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Dutch Perspectives on Palliative Care in the Netherlands

Raphael Cohen-Almagor, D.Phil.*

Abstract: This study reports data gathered via extensive interviews with some of the leading authorities on the euthanasia policy that were conducted in the Netherlands. They were asked: It has been argued that the policy and practice of euthanasia in the Netherlands is the result of undeveloped palliative care. What do you think? I also mentioned the fact that there are only a few hospices in the Netherlands.

The responses were different and contradictory. Many interviewees agreed with the statement. Almost all of those agreeing with it said that only during the late 1990s were people beginning to admit that there was a need to improve palliative care. Some interviewees insisted that doctors first need to explore other options for helping the patient prior to choosing the course of euthanasia. Other interviewees thought that palliative care is well developed in the Netherlands and that euthanasia has actually paved the way for calling more attention to palliative care.

Since the early 1970s, euthanasia and physician-assisted suicide (termed together by many Dutch scholars as "EAS") have been practiced in the Netherlands. The Dutch experience has influenced the debate on euthanasia and death with dignity around the globe, especially with regard to whether euthanasia and physician-assisted suicide should be legitimized or legalized. The three relevant categories of Dutch doctors who are involved in the practice of euthanasia and physician-assisted suicide are General Practitioners (GPs), nursing-home doctors, and spe-

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cialists. Every person in the Netherlands has a more or less permanent relationship with a GP, who provides primary health care and is the point of entry for specialist care. GPs have the most extensive experience with euthanasia insofar as they discuss it most frequently with their patients, they receive two-thirds of all requests, and they are generally the most willing to perform it (about 90% of Dutch doctors have either practiced euthanasia or would be willing to do so).¹ *The level of experience with euthanasia among specialists is about half that of GPs (with 3% of all deaths in their practice attributable to euthanasia). By contrast, euthanasia plays a small role in the practice of nursing-home doctors, who receive relatively few requests (only a fifth of them have ever honored one).*²

The Guidelines of the Royal Dutch Medical Association (KNMG)³ speak of "persistent request." A request made on impulse or as a result of a temporary period of depression should not be honored. The request must have been discussed repeatedly and thoroughly a number of times during several conversations. However, Gerrit van der Wal and colleagues conducted a survey among a random sample of family doctors, showing that in 22% of cases the request was made only once.⁴

The rate of record keeping⁵ and written requests⁶ in euthanasia cases improved during the 1990s, but the situation is still unsatisfactory. There are now written requests in about 60% and written record keeping in some 85% of all cases of euthanasia.⁷ A most troubling phenomenon is the significant number of unreported euthanasia cases. Since November 1990, new state regulations require physicians to report cases of euthanasia to the local coroner and the public prosecutor. The number of reports rose from 454 cases in 1990 to 591 in 1991, to 1323 in 1992, to 1318 in 1993, and to 1424 in 1994. In 1999, the total number of reports was 2216.⁸ This considerable increase suggests that more physicians are willing to ac-

¹ See JOHN GRIFFITHS ET AL., *EUTHANASIA AND LAW IN THE NETHERLANDS* 213 (Amsterdam University Press 1998).

² See John Griffiths, *Effective Regulation of Euthanasia and Other Medical Behavior That Shortens Life, in UNCERTAINTY AND THE LAW* 72-73 (Montreal, Editions Thémis, Ejan Mackaay ed., 1999).

³ THE ROYAL DUTCH MEDICAL REFINEMENTS OF THE 1984 GUIDELINES ON EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE (Dutch Ministry of Justice & Royal Dutch Medical Association, Aug. 25, 1995).

⁴ See G. van der Wal et al., *Euthanasia and Assisted Suicide II. Do Dutch Family Doctors Act Prudently?* 9 FAM. PRAC. 112 (1992).

⁵ A doctor has an obligation to maintain a full dossier on every patient and to accurately record therein what he or she does and why. Keeping adequate records is a general requirement of medical practice, and specifically is one of the requirements of careful practice in the case of euthanasia. Cf. John Griffiths et al., *supra* note 1, at 71.

⁶ Gerrit Kimsma notes in his comments on a draft of this article that written requests for euthanasia are preferable but not mandatory. Dr. Gerrit K. Kimsma, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam) (notes on file with author). Another acceptable solution is a witness.

⁷ See John Griffiths, *supra* note 2, at 72.

