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lands 66 (Amsterdam: Amsterdam University Press 1998).
 can make the patient's suffering bearable. See JOHN GRIFFITHS ET AL., EUTHANASIA AND LAW IN THE NETHER-
 land in any case the doctor's task to investigate whether there are medical or social alternatives that
 verifying whether suffering is unbearable and without prospect of improvement. The Board consid-
 The Medical Association Executive Board emphasized that there are only limited possibilities for

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 kind cooperation. A former version of this article was published in CROATIAN JOURNAL OF PHILOSOPHY,
 Evert van Leeuwen and Martine Bouman for facilitating the research and to the interviewees for their
 ing); editor, Medical Ethics at the Dawn of the 21st Century (2000). The author is most grateful to
 NITY: AN ARGUMENT IN ETHICS, MEDICINE AND LAW (2001) and EUTHANASIA IN THE NETHERLANDS (forthcom-
 *D. Phil., Oxford U., 1991; Assoc. Prof., University of Haifa; author, The Right to Die with Dig-

improvement and no alternative to end the suffering.¹ The patient need not be
 The patient's situation must entail unbearable suffering with no prospect of

2. The patient's request must be well considered, durable and consistent.

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

are as follows:
 tor can successfully invoke the defense of necessity. The substantive requirements
 criteria established in court decisions relating to the conditions under which a doc-
 cal Association set out Guidelines for the performance of euthanasia based on the
 In November 1990, the Dutch Ministry of Justice and the Royal Dutch Medi-

Abstract: During the summer of 1999, twenty-eight interviews with some of the
 leading authorities on euthanasia policy were conducted in the Netherlands. They
 were asked about cases of non-voluntary (when patients are incompetent) and
 involuntary euthanasia (when patients are competent and made no request to
 die). This study reports the main findings, showing that most respondents are
 quite complacent with regard to breaches of the guideline that require the patient's
 consent as a prerequisite to performance of euthanasia.

Raphael Cohen-Almagor, D. Phil.*

Non-voluntary and Involuntary Euthanasia in the Netherlands: Dutch Perspectives

terminally ill to satisfy this requirement and the suffering need not necessarily be physical.

3. Euthanasia must be a last resort.²

The procedural requirements are as follows:

- No doctor is required to perform euthanasia, but those opposed on principle must make this position known to the patient early on and help the patient to 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 themselves, rather than have a doctor apply an injection or intravenous drip.³
- 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,⁴ patients with a psychiatric disorder must 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.⁵

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 in situations where treatment would probably have prolonged life;
- Alleviation of pain and symptoms: administering opioids in such dosages that the patient's life could be shortened;

² See John Keown, *The Law and Practice of Euthanasia in the Netherlands*, 108 *LAW Q. REV.* 55, 56 (1992).

³ ROYAL DUTCH MEDICAL ASSOCIATION'S REFINEMENTS OF THE 1984 GUIDELINES ON EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE (DUTCH MINISTRY OF JUSTICE & ROYAL DUTCH MEDICAL ASS'N, Aug. 25, 1995). Cf. Marlise Simons, *Dutch Doctors Tighten Rules on Mercy Killings*, *N. Y. TIMES*, Sept. 11, 1995 at A3, A3.

⁴ Supreme Court of the Netherlands, Criminal Chamber, June 21, 1994, no. 6.972 [*Nederlandse Jurisprudentie* 1994, nr 656; *Tijdschrift voor Gezondheidsrecht* 1994/96 nr 47]. For translation, see John Griffiths et al., *supra* note 1, at 329-40. For critique of the case, see R. Cohen-Almagor, *The Chabot Case: Analysis and Account of Dutch Perspectives*, 5 *MED. L. INT'L* 141 (2001).

⁵ <<http://www.euthanasia.org/dutch.html#rmm>>. See also Marcia Angell, *Editorial, Euthanasia in the Netherlands—Good News or Bad?* 335 *NEW ENG. J. MED.* 1676, 1676-78 (1996); Adriaan Jacobovits, *Euthanasia in the Netherlands*, *WASH. POST*, Jan. 23, 1997 at A16, A16; GENERAL HEALTH COUNCIL, *A PROPOSAL OF ADVICE CONCERNING REQUIREMENTS FOR CARE IN THE PERFORMANCE OF EUTHANASIA* (The Hague, 1987).

- Euthanasia of drugs at the patient's explicit and

The study was whether there was availability of voluntary valid comparison and also because.

The two Dutch MDEL (i.e., all three Netherlands as a third category of 1 as 2300 persons a year (2.4%) in 1990 and in 1991 suicide in the Netherlands undertaken. The explicit request explicit and persistent 1995.⁹

⁶ Cf. P.J. van der M., *HEALTH POLICY MONOGRAPH*

⁷ See Paul J. van der M., *Involving the End of Life* discussion, see Johann *ETHICS* 200, 200-05 (1995); *BRIT. MED. J.* 1511, 1511-1512 (1995); *New Law*, 20 *J. MED. ETHICS* 151-58 (1994); J.K.M. *ETHICS* 309, 309-12 (1995)

⁸ See P.J. van der M., *End-of-Life Decisions and* et al., eds., Dordrecht, comments on the first discussed with a patient explicit request is defined request. Van der Maas both found frequencies of active cases in cases per year. Person

• Euthanasia and related MDL: 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.⁶

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.⁷

The two Dutch studies were said to give the best estimate of all forms of MDL (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 MDL, the studies gave the best estimate of voluntary euthanasia as 2300 persons each year (1.9% of all deaths) in 1990,⁸ 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 is related to the hastening of death without the explicit request of patients. There were one thousand cases (0.8%) without explicit and persistent request in 1990, and nine hundred such cases (0.7%) in 1995.⁹

⁶ Cf. P.J. van der Maas, et al., EUTHANASIA AND OTHER MEDICAL DECISIONS CONCERNING THE END OF LIFE, HEALTH POLICY MONOGRAPH (Amsterdam, Elsevier 1992).

