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## SHOULD DOCTORS SUGGEST EUTHANASIA TO THEIR PATIENTS? REFLECTIONS ON DUTCH PERSPECTIVES

**ABSTRACT.** During the summer of 1999 and in April 2002 I went to the Netherlands in order to meet some of the leading authorities on the euthanasia policy. They were asked multiple questions. This study reports the main findings to the question: should doctors suggest euthanasia to their patients? Some interviewees did not observe any significant ethical concerns involved in suggesting euthanasia. For various reasons they thought physicians should offer euthanasia as an option. Two interviewees asserted that doctors don't propose euthanasia to their patients. Five interviewees objected to physician's initiative.

**KEY WORDS:** euthanasia, physician-assisted suicide, physician-patient relationship, voluntariness

### INTRODUCTION

The Dutch experience has influenced the debate on euthanasia and death with dignity around the globe, especially with regard to whether physician-assisted suicide and euthanasia should be legitimized or legalized. Having investigated the Dutch experience for a number of years, in the summer of 1999 and also in April 2002<sup>1</sup> I went to the Netherlands to visit the major centers of medical ethics as well as some research hospitals, and to speak with leading figures in the euthanasia policy and practice. This essay reports the answers to an issue that I consider as ethically problematic: whether a physician can suggest euthanasia or assisted suicide to his or her patients. The KNMG (Royal Dutch Medical Association) report on euthanasia describes a situation when the physician has the impression that the patient would like to start a conversation about the end of his life and his wishes concerning the end of his life, but hesitates to start this conversation. If this is the case, then the physician might choose to start this conversation. However, this has to be done with the utmost precaution in order to avoid making the patient feel pushed in a certain direction.<sup>2</sup> The 1990 Rummelink study shows that 36% of specialists, 24% of home physicians, and 65% (!) of general practitioners believed that there can be situations in which the physician should raise euthanasia as a possibility with the patient.<sup>3</sup> This 1990 prospective study shows that the initiative for



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discussion about the action to be performed at the end of life came from the patient in only about half of the cases.<sup>4</sup> Van der Maas and Van der Wal estimated that of all cases of euthanasia, physician-assisted suicide (PAS) and the ending of life without the patient's explicit request, the physician initiated the discussion in 21 percent.<sup>5</sup> Another study holds that 54 percent of physicians believe that in certain situations it is the physician's professional duty to raise euthanasia as an option with the patient.<sup>6</sup> Neither the physicians nor the study's investigators seem to acknowledge how much the voluntariness of the process may be compromised by such a suggestion.<sup>7</sup>

Pieter Admiraal, an outspoken advocate of the Dutch euthanasia policy who practiced the measure himself, reveals that "contrary to most doctors," who will not discuss euthanasia before the patient requests it, he discusses this option with the patient, "for it can be of great value and great comfort for many." Admiraal further explains that not discussing euthanasia with a patient can take the medical team by surprise if a patient suddenly asks for it later. One might question whether this issue is of real concern. Admiraal argues that if one considers euthanasia permissible under some circumstances, then not to broach the possibility with a patient is to deny that patient the full range of available options. Suggesting euthanasia to a patient is thus a measure of respect for the patient's autonomy.<sup>8</sup> Dr. Herbert Cohen, another well-known practitioner of euthanasia, likewise claims that raising the subject of euthanasia by the physician has an emancipating effect.<sup>9</sup>

My own inclination was to contest these arguments for the following reasons. The Dutch health care system is built around the general practitioner that has known his/her patients for many years. Based on this history of trust and confidence, the GP might feel comfortable raising the issue of euthanasia with the patient. This might have devastating implications – the doctor whom the patient has trusted for so long has nothing to offer but death. Knowing that one's physician has given up might cause the patient to give up as well, to surrender his or her life. What if the patient wishes to continue living? Could the patient still trust a physician who offers to kill him? Could the patient trust that the GP would do everything possible to fight to maintain that patient's life? This might create a very uncomfortable situation for both physician and patient.

Furthermore, in the Netherlands, the patient has few options for changing the GP. Usually patients build long term relationships with their GPs, relationships that last decades during which trust and confidence are crystallized. Patients are hesitant to replace the familiar and trusted physician with someone else. Clearly, one does not seek more complications

in the end-of-life fragile stage, and it would be difficult to build trust in a new physician. Moreover, in the Netherlands' cultural atmosphere, where patients generally do not want to become a burden on their families, an offer of euthanasia by their GP might be taken as a sign that they are living on borrowed time, which the GP does not find useful or of high quality. The GP's offer might lead not only to giving up the fight but also to increasing the patient's feelings of guilt for still being alive.<sup>10</sup>

For all these reasons, it was interesting to hear the thoughts of the interviewees about this issue, and whether they were at all aware of this ethical problem. Some interviewees did not share my concerns. For various reasons they thought physicians should offer euthanasia as an option. Two interviewees asserted that doctors don't propose euthanasia to their patients. Five interviewees objected to physician's initiative.

