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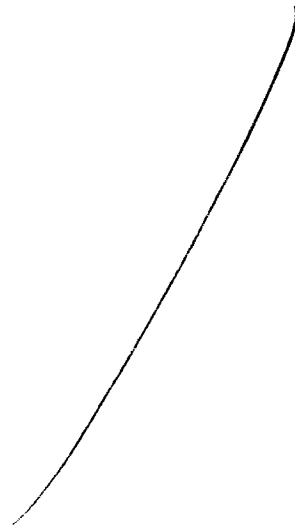
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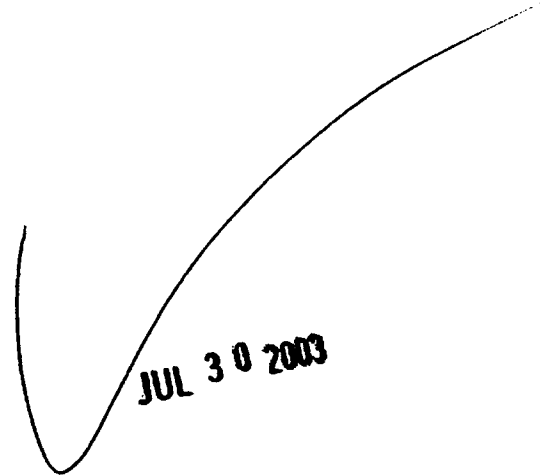
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The Guidelines for Euthanasia in the Netherlands: Reflections on Dutch Perspectives

Raphael Cohen-Almagor

Introduction

The Dutch experience has influenced the debate on euthanasia and death with dignity around the globe, especially with regard to whether physician-assisted suicide and euthanasia should be legitimized or legalized. Review of the literature reveals complex and often contradictory views about this experience. Some claim the Netherlands offers a model for the world to follow; others believe the Netherlands represents danger rather than promise, that the Dutch experience is the definitive answer to why we should *not* make active euthanasia and physician-assisted suicide part of our lives.

Given these contradictory views, fieldwork is essential to develop a fully informed opinion. Having investigated the Dutch experience for a number of years, in the summer of 1999 I went to the Netherlands to visit the major centres of medical ethics as well as some research hospitals, and to speak with leading figures in euthanasia policy and practice. This essay reports some of the main findings of my interviews and provides detailed accounts of the way in which some of the Netherlands' leading experts perceive the policy and practice of euthanasia in their country. These accounts are quite fascinating.

The discussion begins with background information on the guidelines for euthanasia. Next, explanation about the research methodology is outlined and then I discuss the interviewees' views about the guidelines for euthanasia. I conclude by indicating that the Dutch guidelines on the policy and practice of euthanasia do not provide ample mechanisms against abuse. Virtually every guideline has been breached or violated. This finding reiterates Hendin's finding.² I recommend that the Netherlands amend its policy and remedy its troubling practice.

Background

Since November 1990, prosecution is unlikely if a doctor complies with the guidelines on euthanasia and physician-assisted suicide set out in the non-prosecution agreement between the Dutch Ministry of Justice and the Royal Dutch Medical Association. These guidelines are based on the criteria set out in court decisions relating to when a doctor can successfully invoke the defence of necessity. The substantive requirements are as follows:

- 1 The request for euthanasia or physician-assisted suicide must be made by the patient and must be free and voluntary.
- 2 The patient's request must be well considered, durable and consistent.
- 3 The patient's situation must entail unbearable suffering with no prospect of improvement and no alternative to end the suffering.³ The patient need not be terminally ill to satisfy this requirement and the suffering need not necessarily be physical.
- 4 Euthanasia must be a last resort.⁴

The procedural requirements are as follows:

- 1 No doctor is required to perform euthanasia but if he/she is opposed on principle the doctor must make his/her position known to the patient early on and help the patient get in touch with a colleague who has no such moral objections.
- 2 Doctors taking part in euthanasia should preferably and whenever possible have patients administer the fatal drug to themselves, rather than have a doctor apply an injection or intravenous drip.⁵
- 3 A doctor must perform the euthanasia.
- 4 Before the doctor assists the patient, the doctor must consult a second independent doctor who

has no professional or family relationship with either the patient or doctor. Since the 1991 *Chabot* case,⁶ if the patient has a psychiatric disorder the doctor must cause the patient to be examined by at least two other doctors, one of whom must be a psychiatrist.

- 5 The doctor must keep a full written record of the case.
- 6 The death must be reported to the judicial authorities as a case of euthanasia or physician-assisted suicide, and not as a case of death by natural causes.⁷

In 1990, the Dutch government appointed a commission to investigate the medical practice of euthanasia. The Commission, headed by Professor Jan Remmelink, Solicitor-General to the Supreme Court, was asked to conduct a comprehensive nation-wide study of 'medical decisions concerning the end of life (MDEL).' The following broad forms of MDEL were studied:

- 1 Non-treatment decisions: withholding or withdrawing treatment when treatment would probably have prolonged life;
- 2 Alleviation of pain and symptoms: administering opiates in such dosages that the patient's life might be shortened;
- 3 Euthanasia and related MDEL: the prescription, supply or administration of drugs with the explicit intention of shortening life, including euthanasia at the patient's request, assisted suicide, and life termination without explicit and persistent request.⁸

The study was repeated in 1995, making it possible to assess for the first time whether there were harmful effects over time that might have been caused by the availability of voluntary euthanasia in the Netherlands. It is still difficult to make valid comparisons with other countries because of legal and cultural differences, and also because similar comprehensive studies are quite rare.⁹

The two Dutch studies were said to give the best estimate of all forms of MDEL (i.e., all treatment decisions with the possibility of shortening life) in the Netherlands as approximately 39% of all deaths in 1990, and 43% in 1995. In the third

category of MDEL, the studies gave the best estimate of voluntary euthanasia as 2300 persons each year (1.9% of all deaths) in 1990¹⁰ and 3250 persons each year (2.4%) in 1995. The estimate for physician-assisted suicide was about 0.3% in 1990 and in 1995. There were 8900 explicit requests for euthanasia or assisted suicide in the Netherlands in 1990, and 9700 in 1995. Less than 40% were actually undertaken. The most worrisome data are related to the hastening of death without the explicit request of patients. There were 1000 cases (0.8%) without explicit and persistent request in 1990, and 900 such cases (0.7%) in 1995.¹¹

In 1990, 30% of the general practitioners (GPs) interviewed said that they had performed a life-terminating act at some time without explicit request (as compared with 25% of specialists and 10% of nursing-home physicians).¹² Life-terminating acts without explicit request were performed more, on the average, with older patients than were euthanasia or physician-assisted suicide.¹³ There were still treatment alternatives in 8% of cases in which a life-terminating act was performed without explicit request of the patient. The physician did not use these alternatives when the patient indicated a desire to stop treatment because it "only would prolong suffering", or because the expected gain was not enough to make the treatment worthwhile.¹⁴ It should be noted that the level of consultation was significantly lower in life-termination acts without the patient's explicit request than in cases of euthanasia or physician-assisted suicide. A colleague was consulted in 48% of the cases (as compared with 84% in euthanasia and assisted suicide cases). Relatives were consulted in 72% of the cases (as compared with 94% in euthanasia and assisted suicide cases). In 68% of the cases, the physician felt no need for consultation because the situation was clear.¹⁵ Van der Maas and colleagues note that this should be considered in light of the very brief period by which life was shortened.¹⁶ In 67% of the cases, life was shortened by less than 24 hours. In 21% of the cases, life was shortened by up to one week.¹⁷

About a quarter of the 1000 patients had expressed a wish for voluntary euthanasia previously.¹⁸ The patient was no longer competent in almost all of those cases, and death was hastened by a few hours or days. A small number of cases (approximately 15) involved babies who were suffering from a serious congenital disorder and were barely viable; hence the doctor's decision, in consultation with the parents, to hasten the end of life.¹⁹

The Rummelink Commission regarded these cases of involuntary termination of life as "providing assistance to the dying." They were justified because the patients' suffering was unbearable, standard medical practice failed to help and, in any event, death would have occurred within a week. The Commission added that actively ending life when the vital functions have started failing is indisputably normal medical practice: "It deserves recommendation that the reporting procedures in place ... will in the future also cover the active termination of life by a doctor in the framework of help-in-dying without an explicit request by the patient," except in situations where there is "the beginning of irreversible, interrelated failure of vital functions". In this last case, "natural death would very quickly occur even if the doctor did not actively intervene..." The recommendation goes on to say that this is not the case with patients whose vital functions are still intact and who are subject to life-shortening treatment without explicit request. Such cases should be reported.²⁰