⁷ See Paul J. van der Maas et al., Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995, 335 NEW ENG. J. MED. 1699 (1996). For further discussion, see Johannes J.M. van Delden et al., *Deciding Not to Resuscitate in Dutch Hospitals*, 19 J. MED. ETHICS 200, 200-05 (1993); Tony Sheldon, Euthanasia Law Does Not End Debate in the Netherlands, 307 BRIT. MED. J. 1511, 1511-12 (1993); Henk Jochemsen, Euthanasia in Holland: An Ethical Critique of the New Law, 20 J. MED. ETHICS 212, 212-17 (1994); Chrs Ciesielski-Carhucci & Gerrit Kinsma, *The Impact of Reporting Cases of Euthanasia in Holland: A Patient and Family Perspective*, 8 BIOETHICS 151, 151-58 (1994); J.K.M. Gevers, *Physician Assisted Suicide: New Development in the Netherlands*, 9 BIOETHICS 309, 309-12 (1995).

⁸ See P.J. van der Maas et al., *supra* note 6, at 41.

⁹ See Gerrit van der Wal & Paul J. van der Maas, *Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure*, in ASKING TO DIE 171 (David C. Thomasma, et al., eds., Dordrecht: Kluwer Academic Publishers, 1998). See also <www.saves.asn.au>. 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 of ending of life without explicit request of over 3%. He estimated the number of active cases involving ending of life among newborns in the Netherlands to be ten to fifteen cases per year. Personal communication with author (Sept. 18, 2000) (notes on file with author).

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

About a quarter of the one thousand patients had earlier expressed a wish for voluntary euthanasia.¹⁶ 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 fifteen) 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.¹⁷

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.¹⁸

¹⁰ See P.J. Van der Maas et al., *supra* note 6, at 58.

¹¹ See *id.*, at 61.

¹² See *id.*, at 62.

¹³ 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 kind of consultation with any professional health worker. Cf. G. van der Wal, et al., *Euthanasia and Assisted Suicide, II. Do Dutch Family Doctors Act Prudently?* 9 FAM. PRAC. 140 (1992).

¹⁴ See P.J. van der Maas, et al., *supra* note 6, at 65.

¹⁵ See *id.*, at 66.

¹⁶ Henk A.M.J. ten Have, *Euthanasia: The Dutch Experience*, CXII ANNALS DE LA REAL ACADEMIA NACIONAL DE MEDICINA 429 (Madrid, 1995).

¹⁷ See 1996 STUDY FINDINGS, EUTHANASIA AND OTHER DECISIONS CONCERNING THE END OF LIFE IN THE NETHERLANDS (FOREIGN INFORMATION DEPT., NETHERLANDS MINISTRY OF FOREIGN AFFAIRS, 1996).

¹⁸ See REMMELINK COMMISSION, RAPPORT MEDISCHE BESLISSINGEN ROND HET LEVENSEINDE 37 (The Hague: SDU, 1991).

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The aim of this study is to explore how leading figures in the Dutch euthanasia policy and practice conceive this worrisome data. To that end, 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 policymakers.

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. Only one, Dr. Chabot, explicitly declined my request for an interview.¹⁹

The 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 two hundred dense pages. Later the interviews were typed and analyzed.²⁰

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 have a sample of different locations I traveled from Groningen in the north to Maastricht in the south, making extensive use of the Dutch efficient train system.

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. Because I was interested in the problematic aspects of the euthanasia practice, after some general questions I addressed the troublesome aspects reiterated in the Kermelink 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.

¹⁹ 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. Letter from Dr. Chabot to author (June 5, 1999) (on file with author).
²⁰ Due to space limitations, the entire study cannot be reported here. This is done in R. COHEN-ALMAGOR, *EUTHANASIA IN THE NETHERLANDS* (2002).

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The Interviewees' Responses

Hastening of Death without the Patients' Explicit Request

The question that opened the critical line of the interviews was: "Some of the most worrisome data in the two Dutch studies are concerned with the hastening of death without the explicit request of patients. There were one thousand cases (0.8%) without explicit and persistent request in 1990, and nine hundred cases (0.7%) in 1995. What is your opinion?"