### METHODOLOGY

Before arriving in the Netherlands in the summer of 1999, 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.<sup>11</sup> The majority of interviewees were known to me through their writings. The remainder of interviewees was suggested to me by colleagues. Because many of the interviewees are quite known to people who are familiar with the euthanasia policy and practice in the Netherlands, I thought it may be of interest to examine their views on this delicate question of whether physicians should suggest euthanasia to their patients.

The interviews took place during July-August 1999 in the Netherlands. One interview, with Bert Keizer, was conducted in April 2002. 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 to 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.<sup>12</sup>

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 efficient Dutch train system.

The interviews were semi-structured. I began with a list of 15 questions but did not insist on all of them when I saw that the interviewee preferred to speak about subjects that were not included in the original questionnaire. With a few interviewees I spoke only about their direct involvement in the practice of euthanasia. This article reports the answers to the question of whether doctors should initiate discussion on euthanasia. For limitations of space I cannot report the extensive answers to my fifteen questions. This is done in my forthcoming book *Euthanasia in the Netherlands*.<sup>13</sup>

As I noted earlier, 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 the 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.

The majority of interviewees commented on the first draft. Those commenting on the draft included Arie J.G. van der Arend, Rob Houtepen, Henk Jochemsen, H.J.J. Leenen, Heleen Dupuis, Johannes JM van Delden, John Griffiths, Ron Berghmans, Ruud ter Meulen, Govert den Hartogh, Paul van der Maas and Gerrit Kimsma. George Beusmans read the draft and had no problems with my accounts of his views. Chris Rutnefrans has asked to comment on the last draft and promptly provided his concise comments.

#### THE INTERVIEWEES' RESPONSES

John Griffiths' stated that there is no basis for Dutch doctors to propose euthanasia to their patients. He added that although euthanasia is not offered to patients, sometimes it would actually be better to propose it. Later in the interview, Griffiths acknowledged that suggesting euthanasia does happen, albeit infrequently and not on the level of constituting a social problem. In his comments on the first draft of this essay, Griffiths clarified:

What I did say is that the suggestion by Hendin et al. to the effect that doctors steer their patient's decision making is based on a misreading of the relevant data (which refer only

to 'first raising the question'). The latter seems to me good medical practice, in certain circumstances. It does not necessarily imply any sort of pressure or suggestion on the doctor's part. Whether the latter occurs, I do not know (I assume it does, doctors being human and therefore not always perfect). I do think an effective control system needs to guard against the risk.<sup>14</sup>

On the other hand, Arie van der Arend, a medical ethicist from Maastricht, did not think that these were rare incidents. He made a distinction between the physicians' initiation in offering euthanasia as an option, and the physicians' interpretation of patients' indications. While physicians should never offer euthanasia as an option, they should inquire about what their patients want.<sup>15</sup> Physicians may mention euthanasia only after the patient has indicated thinking about it and has discussed the issue while using other terms. In some cases, patients may be reluctant to raise the issue per se, and the physicians are required to label what the patients have indicated.<sup>16</sup>

Paul van der Maas, the principal author of the two major reports of 1990 and 1995, said that most physicians wish to include the euthanasia option in medicine. He thinks that it is important for the physician to be open to discussing all of the options with the patient, making it clear that the euthanasia option is available. If the patient does not initiate the discussion, then the doctor should do so. Van der Maas thinks that such a conversation is necessary when the physician does not know what the patient wants, just in case the patient loses consciousness. In a letter written with Van der Wal in response to Hendin's critique, Van der Maas explains that taking the initiative to create an opportunity for patients to discuss their wishes concerning the end of life is very different from Hendin's portrayal of "telling the patient that his or her life is not worth living."<sup>17</sup>

Two physicians who have been practicing euthanasia for many years, George Beusmans and Gerrit Kimsma, did not share my concerns about driving patients to opt for death by raising the euthanasia option. Beusmans underestimated the ethical concerns, while Kimsma was aware of them but stressed the overriding principles that justify the physician's initiation of a discussion on euthanasia. Both of them believe it necessary for the physician to raise the issue to the patient because some patients may feel uncomfortable raising it themselves. Beusmans and Kimsma, in turn, feel comfortable raising the issue and consider it part of their role as doctors.

