Critical Remarks on the Dutch Policy and Practice of Euthanasia and Proposed Guidelines for Physician-Assisted Suicide

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Abstract

My essay opens with some personal words about my acquaintance with Ivan Šegota. I proceed by explaining the methodology of my research on euthanasia in the Netherlands. I then detail the major findings and end with guidelines for physician-assisted suicide (PAS). My research in the Netherlands made me change my mind: from supporter of euthanasia I became an ardent opposer of this practice. I think, however, that physicians should not turn a deaf ear to patients at the end of life, who suffer miserably and request to die. Therefore, PAS is suggested. To prevent potential abuse, we need to devise very careful guidelines which, I believe, are suitable for democracies as we enter the 21st Century, an era of highly developed technology which brings a lot of good but, in the field of medicine, might prolong patient’s life unnecessarily. At the center of guidelines is the patient, and the underlying values of treatment are respect for the patient and her autonomy, beneficence, non-maleficence and compassion.

Personal Words

The winter of 1994 was a harsh one. There were consecutive snow storms in upstate New York that made a disturbing impact on life. Schools and roads were shut. Many people did not go to work. Not many wanted to leave home anyway, going out to face the freezing weather.

During that winter, Ivan Šegota and I were visiting fellows at the Hastings Center, New York. Sometimes we found ourselves working in a close office, as most of the staff did not come to work. We spent evenings together, talking about life, and about the little things that constitute the essence of happiness. Despite language barriers, we learned to appreciate and like one another. I felt a developing bond with Ivan.
Ivan delivered a poignant lecture at Hastings about the war in his country. It was a moving account which brought several of his listeners to tears. Many years have passed since then but memories from our stay at Hastings are still vivid. Therefore, when I received the invitation to write in Ivan’s honour as he celebrates his 70th birthday, I gladly complied.

Most of my six weeks at the Hastings Center was dedicated to study euthanasia in the Netherlands. It deems appropriate to dedicate this chapter to this subject. The Hastings Center is the perfect place to conduct research in medical ethics as most of the resources are available. The data about the Dutch policy and practice of euthanasia was clear. It was readily available and there was no lack of literature. The interpretations of the data, however, were conflicting. Unlike most pieces of research that debate the various shades of grey, on this subject some interpretations argued that the Netherlands is an example for other nations to follow, while others argued that the Netherlands is the prime example why other countries should not follow this path. Some said the Dutch experience provides a green light to the nations; others said it constitutes a strong red light. As a researcher I was absolutely puzzled. It became clear to me that I need to conduct a fieldwork in the Netherlands and examine the situation from close. The Hastings Center, with all its remarkable advantages, will not suffice.

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 person – Dr. Chabot – explicitly declined my request for an interview, saying that he preferred to stay in the background rather than be interviewed. The majority of interviewees were known to me through their writings. The remainder of interviewees was suggested to me by colleagues.

In the first instance, interviews took place during July – August 1999 in the Netherlands. Prior to each interview I told the interviewee that the interview is conducted as part of my research on euthanasia in the Netherlands, that I intend to use the material compiled during the interview for my research, and that I will send him/her the content of the interview prior publication. The interviews lasted between one to three hours each, with most taking more than two hours. During the interviews, I asked more or less the same series of questions and took extensive notes that fill some 200 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 took place in “neutral” locations, such as coffee shops and restaurants. Two interviews were conducted at the office kindly made available to me at the Department of Medical Ethics, Free University of Amsterdam. To obtain a sampling from different locations, I travelled from Groningen in the north to Maastricht in the south, making extensive use of the efficient train system in the Netherlands.

The interviews were semi-structured. I began with a list of 15 questions, but did not insist on answers to all of them if 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.

Prior to each interview I pledged to my interviewees that I would send them the rough draft of the entire manuscript prior to submitting the study for publication. After completing the first draft of writing in July 2000, I sent it to all the interviewees, inviting their comments and criticisms. In my cover letter, I explained that I wished to give each interviewee an opportunity to see that the references to our discussion adequately represented his or her views. I added that the issue at hand was not my analysis and interpretation. Rather, the aim was to ascertain that the interviewee’s views were characterized in a fair and honest manner, and that the opinions attributed to him/her were correct.

