

Beyond Autonomy and Beneficence

The Moral Basis of Euthanasia in the Netherlands

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Introduction

Euthanasia and physician-assisted suicide are controversial issues in medical ethics and medical law. In the debate, several arguments against the moral acceptability and legal feasibility of active involvement of physicians in bringing about a patient's death can be found. One argument refers back to the Ten Commandments: "Thou shall not kill". Killing another human being is morally abject. According to the argument, this is certainly so for medical doctors, as can be seen in the Hippocratic Oath, which explicitly forbids abortion and euthanasia. A less apodictic argument refers to the slippery slope: if euthanasia would be permitted, a downhill movement is set in motion.¹ The end of this movement would be, on the one hand, that physicians will feel forced to assist people who ask for termination of life on whatever grounds. On the other hand, it might lead to a situation in which it becomes normal to kill people who are no longer useful for society.

In the literature and in the public debate, there are also arguments in favour of euthanasia and physician-assisted suicide. One such argument invokes the right to die. According to this argument, decisions concerning life and death should be up to the individual who is concerned. In many countries, suicide is morally and legally accepted. If people are allowed to kill themselves, why should they be without rights when they are no longer able to perform the act themselves? In medical ethics and medical law, patient autonomy is a central pivot. Patients have the right to refuse treatment even if this leads to their death. Shouldn't people also have the right to determine the moment of dying, if they are in a situation which is unbearable, and without prospect of improvement? Another argument focuses on the duty of the physician to alleviate pain and suffering. If there is no other option, the doctor, in fulfilling this duty, should be allowed to actively end the

patient's life. This argument is not based on autonomy, but on beneficence.

The debate concerning euthanasia involves fundamentally different moral principles. This makes the debate interesting, if not central to medical ethics and medical law. Yet, the principles are normally presented in an abstract way. Discussants stick to very general ideas, which lack reference to specific social and historical conditions, and are not related to concrete experiences. To invoke the Ten Commandments, or plea for a right to die, implies the use of universal standards, which tend to be general and empty. From a philosophical perspective, this type of argumentation can be criticized. Following Aristotle, ethics should be based upon experience. Ethical knowledge requires participation in concrete practices. Central to ethics is a feeling for the concrete situation, which is always contingent and historical. From this perspective, it makes sense to consider how practitioners in specific situations deal with moral issues, for instance concerning euthanasia. What role do they give to notions such as autonomy and beneficence, how do they interpret them and apply them to the concrete situation?

In this paper I will present the Dutch experience with euthanasia. I will focus upon the way in which during the past thirty years the arguments in favour of euthanasia have been developed, in interaction with euthanasia practice. I will show that patient autonomy has been a crucial pivot. Yet, the Dutch interpretation of autonomy is not purely liberal. It does not only involve rights, but also obligations. Next, I will make clear that the physician plays a central role, in that the moral and legal basis of euthanasia is a conflict of duties on the side of the physician. This brings in the issue of beneficence. Yet the Dutch interpretation of the duty to help is not simply paternalistic. In Dutch health care, the physician-patient relationship is based upon deliberation and mutual agreement. Therefore, my conclusion will be that the Dutch practice of euthanasia has a moral ground, which goes beyond the traditional opposition between autonomy and beneficence.

The development of Dutch euthanasia practice

For the last 25 years, euthanasia has been a topic of debate in the Netherlands.² During this period, a practice of helping patients to die has been developed which is unique in the world. Since 1971, court cases have opened the way to euthanasia. Jurisprudence on cases of euthanasia and public debate have helped to bring about a social consensus on what counts as euthanasia ('active ending of a patient's life by a physician on the patient's request') and on the conditions which make euthanasia acceptable. In 1984 the Royal Dutch Medical Association (KNMG) formulated so-called due care criteria. In the nineties, two surveys were performed to establish the number of cases of euthanasia and other decisions concerning the end of life.³ The relative number of cases of euthanasia has risen between 1990 and 1995 (from 1.8% to 2.4%). The percentage of cases reported to the authorities has also increased (from 18% to 41%).

One of the major reasons for not reporting cases appears to be that physicians feel threatened by the procedure, outlined in the Law on Burial of 1994, in which the cases are evaluated by the public prosecutor. Very few cases are ultimately brought to court, but the procedure is unclear and time-consuming. It can also be doubted whether court decisions are the best way to develop a good practice of euthanasia. Therefore, a new policy concerning reporting has been developed. As a part of the new procedure, five regional multidisciplinary committees were installed in November 1998, which are to evaluate the cases that have been reported to the authorities.