The two doctors elaborated on their conduct well beyond the framework of my question and gave interesting accounts that warrant a detailed description. Beusmans explained that most of his patients expressed appreciation for his initiation of the conversation. This is a very difficult issue for patients, who wish to be perceived as strong. They view the initiation of a discussion on euthanasia as a sign of weakness, indicating that the

patient is unable to cope with the suffering. Beusmans articulated that in the first discussion on euthanasia, he does not say much. He offers it as an option and suggests that the patients consult with their families. This first discussion usually takes place when Beusmans estimates that the patient has two to three months to live. He likes to raise the issue then so as to enable the patients some time to crystallize their decision. The patients are more capable of thinking clearly without experiencing a lot of pain that might obscure critical reflection. Two weeks later, Beusmans discusses the options available to the patients: assisted suicide, euthanasia, or optimal treatment. The problem is not only pain. Many patients are fearful of dying and do not know what to expect. Physicians can handle the pain, but it is much more difficult to handle the mental aspects. Ultimately, the patients decide what they want.

Beusmans testifies that some 10 of his patients in the past decade have asked for his help in terminating their lives: nine asked for physician-assisted suicide and one for euthanasia. The one who asked for euthanasia was very sick, could not take any food and fluids, and asked for a lethal injection. Beusmans said that, on the whole, he does not like to give lethal injections.<sup>18</sup> Probably his reluctance to do so influenced his patients to choose physician-assisted suicide. Most Dutch physicians who perform PAS and euthanasia do not exhibit such reluctance, and consequently there are far more cases of euthanasia than cases of PAS.<sup>19</sup> Beusmans performs physician-assisted suicide when the patient's loved ones (usually 3-4 people) are present. All of these cases took place at the patients' homes with their families and/or friends present. Beusmans knew the patients and their families for years. All of them were cancer patients; all were competent and conscious.<sup>20</sup>

Gerrit Kimsma portrays a picture that is similar in some aspects and different in others. Similarly, all of his euthanasia patients had cancer. He knew them for a long time, most of them for more than 10 years. Most of his patients, "maybe all of them," were men. Unlike Beusmans, Kimsma says that in 12 years of performing euthanasia and PAS, only a handful of cases involved PAS.<sup>21</sup> Kimsma sees no substantive ethical difference between the two practices: The effect and motive are exactly the same, and only the method is different. At the same time, he acknowledges that there is a moral difference for him as a physician between injecting the lethal medication and providing the patient with the drugs. He asserts that physicians choose the needle more than the cup (oral medication) because they do not doubt the need for euthanasia and because the patients ask for it. Kimsma says that most of his own patients asked to die by the needle as

soon as possible. As with Beusmans, the patients' choices probably reflect the physician's preferences.

Kimsma thinks that doctors need to promise their patients that they will not abandon them. Patients should not be left alone suffering. When a potentially terminal disease is found, the doctor should discuss the issue of euthanasia with the patient. Accordingly, Kimsma holds conversations about euthanasia with all of his 'terminal' patients. His opening remark to patients who have been informed of their terminal illness is: "Now you have heard this diagnosis, it may be that you have expectations or ideas about the end of life. If you wish to discuss these, I will be available for you, now or in some future time, whenever you feel the need."<sup>22</sup>

Kimsma also advises his patients to join the Dutch Voluntary Euthanasia Society.<sup>23</sup> He maintains that in the Netherlands "we have physicians who never talk about end-of-life issues" because they are afraid that the patient will start a discussion on euthanasia. Doctors and patients alike should be sensitive and open in discussing end-of-life issues. Physicians should discuss with their patients what the expectations are and which options they would like to consider. Sometimes patients do not, or will not, talk about euthanasia. In Kimsma's view, in 80% of the cases, physicians wait until the patient starts talking about euthanasia. In 10% of the cases, physicians are the ones who initiate the conversation, and in another 10% of the cases, it is the families that initiate discussion.

On too many occasions, because everyone is reluctant to initiate the conversation, it is postponed and then the physicians need to act under pressure. Kimsma testifies that because physicians wait too long, in 13% of the cases euthanasia is performed within 24 hours from the request for it, and in 50% within a week. Kimsma's conclusion is that it is medically proper for physicians to initiate the discussion on euthanasia. A patient can make an informed choice only when all options are discussed openly. It is better to open a discussion well ahead of time than for the patient to make hasty decisions, sometimes in a panic. Govert den Hartogh, a philosopher who is a member in the newly instituted Amsterdam regional committee that reviews all reported euthanasia cases in the region, expressed the same argument, while Egbert Schrotten, Director of the Center for Bioethics and Health Law at Utrecht University, said that physicians can and do suggest euthanasia to their patients. After all, they know them very well and know what their needs and aspirations are.