On November 28, 2000, the Dutch Lower House of parliament, by a vote of 104 for and 40 against, approved the legalization of euthanasia. On April 10, 2001 the Dutch Upper House of parliament voted to legalize euthanasia, making the Netherlands the first and at that time only country in the world to legalize euthanasia. Forty-six members of the 75-seat Senate voted for the Termination of Life on Request and Assistance with Suicide Act; twenty-eight voted against; one member was not present. The new legislation makes it legal to end a patient's life, subject to the following criteria: the patient must be suffering unbearable and unremitting pain, with no prospect of improve-


ment. The patient must make a sustained, informed and voluntary request for help to die. All other medical options must have been previously exhausted. A second medical opinion must be sought to confirm diagnosis and prognosis. The termination of life must then be carried out with medically appropriate care and attention. The physician is obliged to report the death to the municipal pathologist, specifying whether the cause of death was euthanasia or assisted suicide.

Doctors will be immune from prosecution for helping a patient to die, as long as they follow this set of guidelines. They will still report cases of voluntary euthanasia to the coroner and a regional committee, who can recommend prosecution leading to a prison sentence of up to 12 years if the guidelines have not been followed.

This new act changed the emphasis on who should prove guilt or innocence if the code of practice is breached. Previously, the onus was squarely on the doctors to prove that they had followed the guidelines and were therefore innocent of any offence. However, the new law shifts the responsibility for proving guilt to the regional committees.²¹

The law contains special provisions dealing with requests from minors for termination of life and assisted suicide. The most controversial aspect of the original act was that incurably ill minors between the ages of 12 and 16 may request and receive help to die, with the agreement of their parents. In exceptional circumstances, doctors may even be able to help the child to die without parental consent, although such cases are likely to be rare. Persons of 16 to 18 years of age would be able to request euthanasia without recourse to their parents' approval.²²

In July 2000, in response to critical questions by members of parliament, the cabinet dropped the provision that euthanasia requests by minors between 12 and 16 years in exceptional cases could be granted without the parents' consent. Some analysts viewed this retreat as a manoeuvre to win approval for other controversial provisions of the new legislation, such as legalizing euthanasia for victims of Alzheimer's disease.²³ Still,



allowing euthanasia for minors 12 years of age and older seriously overestimates the capacity of minors to evaluate the meaning and consequences of a request to die. It places an unacceptable burden on these young people and may well disturb society's confidence in the relationship between physicians, parents and children. Henk Jochemsen rightly says that unless we are prepared to give minors the right to do everything else in life that an adult can do, giving them the right to end life seems out of place.²⁴

The new law also establishes a legal basis for advance euthanasia declarations via a type of living will in which competent patients would request euthanasia in the event they become mentally incompetent. Though such a statement does not imply that a physician has a duty to perform euthanasia, it provides the legal opening to end the life of incompetent patients who had signed such a document.

Methodology

Prior to the enactment of the euthanasia law I decided to conduct fieldwork in the Netherlands and inquire about the policy and practice of euthanasia. Before arriving in the Netherlands, I wrote to some distinguished experts in their respective fields: medicine, psychiatry, philosophy, law, social sciences and ethics, asking to meet with them in order to discuss the Dutch policy and practice of euthanasia. These individuals are known nationally and internationally. Most of them I know through their writings. The others were recommended to me by Dutch colleagues as experts whom I should meet. Only one — Dr. Chabot — explicitly declined my request for an interview.²⁵

The interviews took place during July and August of 1999, in the Netherlands. They lasted between 1 to 3 hours each. Most interviews went on for more than two hours during which I asked more or less the same series of questions. During the interviews I took extensive notes that together comprise some 200 dense pages. Later the interviews were typed and analyzed.

The interviews were conducted in English, usually in the interviewee's office. Four interviews were conducted at the interviewees' private homes, and four interviews in 'neutral' locations: cafés and restaurants. Two interviews were conducted at the office kindly made available to me at the Department of Medical Ethics, Free University of Amsterdam. To have a sample of different locations I traveled from Groningen in the north to Maastricht in the south, making extensive use of the Dutch train system.

The interviews were semi-structured. I began with a list of 15 questions but did not insist on all of them when I saw that the interviewee preferred to speak about subjects that were not included in the original questionnaire. With a few interviewees — most notably the GPs performing euthanasia and the de Boer family, who openly discussed their own personal experience with euthanasia — I spoke only about their direct involvement in the practice of euthanasia. Because I was interested in the problematic aspects of the euthanasia practice, after some general questions I addressed the troublesome aspects reiterated in the Rummelink report. This line of questions disturbed some of the interviewees, who wanted to know my own opinion on the subject matter before continuing to answer my questions. Others seemed eager to bring the interview to a close.

I was struck by the defensiveness expressed by some of the interviewees. Gomez also reported the notions of suspicion and guardedness on the part of his interviewees.²⁶ The attitude of some of my interviewees reminded me of my own initial reaction when I attended debates of post-Zionists outside of Israel during the late 1980s and early 1990s. At that time I felt that the 'dirty laundry' should not be taken out; that the debate should be restricted to Israelis who are familiar with the intricate aspects of the debate, and that all who take part in the dispute should show responsibility when they address the issue before non-Israelis and non-Jews who might then exploit the information to harm Israel's interests. In the Netherlands I sensed that the interviewees did not like



the idea of a foreigner asking these questions. Although they realize the euthanasia policy is imperfect, they tried to defend it to the best of their abilities.²⁷ As a matter of fact, I was somewhat troubled by their lack of criticism and their readiness to accept the euthanasia policy and practice with all their flaws.²⁸ I presume some of the interviewees identify with their government's decision-making to the extent of defending the system and suspecting foreigners like me who press them with difficult questions. I also suspect that after the publications of Gomez,²⁹ Keown³⁰ and Hendin,³¹ they were not enthusiastic about cooperating with me. One interviewee was candid enough to tell me this directly. When I asked why he was willing to sit with me and answer my questions, he replied that he felt obliged as a researcher and scientist to cooperate and wanted his viewpoint to be heard.

Some of the interviewees were nominated by the Dutch government to conduct research on the policy and practice of euthanasia and to submit their recommendations for changes. Science commissioned by the state might be a tricky issue. The researcher might become identified with the project to the extent of becoming 'the voice of the state' and forgoing impartiality. It is preferable that research on controversial matters be funded by non-partisan foundations rather than by an interested government.³²

The remainder of this article reports the answers to the general questions on the practice of euthanasia. For limitations of space I cannot possibly report the extensive answers to my fifteen questions. This is done in my forthcoming book, *Euthanasia in the Netherlands*.

Views on the Practice of Euthanasia

My question was formulated in general terms. I wondered how the interviewees felt in regard to the practice of euthanasia and whether they were content with the way in which it is conducted. The majority of interviewees expressed some reservations, but at the same time felt that the system worked relatively well and that euthanasia should

be permitted. A small minority felt that the system did not work (i.e., that the guidelines were quite often violated) and that euthanasia should not be allowed. This small minority complained that the establishment tried to silence them, labeled them as reactionaries and/or religious fundamentalists, and dismissed their point of view.

Sjef Gevers, a leading legal scholar, has a positive attitude toward the policy. In his opinion, every society will have to address the issue and people will want to have a say about what happens at the end of their lives. The difficult challenge is to develop public policy. Gevers sees that there are risks involved, but that in the Netherlands, these risks are discussed and generally contained and controlled. He feels that there is no abuse and that, on the whole, the policy works.