⁸ I thank Henk Leenen for this piece of information. Professor H.J.J. Leenen, former Professor of Social Medicine and Health Law, Medical Faculty of Law, University of Amsterdam (July 21, 1999) (notes on file with author).

knowledge and report their actions, having seen that their colleagues are not being prosecuted for performing euthanasia. At the same time, the Rummelink Commission established by the Dutch government detected in its 1990 comprehensive report 2300 cases of euthanasia, which means that about half are still unreported.⁹ John Griffiths argues that the reporting rate for euthanasia¹⁰ was 18% in 1990, and that by 1995 it had risen to 41%. A situation in which less than half of all cases are reported is unacceptable from the standpoint of effective control.¹¹

The Dutch approach to euthanasia is said to reflect an open attitude towards tackling a difficult moral issue. For more than twenty years, the debate has been discussed openly in all circles of society. It has been considered in the Parliament, addressed by the courts, debated in religious institutions, and has required the constant attention of the Royal Dutch Medical Association. It continues to be a focus of the media, and polls have been conducted from time to time to examine public attitudes on this issue.¹²

Despite this apparent openness, the 1990 study shows that 22% of physicians feel that they should not always be required to report euthanasia as unnatural death. The legal ambiguity that existed for twenty years made Dutch physicians feel uncomfortable with reporting euthanasia, citing prosecution as an objection. They emphasized that they would be prepared to report euthanasia as such, but did not wish to be considered as a suspect in a criminal act. Thus, the uncertainty of what might happen to the physician was considered an obstacle to reporting an unnatural death.¹³ To address this issue, a careful, clearly stated procedure was needed, one that would be explicitly recognized under the law.

On November 28, 2000, the Dutch Lower House of parliament, by a vote of 104 for and forty 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 seventy-five-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

⁹ See Henk A.M.J. ten Have, *Euthanasia: The Dutch Experience*, in *CXII ANNALS DE LA REAL ACADEMIA NACIONAL DE MEDICINA* 429, 436-37 (Madrid, 1995).

¹⁰ Reporting, as opposed to record keeping, refers to the requirement that a doctor report a case of euthanasia to the authorities as an unnatural death.

¹¹ See Griffiths *supra* note 2, at 74-75. See also R. Cohen-Almagor, *An Outsider's View on Dutch Euthanasia Policy and Practice*, 17 *ISSUES IN LAW & MED.* 35 (2001).

¹² Cf. generally R. Cohen-Almagor, *Why the Netherlands?* 29 *J. L., MED. & ETHICS* 95 (2001).

¹³ See P.J. van der Maas et al., *Euthanasia and Other Medical Decisions Concerning the End of Life*, in *HEALTH POLICY MONOGRAPHS* 98 (Amsterdam, Elsevier 1992).

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.¹⁴

Physicians 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 panel, who can recommend prosecution leading to a prison sentence of up to twelve years if the Guidelines have not been followed. The 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. But the new law shifts the responsibility for proving guilt to the regional panels.¹⁵ Time will tell to what an extent the new law will improve the situation.

The concern of this article lies with the practice of palliative care. The World Health Organization defines palliative care as the "active, total care of patients whose disease is not responsive to curative treatment," maintaining control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount.¹⁶ Impediments to adequate pain treatment include health care providers' fear of inducing physical or psychological addiction, misconceptions about pain tolerance, and assessment biases.¹⁷ Herbert Hendin testified that his experience with a few Dutch physicians who had performed or been consultants in dozens of euthanasia cases indicated that they were uninvolved in palliative care.¹⁸ Zbigniew Zyllicz, one of the few palliative care experts in the Netherlands, regards the lack of hospice care and the fact that there are only seventy palliative care beds in the country as reflections of having the easier option of euthanasia. He argues that palliative care is virtually unknown in the Netherlands and that people mistakenly equate palliative care with the use of morphine or other drugs, not understanding that it involves much more than the use of painkillers.¹⁹ The aim of this study was to determine

¹⁴ See Dutch Parliament Votes to Legalize Euthanasia, REUTERS, Nov. 28, 2000.

¹⁵ See Termination of Life On Request and Assistance With Suicide Act, <http://www.ves.org.uk/news/wld_archive.htm>.

¹⁶ WORLD HEALTH ORGANIZATION, CANCER PAIN RELIEF AND PALLIATIVE CARE: REPORT OF A WHO EXPERT COMMITTEE 11 (Geneva, 1990).

¹⁷ See Kathleen Foley, *Dismantling the Barriers: Providing Palliative and Pain Care*, 283 MED. STUDENT JAMA 115, 115 (2000). See generally D.E. Mele et al., *Improving Palliative Care*, 127 ANNALS INTERNAL MED. 3 (1997).

¹⁸ See Herbert Hendin, *Euthanasia Consultants or Facilitators?* 70 MED. J. AUSTR. 351, 351-52 (1999).

¹⁹ See generally Zbigniew Zyllicz, *Euthanasia*, 338 LANCET 1150 (1991). See also *Palliative Care: Dutch Hospice and Euthanasia*, in ASKING TO DIE 196 (Dordrecht, Kluwer Academic Publishers, David C. Thomasma et al., eds. 1998); H. Matthews, *Better Palliative Care Could Cut Euthanasia*, 317 BRIT. MED. J. 1613 (1998).

what leading authorities in the euthanasia field in the Netherlands think about this issue, i.e., whether they think their country has a developed practice of palliative care.

