

Is Actively Ending Life When the Vital Functions Have Started Failing an Indisputably Normal Medical Practice ?

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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 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 centers of medical ethics as well as some research hospitals, and to speak with leading figures in euthanasia policy and practice. The time spent was extremely beneficial and enriching. One should not exaggerate the importance of a one-month investigation, extensive as it might be, but one should not underestimate it as well. I followed in the footsteps of Carlos Gomez, who published a book following one month of extensive research in the Netherlands.¹

The discussion begins with providing some background information on the guidelines for conducting euthanasia. Next, I explain the research methodology and then detail the interviewees' answers to the query relating to Rummelink's contention that actively ending life when the vital functions have started failing is indisputably normal medical 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

¹. Carlos F. Gomez, *Regulating Death* (New York: The Free Press, 1991).

Association. These Guidelines are based on the criteria set out in court decisions relating to when a doctor can successfully invoke the defense of necessity. The substantive requirements are as follows:

The request for euthanasia or physician-assisted suicide must be made by the patient and must be free and voluntary.

The patient's request must be well considered, durable and consistent. The patient's situation must entail unbearable suffering with no prospect of improvement and no alternative to end the suffering.² The patient need not be terminally ill to satisfy this requirement and the suffering need not necessarily be physical.

Euthanasia must be a last resort.³

The procedural requirements are as follows:

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.

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.⁴

A doctor must perform the euthanasia.

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,⁵ if the patient has a psychiatric disorder

². 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.

³. John Keown, "The Law and Practice of Euthanasia in the Netherlands," *The Law Quarterly Review*, Vol. 108 (January 1992), p. 56.

⁴. The Royal Dutch Medical Association's refinements of the 1984 Guidelines (25 August 1995). Cf. Marlise Simons, "Dutch Doctors to Tighten Rules on Mercy Killings," *The New York Times* (11 September 1995), p. A3.

⁵. Supreme Court of the Netherlands, Criminal Chamber (21 June 1994), no. 96.972. For translation, see John Griffiths, Alex Bood and Heleen Weyers, *Euthanasia and Law in the Netherlands*, *op. cit.*, Appendix II (2), pp. 329-340.

the doctor must cause the patient to be examined by at least two other doctors, one of whom must be a psychiatrist.

The doctor must keep a full written record of the case.

The death must be reported to the prosecutorial authorities as a case of euthanasia or physician-assisted suicide, and not as a case of death by natural causes.⁶

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:

Non-treatment decisions: withholding or withdrawing treatment when treatment would probably have prolonged life;

Alleviation of pain and symptoms: administering opiates in such dosages that the patient’s life might be shortened;

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.⁷

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.⁸

⁶ <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 (28 November 1996), pp. 1676-1678; Adriaan Jacobovits, “Euthanasia in the Netherlands,” *Washington Post* (23 January 1997), p. A16; General Health Council, “A Proposal of Advice Concerning Careful Requirements in the Performance of Euthanasia” (The Hague, 1987).

⁷ 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).

⁸ 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

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 1990⁹ 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 1995.¹⁰

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

Netherlands,” *BMJ*, Vol. 307 (11 December 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.

⁹. 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.

¹⁰. 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 18 September 2000.

with 25% of specialists and 10% of nursing home physicians).¹¹ Life-terminating acts without explicit request were performed more, on the average, with older patients than were euthanasia or physician-assisted suicide.¹² 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.¹³ It should be noted that the level of consultation was significantly lower in life-termination acts without 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.¹⁴ Van der Maas and colleagues note that this should be considered in light of the very brief period by which life was shortened.¹⁵ In 67% of the cases, life was shortened by fewer than 24 hours. In 21% of the cases, life was shortened by up to one week.¹⁶

About a quarter of the 1000 patients had expressed a wish for voluntary euthanasia previously.¹⁷ 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

¹¹. 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.

¹². *Ibid*, p. 61.

¹³. *Ibid*, p. 62.

¹⁴. In another study among family doctors, 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.