As said, the initial fieldwork was conducted during the summer of 1999. On November 28, 2000, the Dutch Lower House of parliament, by a vote of 104 for and 40 against, approved the legalization of euthanasia. On April 10, 2001 the Dutch Upper House of parliament voted to legalize euthanasia. Forty-six members of the 75-seat Senate voted for the Termination of Life on Request and Assistance with Suicide Act; twenty-eight voted against; one member was not present. I thought it is 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 two crucial issues: the legislation process and the role of the regional committees that review all euthanasia cases.¹

On April 1, 2002 the euthanasia law was approved by the Dutch Senate, making the Netherlands the first country in the world to legalize mercy killing. I returned to the Netherlands for a final update and met ten interviewees in

¹This time I contacted only the ethicists, lawyers and psychiatrists whom I thought could offer interesting views on recent developments.
Amsterdam, Maastricht and The Hague. Nine interviews took place in offices and lasted from one hour to two hours each. The main findings of my research are presented in my book, *Euthanasia in the Netherlands*.² This essay draws upon this major research and presents its main conclusions.

A personal note: Prior my visit to the Netherlands I supported euthanasia and physician-assisted suicide. I believed that, in certain cases, we should recognize the necessity for ending life. On such occasions, which should be clearly defined, euthanasia and PAS are morally permissible, and I believed that killing and letting die are morally on a par. I published a few articles articulating these views.³

### Findings

I was struck by the defensiveness expressed by some of the interviewees. Carlos F. Gomez also reported suspicion and guardedness on the part of his interviewees.⁴ I sensed that the interviewees did not like the idea of a foreigner asking these questions. Their attitude spurred me to entitle one of my first articles published as a result of this research *An Outsider’s View on the Dutch Euthanasia Policy*.⁵ Although they realized that their euthanasia policy is imperfect, they tried to defend it to the best of their abilities.

I was somewhat troubled by their lack of criticism and their readiness to accept the euthanasia policy and practice with all of the accompanying flaws. I presume that some of the interviewees identify with their government’s decision-making to the extent of defending the system and suspecting foreigners like me who press them with difficult questions. I also suspect that after the publications of Gomez,⁶ Keown,⁷ and Hendin,⁸ they were not enthusiastic about cooperating with me. One interviewee was candid enough to tell me this

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⁸ Herbert Hendin, *Seduced by Death* (New York: W. W. Norton, 1997).
directly. When I asked why he was willing to sit with me and answer my questions, he replied that he felt obliged as a researcher and scientist to cooperate, and that he wanted his viewpoint to be heard.

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

I came to the Netherlands with mixed feelings about the Dutch practice of euthanasia and left the same way, but with greater anxiety. My study showed that there was cause for concern. The Dutch culture does not welcome a critical plurality of opinions regarding the legitimacy of euthanasia. Critics are regarded quite unfavourably. Obviously, there is scope for more research, for deeper discussion, and for increased awareness of the pitfalls in the practice of euthanasia.

It was strange for me to discuss the issue of euthanasia in the Netherlands. Views that are extremely unpopular in other countries regarding euthanasia’s place in society rule supreme in the Netherlands. The discussions I had with the Dutch experts were almost a mirror image of discussions I had had in Israel, the United States, Britain, Canada and Australia.9 What was striking in my discussions was the prevailing acceptance of the euthanasia procedure. There were only a few dissenters who were willing to go against the euthanasia policy and practice. My first fourteen interviewees were, on the whole, in favour of the policy, and I felt a growing unease in encountering such unanimity of opinion. This conformity worried me. To use Millian phraseology, plurality and diversity of opinion are good for society, leading to a more comprehensive understanding of the issues, as well as a higher level of truth.10

I found it troublesome that scholars and decision-makers would support a system that suffers from serious flaws when the stakes are very high; after all, we are dealing with life and death. There were various opinions regarding specific questions and issues, but only a minority questioned the system as such.

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9 The outcome of this extensive nine-year research project is The Right to Die with Dignity: An Argument in Ethics, Medicine and Law (Piscataway, NJ: Rutgers University Press, 2001).

Many of the experts depicted a society in which it is the role of doctors to help patients. They did not 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 that 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, commissioned by the Dutch government, do not demonstrate a slippery slope, yet ignored the fact that there is already too much abuse.

In this context, one of my interviewees, James Kennedy, made an interesting observation. He said that it is wrong to speak of the euthanasia “system”. The word “system” suggests a kind of logical coherence that Kennedy does not think that Dutch euthanasia has. The Dutch use the word “beleid”, meaning policy. They are proud of fuzziness. They believe that rules and guidelines should not be set in stone. They do take the legal Guidelines for euthanasia seriously, but if the physician has a good reason for not fulfilling a certain Guideline, then that is fine. Thus it is hard to know how much weight the Dutch really put on their Guidelines. The Guidelines are important but not absolutely important. They carry a certain weight but don’t have absolute gravity. Kennedy thinks that the new act of April 2001 added a bit more weight to the Guidelines, but only a little bit.11

Many of the interviewees failed to recognize that the policy does not work because all of the Dutch Guidelines for euthanasia, 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 the patient. Sometimes the family initiates the request. The requirement that the request be voluntary is thus compromised. On occasion, the patient’s request is not well considered. There have been cases in which no request was made and patients were put to death. Furthermore, the patient’s request is not always durable and persistent as required.