Methodology

A review of the literature reveals complex and often contradictory views about the Dutch experience. Some claim that the Netherlands offers a model for the world to follow, that close monitoring of end-of-life decisions is possible, and there are no signs of an unacceptable increase in the number of decisions or of less careful decisionmaking;²⁰ others believe that there is a "culture of death" in the Netherlands,²¹ that its model represents danger, rather than promise, and that the Dutch experience is the definitive answer regarding why we should *not* make active euthanasia and physician-assisted suicide part of our lives.²²

Given these contradictory views, it has become clear that fieldwork is essential to developing a more informed opinion. Having investigated the Dutch experience for a number of years, and after thoroughly reading the vast literature published in English, I went to the Netherlands for one month in the summer of 1999 to get a feel for the local situation. I felt that this would provide the basis on which I could better interpret the findings of the available literature. I visited the major centers of medical ethics, as well as some research hospitals, and spoke with leading figures in the 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.²³

²⁰ See generally Pieter V. Admiral, *Justifiable Euthanasia*, 3 *ISSUES IN LAW & MED.* 361 (1988); MARGARET P. BATTIN, *THE LEAST WORST DEATH* (1994); Johannes J.M. van Delden et al., *Dances With Data*, 7 *BIOETHICS* 323 (1993); H.M. Kuitert, *Euthanasia in the Netherlands: A Practice and Its Justification*, lecture delivered at the First World Congress of Bioethics (Amsterdam, 1992); H.J.J. Leenen, *Euthanasia, Assistance With Suicide and the Law: Developments in the Netherlands*, 8 *HEALTH POL'Y* 197 (1987); and Gerrit van der Wal & Robert J. M. Dillmann, *Euthanasia in the Netherlands*, 308 *BRIT. MED. J.* 1346 (1994).

²¹ Cf. R. Cohen-Almagor, "Culture of Death" in the Netherlands: Dutch Perspectives, 17 *ISSUES IN LAW & MED.* 167 (2001).

²² See generally R. Fenigsen, *A Case Against Dutch Euthanasia*, 19 *HASTINGS CENTER REP.* 22 (Supp. 1989); Herbert Hendin et al., *Physician-Assisted Suicide and Euthanasia in the Netherlands*, 277 *JAMA* 1721 (1997); Henk Jochemsen & John Keown, *Voluntary Euthanasia Under Control? Further Empirical Evidence from the Netherlands*, 25 *J. MED. ETHICS* 16 (1999); J. Keown, *Euthanasia in the Netherlands: Sliding Down the Slippery Slope?* 9 *NOTRE DAME J. L., ETHICS & PUB. POL'Y* 407 (1995); John Keown, *The Law and Practice of Euthanasia in the Netherlands*, 108 *L. Q. REV.* 51 (1992); J.H. Segers, *Elderly Persons on the Subject of Euthanasia*, 3 *ISSUES IN LAW & MED.* 407 (1988). See also Fenigsen's further critique in *The Report of the Dutch Governmental Committee on Euthanasia*, 7 *ISSUES IN LAW & MED.* 339 (1991); *Physician-Assisted Death in the Netherlands: Impact on Long-Term Care*, 11 *ISSUES IN LAW & MED.* 283 (1995), and *Dutch Euthanasia Revisited*, 13 *ISSUES IN LAW & MED.* 301 (1997).

²³ CARLOS F. GOMEZ, *REGULATING DEATH* (1991).

Following the enactment of the euthanasia law in April 2001, I thought it was necessary to examine my interviewees' initial reaction to the new law. In June 2001, I returned to the Netherlands for two additional weeks. Prior to my arrival I had notified most of the interviewees of my arrival and welcomed them to express their views on the legislation process and the role of the regional committees. I also asked whether they have anything to add that is important for the purpose of updating my research.

The first-phase interviews took place during July-August 1999, in the Netherlands. They lasted between one to three 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.

The interviews were semi-structured. I began with a list of fifteen 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. The list of questions was opened with some general and neutral questions and as the interviews progressed I pressed the interviewees with more critical questions. This article reports the answers to only one of the critical questions concerning the qualified use of palliative care. 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*.²⁴

As for the second-phase of my research, seven of the interviewees answered the two queries via electronic or regular mail. Four other interviewees discussed these questions with me over the phone for ten to twenty minutes while in the Netherlands. Six of the other interviewees I met in Amsterdam for discussions that lasted from forty to 120 minutes each. The meetings took place either in the interviewees' offices or in restaurants. During these discussions some of the interviewees raised further issues of concern, one of them was the current improvement in palliative care.

