is not. This view is centred around the age of the sufferer. A young man of 20 or 30 should be vital and robust. He is 'in his prime' and his looks should be attractive. An older person, on the other hand, often suffers from chronic disease, which causes pain and constraints. He is less mobile and more dependent on others. The aggravating results of the disease, such as tiredness, tightness of the chest and incontinence, occur more frequently and are, therefore, 'normal' and not the cause of exceptional suffering. The appearance also changes when people grow older and no longer conform to the standards of youthful beauty: slim and tight-skinned.

Pool also discusses the second aspect of the first requirement of due care, the incurability or the untreatability of the suffering on the basis of Mr. Oosten's case. Only when there are no prospects of improvement left can euthanasia be allowed. According to many people this means that a disease has to be terminal or deadly. Mr. Oosten's physicians mentioned this as well: 'But he's not yet in the terminal phase.' (p. 137); '... the man didn't even have a malignancy. Of course, he has a serious disease, but if you look at the population as a whole, then there are a lot of people with serious diseases like that' (147). According to Mr. Oosten's physician there had to be a serious disease which would cause the patient's death within the foreseeable future. If this was not the case, but the suffering was the result of a more chronic disease – which was not immediately life-threatening – it had to be so serious that the quality of life was unacceptable, and even then under the following condition: 'The patient must have tried, or at least considered, the various options that are available for alleviating his or her suffering, or, rather the doctor must be convinced that this has occurred to a sufficient extent' (p. 149). With regard to this point, patient and physician can have a strong difference of opinion. Older patients who consider they have lived their life and that it is good the way it is ('there isn't much left on the menu'), will reach the limit sooner than their attending specialists who restrict themselves to pathology in a technical sense.

This leads to our first question: could the demand that there must be unbearable and incurable suffering give rise to discrimination in the sense that a request for euthanasia by an older person will be honoured less quickly than the same request made by a younger person?

Competence

The second requirement of due care is that the physician holds the conviction that the request by the patient was voluntary and well-considered (and persistent). We split this requirement into two aspects, which are strongly related, namely that the patient is competent (capable of expressing his/her will) and that there is a carefully considered and persistent request for euthanasia. We will look first at the ability to express one's will.

At the time of their request patients must have complete awareness of their physical situation and the importance of their request. Patients must be able to make the decision themselves. Groups that do not meet these requirements according to Dutch law are minors (even though there is disagreement about the correct age) and mentally handicapped people. These categories are excluded from consideration because other rules apply to them. A more dubious group consists of people who suffer from a psychiatric ailment. Although the psychiatrist Chabot (1996) argues that their suffering is just as unbearable and incurable as is the case with physical diseases, there is still a lot of debate about whether or not requests for euthanasia from people in these groups should be honoured. At present, as far as we know, euthanasia is seldom administered to these people. Another category considered to be incapable of expressing its wishes personally is comatose patients. Even though many elderly people with a serious disease can in due course belong to this group, perhaps as a result of a stroke or another acute disease, or as the last phase of a chronic disease, we will also leave this category out of consideration. According to the law, in these cases euthanasia cannot be granted because these patients cannot make the request themselves.

When are people considered to be incompetent (incapable of expressing their will)? In medical science it is known that older people can become temporarily confused as a result of an acute physical disease, severe pain, use of drugs or just by the stress of hospitalization. As a result, they also run a greater risk of becoming depressed. Whether or not a euthanasia request is made because of confusion, depression or a real death wish, is often unclear. It is particularly hard to determine whether or not a patient is competent when confusion or depression first begins. This can lead to the unjust honouring or rejection of a euthanasia request. From the literature it appears repeatedly that yet another problem can occur: namely, that a formerly expressed real death wish will eventually not be honoured because the patient becomes confused or depressed.

In another study of euthanasia in a Dutch hospital, The (1997) describes the case of Mr De Boer, a cancer patient who arranged everything for possible euthanasia at an early stage: he authorises his sister and finds a general practitioner who is willing to consider euthanasia (The, 1997: 87–108). Mr De Boer is hospitalised as a consequence of suspected brain metastasis; he has fits of confusion and requests euthanasia. The physicians ignore his written euthanasia directive and do not consider his suffering as severe. They only look at his physical condition. They do not know to what extent his death wish is real. 'The psychiatrist thinks Mr De Boer's request is real. Yes, when Mr De Boer has a lucid moment he talks about it in a realistic way. But often he is confused' (p. 93). Ultimately Mr De Boer did not receive euthanasia, despite the fact that he had arranged everything beforehand.