In his very detailed response to this argument, den Hartogh maintains that in the Netherlands, the doctor is supposed to inform patients about all the relevant aspects of the decisions to be made and should never "advise" patients to actively end their life or have it ended. Nevertheless, in the case

of some illnesses (e.g., cancer) in which the doctor knows from experience that the probability of severe suffering is very high, it is advisable to inform the patient at an early stage that when the development of the illness takes a bad turn, euthanasia or assisted suicide can be considered. At the same time, the need for careful action must be explained and it must be clear beyond a doubt that the patient, rather than the doctor or the family, really wants to take this course of action. Even so, euthanasia will never be considered as an option for choice, but only as a measure of last resort in cases of unbearable suffering.

In the Dutch context, argues den Hartogh, providing such information at this stage does not at all convey the meaning that the doctor withdraws his support, but rather the contrary. It may provide the patient with sufficient trust to go on coping with extremely exacting conditions, and so may actually be a way of avoiding euthanasia. Furthermore, it will prevent acting in haste without carefully discussing the request and its meaning, and without allowing room for an open consultation.

Interestingly, Rob Houtepen and Heleen Dupuis, medical ethicists from Maastricht and Leiden respectively, argue that there is no basis for arguing that doctors propose euthanasia to their patients. Rob Houtepen, who never heard of such cases, thinks that physicians are restricted in this respect. Houtepen believes that doctors should not raise the subject, so as to avoid exerting pressure on patients. While the result is sometimes that the decision about what to do is delayed for too long, he feels that we should accept this. It is in the spirit of KNMG guidelines that the patient should raise the issue, not the physician. Dupuis said, in turn, that doctors are horrified by the need to perform euthanasia and that they never offer it to their patients as an option. Henri Wijsbek, a medical ethicist from Rotterdam, thinks that there might be cases in which the physician should offer euthanasia as an option, but that these cases are quite rare.

Five interviewees, Johannes van Delden who co-authored the 1990 study, G.F. Koerselman, a psychiatrist, Henk Jochemsen, a medical ethicist who objects to euthanasia on religious grounds, Chris Rutenfrans, a former law professor and currently a journalist, and Bert Keizer, a physician at a nursing home, objected to physicians' initiating a discussion of euthanasia on ethical and practical grounds. While acknowledging that many doctors conceive it as good and humane to take the initiative and raise the issue of euthanasia, they think that this might compromise the patients' voluntariness, undermine the trusted relationship between physicians and patients, and push patients to forgo life prematurely.

Keizer thinks that only the patient should initiate a request for euthanasia. He testifies that he would never put euthanasia on the menu

of alternatives for treatment. It is for the patient, not the doctor, to state that all hope has gone. Keizer thinks it is awful that doctors offer death. He says he knows how to look after dying patients, and that for him there is always hope that there is something he could do. A precondition for euthanasia is the patient's request for it, evolving from his/her subjective loss of hope.

### DISCUSSION

The physician's role is commonly understood as a healing role.<sup>24</sup> With respect to professional ethics, talking about euthanasia upon a patient's request is different from suggesting it to the patient. By suggesting euthanasia to a patient, the physician implicitly includes euthanasia in the canon of proffered rational treatment options. In light of the professional authority that she is exercising, she thereby establishes euthanasia as a rule, and not as an exception. This conduct conflicts much more with the role of the physician as a healer than it is the case if the physician talks about euthanasia upon the patient's request. This fits into the "interpretative model" of physician-patient relationship.<sup>25</sup> The "interpretive model" portrays the physician as counselor, whose responsibility it is to elucidate the patient's values and to help the patient select the interventions that realize these values. The elucidation of values is complex but crucial to the principle of patient autonomy. It requires physicians to listen more than to talk.<sup>26</sup> Here, the physician is simply responding to an issue which the patient has raised, thereby not including euthanasia in the array of standard treatment options and implicitly emphasizing that euthanasia is an exception of the principle of physicians as healers.

The principle of physicians as healers can be perforated by the rule of allowing euthanasia in specific cases without questioning the general principle.<sup>27</sup> When a physician talks about the option of euthanasia upon the patient's request, we are faced with the exceptional situation in which patient's autonomy and the physician's understanding of beneficence meet and manifest in the option of euthanasia.<sup>28</sup> Thus, in this particular case, the healing model may be compromised in order to allow medical intervention based on a consensus between the patient and the physician, which is in accordance with the principles of beneficence and patient's autonomy. But a physician should not suggest euthanasia to a patient because she would thereby establish euthanasia as a rule rather than as an exception.

Furthermore, it does not occur to Kimsma, den Hartogh and Schroten, who emphasize the autonomy and voluntariness of the patient's actions, that when euthanasia is offered, the very offer might undermine the

patient's voluntary wishes. The patient, who trusts the long-time GP, might feel that he (most of Kimsma's euthanasia patients were men) is being condemned to death and that he is wasting the doctor's time. When all is said and done, all the physician has to offer him is death.

