

Scientific Contribution

Physicians and the End of Life in the Netherlands¹

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Introduction

Although the Netherlands is an extremely flat country, it appears to have slopes that can even be skied down from, when it comes to euthanasia. At least, that is what many authors commenting on the Dutch experience with euthanasia want their readers to believe. Mostly those comments add up different types of end-of-life decisions. Rather than repeating our critique that this kind of reasoning is based on unacceptable simplifications [1], I would like to try to further the discussion by trying to analyse the Dutch situation. I will do so by discussing the different moral frameworks for euthanasia and the public policy with respect to euthanasia and assisted suicide that has been developed in the Netherlands. I will use the term 'euthanasia' in the Dutch way: euthanasia is the intentional ending of a patient's life at the patient's explicit request. I will treat assisted suicide as a variant of this: in this case the patient takes the lethal drug herself instead of this being administered by the physician.

Moral frameworks for euthanasia

The Netherlands are often criticized for their presumed lack of palliative care. The existence of relatively few hospices in The Netherlands, for example, is often interpreted as proof for a neglect of palliative care. Other indicators point in a different direction. There is good general access to good health care in the Netherlands, with full cover for terminal and palliative care. Indeed, our palliative care system does not rely on hospices, but there is good palliative care at home, in nursing homes, or hospitals. Palliative consultation teams have been set up, which can be consulted by the 7800 general practitioners, taking care of the 65% of cancer patients dying at home.

So although we can conclude that much of the mentioned criticism is based on misunderstanding and much effort has been made to improve palliative care in the recent past, it is certainly correct to say that the Netherlands could still improve the provision of

adequate palliative care. Which is, of course, also true for many other countries. But what does this mean for a moral evaluation of euthanasia?

By and large there appear to be three ways of dealing with the issue of euthanasia. [2] The first is to reject it on the grounds that it is forbidden by the principle of respect for life. Proponents of this view often also claim that euthanasia is not necessary at all. With sincere attention for the person who requests euthanasia the 'question behind the question' will surely turn out to be something else than a request for dying and with good palliative care extreme suffering need not remain unanswered. In this view euthanasia and palliative care are incompatible and less euthanasia will result from better palliative care.

An alternative response to the euthanasia issue stresses the importance of compassion. From this point of view, respect for life is of paramount importance as is good palliative care. Sometimes however, supporters of this view admit, illness and dying come with such suffering that life is reduced to pointless surviving. If all other palliative measures fail, then euthanasia may be justified. The result of this view on euthanasia is the medicalisation of the end of life, since whether or not euthanasia is justifiable becomes largely a matter of medical discretion.

These two responses appear to differ foremost in their answer to the questions 'does intractable excruciating suffering exist?' However, even palliative care specialists will state that, unfortunately, this is true. The real difference therefore, will be whether or not one allows the principle of respect for life to be overridden by other considerations in special circumstances or not.

Most proposals to regulate euthanasia follow the second view. This is by and large also true for the law on euthanasia in The Netherlands. This law, effective as of April 1, 2002, states in article 2 that an act of euthanasia will not be punishable if performed by a physician who reports the cases and acted according to the following rules of due care stating that he or she:

- Should be convinced that the request of the patient was voluntary and well-considered (a);
- Should be convinced that the suffering of the patient was unbearable and without a prospect of relief (b);
- Should inform the patient about his or her situation and prospect (c);
- Should come to the conclusion, together with the patient, that there is no reasonable alternative solution for the situation of the patient (d);
- Has consulted another independent physician who has seen the patient and agrees with the evaluation of the physician on these four points (e);
- Performed the euthanasia in a careful way (f).

Parts b and d of this article clearly create room for an independent, professional evaluation of the situation by the physician. So even under this law, there is no right to die in the Netherlands, nor an obligation for the physician to comply with a request of a competent patient if certain conditions are met. Therefore, my conclusion is that euthanasia is officiously treated as a last resort.

The reality of the Dutch euthanasia practice, however, seems to develop itself into another direction, with increasing emphasis on respect for patient autonomy. This could lead to a shift to a third approach in which euthanasia is seen as a choice. Some patients do not want to live through suffering and decline, even if pain can be controlled. They want to autonomously decide about how and when to die and want their relatives to remember them as they were when they were more or less healthy. They want to step out of life before the terminal phase really starts and they want a doctor to do the lethal work.