Heleen Dupuis, an ethicist who has written widely on euthanasia, also expresses satisfaction with the euthanasia policy. She argues that very limited groups (e.g., cancer and AIDS patients) request euthanasia and that their lives are shortened by one or two weeks at the most.³³ Gerrit van der Wal, one of the principal researchers in the field of euthanasia and physician-assisted suicide (PAS), declares, "it is pretty safe to die in Holland". Margo Trappenburg, then a political scientist at the University of Leiden, estimates that it is impossible for her to evaluate the implications of the pending attempt to legislate euthanasia, but that the practice of euthanasia as such is a positive one. According to an empirical study that she conducted, 80% and more of the Dutch population are in favour of euthanasia under certain conditions.³⁴

Upon reading the first draft of this study, Trappenburg wrote the following:³⁵

I had not studied the pending legislation when we had our interview... I studied the pending legislation after our interview in the autumn of 1999 and was not very happy with it. As a matter of fact I wrote a rather critical article about it.³⁶ In this article I took issue with the government's decision to stick with the Chabot guidelines. I also criticized the coming legislation regarding living wills.



Several authorities³⁷ said that the Dutch euthanasia policy is basically a good policy and that attempting to forbid euthanasia by law is misguided in light of how often it is done. They are satisfied that the option of euthanasia is available. In Rob Houtepen's view, the major problem is the low level of reporting, most of which can be attributed to laziness and can hopefully be rectified by the regional committees.³⁸ Hans Van Delden, one of the co-authors of the 1990 comprehensive report on medical decisions at the end of life, maintained that the rules are flexible, and clinical circumstances do not always conform to rock-solid guidelines. However, there is danger in interpretation: what does 'unbearable suffering' mean? At the same time, these authorities voiced their trust in doctors, claiming that neither life-shortening without the patient's explicit request nor administering lethal doses of morphine without apparent justification occurs in the Netherlands more than in other countries.³⁹ Given that it is difficult to deal with the euthanasia policy, that there are and will always be some pitfalls, much of the practice is out in the open and the situation is quite satisfactory.

Similarly, H.J.J. Leenen, who drafted the euthanasia law, is satisfied with the practice of euthanasia, arguing that no slippery slope exists. He emphasizes that very few doctors have been convicted for euthanasia and that there is positive cooperation on this issue among different circles of society. Like Trappenburg, he notes that 88% of the population is in favour of the practice. In his comments on the first draft of this study, he asked to add that he strongly objects to not reporting euthanasia and that he insists on this issue in his law proposal.⁴⁰

Gerrit Kimsma, a physician who practises euthanasia and who teaches medical ethics at the Free University, is "fairly happy with the practice," conceiving it as brave and pragmatic. He does, however, have reservations in the area of clinical care, arguing that inadequate pain relief might lead patients to request euthanasia. He maintains that the Netherlands does well in palliative care, as compared to other countries, but still needs to

improve its expertise in pain treatment. Kimsma notes that there are no comparative studies on the level and quality of expertise in pain management. He also believes that the Dutch neglect the area of transference and counter-transference,⁴¹ claiming that sometimes physicians proceed with euthanasia because their patients manipulate them. But, Kimsma immediately adds, this can be said in only a minority of cases. On the whole, he thinks that the euthanasia policy represents the results of mediation between two competing values: protection of life vs. alleviation of suffering. This policy has caused a dramatic change in medicine because what used to be hidden is now public and open.

Some interviewees expressed reservations regarding the lack of control mechanisms. John Griffiths who co-authored a leading manuscript on euthanasia and the law in the Netherlands, reiterates the problem that many physicians practising euthanasia do not report their conduct because they do not want to be prosecuted or to provide an opportunity for prosecution. He seemed more troubled than Houtepen on this issue but, like Houtepen, Griffiths argued that the situation in the Netherlands is better than in any other place in the world, and that no slippery slope exists.⁴² He assumes that the control system will be improved. Similarly, Evert van Leeuwen and Arie van der Arend, medical ethicists from Amsterdam and Maastricht, think that euthanasia has a place in the medical profession, but at the same time are worried about the lack of reporting. In their view, physicians need to understand that death is not only a medical issue, but also a public issue.

Govert den Hartogh, a philosopher who is a member in the Amsterdam regional committee that reviews all reported euthanasia cases in the region, argues that the ideology of autonomy prevalent in the Netherlands has resulted in some victims — patients were killed prematurely. This is a cause for concern, but, in den Hartogh's view, does not warrant a change in policy. He affirms that the legal situation conforms to the views of both the physicians and the public. Furthermore, it must be recognized that there are cases in which life is



indeed a hell and in which euthanasia constitutes the best solution, despite the problems involved in the actual practice. Therefore, den Hartogh favours continuation of the existing policy.

A few of the interviewees, including Koerselman and Jochemsen as well as Rutenfrans, are well known for their critique of the Dutch policy and practice of euthanasia. G.F. Koerselman, a prominent psychiatrist, was described to me as the most outspoken critic of Dutch euthanasia practice in general and assisted suicide with psychiatric patients in particular. He certainly lived up to his reputation by voicing his grave concern about the developments in the field, warning that the Netherlands is on the wrong road. Koerselman works in two hospitals and says that it is common practice to make euthanasia decisions too quickly and without careful attention. As a psychiatrist, he was invited to investigate and speak with patients requesting to die. Occasionally he was called on Friday, and the medical staff urged him 'to finish the process' during the weekend. Koerselman maintains that his colleagues stopped using his services as a consultant once they realized that he would not easily authorize euthanasia.

Henk Jochemsen, Director of the Professor Lindboom Institute, conceives of euthanasia as unethical insofar as the practice runs contrary to a medical ethic that always seeks to sustain life. He feels that the practice is largely out of control and argues that whatever opinion one may hold about euthanasia, the state must be expected to provide effective control. It is impossible to monitor the work of each and every physician, and having such control would necessitate compromising the values of privacy and confidentiality. In essence, he says, effective control on the one hand, and privacy and confidentiality on the other, are mutually exclusive. Furthermore, he believes that the practice of euthanasia is contrary to a situation in which the state is obligated to protect the life of its citizens.⁴³

Chris Rutenfrans, a Roman Catholic who declares that his opposition to euthanasia does not stem from his religion but from practical reasoning, also objects to the policy and practice of

euthanasia. He contends that euthanasia might have been necessary during the 1920s, but not today, when pain medication is available. He argues that the Dutch have mistakenly generalized from highly exceptional cases, in which painkillers could not help, to a policy of using euthanasia as an easy and acceptable solution for suffering.⁴⁴ It is done in the name of self-determination, even when the patient's self-determination is actually being compromised.

Pros and Cons of the Dutch Euthanasia Policy and Practice

This question supplements the former question and is more specific. In response to the former question, the interviewees could have raised any issue that came to mind. This question provided respondents with the opportunity to elaborate on the positive aspects of the Dutch euthanasia policy and practice and, at the same time, pressed those who did not mention the negative aspects to address the problems involved. Many interviewees were eager to speak about the pros and far more reluctant to address the cons, to the extent that I had to press them to answer also the second part of the question. Some were ambivalent about the euthanasia practice. Koerselman, Jochemsen and Rutenfrans who emerged as the critical voices in my study continued to substantiate their grim assessments about the practice.

Heleen Dupuis and A. van Dantzig voiced the most supportive views on the policy and practice of euthanasia.⁴⁵ Dupuis, who served as president of the Dutch voluntary euthanasia society, sees only positive aspects in the policy and practice. Dying is a private matter and should be a private choice, with society providing safeguard mechanisms and allowing euthanasia as an option. When pressed about the cons, she responded by saying: "Theoretically there are cons, but I never heard about them."

van Dantzig, a well-known psychiatrist, emphasizes the openness of the practice, maintaining that it is rational for one to say that upon reaching a



certain level of dementia life should be ended. The role of the doctor is to verify that the person has indeed reached that stage. He argues that when a doctor ends a person's life, it is not a crime provided that the act was done on medical grounds. van Dantzig thinks that it is wrong to criminalize euthanasia and believes that a doctor does not commit a crime when he provides this service. He recommends that physicians interview every person who requests euthanasia. Many times it is possible to find another solution. In any event, van Dantzig claims, someone who wants to carry out euthanasia will do so regardless of law and policy. He says that after accepting the rationale for euthanasia, all that is left is to solve the practical problems, and these can be sorted out. van Dantzig trusts doctors to carry out their professional responsibilities.⁴⁶

van der Maas and Henri Wijsbek were happy to speak about the pros and far less eager to discuss the cons. Wijsbek, a medical ethicist, praised the guidelines because they insist on a voluntary request by the patient, they attempt to find an answer to the suffering, and they also require consultation. He believes that euthanasia is justified when good reasons are provided. No cons were mentioned.