Interestingly, while Beusmans' patients chose physician-assisted suicide, Kimsma's patients chose euthanasia. My assumption is that patients' choices reflect their physicians' attitude. Physicians' suggestions constitute powerful influence on the patients' choices of treatment. Thus, if the assumption is correct then – as one referee rightly notes – it may challenge autonomous decision-making by the patient, which is the precondition of ethical justification of euthanasia in the Netherlands.

The role of the physician is not to push patients to choose euthanasia. To be sure, today in the Netherlands it is impossible to argue that patients are unaware of the option. Ignorance is not a factor. Hence, physicians need to ask themselves why patients are reluctant to raise the issue. They must examine all relevant and possible answers, including the idea that the patient wishes to live despite her severe illness and medical condition. The physician should consider the consequences of what such an offer might entail for the patient's condition; for the patient's loved ones; and for the doctor-patient relationship built over the years. In a matter of life and death, caution is not only recommended, it is a must.

Den Hartogh finds it significant that in the area assigned to his review committee, cases of undesirable haste in the conduct of euthanasia tend to occur mainly in orthodox Protestant communities in the south, where the patient and the doctor are both reluctant to broach the subject.<sup>29</sup> Yet, to my mind, in the current atmosphere in the Netherlands, where it is a well-known fact that the majority of physicians support the act of euthanasia and are willing to perform it, it would suffice to make a general statement to the effect that: "I would be willing to assist you in every possible way, considering any of your wishes in order to relieve your suffering and help you cope with your condition." I find it difficult to fathom how den Hartogh does not see the compromising effect that the doctor's initiation of discussion on euthanasia might have on the relationship with the patient and on the level of trust between the two parties, as well as on the patient's mental framework.

Physicians need to remain aware of the very powerful role their recommendations can play in people's treatment choices, and of the undue ways their recommendations can influence patients. This is especially true when physicians and patients have long-standing relationships that span over decades. The challenge for physicians is to use their influence for the best purposes. Furthermore, as Ubel warns, physicians should not

make treatment recommendations that might promote their own interests against those of patients. When physicians worry that their own interests or speciality biases are influencing their recommendations, they should encourage patients to get second opinions and also try to make their biases explicit to patients.<sup>30</sup> It is also important to get patients to talk out loud about their values before making treatment recommendations. Often, this type of conversation will make it easier for physicians to determine what recommendation is most appropriate for a patient and whether the patient is comfortable deciding what to do without receiving a recommendation.<sup>31</sup>

It should be noted that at the Free University Hospital, one may never decide to initiate euthanasia in the case of someone who suffers unbearably and without hope, but who has not requested euthanasia.<sup>32</sup> The Alkmaar Euthanasia Protocol instructs that the request for euthanasia must come from the patient himself or herself, and must be well considered, voluntary, expressed repeatedly over time, "and as permanent as possible, such as in written form or by dictation."<sup>33</sup> The voluntary nature of the request must be established before considering it.

### CONCLUSIONS

The aim of this essay was to provide an account of the answers of the interviewees to the question of whether physicians should suggest euthanasia to their patients. The argument is that physicians' initiation of euthanasia might foster a sense of abandonment on the part of the patients, compromise the voluntariness of the request required by the euthanasia Guidelines, exert pressure on patients to die, and undermine seeking alternative treatments short of death, like good palliative care. Professional ethics prescribes that emphasis be put on the procedural requirement that the patient – not the physician – should raise the issue. It is disturbing to note that the majority of interviewees who are very influential in the euthanasia debate in the Netherlands discount the objections to the initiation of euthanasia.

When physicians suggest mercy killing to their patients they maneuver themselves into a situation where it is unclear whether they still act in accordance with professional ethics. The role of a physician is generally defined as the role of a healer. When the physician suggests euthanasia to a patient on her own initiative, she acts as if euthanasia were a normal treatment option, like other options that physicians offer to their patients. However, euthanasia should be handled as an exception rather than as a rule. It should not be included in the array of treatment options that a physician routinely offers to a patient at his/her end of life.

