Abstract

In response to the paper by Keown and Jochemsen in which the latest empirical data concerning euthanasia and other end-of-life decisions in the Netherlands is discussed, this paper discusses three points.

The use of euthanasia in cases in which palliative care was a viable alternative may be taken as proof of a slippery slope. However, it could also be interpreted as an indication of a shift towards more autonomy-based end-of-life decisions.

The cases of non-voluntary euthanasia are a serious problem in the Netherlands and they are only rarely justifiable. However, they do not prove the existence of a slippery slope.

Persuading the physician to bring euthanasia cases to the knowledge of the authorities is a problem of any euthanasia policy. The Dutch notification procedure has recently been changed to reduce the underreporting of cases. However, many questions remain.

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Although the Netherlands is an extremely flat country, it appears to have slopes that can even be skied down, when it comes to euthanasia. At least, that is what many authors who comment on the Dutch experience with euthanasia want their readers to believe. This issue of the journal contains such comment.1 This paper provides yet another example of those comments in which different types of end-of-life decisions are lumped together. Rather than repeating my critique showing that this kind of reasoning is based on unacceptable simplifications,2 I would like to try to further the discussion by trying to analyse the Dutch situation in response to the points put forward by Jochemsen and Keown.1 While doing so, I will touch on some of the points made by Cuperus-Bosma et al in their contribution to this issue of the journal.3

Jochemsen and Keown have three major worries: - the use of euthanasia even when doctors thought that palliative care was a viable alternative; - the incidence of non-voluntary euthanasia; - the underreporting of the euthanasia cases.

The reports that lead to these worries are not disputed, by either Jochemsen and Keown, or by me. Like them, 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. My point, however, is that I think a more interesting analysis of the problem can be given than by repeating the ominous and incriminating slippery slope metaphor.

Euthanasia and palliative care

The Netherlands are often criticised for their presumed lack of palliative care. The existence of only very few hospices in the Netherlands, for example, is often interpreted as proof of a neglect of palliative care. Although much of this criticism is based on misunderstanding and much effort is made to improve palliative care at present, Jochemsen and Keown are right when they say that the Netherlands “have some way to go in 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. 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. They believe that by paying sincere and close attention to the person who requests euthanasia the “question behind the question” will surely be revealed to be something other than a request for death, and that with good palliative care extreme suffering need not remain unanswered. In this view euthanasia and palliative care are incompatible.

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 that sometimes 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 of euthanasia is the medicalisation of the end of life, since whether euthanasia is justifiable becomes largely a matter of medical discretion.
These two responses appear to differ primarily in their answer to the question: "Does intractable excruciating suffering exist?" However, even palliative care specialists will state that, unfortunately, it does. The real difference therefore, will be whether one allows the principle of respect for life to be overridden by other considerations in special circumstances.

Most proposals to regulate euthanasia follow the second view. This is also true for the official legal position in the Netherlands where a conflict of the physician's duties is the basis for not prosecuting him or her, not the granting of a patient's right. There is no right to die in the Netherlands, nor is there an obligation for the physician to comply with the request of a competent patient to die even if certain conditions are met. From an official and legal point of view, therefore, euthanasia is only tolerated as a last resort.

The reality of the Dutch euthanasia practice, however, seems to be developing in 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 autonomously to decide about how and when to die and they 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 all major 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. In 1992 an independent study by Van der Wal showed that in 56% of cases of euthanasia, requests were made because patients thought suffering to be pointless and in 46% because they feared the decline. And the 1996 report showed that many patients asked for euthanasia to prevent more suffering. The research by Cuperus-Bosma et al, reported elsewhere in this issue, shows that the shift to autonomy is not a matter of patients only, but also of members of the public prosecution. The investigators showed that the presence or absence of an explicit request was the most important determinant of the decision whether to hold an inquest. Life expectancy and type of suffering do play a role but a less important one.

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. 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 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 byproduct of a liberal society, with its emphasis on self-government, control and rational choice. A moral evaluation of this development, however, will depend largely on one's normative views. Jochens and Keown 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 into the process of emancipation of the patient that has been going on since the beginning of the 1970s. They might say that it is about time to start thinking about patient decisions concerning the end of life, instead of about medical ones.

The cases of non-voluntary euthanasia

The cases of non-voluntary euthanasia, described both in the 1991 and the 1996 reports, created a new dimension in the Dutch euthanasia debate. Since the middle of the 1980s, this debate had been focused on euthanasia and assisted suicide with the explicit request of the patient as central feature. This in part had been a deliberate narrowing of the discussion because it was felt that consensus was greatest for these cases. The Dutch even changed their definition of euthanasia to mean only the cases in which there was an explicit request by the patient. Thus, a possibly justifying feature (the request) was turned into a necessary condition.

The description of the non-voluntary cases has broadened the discussion again. But what does their appearance in the reports mean? Does this prove the slippery slope? For many years Dutch commentators on euthanasia only talked about cases on request and non-voluntary cases only recently became known. Thus, the impression may have risen that the Dutch began with hastening the end of life on request and ended up with non-voluntary cases.

This, however, is not necessarily true. We simply do not know whether non-voluntary euthanasia occurred less or more often in the past. What we do know is that the occurrence of non-voluntary euthanasia did not increase in the Netherlands between 1991 and 1996, and also that its prevalence is much higher in another
country (Australia), which did not slide down the slope by tolerating euthanasia for years and years.7

But even if they do not prove the existence of the slippery slope, the non-voluntary euthanasia cases do form a very serious problem. They are obviously not justified by the principle of respect for patient autonomy as in the third view described above, and therefore can only be tolerated (if at all) in extreme situations where life termination is really a last resort and non-voluntary euthanasia becomes “mercy-killing”. It is very unlikely that this was the case in all cases described in the Dutch reports.

Underreporting
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 legalise euthanasia can never contain absolute safeguards.6 It 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 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 an unsatisfactory situation of accepting and prohibiting at the same time. This created uncertainty and unclarity both for patients and physicians and probably contributed to some extent to the critical reports such as the one commented upon here.1

Persuading the physician to bring euthanasia cases to the knowledge of the authorities is a problem for any euthanasia policy. The Dutch notification procedure helped to raise the notification rate to 41% in 1995.6 As is briefly discussed in the paper by Cuperus-Bosma,7 the government has tried to diminish further 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 November 1, 1998, five regional multidisciplinary assessment committees have to advise the public prosecutor in all reported cases of euthanasia. The effect of this change in procedure is not clear yet.

Cuperus-Bosma et al hope that reducing the role of the public prosecution will lead to fewer differences in assessment and more legal equality. However, one may ask why would these commit-

tees differ less in their assessment of cases. Their strength is their opportunity to communicate with the reporting physician in a decriminalised setting and, by so doing, influence practice. Uniformity should not be their main concern.

Conclusion
You cannot do ethics until you know the facts. Therefore, the need for empirical research in ethics is very clear. One of its tasks is to describe the morally relevant facts. Another task may be to verify empirical claims (as in the slippery slope argument and as in many consequentialist claims) and to provide insight into the effects of cultural differences on certain practices. Thus, facts provide the ethicist with the information she needs. However, facts will not settle a moral debate. When it comes to the euthanasia issue there is much to be learned from studies that the the Dutch have performed. But the interpretation of these facts remains largely dependent upon our moral views. Not vice versa.

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Slippery slopes in flat countries—a response.

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