Most of the interviewees had similar interpretations of this finding. They said that this group includes cancer patients, PVS patients, newborns with severe health problems, and patients who are suffering that would die within a matter of days or even hours. By so doing, physicians strive to alleviate the pain of very sick patients at the end of their lives. In essence, what they are saying is that it is right to replace autonomy with beneficence in such severe circumstances. Some of the interviewees saw no problem in this, arguing that the balance favors termination of life in such instances. Many interviewees also emphasized that this practice was common long before euthanasia became available in the Netherlands and that it is not a specifically Dutch problem; there is a similar policy in hospitals all over the world.²¹

Consider the view of one of the foremost euthanasia activists, H.J.J. Leenen, on this matter. He argues that these are not cases of euthanasia. Nearly all of them involved cancer patients in the last phase of their lives, who were suffering greatly and who had had so much medication that they were no longer competent. Their physicians sometimes help these suffering, dying patients with the last push. Such cases do not indicate a slippery slope, and they occur in every country. Nevertheless, Leenen is worried that the physicians did not discuss the option of termination of treatment early on with these patients. Physicians know the consequences of increased doses of medication and should discuss the options at the beginning of the dying process. It is a physician's responsibility to verify what patients want.

Bert Thijs, Director of the Medical Intensive Care Unit, VU ziekenhuis in Amsterdam, and Evert Van Leeuwen, Chairperson of the Department of Metamedicine, Free University of Amsterdam, recommend ethical and practical training as well as open discussions to overcome this problem. Physicians should discuss and debate this issue by holding regular consultation sessions. These discussions would make it possible for physicians to reflect on their decision-making process among themselves and with paramedics in their teams.

The two most productive researchers in the field of euthanasia, Gerrit van der Wal and Paul van der Maas, express remarkably similar opinions. Van der Wal of the Institute for Research in Extramural Medicine at the Free University, Amsterdam, explains that this category of patients, who did not make an explicit request for

²¹ See interviews with John Griffiths, Evert van Leeuwen, Govert den Hartogh, Bert Thijs, A. van Dantzig, Heleen Dupuis, Henri Wijsbek, and Arie van der Arend (notes on file with author).

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euthanasia, includes comatose patients whose families asked whether it was necessary to keep the patients alive and who wanted to stop their suffering. In other countries, Van der Wal maintains, ending a patient's life in such cases would be called double effect. In the Netherlands, "we are more explicit, more Calvinistic" (I asked what this meant, and he answered "more open, rigid, honest, straightforward"). He further argues that in most of these cases, the issue of euthanasia was not sufficiently discussed beforehand. Therefore, it is important to make the climate around euthanasia more open and to exchange views between physicians and patients. Van der Wal also notes that the doctors' intentions regarding these patients were unclear. Most of the patients died from large doses of morphine ("double effect"), while the drugs used for euthanasia are muscle paralyzers. The doctors wanted to alleviate the pain and suffering of their patients, most of whom were in the advanced stages of cancer. They had only days or hours left to live and had been rendered incompetent from painkilling drugs. The doctors were then forced to act upon their own initiative without having an opportunity to consult the patients regarding euthanasia.²²

Van der Maas, Professor of Public Health and Social Medicine at the Erasmus University of Rotterdam, reports that he is not worried about the data. In nearly all of the cases in question, the patients suddenly lost consciousness or their ability to communicate. Two-thirds were cancer patients in the advanced stage of the disease. They were suffering extremely, vomiting, unable to express themselves, and totally immersed in their agonizing condition. Most of them would have died within one to three days, and they actually died from opiates (double effect). Very few of these patients had living wills, but about half had indicated in the past that they would prefer to hasten death under such terrible conditions. Half of the patients had given no indication of what they wanted.²³ Similarly, Heleen Dupuis calls the deaths of this group "double effect," rather than euthanasia, given that the opiate doses were increased.

²² For further deliberation, see Gerrit van der Wal, *Unrequested Termination of Life: Is It Permissible?* 7 BIOETHICS 330-39 (1993).
²³ See HERBERT HENDIN, *SEDUCED BY DEATH* 88-89 (1997). Jaap Visser argues in answering this question that in many of these cases, the patients had living wills. In contrast, Van Delden claimed that a very small number of these patients had a living will. The 1990 study reports that about one-quarter of the patients had been previously "indicating something" regarding life termination. Cf. F.J. van der Maas, et al., *supra* note 6, at 69. Van der Wal, Van der Maas et al., report that in about half of all these cases, either the decision was discussed with the patient earlier in the illness or the patient had expressed a wish for euthanasia if suffering became unbearable. In the other cases, the patient was deemed incompetent. See also Paul J. van der Maas, et al., *Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990 - 1995*, 335 *NEW ENG. J. MED.* 1699, 1701 (1996). John Griffiths argues that this category of patients is highly heterogeneous, including severely defective newborn babies, long-term coma patients, and persons who at some earlier time have expressed a wish for euthanasia but who in the final stages of the process of dying are no longer capable of expressing their will. See John Griffiths, *The Slippery Slope: Are the Dutch Sliding Down or Are They Clambering Up?* in *ASKING TO DIE*, *supra* note 9, at 98.