By not offering it to the patient but, instead, talking about it only upon the patient's request, the physician implicitly acknowledges the exceptional character of the case, and the conflict of performing euthanasia and her healing duty. In particular cases, she is willing to do it, because the patient requests it and the individual physician is able to see the request in accordance with her understanding of beneficence.<sup>34</sup>

That is to say, in sum, that euthanasia is an option in the Netherlands but there is a difference between a patient who initiates the discussion about it upon realizing that the end of life is nearing, and a physician who is putting it in the menu of treatment options. The physician should be convinced that euthanasia is, indeed, the wish of the patient and that he/she is sure to have it, sure enough to find the energies within him/herself to raise it. In this context I should emphasize the importance of open and candid communication between patients and their physicians. In *Asking to Die*, a physician testified that he found that when patients know euthanasia can be an option for them, they often keep silent about it. Open discussions help them face their disease because they know that if pain becomes unbearable and euthanasia is really necessary, "I am going to help them." Knowing euthanasia is an option gives the patients comfort and they do not necessarily have to act on it. Satisfied to have this support, most of the time they do not even talk about euthanasia anymore and they go on to die of natural causes.<sup>35</sup>

Parenthetically, it is worth noting that in an American study conducted by Ezekiel Emanuel and his colleagues,<sup>36</sup> oncology patients were interviewed to provide empirical data of patients' attitudes and practices related to euthanasia and physician-assisted suicide. Oncologists and members of the general public were also interviewed to compare their responses with those of the oncology patients. It was found that 53% of oncologists, as compared with 37.2% of patients and 44.4% of the general public, thought that discussions between patients and physicians on "end-of-life care that included explicit mention of euthanasia or physician-assisted suicide" would reduce patients' trust in the physician. By contrast, 41.6% of patients, 32.8% of the general public, and only 15.6% of oncologists thought that such discussions would increase patients' trust in the physician. Patients with depression and psychological distress were significantly more likely to feel that discussions which included explicit mention of euthanasia or physician-assisted suicide would increase trust in their physician, whereas patients with pain believed that such discussions would not increase trust.<sup>37</sup>

Of course, it is not easy to compare between the healthcare conditions of the USA with those of the Netherlands. At the same time, note the

relatively high percentage of oncologists who believe that it is unwise to explicitly mention euthanasia and PAS in discussions with patients. The patients have no clear idea about the issue and present divided opinions. Interestingly, depressed patients and patients with psychological distress saw value in explicit mentioning of euthanasia or physician-assisted suicide. For them, euthanasia and PAS should be considered as viable solutions. Instead, some therapy is advisable to treat the depression and help them find some meaning in life.<sup>38</sup>

## APPENDIX

### *Interviews in the Netherlands*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Dr. Bert Keizer, Vreugdehof Nursing Home (Amsterdam, April 3, 2002).

#### NOTES AND REFERENCES

\* D. Phil. (Oxon.); Chairperson, Library and Information Studies, University of Haifa; Director, Think-tank on Medical Ethics, The Van Leer Jerusalem Institute (1995–1998); author of five books, among them *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (NJ: Rutgers University Press, 2001); *Euthanasia in the Netherlands* (forthcoming); editor of five other books, among them *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000). The author is most grateful to the interviewees for their kind cooperation, to Evert van Leeuwen and Martine Bouman for facilitating the research, and to Barbara Prainsack and three referees of *Theoretical Medicine and Bioethics* for their detailed criticisms and constructive suggestions.

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<sup>2</sup> Inzake Euthanasie. Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (1995), 15. ISBN 90-71994-10-4. See also "Discussienota van de Werkgroep Euthanasie," van de Koninklijke Maatschappij tot Bevordering der Geneeskunst (KNMG), *Medisch Contact* 30 (1975): 7–16.

<sup>3</sup> P.J. van der Maas, J.J.M. van Delden and L. Pijnenborg, "Euthanasia and other Medical Decisions Concerning the End of Life," *Health Policy Monographs* (Amsterdam: Elsevier, 1992), 102.