This development is reflected in the data produced in many studies in the Netherlands. The first nationwide study of end-of-life decisions showed that pain hardly ever was the sole reason for requesting euthanasia.[3] In 1992 Van der Wal in an independent study, already described that (among other reasons) in 56% of cases of euthanasia, requests were made because patients thought suffering to be pointless and in 46% because they feared the decline.[4] And the 1996 report showed that many patients asked for euthanasia to prevent more suffering.[5] The latest study, reflecting the situation in 2010, showed that the most important reasons for a physician to grant euthanasia requests were the wish of the patient (85%), no prospect of improvement (82%), no more options for treatment (73%), and loss of dignity (61%). [6]

Maybe even more importantly, the latest nation-wide study, with data from 2010, showed that the frequency of euthanasia is rising. Not only were there more requests (13400 in 2010, as compared with 9700 in 2001), but the incidence of euthanasia clearly rose (see table 1). [7] The increase in the incidence of euthanasia is related to both an increase in the number of explicit requests for euthanasia (from 4,8% of all deaths surveyed in 2005 to 6,7% in 2010) and the proportion of requests that were granted (from 37% to 45% of requests). [6] The rising trend in incidences is also reflected in the latest annual report from the review committees: 4829 cases of euthanasia or assisted suicide were reported to the committees in 2013. [8]

One may also predict (as an aside) that this emphasis on patient autonomy will lead to a change in the medical circumstances in euthanasia cases. At this moment cancer is by far the predominant diagnosis.[3][5][6] The shift towards autonomy-based decisions, however,

will lead to an increase in the prevalence of situations characterised by a loss of autonomy (such as in case of dementia or after a stroke).

This emerging sense that one does have a right to die, means that more palliative care does not necessarily lead to a decreasing incidence of euthanasia. From a sociological point of view one may be tempted to interpret the shift towards autonomy-based requests for euthanasia as a side effect of a liberal society with its emphasis on self-government, control and rational choice. Opponents of euthanasia will presume that they can rest their case: their prediction of the slippery slope has come true. Others will say that more emphasis on patient autonomy fits perfectly in the process of emancipation of the patient that has been going on since the beginning of the 70s. They might say that it is about time to start thinking about patient decisions concerning the end of life, in stead of about medical ones.

From a moral point of view, however, it should be stressed that euthanasia by a physician can never be exclusively based on respect for patient autonomy. A physician is not in the service of the patient's self-determination, he has his own job to do serving the well-being of the patient. It may be the case that the patient's suffering can only be ended by ending his life. But in that case the physician's motive is compassion, not respect for autonomy. If this is true, and I think it is, the physician should form an independent judgement that the patient is right in considering his suffering hopeless and unbearable. Now of course protagonists of patient autonomy will argue that the question whether a person's suffering is unbearable can only be answered by that person himself. This view however is based on a misunderstanding. Granted that unbearable suffering is subjective in a certain sense, it does not follow that the person himself is always in the best position to assess his condition in terms of even these subjective criteria. The fact that the patient's perspective is relevant (which it is, of course) does not imply that his assessment is final.

This has relevance for an actual development in the Dutch euthanasia debate. Part of the law is an article to legalize living wills containing a clause in which euthanasia is requested in certain circumstances. A well-known example is the dementia-clause stating that the person wishes to be euthanised when he is no longer able to recognize anyone of his close relatives and friends. But on the second view I just described and which is the basic idea of the proposal itself, it is impossible to require a physician to kill a person who, at that moment, does not want to be dead and who is not actually suffering, just because this same person (really the same person?) requested this to be done some years before. Here one can clearly see a growing tension between the dominant view on the morality of euthanasia which relies almost exclusively on the principle of individual self-determination, and the fact that this view has never been accepted by the law, nor by medical practice. [9]

Table 1: Incidences of euthanasia and assisted suicide in the Netherlands, as percentages of annual deaths

Year	euthanasia	assisted suicide
1990	1,70%	0,30%
1995	2,40%	0,30%
2001	2,50%	0,20%
2005	1,70%	0,10%
2010	2,80%	0,10%

Reporting euthanasia

To accept euthanasia in an individual case is one thing, to accept it on a public policy level is quite something else. It is often argued that proposals to legalize euthanasia can never contain absolute safeguards.[10] I think this is true: there is no rule that cannot (and will not) be broken. By the way, this goes for the prohibition of drunk driving as well. The question is whether this justifies a prohibition of euthanasia in an individual case. The Dutch in the past tried to have it both ways by creating a public policy based on individual cases. The least one can say is that this resulted in a unsatisfactory situation of accepting and prohibiting at the same time. This created uncertainty and vagueness both for patients and physicians and contributed probably to some extent to the critical reports of the Netherlands in the early 1990s.