¹⁵. 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.

¹⁶. *Ibid*, p. 66.

¹⁷. Henk A.M.J. ten Have, “Euthanasia: The Dutch Experience,” *Annals de la Real Academia Nacional de Medicina*, Tomo CXII (Madrid, 1995), p. 429.

disorder and were barely viable; hence the doctor's decision, in consultation with the parents, to hasten the end of life.¹⁸

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.¹⁹

The Dutch authorities acknowledge that not every case of termination of life is reported. This does not mean, however, that some doctors report cases and others fail to do so. The distinction is related, so it is claimed, to the nature of the case. Cases in which a patient's life has been terminated without his or her explicit request are usually not reported. The explanation provided for this alarming phenomenon is that doctors may be confronted with appalling suffering on the part of "terminally ill patients who are no longer able to make their wishes known."²⁰ These patients have no prospect of recovery and are no longer able to make their wishes known due to the failure of their body functions. In such circumstances, the doctor, in consultation with the patient's relatives, may decide to actively hasten death. It is claimed that

¹⁸. See 1996 Study Findings, "Euthanasia and other decisions concerning the end of life in the Netherlands," Foreign Information Department, Netherlands Ministry of Foreign Affairs.

¹⁹. 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 25 July 2000.

²⁰. 1996 Study Findings, "Euthanasia and other decisions concerning the end of life in the Netherlands," Foreign Information Department, Netherlands Ministry of Foreign Affairs.

approximately 50% of these patients have clearly made it known at an earlier stage that they would wish to die upon reaching such a condition.²¹

On 28 November 2000, the Dutch Lower House of parliament, by a vote of 104 for and 40 against, approved the legalization of euthanasia. On 10 April 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 improvement. 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 in a 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.²²

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.²³

²¹. *Ibid.*

²². http://www.ves.org.uk/news/wld_archive.htm

²³. "Minderjarige mag euthanasie vragen," *NRC Handelsblad* (10 July 1999), p. 3. See also Marilyn Gardner, "Dutch poised to legalize euthanasia," *The Christian Science Monitor* (30 June 2000).

<http://www.csmonitor.com/durable/2000/06/28/text/p1s4.html>

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 maneuver to win approval for other controversial provisions of the new legislation, such as legalizing euthanasia for victims of Alzheimer's disease.²⁴ 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.²⁵

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

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.²⁶

²⁴. "Dutch call off aided suicide for children," *The International Herald-Tribune* and *The Associated Press* (15 July 2000).

²⁵. Henk Jochemsen, "Update: The Legalization of Euthanasia in The Netherlands," *Ethics & Medicine*, Vol. 17, No. 1 (2001), 7-12.

²⁶. In his letter dated 5 June 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. I am in the process of writing a detailed analysis of the *Chabot* case.

The interviews took place during July-August 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 interviewees' offices. Four interviews were conducted at the interviewees' private homes, and four interviews in "neutral" locations: coffee shops 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 obtain a sampling from different locations, I traveled from Groningen in the north to Maastricht in the south, making extensive use of the efficient train system in the Netherlands.

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 I spoke only about their direct involvement in the practice of euthanasia. This article reports the answers to one of the questions. 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*.²⁷

I was struck by defensiveness expressed by some of the interviewees. Gomez also reported the notions of suspicion and guardedness on the part of his interviewees.²⁸ 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.²⁹ As a matter of fact, I was somewhat troubled by their lack of

²⁷. University of Pennsylvania Press, 2002.

²⁸. Carlos F. Gomez, *Regulating Death* (New York: The Free Press, 1991), pp. 59-60.

²⁹. 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 foreigners come 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

criticism and their readiness to accept the euthanasia policy and practice with all their flaws.³⁰ 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,³¹ Keown³² and Hendin,³³ 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.³⁴

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 25 July 2000.

³⁰. 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 ventilated their opinions elsewhere. Letter dated 25 July 2000.

³¹. Carlos F. Gomez, *Regulating Death*.

³². 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.