The Guidelines speak of “unbearable suffering”, a term that evokes criticism because it is open to interpretation.12 Are dementia patients, for instance, suffering unbearably? Apparently not, yet there were a few euthanasia cases of demented patients.13 The Guidelines instruct that a doctor must perform the

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11 Interview with James Kennedy on June 24, 2001 (Amsterdam).
euthanasia. Yet, there were cases in which nurses had administered the procedure. It was estimated that 10% of the nursing home physicians had let the nurse or even the patient’s family members administer the euthanasia drug.\textsuperscript{14} Another key Guideline requires that before the doctor assists the patient, a second doctor must be consulted. This Guideline has been breached many times. It is instructed that the patient’s GP performs euthanasia, yet on occasion the consultant conducted the final act. The doctor must keep a full written record of every case and report it to the prosecutorial authorities as a case of euthanasia or physician-assisted suicide, and not as a case of death by natural causes. This Guideline has also been violated frequently.\textsuperscript{15} Notwithstanding, many interviewees were quite content with the Guidelines. One cannot expect a policy that would work 100 percent of the time, but given the many frequent breaches of all the Guidelines, the Dutch should invest effort to find remedies and to prevent abuse and lawlessness.

I was surprised during some of the discussions to hear the rosy pictures that were painted.\textsuperscript{16} I asked myself whether I was too cynical and suspicious, or my counterparts too optimistic; after all, they knew the situation in the Netherlands far better than I did. But the unanimity of opinion might suggest that there is not enough reflective thinking about this issue, that the practice of euthanasia is taken for granted; therefore, there might be greater room for abuse in such an environment of trust and lack of critical questioning. Even issues that are acknowledged as problems are not conceived to be serious enough to press.\textsuperscript{17} The Dutch tend to accept highly troublesome contentions and to consider and allow euthanasia in cases where the Guidelines are severely breached and to condone killing when patients did not ask to end their lives. The culture around euthanasia makes the practice accessible within the confines of what is permissible. This culture, however, has a chilling effect upon open, critical debate.\textsuperscript{18} In other parts of the world, under similar circumstances and in light of the justified critique, euthanasia would not be considered an option.

\textsuperscript{14} Martien Tom Muller, \textit{Death on Request} (Amsterdam: Vrije Universiteit, 1996), Thesis, p. 52.


Some troubling questions have arisen as a result of my study in the Netherlands. The high number of unreported cases of euthanasia is alarming. The fact that some patients have been put to death without prior consent is extremely worrisome. Society has to ensure that no abuse takes place and that the existing legal procedure does not open a window for abuse or provide a way to get rid of “unwanted” patients. More research should be done on what is termed outside of the Netherlands “passive euthanasia”, that is, the withholding or withdrawal of treatment and also on the practice of “terminal sedation”. In administering terminal sedation, patients who are dying are given sedation that keeps them in a state of unconsciousness until death. In contrast to euthanasia, terminal sedation is not aimed at ending a patient’s life but the administering of drugs is often part of palliative care to combat pain, fear and distress. Unlike euthanasia, terminal sedation does not need to be reported to authorities. A 2003 study asked 410 Dutch doctors whether they used terminal sedation and why. The answers indicated that 52 percent had applied on occasion terminal sedation and in a large majority of these cases, the sedation was administered partly to hasten a patient’s death. Dutch doctors administer “terminal sedation” in four to 10 percent of patient deaths.19 To close the door for potential abuse, special attention should be given to demented patients, newborns and children. The Guidelines need to be clarified in detail, closing the door to possible misinterpretation that could lead to abuse.20

I agree with most of the experts who contend that euthanasia should not be regarded as an integral part of normal medical care. The fact that many Dutch physicians do not wish to be bothered with the procedures is alarming. It shows that they have not internalized the concept that euthanasia is an exceptional medical procedure and, as such, requires social control. It is possible that the moral ambiguity that surrounded the issue – allowing the practice while it was still prohibited under the Penal Code – made doctors feel that they had better conduct euthanasia in private, keeping it only between the patients, their families and themselves. Wherever euthanasia is practiced, it should be subject to constructive criticism. It is preferable to draft a better legal framework than the one that used to govern the practice in the Netherlands prior to the enactment of the new law, which was ambiguous and presented an illegal-yet-tolerated model. In the event that we see that the new euthanasia policy opens

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19 Expatica News reports from Holland: Fears over “unregulated euthanasia” (August 3, 2004).

the way to abuse, then yet again we should pursue a public debate in which different sectors of society can take part. The understanding of euthanasia and its importance should be changed for it to work properly without abusing the rules of caution.