- <sup>4</sup> Ibid., 156.
- <sup>5</sup> Paul J. van der Maas and Gerrit van der Wal, "A letter to the Editor," *New Eng. J. of Medicine* 336 (19) (May 8, 1997): 1386.
- <sup>6</sup> Paul van der Maas and Linda L. Emanuel, "Factual Findings," in L.L. Emanuel (ed.), *Regulating How We Die* (Cambridge, MA: Harvard University Press, 1998), 168.
- <sup>7</sup> Herbert Hendin, Chris Rutenfrans and Zbigniew Zylicz, "Physician-Assisted Suicide and Euthanasia in the Netherlands," *JAMA* 277(21) (June 4, 1997): 1721.
- <sup>8</sup> Carlos F. Gomez, *Regulating Death* (New York: The Free Press, 1991), 109.
- <sup>9</sup> Herbert Hendin, *Seduced by Death* (New York: W.W. Norton, 1997), 52.
- <sup>10</sup> On the quality of life concept in medicine, see R. Cohen-Almagor and M. Shmueli, "Can Life Be Evaluated? The Jewish Halachic Approach vs. the Quality of Life Approach in Medical Ethics: A Critical View," *Theoretical Medicine and Bioethics* 21 (2) (August 2000): 117-137. On the power of the word and certain terminology, see R. Cohen-Almagor, "Language and Reality at the End of Life," *The Journal of Law, Medicine and Ethics* 28 (3) (Fall 2000): 267-278.
- <sup>11</sup> In his letter dated June 5, 1999, Dr. Chabot wrote: "After four years waiting for the final court judgement (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.
- <sup>12</sup> I am grateful to UCLA School of Law for the generous assistance.
- <sup>13</sup> Some reflections are presented in my "An Outsider's View on the Dutch Euthanasia Policy and Practice," *Issues in Law and Medicine* 17 (1) (Summer 2001): 35-68; "'Culture of Death' in the Netherlands: Dutch Perspectives," *Issues in Law and Medicine* 17 (2) (Fall 2001): 167-179; "The Chabot Case: Analysis and Account of Dutch Perspectives," *Journal of Law, Medicine and Ethics* 30 (1) (2002): 95-104.
- <sup>14</sup> Personal communication on July 10, 2000.
- <sup>15</sup> Cf. Richard B. Balaban, "A Physician's Guide to Talking About End-of-Life Care," *Journal of General Internal Medicine* 15, Issue 3 (March 2000): 195; A. Chopra, "Communicating Effectively at the End of Life," *J. Am. Osteopath. Assoc.* 101 (10) (October 2001): 594-598; S.Z. Pantilat and A.J. Markowitz, "Perspectives on Care at the Close of Life. Initiating End-of-Life Discussions with Seriously Ill Patients," *JAMA* 285 (22) (2001): 2906.
- <sup>16</sup> In a similar fashion, Ron Berghmans and Ruud ter Meulen, medical ethicists from Maastricht, voiced their objections to the doctor's initiation of discussion, but qualified their answers by saying that they could imagine exceptional cases to the general proscription of leaving the issue to be raised by the patient. The physicians should not raise the issue immediately, but they might mention it during the process approaching the end of life.
- <sup>17</sup> A Letter to the Editor, *New Eng. J. of Medicine* 336 (19) (May 8, 1997): 1386.
- <sup>18</sup> Likewise, a family of K who was euthanized told me that their GP was relieved when K was able to take the lethal medication orally. The GP was willing to give the lethal injection if necessary, but was greatly comforted when the patient took the glass and drank the medication by himself. The de B. family, in turn, was reassured by the act that this was, indeed, what K wanted.
- <sup>19</sup> Herbert Hendin, *Seduced by Death*, op. cit., 53. One study, which compared attitudes and practices concerning end-of-life decisions between physicians in Oregon and in the Netherlands, showed that an equal proportion of Dutch physicians considered euthanasia and PAS as ethically acceptable. Conversely, American physicians were consistently less

likely to find euthanasia acceptable as compared with PAS. Cf. Dick L. Willems, Elisabeth R. Daniels, Gerrit van der Wal, P.J. van der Maas and E.L. Emanuel, "Attitudes and Practices Concerning the End of Life: A Comparison Between Physicians from the United States and from the Netherlands," *Arch. Intern. Med.* 160 (2000): 63-68. See also R. Cohen-Almagor and Monica G. Hartman, "The Oregon Death with Dignity Act: Review and Proposals for Improvement," *Journal of Legislation* 27 (2) (2001): 269-298.

<sup>20</sup> Beusmans added that if the patient "agrees with me to do it, and then falls into [a state of] unconsciousness, maybe I would do it." He continued to tell the story of one patient who was in a coma and very unquiet. "The family asked for something. I gave her morphine and after one day she died. It was a normal dose and I did not expect her to die so soon."

<sup>21</sup> I asked Dr. Kimsma how many euthanasia cases he actually performed, and his answer was that the number is not important. It is the quality, not the quantity that is important. He said that he has been performing euthanasia and PAS since 1979, and that he conducts these practices when the patient is suffering and when he autonomously and voluntarily wants either of them.

<sup>22</sup> This is a quote from Kimsma's comments on the first draft. Personal communication on September 9, 2000.

<sup>23</sup> The Dutch Voluntary Euthanasia Society's (NVVE) internet address is: <http://www.nvve.nl/ukframe.htm>

<sup>24</sup> See J.R. Peteet, "Treating Patients Who Request Assisted Suicide. A Closer Look at the Physician's Role," *Arch. Fam. Med.* 3 (8) (August 1994): 723-727; E. Rosenthal, "When A Physician Is Asked, 'Help Me Die,'" *New York Times* (March 13, 1997), pp. A1, B4.