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Johannes van Delden provides the most interesting answer to the question regarding this worrisome data. He said that these findings were in part artifact, the creation of the researchers in the construction of the categories, which included clear-cut expressed wishes, cases of no explicit request, and cases with some remarks. Of the one thousand, 56% expressed some view. However, the authors of the research "decided to have a clear-cut euthanasia group, and this group emerged from the way we chose to analyze." Van Delden explained that "you need autonomy and beneficence to perform euthanasia." There might be very extreme cases in which doctors decide to conduct euthanasia without the patient's explicit request, but these cases are few in number. It is hardly conceivable to act in this way, "maybe in pediatrics." Van Delden did recognize that most of these cases were insufficiently justified and insisted that the autonomy requirement be maintained.²⁴

Henri Wijsbek argues that most of these cases involve situations in which patients are unconscious, suffering greatly, and would have died within two hours.²⁵ This practice occurs in many countries, and Wijsbek sees no problem with it. He adds his hope that under such circumstances, his doctors would do the same for him. When there is hopeless suffering, and doctors cannot alleviate the pain, the option of euthanasia should be available. Similarly, Van der Arend, who teaches at the Health Ethics and Philosophy Department of Maastricht University, explains that there are situations in which patients are suffering, unconscious or half-conscious, in the last stage of disease, and physicians then do not have any other choice but to end the patient's life. He is not worried about the numbers, saying that he could not imagine that termination of life was the result of careless medical practice. Van der Arend added: "There will always be cases like these."

Rob Houtepen, who teaches in the same department in Maastricht, also sees no reason for alarm in regard to this data. He testifies that he is quite liberal about termination of life when people are suffering, even if they are incompetent. He believes that compassion is the primary consideration for euthanasia. Autonomy is a secondary consideration. It is unjust that people be denied the option to end their suffering, an option that is available to competent patients. In his mind, we should

²⁴In another form, Van Delden explained that the type of patients involved were cancer patients with brain metastases who were, consequently, rendered incompetent. It would give "a false picture of Holland if one thought that we put away demented people or the weak ones in society. It really is the patient dying and already fading away." PROCEEDINGS OF EUTHANASIA AND PHYSICIAN ASSISTED SUICIDE IN THE NETHERLANDS AND IN EUROPE, MAASTRICHT, JUNE 10 -11, 1994 47 (Luxembourg: Office for Official Publications of the European Communities 1996).

²⁵According to Van der Wal, Van der Maas, et al., life was shortened by twenty-four hours at most in 33% of these cases, and in a further 58% it was shortened by one week at most. See also Paul J. van der Maas et al., *supra* note 23, at 1702. The 1990 study reports that in 21% of the cases, life was shortened by one to four weeks; in 7% of the cases, life was shortened by one to six months; and in a small number of cases, life was shortened by more than half a year. These patients were not in the terminal stage of their illness. See also P.J. van der Maas et al, *supra* note 6, at 66, 183; & Loes Pijnenborg, et al., LIFE-TERMINATING ACTS WITHOUT EXPLICIT REQUEST OF PATIENT, 341 LANCET 1196-99 (1993).

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not make strict distinctions between competent and incompetent patients. Hence, Houpten is "not shocked" by the figures, though he does recognize the need for stricter notification procedures so as to make more data available about the circumstances of each and every patient who did not make an explicit request.

Ron Bergmans, also from Maastriicht, supports the need for more information about these cases and the circumstances involved in each case, particularly when the patient could have expressed an opinion about the issue. In addition, the issue of advance directives needs to be discussed further. The new law stipulates that ADs have the legal force of the patient's voluntary explicit request. Bergmans reiterates the problem of how to evaluate suffering in cases of dementia and expresses doubt about whether we should honor the ADs of dementia patients.²⁶

In his comments on the first draft of this study, Govern den Hartogh wrote that my implicit assumption is that the worrisome data is the result of the lax Dutch rules. He thinks that probably the opposite is true: in other countries, this figure would probably be much higher, precisely because euthanasia is forbidden and hence cannot safely be discussed with patients. Accordingly, the result of the Dutch rules, on this account, is that the figure is unusually low. This, however, does not mean that the data are not worrisome.

To substantiate his point, Den Hartogh referred to the recent research project in Flanders, which is a replica of the Van der Maas/Van der Wal studies. Belgian law forbade euthanasia and assisted suicide at the time of interview. According to this research, the overall percentage of deaths as a result of euthanasia or assisted suicide in Belgium is somewhat lower, but not very much lower, than it is in the Netherlands. However, the percentage of deaths from "euthanasia" without explicit request is five times as high (3.5%). Den Hartogh's interpretation of these data is not that Belgian doctors, any more than Dutch doctors, "get rid of unwanted patients." Although they believe themselves to be acting in the best interests of the patient and fulfilling the wishes of the patient, they are simply reluctant to discuss the matter openly.²⁷

Even if you do not consider it worrisome that when patients are suffering and on the verge of death the doctor provides morphine to ease the pain and the patient dies, yet in cases where the patients were competent and the doctor took their lives without asking them, this is worrisome. Some of the reasons given by the doctors for euthanizing these patients were invalid, as was the apparent unwillingness of some doctors to consult a colleague.²⁸ Indeed, according to the 1990 report, among the considerations by the physician in performing a life-terminating act without

²⁶ For further deliberation, see R. Bergmans, *Advance Directives and Dementia*, in *MEDICAL ETHICS AT THE DAWN OF THE 21ST CENTURY* 105-10 (R. Cohen-Almagor, ed., 2000).
²⁷ Personal communication on Aug. 27, 2000 (notes on file with author). See also Luc Deliens, et al., *End-of-Life Medical Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey*, 356 *LANCET* 1806, 1806-11 (2000).
²⁸ See Paul J. van der Maas et al., *supra* note 23, at 1704, Table 4.

explicit request of the patient were the patient's low quality of life (31% of the cases), inability of the patient's relatives to cope (32%), and economic considerations (1%).²⁹

Egbert Schrotten, who has served on many medical committees, says that the findings are worrisome but that the discussion about their seriousness is exaggerated. Such medical behavior always existed before the invocation of the euthanasia policy, and a good doctor needs to help patients who are in great pain. Suffering of body and spirit is the most important consideration, and here we speak of incompetent patients in the very last days of their lives, who suffer miserably.