I also think that physicians should not suggest euthanasia to their patients as an option. By now, the Dutch people are fully aware that euthanasia is available. If patients wish, they can raise the issue themselves. Most of the euthanasia cases involve cancer patients, and at some time during the progressive course of their illness, they can take the initiative and discuss it with their physicians if they are so inclined. If they do not initiate such a discussion, then the physician can assume that the patient does not wish to move in this direction.  

I believe that the medical profession should not turn its back on patients who clearly request to shorten their lives. However, this issue should be open to a constant public debate. It is necessary to devise a better working framework to help patients in need. At the same time, respect for human life is and should remain the prime concern. Ending a human life without acquiring the patient’s consent might be motivated by mercy – or, alternatively, the motivation may be quite different. The ending of a patient’s life should be conducted openly in the light and subject to scrutiny.

As said, before coming to the Netherlands, I supported euthanasia and published some articles calling to recognize the need for euthanasia (in the active sense that it is practiced in the Netherlands). The study in the Netherlands caused me to change my views not on the ethics of the principle of euthanasia but rather on the practicality of its implementation. The Dutch study showed that moving from the individual level to the policy level is tricky and complicated. I no longer support euthanasia. Now I restrict my plea to helping patients in need with physician-assisted suicide. This is in order to give patients better control over life and death, until the very last moment, and to provide a further mechanism against abuse. At the same time, I am willing to concede the need for euthanasia in two circumstances: (1) the patient requesting euthanasia is totally paralyzed, from head to toe, and unable to move any muscles that could facilitate assisted suicide; and (2) the patient took oral medication and has been in the process of dying for prolonged hours (see Guideline 11 infra).

The majority of Dutch scholars do not share my view. They lump euthanasia and physician-assisted suicide together and even invented an acronym for this purpose: EAS. It should be noted, however, that in August 1995, in an

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effort to improve the control mechanisms guiding these procedures, the Royal
Dutch Medical Association (KNMG) refined its Guidelines to recommend that
assisted suicide, rather than euthanasia, be performed whenever possible.  

Guidelines for Physician-Assisted Suicide

I believe that the right to die with dignity includes the right to live with
dignity until the last minute and the right to part from life in a dignified man-
ner. There are competent, adult patients who feel that the preferable way for
them to part from life is through physician-assisted suicide. I propose a cir-
cumscribed plea for voluntary physician-assisted suicide on their behalf. The
following guidelines are pertinent:

Guideline 1. The physician should not suggest assisted suicide to the pa-
tient. Instead, it is the patient who should have the option to ask for such
assistance. Initiation by the physician might undermine the trust between the
patient and the physician, conveying to patients that the doctor is giving up
on them and values their lives only to the extent of offering assistance to die.
Such an offer might undermine the will to live and to explore further avenues
for treatment. Many Dutch researchers and physicians do not see this issue
as a significant one. Some of them consider it important to raise the issue
when it seems that patients do not dare to initiate it on their own. Undoubtedly,
however, all people in the Netherlands are aware of the availability of eu-
thanasia and physician-assisted suicide. Any reluctance shown by patients in
regard to this issue should be honoured and respected.

Guideline 2. The request for physician-assisted suicide of an adult, competent
patient who suffers from an intractable, incurable and irreversible
disease must be voluntary. The decision is that of the patient who asks to die
without pressure, because life appears to be the worst alternative in the current

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22 Herbert Hendin, Seduced by Death, op. cit., p. 122.
23 Keith L. Obstein, Gerrit Kimsma and Tod Chambers, “Practicing Euthanasia: The Perspecti-
ve of Physicians”, J. of Clinical Ethics, Vol. 15, No. 3 (Fall 2004): 223–231. See also David Shalowit-
z and Ezekiel Emanuel, “Euthanasia and Physician-Assisted Suicide: Implications for Physicians”,
24 Most bill proposals to legislate PAS in the United States specify that the age of the consenting
patient must be 18 or older to qualify for the procedure. Russell Korobkin, “Physician-Assisted Suic-
cide Legislation: Issues and Preliminary Responses”, Notre Dame J. of Law, Ethics & Public Policy,
25 See the Dutch requirements of careful practice, in John Griffiths, Alex Boed and Heleen
Weyers, Euthanasia and Law in the Netherlands (Amsterdam: Amsterdam University Press, 1998),
p. 66. See also Chap. II. Article 3 of the Belgian Euthanasia Law. http://www.kuleuvan.ac.be/cbmer/
viewpic.php?LAN=E&TABLE=DOCS&ID=23
situation. The patient should state this wish repeatedly over a period of time.\textsuperscript{26} We must verify that the request for physician-assisted suicide does not stem from a momentary urge, an impulse, a product of passing depression. This emphasis of enduring request was one of the requirements of the abolished Northern Territory law in Australia,\textsuperscript{27} and is one of the requirements of the Oregon \textit{Death with Dignity Act},\textsuperscript{28} as well as of the Dutch Guidelines.\textsuperscript{29} We must also verify that the request is not the result of external influences. It should be ascertained with a signed document that the patient is ready to die now, rather than depending solely upon directives from the past. Section 2 of the Oregon Act requires that the written request for medication to end one’s life be signed and dated by the patient and witnessed by at least two individuals who, in the presence of the patient, attest to the best of their knowledge and belief that the patient is capable, is acting voluntarily, and is not being coerced to sign the request.\textsuperscript{30}