Since April 2002, the law gives doctors who terminate life on request an exemption from liability if they have acted in line with due care criteria and have notified death by non-natural causes to the regional euthanasia review committee. According to the criteria, a doctor must be satisfied that the patient's request is voluntary and well considered, and that the patient's suffering is unbearable. Furthermore the doctor should inform the patient about the situation, discuss this and come to the joint conclusion that there is no other reasonable solution, consult at least one other independent physician who must see the patient and declare in writing that the aforementioned criteria are met, and exercise

due medical care in the termination of life. Since the law on euthanasia has become valid, a positive judgement of a regional evaluation committee means that no further action is taken against the doctor.

Patient autonomy in Dutch euthanasia practice

The background of the euthanasia debate and euthanasia practice in the Netherlands is the growing critique of paternalism in the second half of the twentieth century. A pivotal role was played by J.H. Van den Berg. In 1969 he published a small book under the title *Medische macht en medische ethiek* (Medical power and medical ethics).⁴ He argued that as a result of the development of technology, medical doctors had become much more powerful. They were able to keep patients alive who would certainly have died in former times. This, according to Van den Berg, raised problems for medical ethics. Since Hippocrates, physicians were morally trained to make decisions in the interest of the patient. Patients themselves were supposed not to be able to take part in decision-making (because they are frail and vulnerable). Moreover, physicians should try to keep patients alive. The value of life is a central element in Hippocratic ethics; shortening or actively ending a patient's life is clearly immoral. As a result of the combination of new technology and old medical ethics, patients were being kept alive under inhumane conditions. Van den Berg argued in favour of a new medical ethics, which should acknowledge that quality of life is more important than quantity. This new ethics should give patients a say in crucial decisions, since they are more able than physicians to make judgements about quality of life. According to Van den Berg, active ending of life should no longer be a taboo in medical ethics.

In the years following the publication of Van den Berg's booklet, patient's rights became an issue in Dutch health care. In line with international developments, the right to refuse treatment was gradually acknowledged. More than in other western countries, the public and the medical profession came to share the idea that medical interventions should not be performed at all costs. In this situation, euthanasia became a relevant issue for debate. At first, the concept of euthanasia included all kind of decisions concerning the end of

life. No distinction was being made between active and passive euthanasia, or between decisions based upon a patient's request and decisions without it. In the seventies, these distinctions were gradually introduced. H.J.J. Leenen, a central figure in the field of health law, played a crucial role. He argued that the concept of euthanasia should be used only in cases of active ending of life by a physician at the explicit request of the patient. Thus, euthanasia was distinguished from other medical decisions concerning the end of life, such as medical treatment with the shortening of life as a secondary effect, or active ending of life without a patient's request.

The Dutch debate on end-of-life decisions and the resulting definition of euthanasia as active ending of life at the patient's request made patient autonomy a central issue in the debate in more than one way. In the first place, euthanasia became linked to the notion of patient emancipation. In the second place, the patient's wish became a necessary condition. Thus, it may seem as though patient autonomy is the major moral basis for euthanasia in the Netherlands. Several participants in the Dutch debate on euthanasia have taken this position. The Dutch Society for Voluntary Euthanasia (NVVE) has regularly referred to the right to die as a justification for the legalization of euthanasia. The same organization has also emphasized that a person other than the patient cannot establish the condition of unbearable suffering. Whereas the physician should corroborate that the patient's suffering cannot be treated, and that the situation is without any prospect of improvement, only the patient can determine whether it can no longer be endured. Prominent ethicists in the euthanasia debate have supported this line of argumentation. It seems as though euthanasia in the Netherlands is the final outcome of the rise of patient autonomy and the upsurge of liberalism in medical ethics and medical practice.

Yet, this conclusion is too facile. In the first place, the Dutch have a specific view of patient autonomy. In Dutch health-care practice, patient autonomy is not primarily seen as the right to decide for oneself without any external interference. This notion of autonomy, which can also be described in terms of negative freedom⁵, does play a role in health law in the Netherlands, which emphasizes protection of the patient against medical infringements. Yet, in medical practice a different notion of autonomy is to be found. The