Ruud ter Meulen, Director of the Institute for Bioethics and Professor at the University of Maastricht, indicates that the issue worries him. He would like to have in place an explicit policy on termination of life, with no room for interpretation. The policy should insist on the explicit request of the patient and on strict medical criteria. There is also a need to define the concept of suffering. Ter Meulen expresses a critical view of the existing practice of passive euthanasia and the use of morphine to shorten life. He argues that it is not clear on which criteria decisions for passive euthanasia are based and what role the patient has in the decision-making process.

The three most critical voices in the present survey did not justify the existing situation. Both Chris Rutenfrans and Henk Jochemsen express concern about the lack of control mechanisms and the freedom that physicians have to decide the fate of their patients without consulting them. Jochemsen acknowledges that some were probably cases of double effect, but in others patients were competent and were still not apprised of the situation. This is not morally justifiable. The major consideration for physicians must be the suffering of the patient. Autonomy gives an additional justification, but does not constitute the major reason. While recognizing that the termination of life took place in the last stage of the disease, Jochemsen emphasizes that there was no preference expressed by patients in a significant number of cases.³⁰

Most outspoken was Frank Koerselman, who is worried by the phenomenon and contends that junior doctors readily make Do Not Resuscitate (DNR) orders without much thought, especially when patients are old. Young doctors often evaluate a patient's quality of life without even knowing the patient, and many of them do not find compelling reasons for working to save a ninety year old patient.

²⁹ See P.J. van der Maas, et al., *supra* note 6, at 64.

³⁰ According to the 1990 report, patients had given some indication about terminating life in 28% of cases. Interestingly, this consideration is mentioned by physicians in only in 17% of cases. Apparently, it was not so much the wish of the patient but the circumstances that made the physician appreciate the patient's wish. See also P.J. van der Maas et al., *supra* note 6, at 64.

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³² See J.H. Segers, *Eld*
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³⁴ See Richard Fenigse
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³⁵ See HERBERT HENDIN

³⁶ John Keown, *The L*
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412 (1995).

Koerselman testifies that he has seen many cases in which DNR orders were taken by phone or given by a junior physician without consulting a senior colleague.³¹

Fears of Elderly Patients

The next inter-related question was: "Some Dutch studies appear to indicate that some elderly people fear their lives will be ended without their consent"³² and that, in fact, families in the Netherlands request euthanasia more often than the patient.³³ Is this true?

A study of thirty nursing homes showed that when medical indications for hospitalization of elderly patients arose, nursing home physicians decided not to transport the patient to the hospital in 12% of cases, particularly when there was a life-threatening emergency. In a considerable number of cases, the decisions were made without consulting the patients or their families.³⁴ In a study done in Dutch hospitals, doctors and nurses reported that more requests for euthanasia came from families than from patients. The family, the doctors, and the nurses often pressured the patient to request euthanasia.³⁵

Herbert Cohen, one of the country's leading practitioners of euthanasia, said in an interview to John Keown that he would be put in a very difficult position if a patient told him that he really felt he was a nuisance to his relatives because they wanted to enjoy his estate. Asked whether he would rule out euthanasia in such a case, Cohen replied that in the end he wouldn't because "that kind of influence—these children wanting the money now—is the same kind of power from the past that... shaped us all." Cohen maintained that the same thing goes for religion, education, family of origin, "all kinds of influences from the past that we can't put aside."³⁶ It is unclear how this view could be seen as an acceptable interpretation of the Guidelines that speak of free and voluntary request of the patient as well as of unbearable suffering.

³¹ C.I. Dessaut and C.J.C. Rutenfrans wrote that a young doctor expressed objections to the use of pacemakers in people older than seventy-five years and declared that society may not be burdened with the duty of keeping old people alive. See also C.I. Dessaut & C.J.C. Rutenfrans, *The Present Day Practice of Euthanasia*, 3 Issues in Law & Med. 399, 402 (1988).
³² See J.H. Segers, *Elderly Persons on the Subject of Euthanasia*, 3 Issues in Law & Med. 407, 419-21 (1988); R. Fenigsen, *A Case Against Dutch Euthanasia*, Hastings Center Rep., Jan./Feb. 1989 (special supp.), at 24, 24-26.
³³ See R. Fenigsen, *Mercy, Murder and Morality: Perspectives on Euthanasia. A Case Against Dutch Euthanasia*, Hastings Center Rep., Jan./Feb. 1989 (special supp.), at 22, 22-30. In another essay, *A Case Against Dutch Euthanasia*, see Fenigsen *supra* note 32 at 24, Fenigsen argued that spouses have coerced their husbands or wives to undergo 'voluntary' euthanasia.
³⁴ See Richard Fenigsen, *Physician-Assisted Death in the Netherlands: Impact on Long-Term Care*, 11 Issues in Law & Med. 283, 293-94 (1995).
³⁵ See HERBERT HENDIN, *supra* note 23, at 93.
³⁶ John Keown, *The Law and Practice of Euthanasia in the Netherlands*, LAW Q. REV., Jan. 1992, at 63, 63; *Euthanasia in the Netherlands: Sliding Down the Slippery Slope?* 9 NOTRE DAME J.L. ETHICS & PUB. POL'Y 412 (1995).

of life (31% of the economic consider- itees, says that the onness is exagger- n of the euthanasia at pain. Suffering of we speak of incom- aserably. and Professor at the .. He would like to room for interpreta- patient and on strict suffering. Ter Meulen nasia and the use of h criteria decisions as in the decision- t justify the existing concern about the ve to decide the fate dges that some were competent and were . The major consid- Autonomy gives an on. While recogniz- disease, Jochemsen a significant number by the phenomenon cite (DNR) orders doctors often evalu- , and many of them y year old patient.