Paul van der Maas, the principal investigator of the 1990 and 1995 comprehensive studies on decisions at the end of life, points to a number of relevant issues: the Dutch universal health-care coverage that removes the economic pressure of forcing families to spend their resources on their loved ones; the fact that GPs know their patients for many years; and the legal aspect that discourages prosecution if there is ample justification. According to van der Maas, most people feel that there are sufficient safeguards and that the prescribed limits are acceptable and safe, in line with what people want. He also notes that euthanasia is rarely performed — once every 50 deaths — and that it is performed only when people are really suffering.⁴⁷ Finally, van der Maas stresses the self-limiting aspects of euthanasia: most doctors want to avoid euthanasia because they find it too emotional.

Regarding the cons involved in the practice, van der Maas said that the number of requests for euthanasia rose substantially from 1990 to 1995,⁴⁸ and he hypothesized that some doctors may be pressured by their patients' requests for euthanasia. van der Maas also regards it as important that doctors spend sufficient time discussing euthanasia with patients, meaning more than one session. More research should be conducted on this issue.

James Kennedy, who studies the history of the euthanasia practice in the Netherlands, admits that he is ambivalent about the practice. The positive thing about it is that large segments of society participate in the open and long deliberations. Furthermore, there is sensitivity to suffering and respect for autonomy, as well as a genuine attempt to reach a consensus. Having said that, Kennedy feels that despite its openness, the Dutch public really does not know a lot about the practice of euthanasia. Unlike the specialists, the public is not aware of all the problematic aspects revealed in the 1990 Remmelink report and in the 1995 report, the research on withdrawal and withholding of treatment, or the employment of the double-effect doctrine. These issues should be further discussed and researched.

In regard to critics of euthanasia, Kennedy contends that they are not taken seriously enough in the Netherlands. The Dutch are sensitive to criticism from abroad and are defensive about their policies. As Koerselman, Rutenfrans and Jochemsen have testified, Dutch critics are also resented. The common argument against foreign critics is that they do not understand the Dutch policy, whereas the common argument against Dutch critics is that they belong to religious sects.

The Dutch may be overconfident about the need for euthanasia and the justification of its practice. One may assume that if the given guidelines are not complied with, then people will see that there is a serious problem. Yet, the Dutch people do not seem to feel this way.⁴⁹ Indeed, the moral superiority of Dutch euthanasia advocates is evident in Herbert Cohen's claim that they see foreign criticism as evidence that the United States

and the rest of the world are not as enlightened as the Netherlands.⁵⁰

Egbert Schrotten, Director of the Centre for Bioethics and Health Law at Utrecht University, answers the question in general terms, holding that there is no 100% black or white picture in ethics. There are both pros and cons in euthanasia policy and practice but, generally speaking, the pros outweigh the cons. Whereas Schrotten considers the guidelines strict and sufficient, Van Delden feels that the guidelines could be more specific and should clarify such vague terms as 'no prospect of improvement' and 'unbearable suffering'. Van Delden adds that an unfortunate result of such ambiguity might be that some patients would be rejected due to their failure to meet the criteria for receiving euthanasia.

Evert van Leeuwen, Margo Trappenburg and John Griffiths reiterate the problem of lack of reporting. On the positive side, van Leeuwen, Chairperson of the Department of Metamedicine at the Free University of Amsterdam, speaks of allowing people to die when they are conscious of their surroundings, when they are still able to appreciate their lives, and when they can choose the time of their death. He emphasizes that 90% of the reported cases are terminal cancer patients and 10% are ALS patients, who suffer degenerative diseases — all of them patients who are suffering without hope of improvement or cure.

Ruud ter Meulen and Ron Berghmans, both medical ethicists from Maastricht, stress that the positive aspects of euthanasia practice have to do with the ability to conduct an open discussion and that patients are allowed to play an important role in deciding their fate. Berghmans is in favour of providing assistance in dying and considers it humane to have the option. He maintains that in contrast to Germany, where the climate is not conducive to having a rational and productive debate on euthanasia, in the Netherlands it is possible to discuss everything.

As for the negative aspects, ter Meulen sees a dangerous shift from allowing euthanasia for cancer patients to allowing it for psychiatric patients.

The criteria are in flux, shifting too broadly towards what some might call a slippery slope. The Netherlands started the process with cancer patients and then expanded euthanasia practice to other groups of patients, including psychiatric patients, sick children, and cases of dementia. First, there was insistence on respecting the autonomy of the patient and honouring his/her desire to determine the moment of death. Now the discussion is shifting to mercy killings without the explicit request of the patient. Koerselman, Rutenfrans and Jochemsen have voiced similar concerns.

Ron Berghmans points to the significant number of cases of non-voluntary euthanasia, emphasizing the need to seek more information about these cases. Moreover, like Frank Koerselman, he feels that there is a need to further discuss the issue of advance directives,⁵¹ particularly with regard to dementia patients. The main problem in cases of dementia is in determining how to evaluate suffering, because the regulations require meeting the condition of unbearable suffering. In addition, there is the issue of control. Berghmans fears that this will always remain a problem in regulating euthanasia. He asserts that the Netherlands should strive for 100% transparency, but he is pessimistic about the probability that this will happen. As long as euthanasia remains criminal, Berghmans does not think that the level of doctors' reporting will increase. At the same time, he does not have a clear position on whether euthanasia should be decriminalized.⁵²

Chris Rutenfrans focuses only on the cons, arguing that there are many cases of people who are killed prematurely. He claims that euthanasia policy has shifted from voluntary to involuntary, from terminal illness to earlier stages of the disease. Patients are killed when the prospects for health improvement are slim.⁵³

van der Arend, a nurse, is not satisfied with the role of nurses in the euthanasia procedure. Nurses are not systematically involved in the decision about whether to honour euthanasia requests. Furthermore, nurses perform euthanasia in 20% of the cases in hospitals, in clear violation of the guidelines, which require a doctor to perform euthana-



sia. According to van der Arend, nurses are often unaware that they are administering euthanasia in violation of the guidelines. When euthanasia is conducted at patients' homes, nurses are often not consulted about the decision and sometimes discover it only after the death.⁵⁴ It should be added that research shows that approximately half of the GPs did not consult with nurses about a patient's request for either euthanasia or assisted suicide, the intention to administer them, and the actual administration.⁵⁵

Discussion

I came to the Netherlands with mixed feelings and left the same way, but with greater anxiety. The study shows that there is room for concern. Furthermore, it seems that the Dutch culture does not welcome a critical plurality of opinions regarding the legitimacy of euthanasia. Critics are regarded quite unfavourably.⁵⁶

It was strange for me to discuss the issue of euthanasia in the Netherlands. Views that are extremely unpopular in other countries regarding euthanasia's place in society rule supreme in the Netherlands. These discussions were almost a mirror image of discussions I had in Israel, the United States, Britain, Canada and Australia. What was striking in my discussions with the Dutch experts was the prevailing acceptance of the euthanasia procedure. There were only a few dissenters, people who were willing to go against the system. My first fourteen interviewees were, on the whole, in favour of the policy, and I felt a growing unease encountering such unanimity of opinion. This conformity worried me. Plurality and diversity of opinion are good for society, leading to a more comprehensive understanding of the issues, as well as a higher level of truth, as John Stuart Mill used to say.⁵⁷


A further concern is the way critics are treated in the Netherlands. The three dominant critical voices in the interviews, Koerselman, Rutenfrans and Jochemsen, complained about the atmosphere surrounding the policy and practice of euthanasia,

and voiced their dissent against the institutional mechanisms that are used to de-legitimize them and undermine their position. Koerselman said that advocates of euthanasia dismissed him as a Catholic fundamentalist. In fact, he is not a Catholic at all. He was brought up without any religious background, but his critics find it difficult to believe that a secular person would object to euthanasia with so much passion as Koerselman does. He also testified that he often felt treated like a clown. The media invited him to debate on euthanasia issues only because they needed to depict 'the other side', not because they were really interested in exploring the anti-euthanasia arguments. Koerselman declared that he was fed up with this treatment and with the dismissive attitude that he received from scholars and colleagues.