Persuading the physician to bring euthanasia cases to the knowledge of the authorities is a problem of any euthanasia policy. The Dutch notification procedure helped to raise the notification rate from 18% in 1990 to 41% in 1995.[5] The government has tried to further diminish the number of unreported cases by developing a new notification procedure, in which much of the assessment is done 'outside of' the legal system. Since 1998, five regional multidisciplinary review committees have to assess all reported cases of euthanasia and assisted suicide. Since 2002 (under the euthanasia law) the assessment of the committees even is the final evaluation (and not just an advise) in cases judged to be careful. Only cases in which the physician did not meet the criteria, are transferred to the public prosecutor.

These committees consist of a lawyer, a physician and a ethicist. They meet approximately once every three weeks to discuss the reported cases. The outcome of these discussions can be one out of three things. Mostly the committee will conclude (perhaps after being further explained by the reporting physician) that the physician has acted carefully

and has met the standards. If the committee feels that the physician had not acted in a careful way, that case is handed over to the prosecutor who will then certainly start a legal investigation. In other cases where legal standards were met, but the case was not sufficiently careful from a professional point of view, the medical inspector may be alerted. In the 5-year period from 2007 to 2011 14.177 cases of euthanasia or assisted suicide were reported to the committees. Of these 36 did not fulfill the legal criteria (0,003%) [7].

The absolute number of cases of euthanasia or physician-assisted suicide in 2010 was about 4050. In 2010, 3136 cases of euthanasia or physician-assisted suicide were reported to euthanasia review committees in the Netherlands. In the questionnaire of the nation-wide study it was also asked whether physicians had reported their act to a euthanasia review committee. With these data a reporting rate was calculated. The reporting rate in 2010 is comparable with the reporting rate of 2005 (80%), and higher than the reporting rate before enactment of the law (18% in 1990; 41% in 1995, and 54% in 2001).[6]

In the unreported cases the drugs used were hardly ever neuromuscular relaxants or barbiturates and the most appropriate term according to the physician was never “euthanasia” or “assisted suicide”. Furthermore, in cases in which the physician had reported to a euthanasia review committee the estimated shortening of life was more often a week or more than in unreported cases. Finally general practitioners were more inclined to report whereas clinical specialists were less inclined to report.[6]

One may conclude that almost a decade after the enactment of the euthanasia law the percentage of cases that were reported to the review committees stabilised. In unreported cases almost all physicians labelled their decision themselves as “palliative or terminal sedation” or as “alleviation of symptoms”. By contrast, in reported cases virtually all physicians labelled their act as “euthanasia” or “assisted suicide”, and all used neuromuscular relaxants or barbiturates, the drugs advised by the Royal Dutch Association for Pharmacy. These characteristics of unreported cases have led some to argue that cases of euthanasia in which opioids were used should not be included in the euthanasia rate. Excluding unreported cases would obviously make for a reporting rate of about 100%, both in 2005 and 2010. However, the use of opioids was only classified as euthanasia when physicians affirmed that death was caused by administering this drug with the intention to end life. Hastening of death by administration of opioids in these cases cannot be ruled out. Obviously, the classification scheme used in the nation-wide studies is more likely to result in an overestimation than in an underestimation of the euthanasia frequency. In any case, the finding that about 100% of the cases in which the advised drugs were used were reported suggests that non-reporting by physicians is not related to unwillingness to report cases of euthanasia. This finding seems more related to lack of clarity about the correct

labelling of one's actions or to a discrepancy between effects of drugs and intention with regard to hastening death. Further education seems the most appropriate way to further increase the reporting rate.[6]

Conclusion

When reflecting on the Dutch euthanasia practice and discussion one may get the impression that there are two ideologies present. One is dominated by individual self-determination, the other focuses on compassion. Although both the official medical standpoint [10] and the new law reflect the second ideology, I see a growing tension between this view and the ideas of the public, which are more autonomy-oriented. In this latter view euthanasia becomes a right, something you can make your doctor do.

I think both systems have obvious advantages and disadvantages. The amount of liberty is clearly higher in the autonomy oriented approach, but so are the perils of misuse of this liberty. The medicalised approach offers at least some protection against some of these disadvantages, but at the cost of some liberty. Whatever one's stance on this will be, I think it is clear that the Netherlands can not have it both ways. I think that at present there is a tendency to stretch the official medicalised approach to allow for autonomy driven decisions. This, however, will only lead to a practice that lacks a clear picture of the moral framework within which it operates. Such a practice will be less open to any assessment procedure. After forty years of open debate in the Netherlands that would surely be the wrong way to go.

Note

¹ This article is an updated and elaborated version of: Delden JJM van. Euthanasia as a last resort. In: Council of Europe Publishing (ed). *Ethical Eye: Euthanasia vol II- National and European perspectives*. Strasbourg: Council of Europe, 2004. (p65-74).

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