A minority of the interviewees dismissed the question as "ridiculous." Heleen Dupuis and A. van Dantzig expressed the most supportive voices for the existing policy and practice of euthanasia.³⁷ Dupuis explains that when the patient is incompetent, the only available option for physicians is to cease treatment, not to perform euthanasia. Doctors will not euthanize a patient who cannot express his/her will to die, even if euthanasia was requested in his/her living will. She maintains that most people are afraid of having no option at the end of life and that in any event, old and demented patients receive treatment. There is no room for fear, and it is ridiculous to be afraid. In turn, Van Dantzig dismissed the question as propaganda of the anti-euthanasia lobby. Cases that include bad relations in a family should not prevent euthanasia in the many other cases where the motivation is sincere. However, the patient needs to express a will to die. If the patient does not express such a will and does not suffer, then it is not an appropriate case for euthanasia. If the patient had a living will, then the living will should be respected.

Likewise, Van der Wal dismissed the question, saying that Segers was speculating, and that the articles I cited are "nonsense" and "scientifically unsound." In one of the articles he co-authored, Van der Wal wrote that Dutch studies do not provide any evidence for the elderly being in danger of becoming "victims" of euthanasia or assisted suicide.³⁸ Furthermore, Van der Wal did not know of any study on the role of families (according to Henk Leenen and Govert den Hartogh, no research has been done on the role of the family), and he and his research team were exploring the issue of conducting such research at the time of the interview. Van der Wal knows of only one opinion poll designed to investigate the issue, which, in his opinion, was conducted by a biased fundamentalist organization and was scientifically unsound. He further notes that euthanasia and assisted suicide among the elderly are rare. The age of most patients requesting euthanasia varies between fifty-five to seventy-five.³⁹

Having said that, although Van der Wal dismissed the issue as "nonsense," he acknowledges that sometimes families find the suffering of their loved one unbearable and that there has been incidental anecdotal evidence of family pressure being brought to bear in the termination of a patient's life. That is to say that family pressures do exist, but doctors testify that they are not affected by such pressures, and that most of the time they resist those pressures. Van der Wal emphasizes that, unlike other countries, there are no financial incentives for requesting euthanasia in the Netherlands because the costs of maintaining patients are not borne by their families.

³⁷ In his comments on the first draft of this study, Van Dantzig wrote succinctly: "I do not wholeheartedly support the existing system." Personal communication of July 6, 2000 (notes on file with author).

³⁸ See Martien T. Muller et al., *Euthanasia and Assisted Suicide: Facts, Figures and Fancies with Special Regard to Old Age*, DRUGS & AGING, Sept. 1998, at 185, 185.

³⁹ See also P.J. van der Maas et al., *supra* note 6, at 44, 137.

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⁴¹ Egbert Schroter

⁴² BERT KEIZER, DA

H.J.J. Leenen says that he has never heard of patients who are afraid of euthanasia. On the contrary, one hears more about patients who fear that they will ask for euthanasia when their time comes, but their request will not be honored. J.K. Gevers and Goven den Hartogh do not think that families request euthanasia any more than patients do, or that physicians act on the wish of the family more than on the wish of the patient. In his comments on the first draft of this study, Den Hartogh wrote that in all of the cases reported, the doctor acted on the request of the patient, and that in almost all instances the family supported the request of the patient. There is hardly any evidence of undue influence of the wishes of the family on the decision of the doctor, either from the reported cases or from other sources.

On the other hand, some physicians and consultants are insufficiently aware of the possibility of subtle forms of psychological pressure exerted on patients by their families. They routinely allow the family to be present at all discussions with the patient. This is one of the ways in which the SCEN-project⁴⁰ may lead to substantial improvement, as SCEN-doctors are trained to be alert to this possibility.

Two interviewees⁴¹ argued that even if such fears on the part of patients exist, they are unfounded. Opinion polls show that the public thinks it is unacceptable for the family to request euthanasia because they cannot cope with the patient's condition. Families may request euthanasia for the patient because they might become exhausted by dealing with the patient's suffering and illness, but such a request would not be granted because testimony of a relative does not constitute sufficient grounds for euthanasia. Schrotten and Wijtsbek have heard that elderly patients fear their lives might be terminated prematurely without their consent. They believe that these fears often arise from religious convictions and are totally unrealistic.