Individuals may express general attitudes regarding euthanasia in an informal discussion made in a social setting, possibly saying that they would not want to live if they were unable to function alone and had to depend on the mercy of others. However, such hypothetical observations do not constitute reliable evidence of a patient’s current desires once an actual illness is in progress. This is especially true if the wish was stated when young and healthy. The younger people are and the further they are from serious disease, the more inclined they are to claim that in a hypothetical state of pain, degradation and hopelessness, they would prefer to end their lives. On the other hand, there is a tendency to come to terms with suffering, to compromise with physical disabilities, and to struggle to sustain life. This tendency grows as the body weakens. Many people change their minds when they confront the unattractive alternatives, preferring to remain in what others term the “cruel” world, and continue the Sisyphean struggle for their lives.

\footnotesize{\textsuperscript{26} Many bill proposals to legislate PAS in the United States require a waiting period of 14 or 15 days. Cf. Russell Korobkin, “Physician-assisted Suicide Legislation: Issues and Preliminary Responses”, op. cit., p. 468.  
\textsuperscript{27} Section 7, \textit{Rights of the Terminally Ill Act (1995)} (NT).  
\textsuperscript{28} In Australia, the law required a “cooling off” period of nine days. In Belgium, the law requires a “cooling off” period of one month. In Oregon, the Act requires a waiting period of fifteen days. I do not wish to suggest an arbitrary time period of waiting, saying instead that the patient should state her wish several times “over a period of time”. I concur with Miller and colleagues who think that a fifteen days waiting period may be highly burdensome for patients who are suffering intolerably and may preclude access to assisted death for those who request it at the point when they are imminently dying. Franklin G. Miller, Howard Brody and Timothy E. Quill, “Can Physician-Assisted Suicide Be Regulated Effectively?”, \textit{J. of Law. Medicine & Ethics}, Vol. 24 (1996), p. 226. See also Oregon \textit{Death with Dignity Act}, \textit{Oregon Revised Statutes}, Vol. 8 (1998 Supplement), at 982.  
\textsuperscript{29} John Griffiths \textit{et al.}, \textit{Euthanasia and Law in the Netherlands}, op. cit., p. 66.  
\textsuperscript{30} Oregon \textit{Death with Dignity Act}, \textit{Oregon Revised Statutes}, Vol. 8 (1998 Supplement), at 980.}
Guideline 3. At times, the patient’s decision might be influenced by severe pain. In this context, the role of palliative care can be crucial. Ganzini and colleagues report that as a result of palliative care, some patients in Oregon changed their minds about assisted suicide. The World Health Organization defines palliative care as the “active, total care of patients whose disease is not responsive to curative treatment”, maintaining that control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount. The medical staff must examine whether it is possible to prevent or to ease the pain by means of medication and palliative care. The Oregon Death with Dignity Act requires the attending physician to inform the patient of all feasible alternatives, including comfort care, hospice care and pain control. A study designed to examine Oregon physicians’ attitudes toward and practices regarding care of dying patients since the passage of the Act shows that 30 percent of the 791 respondents reported that they had increased referrals to hospice. Of the 2094 respondents who cared for patients termed “terminally ill”, 76 percent reported that they made efforts to improve their knowledge


of the use of pain medications. Bill proposals to legislate PAS in Illinois, Hawaii, Maine, Michigan, Vermont, Washington and Wisconsin explicitly require the attending physician to review options for palliative care with the patient, including hospice and/or pain control options. If it is possible to prevent or to ease the patient’s pain, then the patient’s request for assisted suicide should not be fulfilled; instead, the necessary treatment should be prescribed. This is provided that the educated patient (i.e., a patient who was advised by the medical staff about the available palliative care options) does not refuse to take the painkillers, and that when the pain subsides so does the motive (or one of the main motives) for assisted suicide. If the patient insists on denying all medication, then doctors must first try to find the reasons for this insistence before they comply with the request.