³³. Herbert Hendin, *Seduced by Death* (New York: W.W. Norton, 1997).

³⁴. 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

REMMELINK'S CONTENTION

The question was: The Rummelink Commission held that actively ending life when the vital functions have started failing is indisputably normal medical practice.³⁵ Is this correct? What is your opinion?

When I first read this statement, I was puzzled. It is unclear what "the vital functions have started failing" exactly means. What vital functions? What does "started failing" mean? Moreover, is this really the common practice in the Netherlands? The assertion is unqualified. The consent of the patient does not appear in it. To say that it is "indisputably normal medical practice" seemed to be quite dangerous.

Interestingly, some interviewees denied that the Report actually said this. Most of them disagreed with the unqualified statement. Two interviewees agreed with the statement and two others understood it to refer to double effect, which is an acceptable doctrine in the Netherlands as well as in other countries.

Paul van der Maas, Director of the Department of Public Health at Erasmus University, who co-authored the 1990 study report (to be distinguished from the committee's report), said that maybe there is a problem in the translation, which he thinks is biased and incorrect. Others³⁶ disagreed with the Rummelink statement and added that they did not think the Commission had actually expressed such a vague statement. "Failing of vital functions" is not a common phrase, and it does not convey a clear meaning. They questioned the statement's rationale: If vital functions are failing, that means the patient is dying. If someone is dying, why is there a need to kill him? Heleen Dupuis wondered: What does "vital functions" mean? If the statement refers to patients in a coma, the practice is to stop treatment after several months. But this rule as stated here "is nonsense." The doctor must know more in order to terminate life. Three interviewees, Schrotten, Koerselman and Van Delden, said that if the vital organs are irreversibly failing, then the patient is dying. Switching ventilators is a normal practice, but not injections designed to kill. Medical treatment should stop under such circumstances, but this does not mean actively ending life. In any event,

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 18 September 2000.

³⁵ . Henk A.M.J. ten Have, "Euthanasia: The Dutch Experience," *Annals de la Real Academia Nacional de Medicina*, Tomo CXII (Madrid, 1995), p. 429.

³⁶ . Dick Willems, Evert van Leeuwen and Heleen Dupuis.

lethal injections are not normal treatment, and euthanasia is not a normal practice. It is an exceptional treatment used in cases of exceptional suffering of the patients concerned.

Van Delden was familiar with the statement, which accompanied the 1990 study report that he co-authored with Van der Maas and Pijnenborg, and expressed disagreement with it. He emphasized that there were two documents: one of the Commission and one of the Van der Maas research group, in which he participated. This contention was made in the Commission's Report, and this part of the Report was not accepted by the Dutch parliament. Van Delden explained that the contention was made by the Commission to justify what was going on, but that this was not something he would condone. Likewise, Van der Wal was familiar with the statement and thought that the Commission erred in including it. In his view, this went a step too far, and he did not endorse this reasoning. He asserted that euthanasia is *not* a normal practice and should be avoided as much as possible. As such, we pass a boundary when we say that it is normal and accept ending life without an explicit request of the patient.

Arie van der Arend, a nurse and medical ethicist, also did not agree with the Rummelink statement, saying that physicians in general do not want to terminate life. They want to do whatever they can to save the lives of their patients. Preserving life is the normal medical practice, and he doubted that the Rummelink Commission actually made the above statement. In his view, the normal practice, if any at all, with respect to hopeless situations is to withhold treatment, not to actively end the life of the patient. He testified from personal experience in the neonatal department that withholding treatment occurs, but not active euthanasia. Van der Arend is convinced that doctors in the Netherlands do not accept or follow the Rummelink statement.

Bert Thijs, Director of the Medical Intensive Care Unit, VU Hospital in Amsterdam, remarks that the entire function of the ICU is to try to save patients whose vital functions have failed, whose breathing is difficult, and whose blood pressure has dropped considerably. The normal practice in ICUs is to try to save the lives of these patients.