Parenthetically, let me refer to Bert Keizer's exchange with a nephew of one of his patients, who assured him that "this is not at all what he [the patient] wanted, ending his days in a place like this." Keizer, who practices medicine in a nursing home in Amsterdam, writes: "it always annoys me, that tone of voice in which people say, Uncle would never have wanted this. What they mean is, he's not as stupid as those other 56,000 Dutch people staying in nursing homes who have let things go too far."⁴²

Van Delden, one of the authors of the 1990 comprehensive study, based his answer on this study. The study shows that relatives made an explicit request to

⁴⁰In May 1999, the government initiated the organization of consultancy teams all over the country. Consultants travel to small villages to examine medical files and to see patients. See Bregje Onwuteaka-Phillipsen, Consultation of Another Physician in Cases of Euthanasia and Physician-Assisted Suicide (Amsterdam: Dept of Social Medicine, Vrije Universiteit, 1999), unpublished doctoral thesis, especially at 91.

⁴¹Egbert Schrotten and Henri Wijtsbek.

⁴²Bert Keizer, DANCING WITH MISTER D 301-02, 306, 312 (London: Black Swan, 1997).

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hasten the death of the patient in 14% of the cases, and others (physician, nurse or someone else who is not a relative) made the request in 1% of cases.⁴³

Van der Arend tells of arguments he witnessed between relatives over financial affairs, even about an inheritance while the patient was still alive. Therefore, families should be engaged in the decision-making, but should not be given the last word. All parties should be involved in the euthanasia decision: the patient, the physicians and nurses, and the patient's family. If members of the family are not involved, they might end up going to court. Van der Arend added that patients usually trust physicians not to terminate their lives without their consent. When the patient is rendered incompetent and has not prepared a living will, the family assumes a larger role in the decision-making process, but still does not have the last word.

George Beusmans and Gerrit Kimsma, both physicians who practice euthanasia, testified that they always provide information to the patient as well as to the family. It is irrelevant if the family wants to take a certain course of action when the patient does not share the same preference. It is only the patient's request that counts. When they practice euthanasia, it is done in the open with the consent of the patient, who must voice repeated requests and sign a written document. Kimsma asserts that his patients' families have always been satisfied with the euthanasia procedure. He has never had a family member object to euthanasia, and he has sometimes organized family meetings to resolve differences of opinion. At the same time, Kimsma declares that euthanasia is an individual matter of the patient and that he always resists family pressures for euthanasia when the patient does not want it.

Evert van Leeuwen argues that there are elderly people in nursing homes who fear that their lives will be ended without consent. However, euthanasia is rarely conducted in nursing homes. Indeed, studies show that Dutch nursing home physicians together receive an average of three hundred requests for euthanasia and assisted suicide annually, of which they comply with only twenty-five.⁴⁴ In comparison to general hospitals, nursing homes have a less permissive policy on euthanasia.⁴⁵ Bert Keizer writes that most of the patients in nursing homes belong to the generation that still associates "euthanasia" with "mass murder."⁴⁶

Van Leeuwen maintains that there might be cases of inadequate care and, as a result, patients may die earlier than expected. Van Leeuwen further testifies that he

⁴³ See P.J. van der Maas et al., *supra* note 6, at 134.

⁴⁴ See Martien Tom Muller, *Death on Request* (Amsterdam, Vrije Universiteit, 1996) unpublished thesis, at 18. See also Table 3 in Paul J. van der Maas, *supra* note 23, at 1703, and in Gerrit van der Wal & P.J. van der Maas, *supra* note 9, at 172 (Table 2).

⁴⁵ See Dick J. Hessing et al., *Practical Reasons and Reasonable Practice: The Case of Euthanasia in the Netherlands*, 52 J. SOCIAL ISSUES 155, 155 (1996).

⁴⁶ BERT KEIZER, *supra* note 43, at 258. Keizer also testifies that only a small percentage of his patients really want to die (emphasis added). KEIZER, *supra* note 43, at 268.

once heard a physician describe the patient's situation, but his family members were his condition. In addition, when the patient is indirectly exerting t

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Ruud ter Meulen critical voices on the part of the people, given that the Netherlands is facing a large number of the elderly and a decline in the quality of care for the elderly. Euthanasia is not a solution, especially true with respect to the families. This consideration, however, in his commercial context, no evidence of this

Henk Jochem often the case of the patient has become. Indeed, they have good reasons to believe that treatment will continue providing unnecess

⁴⁷ In his comments, Personal communication.

⁴⁸ According to the specialists consulted with me. According to the 1995 study on euthanasia and assisted suicide, and, interestingly, another study shows that euthanasia and assisted-suicide are often Physician-Assisted Death

once heard a physician describe how he and his colleagues could have improved a patient's situation, but did not do so because the patient had no family to care for him were his condition to improve, thus leaving him alone in a difficult situation.⁴⁷ In addition, when some families request that the elderly die peacefully, they are indirectly exerting their influence on the decision makers.

Rob Houpten and Ron Bergmans argue that families do exert pressure for, but also against, euthanasia. Most physicians are aware of the pressure on them to perform euthanasia, and they resist it. The common procedure is to inform and to speak with family members.⁴⁸ In turn, John Griffiths identified the issue of family pressure as one of the problems that needs to be addressed by effective regulation. Families that can no longer cope with the patient's situation might exert pressure on doctors and influence them to opt for euthanasia rather than to provide adequate pain relief. Griffiths maintained in a later communication that this problem is in no way limited to euthanasia. His impression is that it is far more important quantitatively in connection with abstention decisions.