Coping with pain and suffering can drain all of the patient’s emotional strength, exhausting the ability to deal with other issues. In cases of competent patients, the assumption is that the patient understands the meaning of the decision. A psychiatrist’s assessment can confirm whether the patient is able to make a decision of such ultimate significance to the patient’s life and whether the decision is truly that of the patient, expressed consistently and of his/her own free will. The Northern Territory Rights of Terminally Ill Act required that the patient meet with a qualified psychiatrist to confirm that the patient was not clinically depressed. It is worthwhile to hold several such conversations, separated by a few days. The patient’s loved ones and the attending physician should be included in at least one of the conversations.

General practitioners in the Netherlands express discomfort about their competence to perform palliative care adequately. There is a clear need to involve palliative care consultants so as to enhance the general knowledge and experience of physicians in palliative care. Moreover, a recent Dutch study

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showed that independent, small-scale palliative care units with specialized staff have a good concept of care for patients who suffer for incurable diseases in terms of patient outcomes at the end of life.41

**Guideline 4.** The patient must be informed of the situation and the prognosis for recovery or escalation of the disease, with the suffering that it may involve. There must be an exchange of information between doctors and patients.42 Bearing this in mind, we should be careful to use neutral terms and to refrain from terms that might offend patients and their loved ones.43

**Guideline 5.** It must be ensured that the patient’s decision is not a result of familial and environmental pressures. At times, patients may feel that they constitute a burden on their loved ones. It is the task of social workers to examine patients’ motives and to see to what extent they are affected by various external pressures (as opposed to a truly free will to die). A situation could exist in which the patient is under no such pressure, but still does not wish to be a burden on others. Obviously, we cannot say that the feelings of patients toward their loved ones are not relevant to the decision-making process.44

**Guideline 6.** The decision-making process should include a second opinion in order to verify the diagnosis and minimize the chances of misdiagnosis, as well as to allow the discovery of other medical options. A specialist, who is not dependent on the first doctor, either professionally or otherwise, should provide the second opinion.45 The patient’s attending physician, who suppo-

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45 Most bill proposals to legislate PAS in the United States required that the treating physician refer the patient to a second consulting physician to verify the terminal nature of the disease. The Massachusetts bill required a third confirming opinion. Cf. Russell Korobkin, “Physician-Assisted Suicide Legislation: Issues and Preliminary Responses”, op. cit., p. 453. See also Chap. II, Article 3 of the Belgian Euthanasia Law.
sedly knows the patient’s case better than any other expert, must be consulted, and all reasonable alternative treatments must be explored. The Oregon *Death with Dignity Act* requires that a consulting physician shall examine the patient and his/her relevant medical records and subsequently confirm, in writing, the attending physician’s diagnosis that “the patient is suffering from a terminal disease”. Furthermore, the consulting physician must verify that the patient is capable, is acting voluntarily, and has made an informed decision. The Dutch Guidelines require that the physician consult a colleague. The Northern Territory *Rights of Terminally Ill Act* required that a physician who specialized in treating terminal illness examine the patient.

*Guideline 7.* It is advisable for the identity of the consultant to be determined by a small committee of specialists (like SCEN), who will review the requests for physician-assisted suicide. This is in order to avoid the possibility of arranging deals between doctors (“you will consult for me regarding Mr. Jones, approving my decision, and I will consult for you regarding Ms. Smith, approving your decision”).

*Guideline 8.* Some time prior to the performance of physician-assisted suicide, a doctor and a psychiatrist are required to visit and examine the patient so as to verify that this is the genuine wish of a person of sound mind who is not being coerced or influenced by a third party. The conversation between the doctors and the patient should be held without the presence of family members in the room in order to avoid familial pressure. A date for the procedure is then agreed upon. The patient’s loved ones will be notified so that they can be present right until the performance of the act, making the day an intimate, family occasion.

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50 Proposals to legislate PAS in Illinois, Massachusetts and Maine required that a patient seeking PAS obtain a consultation with a mental health professional in order to insure that the patient can pass the “impaired judgment” standard. Cf. Russell Korobkin, “Physician-Assisted Suicide Legislation: Issues and Preliminary Responses”, op. cit., p. 456. This Guideline is somewhat similar to the guidelines of the Swiss EXIT protocol.
Guideline 9. The patient can rescind at any time and in any manner. This provision was granted under the Australian Northern Territory Act\textsuperscript{51} and under the Oregon Death with Dignity Act.\textsuperscript{52} Chapter III, Article 4 of the Belgian Euthanasia Law says that patients can withdraw or adjust their euthanasia declaration at any time.\textsuperscript{53}

Guideline 10. Physician-assisted suicide may be performed only by a doctor and in the presence of another doctor. The decision-making team should include at least two doctors and a lawyer, who will examine the legal aspects involved. Insisting on this protocol would serve as a safety valve against possible abuse. Perhaps a public representative should also be present during the entire procedure, including the decision-making process and the performance of the act. This extra caution should ensure that the right to die with dignity does not become a duty. The doctor performing the assisted suicide should be the one who knows the patient best, having been involved in the patient’s treatment, taken part in the consultations, and verified through the help of social workers, nurses and psychologists that euthanasia is the true wish of the patient.