Henk Jochemsen, H.J.J. Leenen and Govert den Hartogh expressed strong disagreement with the Rummelink statement. Jochemsen, Director of the Professor Lindeboom Institute, explained that the Rummelink statement concerned the 900 and 1000 patients who had not given their consent. He noted his strong disagreement, arguing that actively shortening life is not normal medical practice and that the government and the courts do not conceive of this as normal medical practice. After all, if such a practice is considered normal, then why report? Why control? It does not make sense.

Henk Leenen, who drafted the euthanasia law, insisted time and again that euthanasia is not normal medical practice, and that the Rummelink's view is

absolutely unacceptable in the Netherlands. The Guidelines speak of autonomous decision-making, whereas the Rummelink statement does not refer to autonomy. In his later comments, Leenen asserted that the Rummelink contention had no relevance in the debate. Hence, “why give it so much accent?”³⁷ Den Hartogh, a philosopher who is a member in the Amsterdam regional committee that reviews all reported euthanasia cases in the region, explained that when dealing with patients whose vital functions are failing, doctors should cease treatment but continue with palliative care. They should not actively end life. He maintained that the Rummelink statement is contrary to what is accepted today in the Netherlands and that euthanasia should remain an exceptional medical practice conducted in cases of unbearable suffering.³⁸

On the other hand, Henri Wijsbek and A. van Dantzig agreed with the Rummelink statement, arguing that it is senseless to continue treatment and medications when vital functions start failing. Although there is no consent on the part of the patient, life beyond repair is senseless and euthanasia is permitted under these conditions. Van Dantzig, a well-known psychiatrist, explained that “failing vital functions” means keeping a person alive by external means, such as respirators and heart stimulation. The welfare of the patient is the main concern, and in such severe circumstances the patient should be allowed to die. In turn, John Griffiths, who co-authored a leading manuscript on euthanasia and law, explains that “normal medical practice” is a legal term referring to the behavior (otherwise illegal) that doctors can perform by virtue of the authority to practice medicine. Therefore, there is no need for legal control where they are concerned. The statement refers to people who would have died within *hours*, who were suffering an irreversible failure of all functions, and whose doctors shortened the process of death. Upon expressing my pity that Rummelink did not state all of this explicitly, Griffiths answered that Rummelink thought the point was obvious and, therefore, did not explain.³⁹

³⁷. Letter dated 25 July 2000.

³⁸. Similarly, Rob Houtepen, Ruud ter Meulen and Ron Berghmans rejected the contention, saying that no form of active termination of life is normal medical procedure. Rather, euthanasia is an exceptional practice and should remain so.

³⁹. In his comments on the first draft of this essay, Griffiths referred me to p. 132 of his book, *Euthanasia & Law in the Netherlands* (Amsterdam: Amsterdam University Press, 1998), in which he relates to the Rummelink contention about patients whose bodily functions are “successively and irreversibly failing.” Griffiths thinks that understanding the contention in these terms makes a big difference, claiming that “you will find that doctors know perfectly well what this means, and furthermore that it is standard practice in a large number of countries and has been for many years

J.K. (Sjef) Gevers, who succeeded Henk Leenen as Professor of Health Law at the University of Amsterdam after Leenen's retirement, also understands this statement to mean providing extra morphine to ease suffering during the final hours of the patient's life. In his mind, it is a gray area that needs to be discussed, not a matter only for doctors to decide. Gevers did maintain that it would have been preferable to elaborate on this statement, but unfortunately Rummelink did not do so.

CONCLUSIONS

I found it most troublesome that the person who was nominated by the Dutch government to study the practice of euthanasia had made the above ambiguous statement, disregarding one of the basic components required for the euthanasia practice: the will of the patient. Many of the interviewees also found this statement troublesome this and other reasons. Critics of the Dutch practice might possibly note that the unqualified statement reflects a certain dangerous culture that is unhealthy for patients, culture that tends to forego life too easily.⁴⁰

(although only in the Netherlands is anyone prepared to talk about it)." Personal communication on 10 July 2000.