Chris Rutenfrans, who used to teach at the Catholic University of Nijmegen and later in his life became a journalist, argued that it is bad for one's reputation to be against euthanasia in the Netherlands because it gives the appearance of being conservative, and it is not good to be conservative in the Netherlands. This is why Rutenfrans wants to disassociate himself from the subject and is inclined to write on other issues. In his view, the country is not very liberal, but rather is conformist in its liberalism. Its people do not want to hear ideas that clash with their liberal values.

Rutenfrans recounted that in 1986 he had co-authored a booklet against euthanasia, entitled *May the Doctor Kill*, with Caterina I. Dessaur, a novelist known under the pen name Andreas Burnier. This was a highly polemical, very controversial book. Rutenfrans maintained that Dessaur had been quite a famous novelist before publishing this book. After publication, Dessaur's consecutive novels were more harshly criticized than before, depicting her as a conservative reactionary. In effect, she was cast out of the country's literary circles.⁵⁸

Henk Jochemsen indicated that during the past 20 years, the general atmosphere has been in favour of euthanasia.⁵⁹ The mentality now is to stop treatment at an early stage when the patient is



suffering. Quality of life has become the major principle at the expense of respect for life. Jochemsen claimed that physicians had told him about the difficulties they would face in finding a job in some institutions if they declared themselves to be opposed to euthanasia. The establishment view is pro-euthanasia, and one might be harmed if one takes a contrary view.

I found it troublesome that scholars and decision-makers support a system that suffers from serious flaws while the stakes are very high; after all, we are dealing with life and death.⁶⁰ There were variants of opinion regarding specific questions and issues, but only a minority questioned the system *as such*. Many of the experts depicted a society in which it is the role of doctors to help patients. They didn't question the doctors' motives, and saw no reason why doctors would perform euthanasia without compelling reasons. They argued that, of course, criminals exist in every society, in every sphere of life, but policy is not built around this small number of criminals. They believed there is a need to install control mechanisms against the possibility of abuse, but that the system's rationale is good — to help people in their time of need. They emphasized that the two major reports of 1990 and 1995 indicate there is no slippery slope, yet ignored the fact that there is already too much abuse. Many of the interviewees failed to recognize that the system does not work because *all* the guidelines, without exception, are broken time and time again. It is not always the patient who makes the request for euthanasia or physician-assisted suicide. Often the doctor proposes euthanasia to his patient. Sometimes the family initiates the request. The voluntariness of the request is thus compromised. On occasions, the patient's request is not well considered. There were cases in which no request was made and patients were put to death. Furthermore, the patient's request is not always durable and persistent as required.

The guidelines speak of 'unbearable suffering', a term that evokes criticisms because is opened to interpretations.⁶¹ Are dementia patients, for instance, suffering unbearably? Was Dr. Chabot's

patient in an unbearable state of suffering?⁶² The guidelines stipulate that a doctor must perform the euthanasia, but there are cases in which nurses administered euthanasia. It is estimated that 10% of the nursing-home physicians let the nurse or even the patient's family members administer the euthanasia drug.⁶³ Before the doctor assists the patient the doctor must consult a second doctor. This guideline has been breached many times. The doctor must keep a full written record of each and every case and report it to the prosecutorial authorities as a case of euthanasia or physician-assisted suicide, and not as a case of death by natural causes. This guideline has also been violated very often.⁶⁴ Notwithstanding, many interviewees were quite content with the guidelines.

I was surprised during some of the discussions at the rosy picture that was painted. I asked myself whether I was too cynical and suspicious, or my counterparts too optimistic; after all, they knew the situation in the Netherlands far better than I did. But the unanimity of opinion might suggest that there is not enough reflective thinking about this issue, that the practice of euthanasia is taken for granted;⁶⁵ therefore, there might be greater room for abuse because those who wish to abuse would find it easy to do so given this high level of trust and lack of critical questioning. Even issues that are acknowledged as problems are not conceived to be serious enough to press. The Dutch tend to argue and to accept highly troublesome contentions and to consider and allow euthanasia in cases where even the guidelines are not satisfied. The surrounding culture around euthanasia makes the practice accessible within the confines of what is permissible. This culture has a chilling effect on the open, critical debates.⁶⁶ In other parts of the world, under similar circumstances, in light of the justified critique, euthanasia would not be considered an option.

Some troubling questions have arisen as a result of my studying this Dutch phenomenon. The high number of unreported cases of euthanasia is alarming. The fact that some of the patients were put to death without prior consent is extremely worrisome. Society has to ensure ways that no



abuse takes place and that the existing legal procedure does not open a window for abuse, or a way to get rid of 'unwanted' patients. More research should be done on what outside of the Netherlands is termed 'passive euthanasia', the withholding or withdrawal of treatment. More attention should be given to demented patients, newborns and children. The guidelines need to be clarified in detail, closing the door to possible misinterpretation that could lead to abuse.

I agree with most of the experts who contend that euthanasia should not be regarded as an integral part of the normal medical care. However, the fact that many physicians do not wish to be bothered with the procedures is alarming. It shows that they have not internalized the idea that euthanasia is an exceptional medical procedure and, as such, requires social control. It is possible that the moral ambiguity surrounding the issue — allowing the practice while it was still prohibited under the penal code — made doctors feel that they had better conduct euthanasia in private, keeping it between the patients, their families and themselves only. The understanding of euthanasia and its importance should be changed for it to work without abusing the rules of carefulness.

I also think physicians should not suggest euthanasia to their patients as an option. By now, the Dutch people are fully aware that euthanasia is available. If patients wish, they can raise the issue themselves. Most of the euthanasia cases involve cancer patients, and at some time during the progressive course of their illness, they can take the initiative and discuss it with their physicians. If they don't, the physician can assume that the patient does not wish to have euthanasia.⁶⁷

I believe the medical profession should not turn its back on patients who clearly request to shorten their lives. However, this issue should be open to a constant public debate. Wherever euthanasia is practised, it should be subject to constructive criticism. It is preferable to draft a better legal framework than that of the Netherlands,⁶⁸ which was at the time of the interviews ambiguous and presented an illegal-yet-tolerated model. In the event

a new euthanasia policy is introduced, and we see that it opens the way to abuse, then yet again we should pursue a public debate in which different sectors of society will take part. Respect for human life is and should remain the prime concern. Ending a human life without acquiring the patient's consent might be motivated by mercy — or, the motivation may be quite different. Because ending of patients' lives should be conducted in the light, not in shadowy areas where only selected people may enter, we should devise a better working framework to help patients in need.

Before coming to the Netherlands I supported euthanasia and published some articles calling to recognize the need for euthanasia (in the active sense that is practised in the Netherlands).⁶⁹ After my visit I changed my view. I no longer support euthanasia and restrict my plea for helping patients in need to physician-assisted suicide. This is in order to enable patients control over their lives, and death, until the very last moment, and provide a further mechanism against abuse. At the same time, I am willing to concede the need for euthanasia in two circumstances: (1) the patient who asked for euthanasia is totally paralyzed, from head to toes, unable to move any muscles that could facilitate assisted suicide; and (2) the patient took oral medication and is dying a protracted death.

The majority of Dutch scholars do not share my view. They lump euthanasia and physician-assisted suicide together and even invented an abbreviation for this purpose: EAS. It should be noted, however, that in August 1995, in an effort to improve the control mechanisms the KNMG refined its guidelines to recommend that assisted suicide rather than euthanasia should be performed whenever possible.⁷⁰

I believe that the right to die with dignity includes the right to live with dignity until the last minute and the right to part from life in a dignified manner. There are competent, adult patients who feel that the preferable way for them to part from life is through physician-assisted suicide. The practice, however, should be much more careful than it is nowadays in the Netherlands.⁷¹

Appendix

Interviews in the Netherlands (summer 1999)