The Question and Interviewees' Responses

The question was posed as follows: It has been argued that the policy and practice of euthanasia in the Netherlands is the result of undeveloped palliative

²⁴ RAFAEL COHEN-ALMAGOR, *EUTHANASIA IN THE NETHERLANDS* (forthcoming).

care. What do you think? I also mentioned the fact that there are only a few hospices in the Netherlands.

This is, of course, a loaded, critical question. It speaks of a possible link between the euthanasia practice and the lack of adequate palliative care treatment. Many interviewees agreed with the critical tone.²⁵ Almost all of those agreeing with it said that only during the late 1990s were people beginning to admit that there was a need to improve palliative care. Today there are pain specialists in nursing homes and hospitals. Despite the increased investment in palliative care on the part of the government, the interviewees argued that still more attention should be paid to it, especially in medical schools and hospitals. Some interviewees insisted that doctors first need to explore other options for helping the patient prior to choosing the course of euthanasia.²⁶

Arie van der Arend, a nurse and medical ethicist from Maastricht, argues that there is a balance between cases of euthanasia and the quality of palliative care. If there is poor palliative care, then the number of euthanasia cases will increase, and *vice versa*. Van der Arend suggests including in the Guidelines a requirement to provide good palliative care before considering euthanasia. He maintains that the quality of palliative care in the Netherlands is not high enough and that physicians are lacking the information on how to give palliative care because it is not part of medical education. There is also a need to increase the number of hospices in the country.

Henk Jochemsen, Director of the Professor Lindeboom Institute, notes that only the Catholic University of Nijmegen has a professor for pain relief.²⁷ Jochemsen,

²⁵ Dr. Arie J.G. van der Arend, Health Ethics & Philosophy, Maastricht University (July 26, 1999); Prof. Govert den Hartogh, Faculty of Philosophy, University of Amsterdam (Aug. 10, 1999); Prof. Henk Jochemsen, Lindeboom Institute, Ede Wageningen (July 27, 1999); Dr. James Kennedy, Dept of History, Hope College, Michigan, Visiting Research Fellow, Institute for Social Research, Amsterdam (July 29, 1999); Prof. G.F. Koerselman, Sint Lucas Andreas Hospital, Amsterdam (July 27, 1999); Prof. Evert van Leuzen, Dept of Metamedicine, Free University of Amsterdam, Amsterdam (July 19, 1999), Haarlem (July 28, 1999); Prof. Ruud ter Meulen, Director, Institute for Bioethics and Professor, University of Maastricht (Aug. 11, 1999); and Dr. Chris Rutenfrans, Trouw, Amsterdam (June 22, 2001) (Personal interviews and phone conversations) (notes on file with author).

²⁶ Dr. Arie J.G. van der Arend, Health Ethics & Philosophy, Maastricht University, Maastricht (July 26, 1999); Dr. Johannes J.M. van Delden, Senior Researcher, Center for Bioethics & Health Law, Utrecht University, Utrecht (Aug. 10, 1999); Prof. G.F. Koerselman, Sint Lucas Andreas Hospital, Amsterdam (July 27, 1999); Prof. Egbert Schrotten, Center for Bioethics & Health Law, Utrecht University, Utrecht (Aug. 5, 1999); and Dr. Jaap Visser, Ministry of Health, Dept of Medical Ethics, The Hague (phone conversation, June 20, 2001).

²⁷ Henk Jochemsen, *supra* note 25. In his comments, Arko Oderwald wrote that this is not true, and that the Free University of Amsterdam also has at least one such professor. Oderwald added that there are certainly more specialized pain centers in university clinics and other hospitals. Personal communication from Dr. Arko Oderwald, Dept of Metamedicine, Free University of Amsterdam, to author (Aug. 28, 2000) (on file with author).

a Calvinist bioethicist, also sees this as an indication of the place of palliative care in the Netherlands. He argues that when the discussion on euthanasia evolved during the 1970s and 1980s, the field of palliative care was developed in many parts of the world. In the Netherlands, there was no room for both concepts to develop simultaneously and as euthanasia became an accepted practice, palliative care was pushed aside. Jochemsen maintained that the Guidelines are not precise enough, explaining that the KNMG (Royal Dutch Medical Association) statement depicts the performance of euthanasia only as a last resort. If we follow this statement seriously, then it means that the general practitioners performing euthanasia need to consult a palliative care expert prior to the mercy killing. But GPs are not equipped to decide on the various alternatives designed to alleviate suffering.²⁸ Furthermore, if the patient is suffering mentally, then the GP has to consult a psychiatrist. Jochemsen thinks that the government and the KNMG have recently put more emphasis on palliative care.²⁹

Ruud ter Meulen, Director of the Institute for Bioethics at the University of Maastricht, argues that the criticisms are correct: Euthanasia is practiced too quickly because palliative care is not a real option. The acceptance of euthanasia has led to the undermining of palliative care.³⁰ There are only two or three hospices in the Netherlands, and palliative care in nursing homes remains undeveloped. Hospitals, though somewhat more advanced than nursing homes, still have a long way to go. In comparison, Belgium, for instance, boasts a far better practice of palliative care.