⁴⁰. Cf. R. Cohen-Almagor, "'Culture of Death' in the Netherlands: Dutch Perspectives", *Issues in Law and Medicine*, Vol. 17, No. 2 (Fall 2001).

APPENDIX

Interviews in the Netherlands (summer 1999)

Professor John Griffiths, Department of Legal Theory, Faculty of Law, University of Groningen (Groningen, 16 July 1999).

Professor J.K. Gevers, Professor of Health Law, University of Amsterdam (Amsterdam, 19 July 1999).

Professor Evert van Leeuwen, Department of Metamedicine, Free University of Amsterdam (Amsterdam, 19 July 1999; Haarlem, 28 July 1999).

Dr. Dick Willems, Institute for Research in Extramural Medicine, Department of Social Medicine, Amsterdam (Amsterdam, 20 July 1999).

Professor Bert Thijs, Medical Intensive Care Unit, VU Hospital, Amsterdam (Amsterdam, 20 July 1999).

Professor A. van Dantzig, retired expert in psychiatry (Amsterdam, 20 July 1999).

Professor H.J.J. Leenen, formerly professor of social medicine and health law, Medical Faculty and Faculty of Law, University of Amsterdam (Amsterdam, 21 July 1999).

Professor Gerrit van der Wal, Institute for Research in Extramural Medicine, Department of Social Medicine, Free University of Amsterdam (Amsterdam, 21 July 1999).

Dr. Jaap J.F. Visser, Ministry of Health, Department of Medical Ethics, The Hague (Amsterdam, 21 July 1999).

Professor Heleen Dupuis, Department of Metamedicine, University of Leiden (Leiden, 22 July 1999).

Dr. Margo Trappenburg, Department of Political Science, University of Leiden (Leiden, 22 July 1999).

Dr. Henri Wijsbek, Department of Medical Ethics, Erasmus University of Rotterdam (Rotterdam, 23 July 1999).

Dr. Arie J.G. van der Arend, Health Ethics and Philosophy, Maastricht University (Maastricht, 26 July 1999).

Dr. George Beusmans, Maastricht Hospital (Maastricht, 26 July 1999).

Professor G.F. Koerselman, Sint Lucas Andreas Hospital, Amsterdam (Amsterdam, 27 July 1999).

Professor Henk Jochemsen, Professor Lindeboom Institute (Ede Wageningen, 27 July 1999).

Dr. Gerrit K. Kimsma, Department of Metamedicine, Free University of Amsterdam (Koog 'aan de Zaan, 28 July 1999).

Dr. James Kennedy, Department of History, Hope College, Michigan. Visiting Research Fellow at the Institute for Social Research, Amsterdam (Amsterdam, 29 July 1999).

Professor Paul van der Maas, Department of Public Health, Faculty of Medicine, Erasmus University, Rotterdam (Amsterdam, 29 July 1999).

Dr. Chris Rutenfrans, *Trouw* (Amsterdam, 30 July 1999).

Dr. Arko Oderwald, Department of Metamedicine, Free University of Amsterdam (Amsterdam, 30 July 1999, 8 August 1999).

Ms. Barbara de Boer and her three children (Amsterdam, 2 August 1999).

Professor Egbert Schroten, Director, Center for Bioethics and Health Law, Utrecht University (Utrecht, 5 August 1999).

Professor Govert den Hartogh, Faculty of Philosophy, University of Amsterdam (Amsterdam, 10 August 1999).

Dr. Johannes JM van Delden, Senior Researcher, Center for Bioethics and Health Law, Utrecht University (Utrecht, 10 August 1999).

Dr. Rob Houtepen, Health Ethics and Philosophy, Maastricht University (Maastricht, 11 August 1999).

Dr. Ron Berghmans, Institute for Bioethics, Maastricht University (Maastricht, 11 August 1999).

Professor Ruud ter Meulen, Director, Institute for Bioethics and Professor at the University of Maastricht (Maastricht, 11 August 1999).