- Professor John Griffiths, Department of Legal Theory, Faculty of Law, University of Groningen (Groningen, July 16, 1999).
- Professor J.K. Gevers, Professor of Health Law, University of Amsterdam (Amsterdam, July 19, 1999).
- Professor Evert van Leeuwen, Department of Metamedicine, Free University of Amsterdam (Amsterdam, July 19, 1999; Haarlem, July 28, 1999).
- Dr. Dick Willems, Institute for Research in Extramural Medicine, Department of Social Medicine, Amsterdam (Amsterdam, July 20, 1999).
- Professor Bert Thijs, Medical Intensive Care Unit, VU Hospital, Amsterdam (Amsterdam, July 20, 1999).
- Professor A. van Dantzig, retired expert in psychiatry (Amsterdam, July 20, 1999).
- Professor H.J.J. Leenen, formerly professor of social medicine and health law, Medical Faculty and Faculty of Law, University of Amsterdam (Amsterdam, July 21, 1999).
- Professor Gerrit van der Wal, Institute for Research in Extramural Medicine, Department of Social Medicine, Free University of Amsterdam (Amsterdam, July 21, 1999).
- Dr. Jaap J.F. Visser, Ministry of Health, Department of Medical Ethics, The Hague (Amsterdam, July 21, 1999).
- Professor Heleen Dupuis, Department of Metamedicine, University of Leiden (Leiden, July 22, 1999).
- Dr. Margo Trappenburg, Department of Political Science, University of Leiden (Leiden, July 22, 1999).
- Dr. Henri Wijsbek, Department of Medical Ethics, Erasmus University of Rotterdam (Rotterdam, July 23, 1999).
- Dr. Arie J.G. van der Arend, Health Ethics and Philosophy, Maastricht University (Maastricht, July 26, 1999).
- Dr. George Beusmans, Maastricht Hospital (Maastricht, July 26, 1999).
- Professor G.F. Koerselman, Sint Lucas Andreas Hospital, Amsterdam (Amsterdam, July 27, 1999).
- Professor Henk Jochemsen, Professor Lindeboom Institute (Ede Wageningen, July 27, 1999).
- Dr. Gerrit K. Kimsma, Department of Metamedicine, Free University of Amsterdam (Koog aan de Zaan, July 28, 1999).
- Dr. James Kennedy, Department of History, Hope College, Michigan. Visiting Research Fellow at the Institute for Social Research, Amsterdam (Amsterdam, July 29, 1999).
- Professor Paul van der Maas, Department of Public Health, Faculty of Medicine, Erasmus University, Rotterdam (Amsterdam, July 29, 1999).
- Dr. Chris Rutenfrans, *Trouw* (Amsterdam, July 30, 1999).
- Dr. Arko Oderwald, Department of Metamedicine, Free University of Amsterdam (Amsterdam, July 30, 1999; August 8, 1999).
- Ms. Barbara de B. and her three children (Amsterdam, August 2, 1999).
- Professor Egbert Schroten, Director, Centre for Bioethics and Health Law, Utrecht University (Utrecht, August 5, 1999).
- Professor Govert den Hartogh, Faculty of Philosophy, University of Amsterdam (Amsterdam, August 10, 1999).
- Dr. Johannes JM van Delden, Senior Researcher, Centre for Bioethics and Health Law, Utrecht University (Utrecht, August 10, 1999).
- Dr. Rob Houtepen, Health Ethics and Philosophy, Maastricht University (Maastricht, August 11, 1999).
- Dr. Ron Berghmans, Institute for Bioethics, Maastricht University (Maastricht, August 11, 1999).
- Professor Ruud ter Meulen, Director, Institute for Bioethics and Professor at the University of Maastricht (Maastricht, August 11, 1999).



Notes

1. D.Phil. (Oxon., 1991); Associate Professor, University of Haifa; Visiting Professor and the Fulbright-Yitzhak Rabin scholar for 1999-2000, UCLA School of Law; Director, Think-tank on Medical Ethics, The Van Leer Jerusalem Institute (1995-1998); author of five books, among them *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (Piscataway, NJ: Rutgers University Press, 2001) and *Euthanasia in the Netherlands* (forthcoming); editor of five further books, among them *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000).
2. Herbert Hendin, *Seduced by Death* (New York: W.W. Norton, 1997), p. 23.
3. The Medical Association Executive Board emphasized that there are only limited possibilities for verifying whether suffering is unbearable and without prospect of improvement. The Board considered it in any case the doctor's task to investigate whether there are medical or social alternatives that can make the patient's suffering bearable. John Griffiths, Alex Bood and Heleen Wevers, *Euthanasia and Law in the Netherlands* (Amsterdam: Amsterdam University Press, 1998), p. 66.
4. John Keown, "The Law and Practice of Euthanasia in the Netherlands," *The Law Quarterly Review*, Vol. 108 (January 1992), p. 56.
5. The Royal Dutch Medical Association's refinements of the 1984 guidelines (August 25, 1995). Cf. Marlise Simons, "Dutch Doctors to Tighten Rules on Mercy Killings," *The New York Times* (September 11, 1995), p. A3.
6. Supreme Court of the Netherlands, Criminal Chamber (June 21, 1994), no. 96.972. For translation, see John Griffiths, Alex Bood and Heleen Wevers, *Euthanasia and Law in the Netherlands*, *op. cit.*, Appendix II (2), pp. 329-340. See also R. Cohen-Almagor, "The Chabot Case: Analysis and Account of Dutch Perspectives", *Medical Law International*, Vol. 5 (2001), pp. 141-159.
7. <http://www.euthanasia.org/dutch.html#remm>. See also Marcia Angell's Editorial, "Euthanasia in the Netherlands - Good News or Bad?," *New Eng. J. of Medicine*, Vol. 335, No. 22 (November 28, 1996), pp. 1676-1678; Adriaan Jacobovits, "Euthanasia in the Netherlands," *Washington Post* (January 23, 1997), p. A16; General Health Council, "A Proposal of Advice Concerning Careful Requirements in the Performance of Euthanasia" (The Hague, 1987).
8. Cf. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, Health Policy Monographs (Amsterdam: Elsevier, 1992).
9. Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate *et al.*, "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," *New Eng. J. of Med.*, Vol. 335, No. 22 (November 28, 1996): 1699-1705. For further discussion, see Johannes J.M. van Delden *et al.*, "Deciding Not to Resuscitate in Dutch Hospitals," *J. of Medical Ethics*, Vol. 19 (1993): 200-205; Tony Sheldon, "Euthanasia Law Does Not End Debate in the Netherlands," *BMJ*, Vol. 307 (December 11, 1993): 1511-1512; Henk Jochemsen, "Euthanasia in Holland: An Ethical Critique of the New Law," *J. of Medical Ethics*, Vol. 20 (1994): 212-217; Chris Ciesielski-Carlucci and Gerrit Kimsma, "The Impact of Reporting Cases of Euthanasia in Holland: A Patient and Family Perspective," *Bioethics*, Vol. 8, No. 2 (1994): 151-158; J.K.M. Gevers, "Physician Assisted Suicide: New Developments in the Netherlands," *Bioethics*, Vol. 9, No. 3/4 (1995): 309-312.
10. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, *op. cit.*, p. 41.
11. Gerrit van der Wal and Paul J. van der Maas, "Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure," in David C. Thomasma, Thomasine Kimbrough-Kushner, Gerrit K. Kimsma, and Chris Ciesielski-Carlucci (eds.), *Asking to Die* (Dordrecht: Kluwer Academic Publishers, 1998), p. 171. See also Bill Mettyear, "advocating legalising voluntary euthanasia" (February 1997), <http://www.on.net/clients/saves/> South Australian Voluntary Euthanasia Society. In his comments on the first draft of this study, Van der Maas wrote that in 1990 the decision had been discussed with a patient in 46% of the cases and in 14% there had been an expressed wish. Because explicit request is defined very strictly in our studies, these were not counted as euthanasia on request. Van der Maas noted an interesting comparison: replication studies in Australia and Belgium both found frequencies over 3% for ending of life without explicit request. He estimated the number of active cases involving ending of life among newborns in the Netherlands to be 10-15 cases per year. Personal communication on September 18, 2000.



12. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, *op. cit.*, p. 58.
13. *Ibid*, p. 61.
14. *Ibid*, p. 62.
15. In another study among general practitioners, one quarter of the physicians said that they did not ask for a second opinion before administering euthanasia or assisted suicide, and 12% of the GPs had no consultation with any professional health worker. Cf. G. van der Wal, J.Th.M. van Eijk, H.J.J. Leenen and C. Spreeuwenberg, "Euthanasia and Assisted Suicide. II. Do Dutch Family Doctors Act Prudently?," *Family Practice*, Vol. 9, No. 2 (1992), p. 140.
16. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, *op. cit.*, p. 65.
17. *Ibid*, p. 66.
18. Henk A.M.J. ten Have, "Euthanasia: The Dutch Experience," *Annals de la Real Academia Nacional de Medicina*, Tomo CXII (Madrid, 1995), p. 429.
19. See 1996 Study Findings, "Euthanasia and other decisions concerning the end of life in the Netherlands," Foreign Information Department, Netherlands Ministry of Foreign Affairs.
20. Rummelink Commission, *Rapport Medische Beslissingen Rond het Levenseinde* (The Hague: SDU, 1991), p. 37. See also Henk A.M.J. ten Have, "Euthanasia: The Dutch Experience," *Annals de la Real Academia Nacional de Medicina*, Tomo CXII (Madrid, 1995), p. 429. In his comments on the first draft of this study, Leenen wrote that the proposal of the Rummelink Commission was rejected by nearly all the Dutch commentators and also by the government. Letter dated July 25, 2000.
21. http://www.ves.org.uk/news/wld_archive.htm
22. "Minderjarige mag euthanasie vragen," *NRC Handelsblad* (July 10, 1999), p. 3. See also Marilyn Gardner, "Dutch poised to legalize euthanasia," *The Christian Science Monitor* (June 30, 2000). <http://www.csmonitor.com/durable/2000/06/28/text/p1s4.html>
23. "Dutch call off aided suicide for children," *The International Herald Tribune* and *The Associated Press* (July 15, 2000).
24. Henk Jochemsen, "Update: The Legalization of Euthanasia in The Netherlands," *Ethics & Medicine*, Vol. 17, No. 1 (2001), 7-12.
25. In his letter dated June 5, 1999, Dr. Chabot wrote: "After four years waiting for the final court judgment (1991-1995) and discussing the case with many people from abroad, I hope you will understand that I prefer to remain in the background now and not to make an appointment with you." He, however, agreed to answer via e-mail some specific questions relating to his conduct that brought about the charges against him.
26. Carlos F. Gomez, *Regulating Death* (New York: The Free Press, 1991), pp. 59-60.
27. In her remarks on the first draft of this essay, Heleen Dupuis wrote: "We do not want to defend our views, nor do we want to persuade others to adopt them. We are just very weary when the hundred and umpteenth foreigner comes with questions we already have discussed the same number of times. Personally I am very tired by the endless interrogations, whereas I feel that euthanasia is a private matter, such as abortion, and even more so. I also feel that there is a certain exaggeration when it comes to the gravity of the problem." Personal communication on July 25, 2000.
28. In his comments on the first draft of this study, Leenen wrote that he doesn't agree that there is a lack of criticism in the Netherlands: "We have for more than 25 years discussed euthanasia publicly and between all kinds of opinions in a good atmosphere. Nobody was excluded. I personally lectured in meetings of opponents who invited me. I don't know of a country where this is possible." Leenen maintained that gradually a kind of consensus has grown "within a majority" and the problem is that "people like Fenigsen" never took part in this debate and only vented their opinions elsewhere. Letter dated July 25, 2000.
29. Carlos F. Gomez, *Regulating Death*.
30. John Keown, "The Law and Practice of Euthanasia in the Netherlands," *The Law Quarterly Review*, Vol. 108 (January 1992), pp. 51-78; *idem*, "Euthanasia in the Netherlands: Sliding Down the Slippery Slope?," *Notre Dame J. of Law, Ethics and Public Policy*, Vol. 9 (1995), pp. 407-448.
31. Herbert Hendin, *Seduced by Death* (New York: W.W. Norton, 1997).



32. This statement spurred Paul van der Maas to react by saying: "I consider myself as an independent researcher, with a primary responsibility in collecting reliable data and basing impartial estimates and interpretations on that empirical information. I see no position for myself in a pro versus contra euthanasia debate and I think such kind of debate is entirely unproductive. As a researcher I think my responsibility is to find out what people do and how that might fit in high quality end of life medicine. During the last years part of our study has been replicated in Australia and Belgium and we have obtained funding from the European Union for an international collaborative study in order to establish empirical comparisons between countries." Personal communication on September 18, 2000.

33. In her comments on the first draft of this essay, Dupuis clarified: "What I wanted to say by that is that clearly euthanasia is not about 'life and death,' as you say somewhere in the book, but about a way of dying of patients who will die anyway in a short period of time. Assisted suicide is a different matter, and morally much more complicated." Personal communication on July 25, 2000.

34. Joop van Holsteyn and Margo Trappenburg, *Het laatste oordeel. Meningen over nieuwe vormen van euthanasie* (Ambo, Baarn 1996). Likewise, Govert den Hartogh and Egbert Schrotten are satisfied with the existing arrangement. At the same time, they voice their fear that the new legislation under consideration might extend the options for euthanasia too far. For discussion on the law proposal, see H.J.J. Leenen, "Bill on Euthanasia and Assisting Suicide in the Netherlands," *European J. of Health Law*, Vol. 5 (1998): 299-324.

35. Personal communication on July 6, 2000.

36. Margo Trappenburg, "Willen we dit nu echt? Kanttekeningen bij de nieuwe voorstellen abortus en euthanasie," in *Socialisme & Democratie*, jrg. 57, nr. 1 (January 2000), pp. 2-9.

37. A. van Dantzig, Rob Houtepen, Johannes van Delden and Henri Wijsbek.

38. In November 1997, the Secretaries of Justice and of Healthcare, Well Being and Sports published their intention to inaugurate five regional review committees to supervise physicians in actively ending the lives of their patients. The five regions are Groningen, Friesland and Drenthe; Overijssel, Gelderland, Utrecht and Flevoland; North Holland; South Holland and Zeeland; North Brabant and Limburg. These committees have been functioning since November 1998 and retrospectively evaluate the reported cases of euthanasia and physician-assisted suicide. The committees' members consist of a lawyer (who serves as chairperson), a physician, and an ethicist, and their responsibility encompasses all cases in which a voluntary request has been made by a competent patient. Cases of physician-assisted death without such a request are sent directly to the Office of the Prosecution. The primary goal of having regional committees is to evaluate the prudence of the practice of physician-assisted death, with the intent of public control of a highly sensitive medical practice and moral issue. The secondary goal is to increase the number of reported cases and thus make public control more effective. Evert van Leeuwen and Gerrit Kimsma, "Problems Involved in the Moral Justification of Medical Assistance in Dying: Coming to Terms with Euthanasia and Physician Assisted Suicide," in R. Cohen-Almagor (ed.), *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000): 157-173.

39. However, there are studies that show euthanasia is more prevalent in the Netherlands than in other countries. See, for instance, Martien T. Muller, Gerrit K. Kimsma and Gerrit van der Wal, "Euthanasia and Assisted Suicide: Facts, Figures and Fancies with Special Regard to Old Age," *Drugs & Aging*, Vol. 13, No. 3 (September 1998): 185-191.

40. Letter dated July 25, 2000.

41. For discussion of these concepts, see Jay Katz, *The Silent World of Doctor and Patient* (New York: The Free Press, 1984): 142-150.

42. See also John Griffiths, Alex Bood and Heleen Weyers, *Euthanasia and Law in the Netherlands*, *op. cit.*, pp. 299-305.

43. For further deliberation, see Henk Jochemsen, "The Netherlands Experiment," in John F. Kilner, Arlene B. Miller and Edmund D. Pellegrino (eds.), *Dignity and Dying* (Grand Rapids, MI.: William B. Eerdmans Publishing Co., 1996): 165-179.

44. van der Maas contests this view. In his comments, he wrote that not only his studies but also studies in other countries have established time and again that pain is rarely the reason for a euthanasia request. Personal communication on September 18, 2000. However, van der Maas's own study from 1990 shows that in 46% of cases, pain was the reason given by the patient for requesting euthanasia or PAS. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, Health Policy Monographs (Amsterdam: Elsevier, 1992), pp. 43-44.



45. In his comments, van Dantzig wrote: "I have different opinions from Prof. Dupuis. I do not believe in the autonomous decision of the patient, as she does." He noted that his views "are not as radical as you think." Personal communication on July 6, 2000.

46. In his comments on the first draft of this study, van Dantzig added a general remark: "euthanasia is not killing, it is ending a life. Killing has criminal associations, and should not be used for the professional actions of a doctor." Personal communication on July 6, 2000.