The most vocal critic of euthanasia was G.F. Koerselman, a renowned psychiatrist,³¹ who asserted that with adequate palliative care, euthanasia becomes unnecessary. Good palliative care enables people to continue living and coping with suffering without opting for euthanasia. Koerselman stated that "palliative care is absolutely under-developed. None of our medical faculties has a professor of palliative care. There are no palliative care experts in academic hospitals."³²

Evert van Leeuwen, Chairperson of the Department of Metamedicine at the Free University of Amsterdam, and Egbert Schrotten, Director of the Center for Bioethics and Health Law at Utrecht University, explained that until the 1980s it was argued that specialists in palliative care were not needed.³³ Consequently, new developments in the field were not adopted, and the issue was left quite neglected. During the 1990s, the idea of using palliative care experts became increasingly accepted, but there remains much to do in this area. James Kennedy,³⁴ an historian

²⁸ See Jochemsen, *supra* note 25.

²⁹ *Id.*

³⁰ See Ruud ter Meulen, *supra* note 25.

³¹ See G.F. Koerselman, *supra* note 25.

³² *Id.*

³³ See Evert van Leeuwen and Egbert Schrotten, *supra* note 25.

³⁴ See James Kennedy, *supra* note 25.

who studies the origins of the euthanasia policy, clarified that there are very few hospices in the Netherlands because home care is the prevalent phenomenon and the role of the GP in providing care is conceived to be sufficient.³⁵ It should be noted that Paul van der Maas contests this view. He wrote in his comments that the low number of hospices in the Netherlands is attributable not to the specific role of the GP, but to the fact that many nursing homes have specialized departments for end-of-life care.³⁶

Likewise, Ron Berghmans, a medical ethicist at Maastricht, argued that palliative care is well-developed in nursing homes, where care for spiritual and psychological needs is provided in addition to care for physical needs.³⁷ In contrast, palliative care is less developed in the practice of individual GPs. Berghmans did not believe that palliative care would eliminate euthanasia. At most, it might decrease the number of requests. He also doubted whether the policy and practice of euthanasia had actually frustrated the development of palliative care. Berghmans confirmed that recently the government had stimulated the development of palliative care by making available large amounts of money for universities to develop units and expertise in the field. It is intended that these trained experts will provide consultation to GPs who deal with terminal patients.³⁸

Johannes van Delden³⁹ estimated that the fact that the Netherlands does not have many hospices should not be taken as an indication that "we don't have palliative care." Rather, "we organize things differently."⁴⁰ Van Delden, who co-authored the 1990 comprehensive research project, asserted that doctors know how to deal with pain, GPs do receive adequate education and training in this sphere, and, in any event, palliative care involves more than just ameliorating pain. It also involves providing psychological support for the patient. While acknowledging that there is room for improvement in this area, Van Delden argued that euthanasia has actually paved the way for calling more attention to palliative care. He emphasized that

³⁵ One referee notes in his/her comments on a previous draft of this article that Dutch euthanasia started before the hospice movement and developments of palliative care in Britain and other countries, independently from, and in no relation whatsoever to these developments. S/he refers readers to the following Dutch writings: P.J. ROSCAM ABBING, *TOEGENOMEN VERANTWOORDELIJKHEID. EUTHANASIE, EUGENETIEK EN MODERNE BIOLOGIE* [The Increased Responsibility. Euthanasia, Eugenics and Modern Biology] (Nijkerk, G.F. Callenbach, 1972); J.H. VAN DEN BERGH, *MEDISCHE MACHT EN MEDISCHE ETHIEK* [Medicine's Power and Medical Ethics] (Nijkerk, G.F. Callenbach, 1969).

³⁶ Written comments from Prof. Paul van der Maas, Dep't of Public Health, Faculty of Medicine, Erasmus University, Rotterdam (Sept. 18, 2000) (on file with author).

³⁷ Interview with Dr. Ron Berghmans, Institute for Bioethics and Health Law, Utrecht University, Utrecht (Aug. 10, 1999) (notes on file with author).

³⁸ *Id.*

³⁹ See Johannes van Delden, *supra* note 26.