<sup>25</sup> See E.J. Emanuel and L.L. Emanuel, "Four Models of the Physician Patient Relationship," *JAMA* 267 (1992): 2221-2226.

<sup>26</sup> Deborah Cook, "Patient Autonomy vs. Paternalism," *Critical Care Medicine* 29 (2001): N24-N25.

<sup>27</sup> Cf. Ronald Dworkin, *Taking Rights Seriously* (London: Duckworth, 1977), 22-28.

<sup>28</sup> The principles of autonomy and beneficence would also not be conflicting in a case when both, the autonomous patient and the beneficent physician, do not consider euthanasia. Conflicts arise if the autonomous patient favours an option that the physician does not see as in accordance with what she considers beneficent (of course, the content of beneficence is dependent on the particular culture). Other examples for a conflict between autonomy and beneficence may be a healthy "patient" who demands to have a good tooth extracted. The physician refuses. Or the beneficent physician offers a treatment which the patient, exercising autonomy, rejects. Those cases are not hard cases like performing euthanasia because they don't conflict with the role of the physician as a healer.

<sup>29</sup> Personal communication on August 27, 2000.

<sup>30</sup> Of course, second opinions may lead to contradictory recommendations. As difficult as conflicting recommendations can be for patients, these recommendations still leave patients with the option of accepting one recommendation or another, rather than feeling like they made the entire decision by themselves. When patients face difficult decisions, they are often going to learn that there is no simple right or wrong medical answer. In these situations, it is plausible to think that a series of even contradictory physician recommendations is more comforting than a series of nonrecommendations. Cf. Peter A. Ubel, "'What Should I Do, Doc?' Some Psychologic Benefits of Physician Recommendations," *Archives of Internal Medicine* 162 (9) (May 13, 2002).

<sup>31</sup> *Ibid.*

<sup>32</sup> Gerrit K. Kimsma and Evert van Leeuwen, "Comparing Two Euthanasia Protocols: The Free University of Academic Hospital Amsterdam and the Medical Center of

Alkmaar," in David C. Thomasma, Thomasine Kimbrough-Kushner, Gerrit K. Kimsma and Chris Ciesielski-Carlucci (eds.), *Asking to Die* (Dordrecht: Kluwer Academic Publishers, 1998), 119.

<sup>33</sup> *Ibid.*, 124.

<sup>34</sup> Cf. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 3rd edn. (New York: Oxford University Press, 1989); Tom L. Beauchamp and LeRoy Walters, *Contemporary Issues in Bioethics* (Belmont, CA: Wadsworth, 1989), esp. pp. 28–34.

<sup>35</sup> "Annie Asked, 'Are You Going to Help Me?'," in David C. Thomasma, Thomasine Kimbrough-Kushner, Gerrit K. Kimsma and Chris Ciesielski-Carlucci (eds.), *Asking to Die*, 279.

<sup>36</sup> Leenen wrote in his comments that the conclusions of this study are not applicable to the Netherlands because the United States lacks the family-doctor system "as we have it." Letter dated July 25, 2000. For further discussion, see R. Cohen-Almagor, "Why the Netherlands?," *Journal of Law, Medicine and Ethics* 30 (1) (2002): 95–104.

<sup>37</sup> Ezekiel J. Emanuel, Diane L. Fairclough, Elisabeth R. Daniels and Brian R. Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences of Oncology Patients, Oncologists, and the Public," *Lancet* 347 (June 29, 1996): 1808. The Assisted Suicide Consensus Panel asserts that physicians should not encourage patients to hasten death, even when practicing in jurisdictions that allow assisted dying. Cf. James A. Tulsky, Ralph Ciampa and Elliot J. Rosen, "Responding to Legal Requests for Physician-Assisted Suicide," *Annals of Internal Medicine* 132 (March 21, 2000): 494–499. For further deliberation, see Timothy E. Quill, "Initiating End-of-Life Discussions with Seriously Ill Patients: Addressing the 'Elephant in the Room'," *JAMA* 284 (19) (November 15, 2000): 2502; Susan D. Block, "Psychological Considerations, Growth, and Transcendence at the End of Life," *JAMA* 285 (22) (June 13, 2001): 2898; Maria E. Suarez-Almazor, Catherine Newman, John Hanson and Eduardo Bruera, "Attitudes of Terminally Ill Cancer Patients About Euthanasia and Assisted Suicide: Predominance of Psychosocial Determinants and Beliefs Over Symptom Distress and Subsequent Survival," *Journal of Clinical Oncology* 20, Issue 8 (April 2002): 2134–2141.

<sup>38</sup> Cf. Raphael Cohen-Almagor, *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law* (Piscataway, N.J.: Rutgers University Press, 2001), esp. Conclusions.

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