Rund ter Meulen, Henk Jochemsen and Frank Koerseman voiced the most critical voices on this matter. Ter Meulen is worried about the position of elderly people, given that there are waiting lists for nursing homes and for home care. The Netherlands is facing a shortage of resources, cuts in the nursing staff and a larger number of the elderly who wish to be in nursing homes. We can expect that the quality of care for the elderly will deteriorate. Euthanasia may be a promising alternative as a solution to a pressing problem, and Ter Meulen adds that this is especially true with respect to elderly patients who do not want to be a burden on their families. This consideration may play a role in their request for euthanasia. However, in his comments on the first draft of this paper, Ter Meulen added that there is no evidence of this issue playing a role in the practice of euthanasia at this point. Henk Jochemsen, professor of Christian medical ethics, contends that it is often the case of the family, rather than the patient, asking for euthanasia when the patient has become a burden. Hence, Jochemsen thinks that some elderly patients indeed have good reason for this fear. He adds that patients sometimes also fear that treatment will continue beyond the necessary point. Jochemsen also objects to providing unnecessary treatment.

⁴⁷ In his comments, Van Leeuwen asked me to emphasize that he heard this once, and only once. Personal communication on Aug. 30, 2000 (notes on file with author).
⁴⁸ According to the 1990 study, GPs consulted with patients' relatives in 97% of the cases, and specialists consulted with relatives in 85% of cases. P.J. van der Maas et al., *supra* note 6, at 47. According to the 1995 death-certificate study, "relatives or others" were consulted only in 70% of euthanasia and assisted-suicide cases. See Paul J. van der Maas et al., *supra* note 23, at 1704. Interestingly, another study shows that patients' relatives were "contacted" in more than 90% of the euthanasia and assisted-suicide cases. See Gerrit van der Wal et al., *Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands*, 335 *New Eng. J. Med.* 1709 (1996).

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As usual, Koerselman expresses the most critical view, agreeing with the studies of Segers and Fenigsen, and testifying about his own experience. He argues that such fears on the part of the elderly do exist. In his view, families have informal influence on doctors, and it is impossible to ascertain that families who find it difficult to cope with the suffering of their loved ones do not influence the decision-making process. Koerselman told the story of an eighty-five-year-old patient with pneumonia and depression, both of which are treatable conditions. His family did not wish to treat him, and the GP agreed with the family that there was no point in treatment. Koerselman was invited to consult on the patient's depression and said that if he had not taken an active role in this case, they would have taken the easy way out: "He would die, all would say that I acted humanely and would receive a nice bottle of wine from the family who physically wanted to prevent me from treating him." Koerselman asked the patient's GP whether he had spoken with the patient alone. The response was negative. Koerselman had to order security guards to remove the family from the room so that he could speak privately with the patient. The patient said at first that there was no reason to continue treatment and that he did not want to become a burden on his family. Koerselman explained to him that he suffered from pneumonia and depression, two perfectly treatable conditions, and that he might as well try to be a healthy eighty-five-year-old man. The patient then agreed to treatment and was eventually discharged from the hospital in very good condition, both mentally and physically.

Conclusions

The aim of this essay was to provide an account of Dutch policy makers' perceptions of some of the worrisome data revealed in the Rimmelink Report. The present study reveals that most of the interviewed Dutch authorities in the field of medical ethics are quite complacent about involuntary and non-voluntary euthanasia, recruiting an array of justifications to show that there is no real cause for alarm even when patients' lives are terminated without their consent.

In the United States, Oregon's Measure 16 that allows assisted suicide is facing a challenge. In Australia, the Northern Territory Bill that allowed terminally ill patients to commit suicide with a doctor's help was declared void. The legislatures of Canada and England resist attempts to legalize assisted suicide and euthanasia. The Netherlands represents a country in the liberal world that generally accepts the policy and practice of both euthanasia and physician-assisted suicide, without seeing much difference between the two, and whose legislatures advance more bills that would legitimize euthanasia further, while broadening the scope of the practice.

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. 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 that question the doctor thanasia without co every society, in eve ber of criminals. Th the possibility of at their time of need. indicate there is no much abuse. Many work because *all th* It is not always th assisted suicide. O the family initiates mised. On occasio in which no requ patient's request is n condition does not ment. Sometimes r cases, physicians fa are reported as nat

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⁴⁹ See R. COHEN-ALL

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 occasion, 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 patient's medical condition does not always entail unbearable suffering with no prospect of improvement. Sometimes nurses, instead of doctors, perform euthanasia. In quite a few cases, physicians fail to consult an independent colleague and/or euthanasia cases are reported as natural deaths.⁴⁹

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).

Professor Bert Thijss, 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).

⁴⁹ See R. COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS (forthcoming).

being with the student. He argues that families have informal policies who find it influence the decision-making of the patient with his family did not point in depression and said have taken the easy and would receive a to prevent me from had spoken with the order security guards immediately with the patient's treatment and elman explained to directly treatable con-year-old man. The from the hospital in

rich policy makers' melink Report. The writes in the field of -voluntary euthanasia-real cause for alarm

ted suicide is facing ed terminally ill patients. The legislatures of and euthanasia. The generally accepts the nicide, without seeing advance more bills scope of the practice

rs support a system. After all, we are dealing with specific questions. Many of the experts

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

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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).

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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).

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