⁴⁰ Mrs. E. Borst-Eilers gave a similar explanation. Cf. *PROCEEDINGS ON EUTHANASIA AND ASSISTED SUICIDE IN THE NETHERLANDS AND IN EUROPE, MAASTRICHT, JUNE 10-11, 1994*, at 64-65 (Luxembourg, Office for Official Publications of the European Communities, 1996) (hereinafter "PROCEEDINGS").

euthanasia does not exclude palliative care, but the reverse, and adamantly objected to the accusation that lack of palliative care has resulted in greater acceptance of euthanasia. Van Delden noted the problem that sometimes patients refuse to receive palliative care and expressed his uncertainty about whether doctors should comply with euthanasia requests under such circumstances.⁴¹

George Beusmans, a GP who practices euthanasia, substantiated Van Delden's arguments,⁴² testifying that he received education on palliative care and contending that this aspect does not present a major problem. He considers himself to be qualified in evaluating suffering and in providing proper medication and palliative care. But pain is not the primary issue in question. People that request euthanasia suffer not only from physical pain, but also from anguish, dependence on others, and anxiety regarding the unknown. They ask for help because they have lost the sense of purpose in waiting and see no good reason for prolonging their situation.

Govert den Hartogh, a philosopher who is a member in the Amsterdam regional committee that reviews all reported euthanasia cases in the region, provided the most extensive answer, claiming that the flip side of the fact that GPs are involved in euthanasia is that they are not fully aware of palliative care.⁴³ While acknowledging that palliative care cannot serve as a complete substitute for euthanasia, Den Hartogh insists that euthanasia should be used only as the last resort. The doctor should first try to alleviate suffering by other means and resort to euthanasia only when all those other means have failed. At the same time, Den Hartogh does not think that Dutch doctors are less knowledgeable about palliative care than doctors in other countries. Furthermore, Den Hartogh holds that while palliative care is available to patients in hospitals, many patients still choose to leave the hospital and return home to die by requesting euthanasia. This can be seen as an indication that euthanasia is in fact performed on many occasions after palliative care has been tried.

In his comments on the first draft of this study, Den Hartogh elaborated on his answer, arguing that it is false to think that palliative care can provide a viable alternative to euthanasia in all cases. There are many instances in which no pain relief can be given, except by sedating the patient into unconsciousness. Furthermore, we need to take into account the many other forms of suffering besides pain,

⁴¹ See Van Delden, *supra* note 26. Dr. Cohen, who practiced euthanasia for many years, contended that euthanasia is not opposed to palliative care. Conversely, the possibility of euthanasia is a stimulant for palliative care because "confronted with [this] request, this heavy, heavy task and burden, you try to find a way out and you will look for ways to alleviate the patient's suffering in [many] ways." PROCEEDINGS, *supra* note 40, at 53.

⁴² Interview with Dr. George Beusmans, Maastricht Hospital, Maastricht (July 26, 1999) (notes on file with author).

⁴³ See Govert den Hartogh, *supra* note 25. One unnamed referee notes in his/her comments that the Dutch have not developed palliative care because "they were busy with [a] farther-reaching solution, euthanasia."

which can be part of the process of dying, and for which relief may be unavailable or insufficient. Den Hartogh rejects the suggestion that palliative care is neglected because the Netherlands has euthanasia as an alternative. It is essential in this respect to see palliative care as an integral part of medical care for the dying, whether it is given in an institutional setting or (as the Dutch generally prefer) at home. It is nowadays a normal practice for a GP who is responsible for the treatment of cancer patients to act in constant consultation with a hospital's pain-relief team. Of course, there is more to palliative care than pain relief.⁴⁴

Den Hartogh testifies that most of the reported cases to his regional committees (95%) were cancer patients. Van Leeuwen testifies that 80-90% of the cases reported to his committee were cancer patients.⁴⁵ American studies showed that pain control for cancer patients is often inadequate and that physicians typically underestimate pain. Patients with significant pain caused by cancer visit their physicians and frequently leave with as much pain as they came with because their pain was never discussed or treated. Furthermore, communication about pain often depends on the patients' complaining of it. Patients, however, are often reluctant to report pain for a variety of reasons, including wanting to be a "good" (noncomplaining) patient, concern about having to take strong painkillers, or worries that talking about pain might take too much time and distract the physician from dealing with the disease itself.⁴⁶ Moreover, many patients seek pain relief from complementary therapies. Often they feel that these methods offer a holistic approach that is lacking in the traditional allopathic model.⁴⁷ It is advisable that doctors examine whether the prescribed pain control is adequate. Palliative care is able to prevent or at least to ease most manifestations of physical pain.⁴⁸

One of the three referees who reviewed this piece wrote that from the very beginning and until the present time euthanasia has been performed in Holland also on patients who are entirely beyond the scope of palliative care, on patients who require no palliative care but surgical treatment, newborns with Down syn-

⁴⁴ Written comments from Prof. Gover den Hartogh, Faculty of Philosophy, University of Amsterdam (Aug. 27, 2000) (on file with author).

⁴⁵ See Gover den Hartogh and Evert van Leeuwen, *supra* note 25.