47. Cf. Gerrit van der Wal and P.J. van der Maas, "Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure," in David C. Thomasma *et al.* (eds.), *Asking to Die* (Dordrecht: Kluwer Academic Publishers, 1998), p. 155.

48. In 1995, the annual number of requests made to doctors for euthanasia or PAS "at a later time" was estimated at 34,500, an increase of 37% as compared with 1990. In total, 9,700 explicit requests were made for euthanasia or PAS, an increase of 9%. Gerrit van der Wal and P.J. van der Maas, "Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure," *Ibid.*, p. 155.

49. In his comments on the first draft of this study, Leenen wrote that the guidelines are working. Only the procedural requirement of reporting is still defective. Letter dated July 25, 2000.

50. Herbert Hendin, *Seduced by Death* (New York: W.W. Norton, 1997), p. 148.

51. An advance directive (AD) is a document that allows patients to express what life-sustaining treatments they want and whom they want to make these decisions for them. In the United States, more than forty states have enacted legislation supporting the use of ADs. For further discussion, see Joseph J. Fins, "The Patient Self-determination Act and Patient-Physician Collaboration in New York State," *N.Y. State J. of Medicine*, Vol. 92 (November 1992): 489-493; Nitsa Kohut and Peter A. Singer, "Advance Directives in Family Practice," *Canadian Family Physician*, Vol. 39 (May 1993): 1087-1093; Maarten Reinders and Peter A. Singer, "Which Advance Directive Do Patients Prefer?," *Journal of General Internal Medicine*, Vol. 9 (January 1994): 49-51; Dallas M. High, "Families' Roles in Advance Directives," *Hastings Center Report*, Special Supplement (November-December 1994): S16-S18; Hans-Martin Sass, Robert M. Veatch and Rihito Kimura (eds.), *Advance Directives and Surrogate Decision Making in Health Care* (Baltimore: Johns Hopkins University Press, 1998); Lawrence P. Ulrich, *The Patient Self-Determination Act* (Washington, D.C.: Georgetown University Press, 1999): 219-251; David Degrazia, "Advance Directives, Dementia, and 'The Someone Else Problem,'" *Bioethics*, Vol. 13, No. 5 (1999): 373-391; D. William Molloy, Gordon H. Guyatt, Rosalie Russo *et al.* "Systematic Implementation of an Advance Directive Program in Nursing Homes," *JAMA*, Vol. 283, No. 11 (March 15, 2000); Joan M. Teno, "Advanced Directives for Nursing Home Residents," *JAMA*, Vol. 283, No. 11 (March 15, 2000). <http://jama.ama-assn.org/issues/v283n11/toc.html>; Paul Biegler, Cameron Stewart, Julian Savulescu and Loane Skene, "Determining the Validity of Advance Directives," *Medical J. of Australia*, Vol. 172 (2000): 545-548. http://www.mja.com.au/public/issues/172_11_050600/biegler/biegler.html

52. Henk Leenen is similarly happy that Dutch society discusses controversial matters, like euthanasia, in the open. However, he reiterates the need for better control, stressing that euthanasia is not a matter for doctors and patients alone. The entire society needs to get involved in the process, and then the level of reporting should improve.

53. In his comments, van der Maas asks: "Is there any serious research on which Mr. Rutenfrans can establish these claims? I have never seen any." He maintains that he fails to understand how I am using the results of his extensive research, claiming that they may not be impartial because the government funded those studies, and at the same time use "the kind of undocumented insinuations by Mr. Rutenfrans." Personal communication on September 18, 2000.

54. van der Maas and colleagues report that a nurse or someone else sometimes performs euthanasia with a drug that was prescribed for this purpose by a physician. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, *Euthanasia and other Medical Decisions Concerning the End of Life*, *op. cit.*, p. 193.

55. Martien Tom Muller, *Death on Request* (Amsterdam, Vrije Universiteit Thesis, 1996), p. 80.

56. In his comments on the first draft of this study, van Dantzig wrote that this assertion is fundamentally incorrect: "The whole of Dutch society is based on the cohabitation of people who fundamentally disagree on everything. The sometimes very creative solutions (soft drugs may not be bought by coffee shops, but their sale is not punished within certain limits) have given rise to the word "poldermodel," which expressly means living by compromise, or as I have once put it, the fair division of discontent. I write to you because such a fundamental misunderstanding may harm the quality of your paper." Personal communication on July 14, 2000.



57. J. S. Mill, *Utilitarianism, Liberty, and Representative Government* (London: J. M. Dent, 1948), Everyman edition.
58. For further deliberation, see Herbert Hendin, *Seduced by Death*, *op. cit.*, pp. 105-107.
59. A poll in 1996 showed that 84% of the population is in favour of euthanasia if a fellow human being is in an unacceptable and futureless situation. Cf. <http://www.ves.org.uk/library/smook.htm>
60. In his comments on the first draft of this essay, Griffiths reacted to this statement by writing: "Nowhere do you suggest that anywhere else there is a *better* system. The Dutch know about the system's defects and are working to improve it. Can you tell me about another country where that is true? In short, I think you need to think again, and a lot more carefully, about what you are writing about, before you can expect to be taken seriously." Personal communication on July 10, 2000. Griffiths, it seems, finds a lot of comfort in comparative studies to the point of blurring his own careful thinking about the happenings in his country.
61. For deliberation on the range of what 'unbearable suffering' means, see Carlos F. Gomez, *Regulating Death* (New York: The Free Press, 1991), pp. 99-104.
62. See Griffiths' analysis in "Assisted Suicide in the Netherlands: The *Chabot* Case," *Modern L. Rev.*, Vol. 58 (March 1995), pp. 239-248, and R. Cohen-Almagor, "The *Chabot* Case: Analysis and Account of Dutch Perspectives", *Medical Law International*, Vol. 5 (2001), pp. 141-159.
63. Martien Tom Muller, *Death on Request* (Amsterdam: Vrije Universiteit, Thesis, 1996), p. 52.
64. For deliberation, see Jacqueline M. Cuperus-Bosma, Gerrit van der Wal and Paul J. van der Maas, "Physician-assisted Death: Policy-making by the Assembly of Prosecutors General in the Netherlands," *European J. of Health Law*, Vol. 4 (1997), pp. 225-238.
65. In his comments, Arie van der Arend contested my argument that there is not enough reflective thinking about euthanasia, arguing that (a) I cannot expect extensive and balanced reflective thinking during interviews that were taken from people who were busy with totally different tasks at that moment; (b) my study does not cover the extensive Dutch literature on the subject; (c) I did not interview one of the best 'reflective thinkers', Theo Beemer, Professor of Moral Theology and Health Care Ethics at the Catholic University of Nijmegen, and (d) that such a value judgment could have been justified only after comparing the Dutch practice to the situation in other countries. Personal communication on July 3, 2000.
66. Hendin reached a similar conclusion. Cf. Herbert Hendin, *Seduced by Death*, *op. cit.*, p. 100.
67. See R. Cohen-Almagor, "Should Doctors Suggest Euthanasia to Their Patients? Reflections on Dutch Perspectives", *Theoretical Medicine and Bioethics* (forthcoming).
68. See R. Cohen-Almagor, "Euthanasia and Physician-Assisted Suicide in the Democratic World: Legal Overview", *NY Int. L. Rev.* Vol. 15, No. 2 (forthcoming); *idem*, "A Circumscribed Plea for Voluntary Physician-Assisted Suicide," in R. Cohen-Almagor (ed.), *Medical Ethics at the Dawn of the 21st Century* (NY: NY Academy of Sciences, 2000): 127-149, esp. at 140-144.
69. Cf. R. Cohen-Almagor, "The Patients' Right to Die in Dignity and the Role of Their Beloved People," *Annual Review of Law and Ethics*, Vol. 4 (1996), pp. 213-232; "Reflections on the Intriguing Issue of the Right to Die in Dignity," *Israel Law Review*, Vol. 29, No. 4 (1995), pp. 677-701; "Autonomy, Life as an Intrinsic Value, and Death with Dignity," *Science and Engineering Ethics*, Vol. 1, No. 3 (1995), pp. 261-272.
70. Cf. Herbert Hendin, *Seduced by Death*, *op. cit.*, p. 122.
71. I explain my standpoint in detail in *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (Piscataway, NJ.: Rutgers University Press, 2001).