Dutch expect patients to act in a responsible way. In the euthanasia debate, the prevailing notion of autonomy is 'responsible autonomy'.⁶ Thus, elements of positive freedom are crucial to the debate. The focus is not on freedom to make one's own decisions, but on deciding in a way which shows consideration for others. This is also apparent in the requirements of due care, which have been developed by the Royal Dutch Medical Association and have become codified in the Dutch law on euthanasia. In the law it is stated that the patient's request should be durable and well considered. Although it is not stated what kind of consideration is required, it is clear that patients are to take into account the consequences of their requests. The request should be discussed with the physician. In the context of Dutch health care, in which the physician performing euthanasia is supposed to know the patient (and in most cases acts as a family physician), such discussions are expected to involve more than just the affirmation that one really wishes the euthanasia to be performed. Concerning the issue of suffering, it may be doubted whether it is totally up to the patient to decide what counts as unbearable. Dutch physicians will not be satisfied with a simple declaration by the patient on the subject of suffering. They will interpret such declarations in the context of the patient's total situation. Again, the law puts much emphasis on the physician. It is the physician who has to be convinced that the patient's suffering is both without prospect and unendurable. If one reads the law carefully, and takes into account the context of Dutch health care, it is evident that the concept of patient autonomy plays a quite specific and also limited role in euthanasia in the Netherlands.

The role of the physician in decisions concerning euthanasia in the Netherlands

If patient autonomy in the sense of self-determination is not the most central value in Dutch euthanasia practice, one may wonder which other values are involved. A likely candidate is beneficence. Beneficence is a central value in medical ethics, to be clearly distinguished from respect for autonomy.⁷ If a physician acts on the principle of beneficence, he or she takes a paternalistic stance. The emphasis is on what the physician considers to be good for the patient. Not the patient's, but the physician's view of the situation is crucial. If the views of physician and patient conflict, the physician's

perspective is regarded as the more important one.

It can be argued that beneficence plays a central role in Dutch euthanasia practice. As remarked above, the physician has to decide for euthanasia. The physician has to be convinced that euthanasia is the only alternative left. Dutch critics of euthanasia have commented that this means that the patient has little say in the process.⁸ Proponents of euthanasia do not draw this conclusion, but they do emphasize the physician's responsibility. The Royal Dutch Medical Association, from early in the debate, has stressed the physician's key role as the central actor in euthanasia. Euthanasia is acceptable only if the physician is convinced that suffering cannot be allowed to continue. It has been argued that in deciding for euthanasia, the physician acts out of compassion or mercy.⁹ These arguments point in the direction of beneficence as a central value.

Yet once again, this conclusion is too simple. Several aspects of Dutch euthanasia practice are overlooked if one regards beneficence as the key moral element. In the first place, a crucial issue in the debate resulting in the legal acceptance of euthanasia is the exceptional character of active termination of life by the physician. Whereas beneficence is a common value in medical practice, in euthanasia there is more at stake. Euthanasia requires a conflict of duties on the side of the physician. The principlist approach, which focuses on the balancing of beneficence with other values, is not really applicable to the situation of euthanasia. It does no justice to the tragic aspects of a situation in which there is no option but to end a patient's life in order to prevent further suffering. Secondly, it can be doubted whether the physician is the one who decides what has to be done on the basis of his knowledge about the patient's condition. Whereas the argument for autonomy mistakenly regards the patient as the one who decides, and overlooks the role of the physician, the argument for beneficence tends to disregard the crucial contribution of people other than the physician who performs the euthanasia. In Dutch euthanasia practice, the patient's role is more than agreeing with the physician's decision and undergoing the consequences. The patient is a partner in the process of gradually reaching the decision that euthanasia is the only option left. The second physician, who

acts as a consultant, plays a further significant role. The physician consulted has an important say in the matter. He or she must visit the patient and check whether the patient's situation is such that euthanasia is justified. This involves not just a physical examination, establishing the patient's disease, as is the case in the Belgian law. In the Netherlands, the consulted physician also has to establish the nature of the patient's request (is it voluntary and well considered?) and the character of the patient's suffering (is it unendurable?). Thus, the second physician has to verify that all the necessary conditions are fulfilled, and thereby plays a role which goes beyond mere professional advice based on knowledge of the disease. The situation around euthanasia involves more aspects than the concept of beneficence can account for.

Beyond autonomy and beneficence

If neither autonomy, in the sense of self-determination, nor beneficence, in the sense of the physician deciding in the interest of the patient, are suitable to serve as the moral basis for Dutch euthanasia practice, what other values can be relevant in this regard? Some such values have already been mentioned. The Dutch expect patients to be responsible. They tend to see the relationship between physician and patient as a partnership. This means that decisions in health care are seen as joint enterprises, in which physician and patient come to a shared conclusion. The physician-patient relationship, which is prevalent in Dutch health care in general, and in euthanasia in particular, is in line with the deliberative model.¹⁰ In this model, patients' values are regarded as important, but also in need of discussion; in the process of discussing values, the physician plays an active role. The patient is supposed to be able to learn to take a responsible stance, helped by the physician as a teacher or friend. The deliberative model is fundamentally different from an approach in which patient autonomy prevails (the informative model) or an approach in which the doctor is supposed to know best (the paternalist model). The emphasis is not on the point of view of one of the participants (either the patient or the physician), but on the development of a new, mutual perspective. The model embodies the principles of hermeneutic dialogue.¹¹ This aspect of mutuality is pervasive in Dutch health care. It is clearly expressed in one of the due care criteria, in

which it is stated that the physician should discuss the situation with the patient and that the discussion should lead to the shared conclusion that no other options are available.