⁴⁶ See generally Charles S. Cleeland, *Controlling Cancer Pain: Many Missed Opportunities*, 283 *MED. STUDENT JAMA* 114 (2000); Charles S. Cleeland et al., *Pain and Its Treatment in Outpatients with Metastatic Cancer*, 330 *NEW ENG. J. MED.* 592 (1994); S. Ward et al., *Patient-Related Barriers to Management of Cancer Pain*, 53 *PAIN* 319 (1993).

⁴⁷ See generally Catherine S. Magid, *Pain, Suffering, and Meaning*, 283 *MED. STUDENT JAMA* 114 (2000).

⁴⁸ To institute effective pain control, new programs for the training and certification of palliative care consultants need to be developed and implemented. See generally *TEXTBOOK OF PALLIATIVE MEDICINE* (P. D. Doyle et al. eds., 1998); Janet L. Abraham, *The Role of the Clinician in Palliative Medicine*, 283 *MED. STUDENT JAMA* 116 (2000); Franklin G. Miller et al., *Regulating Physician-Assisted Death*, 331 *NEW ENG. J. MED.* 119 (1994); Timothy E. Quill et al., *Palliative Options of Last Resort*, 278 *JAMA* 2099 (1997); Anne Scott, *Autonomy, Power, and Control in Palliative Care*, 8 *CAMBRIDGE Q. HEALTHCARE ETHICS* 139 (1999).

drome and duodenal atresia, cases of spina bifida with hydrocephalus, on spastics due to birth trauma who need revalidation, and even on diabetic children who need insulin treatment.⁴⁹

The 2001 Update

Four of the ten interviewees had initiated discussion on palliative care. Dick Willems, Evert van Leeuwen and James Kennedy noted a positive development regarding the use of palliative care.⁵⁰ The government has put a lot of money into developing this field of expertise. Courses in this area are provided to physicians and more research is performed. A lot was done to improve palliative care in hospitals and in medical care at large. Willems hopes that now that the euthanasia law has passed, the discussion about euthanasia will calm down and leave room for other concerns, no less important. He advises dedicating much less time to discussing euthanasia and much more to improving the care provided to dying patients and to developing an efficient system of palliative care. After all, only a small percentage of patients ask for euthanasia.⁵¹ I could not agree more.

On the other hand, Ruud ter Meulen argues that palliative care is indeed improving in the Netherlands but it is still not integrated well into the nursing care system. It is still underdeveloped. Ter Meulen suggests (and I fully agree) that the Guidelines include a provision for palliative care before considering euthanasia. This would prevent administering euthanasia too quickly.⁵² James Kennedy remarks in this context that there is some indication that some physicians perform euthanasia simply because they do not know what else to do.⁵³ With the growing attention to palliative care, physicians may recognize new vistas that are open to them and not rush to perform mercy killing.

The Ministry of Health, Welfare and Sport announced that the government has set aside NLG 7 million a year for a period of five years to improve palliative

⁴⁹ The referee recommends the following readings, all in Dutch: ADVIES INZAKE EUTHANASIE BIJ PASGEBORENEN. INTERIMADVIES, UITGEBRACHT DOOR DE COMMISSIE MEDISCHE ETHIEK VAN DE GEZONDHEIDSRaad [Pronouncement Concerning Euthanasia on the Newborn. Interim Opinion Issued by the Committee on Medical Ethics of the Health Council] (Rijswijk, Gezondheidsraad 1975), and the following related articles on treatment of newborns, J.M. Boom, *Behandeling en Absterend Beleid Bij Pasgeborenen Met Een Slechte Levensprognose* [Treatment and Non-treatment Decisions in Newborns with a Bad Vital Prognosis], 131 NEDERLANDS TIJDSCHRIFT V. GENEESKUNDE 1444 (1987); R. de Leeuw, *Over Euthanasia Bij Pasgeborenen Wordt Niet Gesproken* [Euthanasia on the Newborn is Passed Over With Silence], 131 NEDERLANDS TIJDSCHRIFT V. GENEESKUNDE 772 (1987); and R. de Leeuw & P.E. Treffers, *Een Zachte Dood voor Pasgeborenen* [Mild Death for the Newborn], 128 NEDERLANDS TIJDSCHRIFT V. GENEESKUNDE 841 (1984).

⁵⁰ See Evert van Leeuwen (June 20, 2001) and James Kennedy (June 24, 2001), *supra* note 25; Dr. Dick Willems, Dept of General Practice, Academic Medical Center, University of Amsterdam, Amsterdam (June 22, 2001) (notes on file with author).

⁵¹ See Dick Willems, *supra* note 50.

⁵² See Ruud ter Meulen (June 22, 2001), *supra* note 25.