Guideline 11. Physician-assisted suicide may be conducted in one of three ways, all of them discussed openly and decided upon by the physician and the patient together: (1) oral medication; (2) self-administered, lethal intravenous infusion; (3) self-administered lethal injection. Oral medication may be difficult or impossible for many patients to ingest because of nausea or other side effects of their illnesses. In the event that oral medication is provided and the dying process is lingering on for long hours, the physician is allowed to administer a lethal injection.\textsuperscript{54}

Guideline 12. Doctors may not demand a special fee for the performance of assisted suicide. The motive for physician-assisted suicide is humane, so there must be no financial incentive and no special payment that might cause commercialization and promotion of such procedures.


Guideline 13. There must be extensive documentation in the patient’s medical file, including the following: diagnosis and prognosis of the disease by the attending and the consulting physicians; attempted treatments; the patient’s reasons for seeking physician-assisted suicide; the patient’s request in writing or documented on a video recording; documentation of conversations with the patient; the physician’s offer to the patient to rescind her request; documentation of discussions with the patient’s loved ones; and a psychological report confirming the patient’s condition. This meticulous documentation is meant to prevent exploitation of any kind – personal, medical, or institutional. Each report should be examined by a coroner following completion of the physician-assisted suicide.55

Guideline 14. Pharmacists should also be required to report all prescriptions for lethal medication, thus providing a further check on physicians’ reporting.56

Guideline 15. Doctors must not be coerced into taking actions that contradict their conscience or their understanding of their role. This was provided under the Northern Territory Act.57

Guideline 16. The local medical association should establish a committee, whose role will be not only to investigate the underlying facts that were reported but also to investigate whether there are “mercy” cases that were not reported and/or that did not comply with the Guidelines.

Guideline 17. Licensing sanctions will be taken to punish those health care professionals who violated the Guidelines, failed to consult or to file reports, engaged in involuntary euthanasia without the patient’s consent or with patients lacking proper decision-making capacity. Physicians who failed to comply with the above Guidelines will be charged and procedures to sanction them will be brought by the Disciplinary Tribunal of the Medical Association. The maximum penalty for violation of the Guidelines will be the revoking of the physician’s medical license. In the event that this penalty proves insuf-

55 Directive 6 in The General Manager Circular, Israel Ministry of Health, no. 2/96 (January 31, 1996) states: “The decision to respect a patient’s objection to a life prolonging treatment shall be documented in the medical statutes, expressing maximum reasons for the decision and the discussions with the patient”, p. 12 (Hebrew). See also Israeli Patients’ Rights Law (1996), 1591, Chapter E: medical documentation and medical information, p. 331.
ficient in deterring potential abusers, there will be room to consider further penalties, including heavy fines and prison sentences.\textsuperscript{58}

Conclusion

What is presented here is a circumscribed reasoning for physician-assisted suicide to help a designated group of patients that require and deserve help from the medical profession in departing from life. With human life at stake, detailed procedures are required in order to prevent abuse. I suggest that this reasoning be adopted for a trial period of one year, at which time the consequences will be examined to determine whether further implementation of the policy for a lengthy period of time is justified. During this one-year trial period, feedback between physicians, ethicists and the public at large in reviewing the policy and practice of physician-assisted suicide should be welcomed and encouraged. If the proposal fails (for instance, if physicians do not adequately report incidents of physician-assisted suicide), then all the data should be brought before a review committee to closely study the policy and practice. Members of the committee will issue a report recommending whether they wish to continue the practice, to amend the Guidelines, or to abolish physician-assisted suicide entirely. Preferably, the final decision should be made through active participation of all those involved.