Keizer (1995: 34) mentions a similar case: a 93-year-old woman who has a longstanding willingness to die and has also indicated this wish. Now her children request that this wish be honoured. The answer is: 'I am afraid she and you, and others, have waited too long. Now she has moments that she loses her bearings and she has become too mentally confused to express her death wish coherently.'

Even though a patient has arranged everything beforehand, the moment he/she becomes confused, everything changes. There is no right time; you are either too good or too bad. Keizer comments '(t)he cruelty of old age, and especially of very old age, is that it is a trap you walk into unexpectedly. When you want to turn around to flee, it has closed, without you ever noticing it. . . . You can only establish the right moment when it is too late' (Keizer, 1995: 292). Dementia, the fate of many older people, disqualifies people for euthanasia in The Netherlands for two reasons: it is seen to be a component of old age (and therefore is 'normal') and it renders the sufferer incompetent.

The seemingly objective requirement of competence appears to be open to many interpretations and leads to our second question: could this confusion about competence lead to the unjust denial of euthanasia to an older patient?

Consistent request

According to the second requirement of due care, there must also be a consistent request, which means: a voluntary, well-considered and lasting request. Lam (1997: 15) remarks that a request for euthanasia can only be honoured 'when the care provider hears the request in his own social and cultural context, and recognises and acknowledges the request. In every society, only the requests made by a certain category of people are honoured.' In their studies Pool (2000) and The (1997) it is repeatedly remarked that good communication is essential in order to recognise a consistent request for euthanasia. From examples of both studies it becomes clear that the form of communication can determine whether or not a euthanasia request is honoured. The (1997: 65) indicates that patients with a strong personality who are very decided and persistent have a better starting position. Pool shares this conclusion. It would mean that patients with a higher level of education (i.e. fewer older patients, as the average level of education among older people is lower than among younger generations) stand a better chance of being granted their request than patients with less or no education. The former have learned to express themselves in a way that doctors acknowledge.

Another factor is that the physician–patient relationship is a hierarchical one. The physician has the medical knowledge and therefore the patient is dependent on the physician. A patient who takes a more equal position, due to equality in the social and cultural world, will suffer less from the consequences of this. This also seems to be the case with the AIDS patients Jules and David discussed earlier, both well-educated, young men. Older patients usually accept more distance from the physician; they are used to 'paternalistic physicians' who only partly inform their patients about their diseases and often take decisions on their patients' behalf. In such a relationship patients are less likely to convey their wishes directly to the physician and are more easily impressed by medical language and physicians' claims that their time is 'precious.' It is plausible, therefore, that older patients pose their request for euthanasia less directly and less effectively. If they are not able to formulate their arguments clearly, they run the risk that their request will be rejected.

This brings us to our third question: do older people run a greater risk that their request for euthanasia will be rejected because physicians take their requests less seriously?

Conclusion

The fact that ‘others’ make decisions about the euthanasia request made by people who want to die, is, on the one hand, understandable. It concerns a medical–technical action and great care must be taken. On the other hand, it is notable that people are dependent on relative strangers for this important decision—people who cannot feel what they experience. It is not surprising that such regulations can lead to unwanted developments. Our discussion of qualitative research on euthanasia in The Netherlands poses the question of whether or not older people who choose to die run the risk of having this choice handled badly.

Pool noted that euthanasia occurred only rarely in hospital wards with many older patients, such as those for internal medicine, neurology and geriatrics, and that physicians on these wards were rarely open to requests for euthanasia. It could be that as elderly people often die at home or in a nursing home, the occurrence of euthanasia will be higher in these places. However, research by Van der Wal (1992: 137) on euthanasia in a general practitioner’s practice showed that here too there were many fewer cases of euthanasia among older patients than among younger ones, especially among those older than 75. The author wondered why and concluded that more research was needed. In nursing homes it seems that there are also relatively few cases of euthanasia. Thus the frequently used argument by opponents of euthanasia, that there is a great risk that elderly people become ‘victims’ of euthanasia, is not confirmed by the—admittedly scarce—literature. It seems that euthanasia is indeed practiced less often on older compared to younger people.

Hard conclusions cannot be drawn from this exploration of literature. There is little known about the use of euthanasia, especially in nursing homes and in home situations where most older people in The Netherlands die. It is possible that physicians who grant euthanasia to older people make less mention of it, exactly because this form of euthanasia is regarded with more suspicion and they want to avoid any impression of ‘ageism’. For the time being, however, there are indications that point in another direction. There are reasons to believe that older people who make a euthanasia request are taken less seriously and are thus the victim of another type of ‘ageism’. Only further research can point out whether this is indeed the case.

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