⁵³ See James Kennedy, *supra* note 50.

care. Some of this money is used for research and some of it to find ways of increasing the scope for its use in the closing stages of life. Six teaching hospitals have set up centers for the development of palliative care. Some of these centers have expert teams of consultants who can answer questions from GPs, nurses and home care providers about patient care.³⁴

Conclusions

The interviewees revealed mixed views on the place of palliative care in the Netherlands. Some think that the field is not adequately developed, whereas others seemed quite content with the situation. Evert van Leeuwen is a member of one of the regional committees whose role is to review reported euthanasia cases and to see that the rules of carefulness were observed. His committee had reviewed some three hundred cases by the time of the interview, and in most of these cases the Guidelines had been observed. In a small number of cases (between four and eight), the requests were very clear, the physicians could do nothing to help, and the patients were suffering, but were not on the verge of death; they still had four to six months to live. Van Leeuwen felt that these were cases in which palliative care could have helped.³⁵

It seems that the developed practice of euthanasia came at the expense of developing adequate palliative care. Only during the last few years, the Netherlands has started to invest in this sphere. This is a very positive development. Many times patients may contemplate ending their lives because they are unable to cope with their pain. Once good palliative care is developed we may expect that the number of euthanasia requests will be reduced, this is provided that general practitioners will offer this option first and not euthanasia, and that they are able to provide good palliative care to their patients, or at least refer them to palliative care experts. Even when cure of the underlying disease is not possible, there is still much that medical teams can do to relieve physical and psychological suffering.³⁶ The entire euthanasia practice could be transformed for the better once nursing-home doctors, specialists, and especially general practitioners will be aware of the positive consequences of good palliative care at the end of life.

³⁴ See Ministerie van Volksgezondheid, Welzijn en Sport, *Snel Zochen*, <<http://www.minvws.nl/english/normal.html>>.

³⁵ See Evert van Leeuwen, *supra* note 50. One of the referees commenting on this essay criticizes the work of the regional committees for not including a palliative care specialist. There is only one physician on each of the three-person review teams. In essence, none of the regional committees' members is qualified to say whether the medical treatment was adequate prior to the performance of euthanasia.

³⁶ See generally Catherine S. Magid, *supra* note 47, at 114; Timothy E. Quill et al., *Choosing the Least Harmful Alternative*, 132 *ANNALS INTERNAL MED.* 488 (2000).

Appendix***Interviews in the Netherlands (summer 1999)***

Professor John Griffiths, Dep't of Legal Theory, Faculty of Law, University of Groningen (Groningen, July 16, 1999).

Professor Evert van Leeuwen, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam, July 19, 1999; Haarlem, July 28, 1999).

Dr. Dick Willems, Institute for Research in Extramural Medicine, Dep't of Social Medicine, Free University of Amsterdam (Amsterdam, July 20, 1999).

Professor Bert Thijs, Medical Intensive Care Unit, VU Hospital, Amsterdam (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, Dep't of Social Medicine, Free University of Amsterdam (Amsterdam, July 21, 1999).

Dr. Jaap J.F. Visser, Ministry of Health, Dep't of Medical Ethics, The Hague (Amsterdam, July 21, 1999).

Professor Heleen Dupuis, Dep't of Metamedicine, University of Leiden (Leiden, July 22, 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, Dep't of Metamedicine, Free University of Amsterdam (Koog aan de Zaan, July 28, 1999).

Dr. James Kennedy, Dep't of History, Hope College, Michigan Visiting Research Fellow at the Institute for Social Research, Amsterdam (Amsterdam, July 29, 1999).

Professor Paul van der Maas, Dep't of Public Health, Faculty of Medicine, Erasmus University, Rotterdam (Amsterdam, July 29, 1999).

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

Dr. Arko Oderwald, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam, July 30, 1999; Aug. 8, 1999).

Professor Egbert Schrotten, Center for Bioethics and Health Law, Utrecht University (Utrecht, Aug. 5, 1999).

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

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

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

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

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

Interviews and telephone conversations in the Netherlands (summer 2001)

Dr. Jaap J.F. Visser, Ministry of Health, Dep't of Medical Ethics, The Hague (phone conversation on June 20, 2001).

Professor Evert van Leeuwen, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam, June 20, 2001).

Dr. Gerrit K. Kimsma, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam, June 21, 2001).

Professor Ruud ter Meulen, Director, Institute for Bioethics and Professor, University of Maastricht (phone conversation on June 22, 2001).

Dr. Chris Rutenfrans, Trouw (Amsterdam, June 22, 2001).

Dr. Dick Willems, Dep't of General Practice, Academic Medical Center, University of Amsterdam (Amsterdam, June 22, 2001).

Dr. James Kennedy, Dep't of History, Hope College, Michigan (Amsterdam, June 24, 2001).

Dr. Arko Oderwald, Dep't of Metamedicine, Free University of Amsterdam (Amsterdam, June 25, 2001).