The role of palliative care, its importance and practice in making decisions at the end of life cannot be underestimated. Since 1991 I have been studying end-of-life issues. My research was not confined to libraries and research seminars. I visited dozens of hospitals and medical research centers in different countries: Israel, England, United States, Canada, Australia, New Zealand, the Netherlands and Belgium. Most of patients, according to testimonials of heads of departments and heads of ethics committees cling to life not matter what. Even in the most miserable and painful situations (mainly cancer), patients opt for life. This is hardly surprising given the alternative. In Jewish and Catholic hospitals I was told that 99% of patients cling to life. In less religious hospitals, 90% to 95% prefer to continue living. The majority of those who express a wish to die do this out of fear of suffering. Once physicians are able to control pain, many who expressed a wish to die cease expressing the death wish. Thus we are left with a very small number of patients who wish to deci-

de the moment of their death. These are strong-willed patients who emphasize autonomy and dignity. Medicine should cater for all patients, not only the majority of them. But palliative care enjoys precedent over euthanasia. The two are not on equal footing. Only when palliative care fails to address the patient’s wishes and is unable to adequately mitigate her physical and mental suffering, physicians in the Netherlands should offer euthanasia.

The last evaluation of euthanasia legislation that was presented to the Dutch State secretary for public health Jet Bussemaker in May 2007 showed that the number of euthanasia cases has dropped over the past few years. In 2005, 1.7% of all deaths in the Netherlands (2,297 people) were the result of euthanasia, more than a third less than the 3,500 cases in 2001, 113 patients died as a result of physician-assisted suicide. In both 2005 and 2001, the highest rates of euthanasia or assisted suicide were found for patients aged 64 years or younger, for men, and for patients with cancer. Furthermore, most acts of euthanasia or assisted suicide were carried out by general practitioners. 59

0.4% of all deaths were the result of the use of lethal drugs not at the explicit request of the patient; this percentage was not significantly different from those in previous years. When life was ended without the explicit request of the patient, there had been discussion about the act or a previous wish of the patient for the act in 60.0% of patients, as compared with 26.5% in 2001. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%). Of all cases of the ending of life in 2005 without an explicit request by the patient, 80.9% had been discussed with relatives. In 65.3% of cases, the physician had discussed the decision with one or more colleagues. 60

As could have been expected, the number of terminal patients receiving palliative sedation has increased. Palliative sedation involves the administration of deep sleep-inducing medication to terminal patients who have at most two weeks to live. These patients are not administered liquid in this state. There was a substantive increase in the use of palliative sedation in the same period from 8,500 to 9,600. 61


61 Ibid.; “Number of euthanasia cases drops”, Expatica Report (May 10, 2007), circulated by org.opn.lists.right-to-die@lists.opn.org
The number of doctor-assisted suicides also decreased, from 300 in 2001 to 100 in 2005. There were also fewer patient requests for euthanasia or suicide assistance: 8,400, compared to 9,700 in 2001.\textsuperscript{62} Furthermore, 0.4\% of all deaths were the result of use of lethal drugs without the explicit request of the patient.\textsuperscript{63} Although this percentage is not significantly different from those in previous years, it is still most worrisome.

The good news are concerned with reporting. Doctors are required to report euthanasia cases to a regional review committee which monitors that all conditions have been met. The evaluation indicates that more and more doctors are honouring this reporting requirement. While only 18\% reported euthanasia cases in 1990, 54 in 2001, 80\% did so in 2005.\textsuperscript{64} There is a steady increase in the reporting rate although the Dutch interest is to reach full level of reporting.

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Kritički osvrt na nizozemsku politiku i praksu eutanazije i predložene smjernice za liječnički potpomognuto samoubojstvo

\textbf{Sažetak}

Moj članak započinje s nekoliko osobnih riječi o mojem poznanstvu s Ivanom Šegotom. Nastavljam objašnjavajući metodologiju svojeg istraživanja eutanazije u Nizozemskoj. Zatim dajem detaljan prikaz glavnih pronalaza i završavam smjernicama za liječnički potpomognuto samoubojstvo. Moje istraživanje u Nizozemskoj navelo me je da promijeni mišljenje: od zagovornika postao sam vatreni protivnik eutanazije.

Smatram, međutim, da liječnici ne bi smjeli okrenuti leđa pacijentima na kraju života koji jako pate i zahtijevaju smrt. Zbog toga se sugerira liječnički potpomognuto samoubojstvo. Da bi se spriječila mogućazlouporeda, moramo brižljivo osmisliti smjernice koje su, vjerujem, prikladne demokracijama s ulaskom u 21. stoljeće, doba visokorazvijene tehnologije koja donosi mnogo dobra, ali u području medicine može nepotreban produbljavati život pacijenta. U središtu smjernica je pacijent, a u podlozi postupaka nalaze se vrijednosti poštovanja pacijenta i njegove autonomije, dobročinstva, neškodljivosti i suočanja.

\textsuperscript{62} ibid.


\textsuperscript{64} Ibid. See also \textit{Magazine of Right to Die-NL (NVVE)} Volume 33, No. 2 (June 2007); Timothy E. Quill, “Physician Assisted Death in Vulnerable Populations”, \textit{BMJ}, Vol. 335 (September 2007): 625–626.