The Dutch expect help and support from their physician. Patients want to be sure that they can rely upon their physician in hard times. They hope that their physician will not let them die in a miserable way. A central value in this respect is trust. Concerning euthanasia, trust not only means that one can be sure that the physician will not misuse his or her power. It means first and foremost that one can be sure one will not be left alone in a hopeless situation. Concerning end-of-life issues, fear of abandonment is more pervasive in the Netherlands than fear of unwanted interventions by the physician. Patients express the need to be cared for, and not to be left alone to die. The values of support, trust and care are central to Dutch euthanasia practice. These values are hardly considered in the current debate in medical ethics, which focuses on autonomy and beneficence. They are elaborated by alternative approaches, such as the ethics of care.¹² The ethics of care might provide a better basis for understanding the moral issues involved in Dutch euthanasia practice than medical ethics, which tends to oscillate between arguments from autonomy and arguments from beneficence.

Central values in Dutch euthanasia practice cannot be reduced to the principlist canon of autonomy and beneficence. Responsibility, deliberation and care introduce moral concerns that are neither strictly liberal, nor strictly paternalist. The central position of such values in Dutch health-care practice might also put into question one of the central arguments against allowing euthanasia, the slippery-slope argument. In so far as the slippery-slope argument is based upon the idea that physicians might not be able to resist a patient's wish to die, or, alternatively, that patients may become increasingly at the mercy of others who decide that it is better for them to die, these arguments use the same notions of autonomy and beneficence as the proponents of euthanasia do. If such notions are not adequate to describe Dutch euthanasia practice, the slippery-slope argument is not as easily applicable as it is often thought to be.

Conclusion

By focusing on responsibility, deliberation, and care as central elements in the moral justification of euthanasia, Dutch euthanasia practice highlights moral concerns which get little attention in the current debate on euthanasia. Dutch euthanasia practice does not support the view that patient autonomy is the most important argument for euthanasia, as long as autonomy is equated with the right to self-determination. The right to decide for oneself, without interference from others, is not the ultimate value in Dutch euthanasia practice. Likewise, Dutch euthanasia practice does not support the view that paternalism can serve as a moral ground for euthanasia. Although the physician plays an active role, this does not imply that the patient is merely subjected to what is regarded as being in the patient's interest. The Dutch experience not only can serve as a correction to arguments in favour of euthanasia, emphasizing either autonomy or beneficence. It can also raise some doubts about arguments against euthanasia, such as the slippery-slope argument.

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⁴ J.H. van den Berg, *Medische macht en medische ethiek* (Nijmegen: Callenbach, 1969).

⁵ Isaiah Berlin, *Four Essays on Liberty* (Oxford: Oxford University Press, 1969).

⁶ James Kennedy, *Een weloverwogen dood. Euthanasie in Nederland* (Amsterdam: Bert Bakker, 2002).

⁷ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (Oxford: Oxford University Press, 2001).

⁸ Henk A.M.J. ten Have and Jos V.M. Welie, "Euthanasia: Normal Medical Practice?" *Hastings Center Report* 22 (1992): 34-38.

⁹ R.J.M. Dillmann, "Euthanasie: de morele legitimatie van de arts", in *Levensbeëindigend handelen door een arts: tussen norm en praktijk*, eds. J. Legemaate & R.J.M. Dillmann (Houten: Bohn Stafleu Van Loghum, 1998), 11-25.

¹⁰ Ezekiel J. Emanuel & L.L. Emanuel, "Four Models of the Physician-Patient Relationship", *JAMA* 267(1992): 2221-2226.

¹¹ Guy A.M. Widdershoven, "The Physician-Patient Relationship: A Hermeneutic Perspective", in *Healthy Thoughts. European Perspectives on Health Care Ethics*, eds. R.K. Lie, P.T. Schotsmans, B. Hansen and T. Meulenbergs (Leuven/Paris/Sterling VA: Peeters Publishers), 69-80.

¹² Annette Baier, "Trust and antitrust," *Ethics* 96 (1989): 231-260; Joan C. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York/London: Routledge, 1993).