Seven (More) Caveats Concerning The Discussion of Euthanasia in the Netherlands

Margaret P. Battin
University of Utah

Discussion in the U.S. about euthanasia in the Netherlands is characterized by profound disagreement, both about what the practice actually is and what risks it involves. Some time ago, I put together a little list[1] of seven warnings for bioethicists embroiled in this discussion—things one ought to keep in mind in order to avoid the kinds of basic misunderstandings that have been so prevalent in the discussions about Holland, and that contribute so dramatically to polarization. That little list, published before the first empirical studies of euthanasia in the Netherlands had appeared, pointed to the lack of hard data and to exaggerations about the frequency of euthanasia; it clarified terminological differences between the way the Dutch use the term 'euthanasia' and the way we do; it pointed out that the

legal claims concerning whether euthanasia is or is not legal are misleading; and it described the very different institutional, economic, and social circumstances of euthanasia as it is practiced in the Netherlands. But there are a few more things participants in the discussion of euthanasia in Holland ought to beware of; so in order to avoid continuing misunderstanding, I'd like to expand the first seven caveats by adding another seven here:

1. *There still isn't enough hard data about the practice of euthanasia in the Netherlands.* --Until the appearance of two large empirical studies in 1991-92, there had been very little hard data available about the practice of euthanasia in the Netherlands, even though the practice had become open, vigorously discussed, and legally tolerated. Despite the policy that cases of euthanasia were to be reported to the Ministry of Justice by the physicians who performed them, very few were in fact reported; this generated an extensive amount of conjecture about the unreported cases, variously estimated to range in actual frequency somewhere between 2,000 and 20,000, and invited the accusation that the unreported cases were unreported because Dutch physicians had something to hide.

Two major empirical studies of the actual practice of euthanasia in the Netherlands were published in 1991-92: the government-sponsored study popularly known as the Remmelink Commission report (named after Professor J. Remmelink, attorney-general of the Dutch Supreme Court, who chaired the committee to which it was presented)[2] and a dissertation presented at the Free University in Amsterdam by Gerrit van der Wal.[3] While the Remmelink Commission study involved a more complex design, covered a wider range of physicians (including specialists and nursing home physicians), and received a great deal more attention than the van der Wal study of family-practice physicians only, the two studies were similar in many respects. Although their range was different, both sought to discover what Dutch physicians actually do and do not do as their patients approach death; both attempted to assess the frequency of euthanasia in the Netherlands; both attempted to assemble information about the characteristics of patients, the nature of their requests for euthanasia, and the nature of the physician's response; and both were alert to the possibility of abuse. Both studies involved surveys of physicians under the strictest guarantees of confidentiality, and both achieved quite high response rates. The Remmelink study also included extensive direct interviews with a large sample of physicians; the van der Wal study examined other records, including hospital records and police reports. Both studies were well designed, and both quite informative.

Furthermore, the two studies agreed in many of their results. Although based on extrapolations from different survey populations, they came very close in their estimates of the overall frequency of euthanasia in the Netherlands. According to the Remmelink report, of the approximately 2,300 case of euthanasia a year, about 1,500 are performed by general practitioners, 750 are performed by specialist physicians, and about 20 are performed by nursing home physicians. In addition, there are another 400 cases of physician-assisted suicide. Van der Wal found a combined total of about 2,000 euthanasia and assisted-suicide cases per year in general practice alone. These studies thus revised the previously accepted best estimate of 6,000 cases a year (not to mention the extreme estimate of 20,000 cases a year) dramatically downward. Both studies agreed that euthanasia was far more frequent than assisted suicide. Both found that only a minority of requests for euthanasia are honored. Both studies examined the reasons why patients request euthanasia, and both found that pain is very seldom (about 5% in both studies) the sole reason, though pain is often (46%) one reason among others. Both found that the diagnosis in the majority of cases is cancer and that the average age of euthanasia patients is in the 60's, though the Remmelink study found that euthanasia is slightly less common among men than women (48% males) while assisted suicide is more common for men than women (61% males) and van der Wal found that euthanasia is about equal for both sexes. Both studies found that the estimated life expectancy for patients receiving euthanasia is usually a week or two, though in a small fraction of cases it is longer than six months and in another small fraction it is less than a day. And both also revealed the existence of cases that do not strictly fit the guidelines.

As extensive as the contributions of these two studies to the discussion of euthanasia in Holland have been, however, there still is not enough hard data. Some further exploration is in progress: for example, the researchers who prepared the report to the Remmelink Commission are currently preparing for publication a more intensive study of the findings concerning a group of about 1000 cases, about 0.8% of the total annual mortality, which involve active termination but in which there is no explicit, current request from the patient. There is also not yet a broad collection of what one might call phenomenological data; interior narrations by patients themselves of their experiences as they come to request euthanasia—perhaps available from personal journals, dictations to family members, direct interviews, diaries, and the like—that might shed further light on the nature of such choices, though there have been a few real-life interviews (for instance, on TV) between physicians and patients. A participant-observer study of euthanasia is now in progress,[4] and a small, anecdotal study is also in progress involving interviews of family members concerning their grieving processes following the euthanasia of a loved one.[5] But there are neither hard nor soft comprehensive data on the perceptions of family members, nurses, clergy, or others who might have played an observer's role, nor on the perceptions of patients themselves. In short, there is still a great deal more to be learned about the practice of euthanasia in Holland. The two studies now available should be understood as crucial first contributions of empirical information, rather than as the last word.

2. *The Dutch don't want to defend everything.*—The Dutch are sometimes accused of being self-serving or, alternatively, of being self-deceived in their efforts to defend the practice of euthanasia. To be sure, not all Dutch accept the practice. There is a vocal group of about a thousand physicians adamantly opposed to it, and there is some opposition among the public and within specific political parties (in particular, the Christian Democratic party, which has for years controlled the Netherlands' coalition government and religious groups (especially the Catholic Church). Yet the practice is supported by a majority of the Dutch populace (rising from 40% in 1966 to 81% in 1989[6]) as well as a majority of Dutch physicians. Of physicians interviewed for the Remmelink Commission study, 54% said they had practiced euthanasia at the explicit and persistent request of the patient or had

assisted in suicide at least once (62% of the general practitioners, 44% of specialists, and 12% of nursing home physicians), and only 4% said they would never either perform euthanasia or refer a patient to a physician who would. 91% said that euthanasia must only be performed by a physician. In the words of the Remmelink Commission's comment on the report, "a large majority of physicians in the Netherlands see euthanasia as an accepted element of medical practice under certain circumstances."[7]

But this is not to say that the Dutch seek to whitewash the practice. They are disturbed by reports of cases which do not fit the guidelines and are not explained by other moral considerations, though these may be quite infrequent. Of the approximately 1000 cases of active termination in which there was no explicit, current request—cases sometimes described in the U.S. as coldblooded murder—most are explained by other moral considerations. Of these 1000 cases, according to the Remmelink report, about 600 did involve some form of antecedent discussion of euthanasia with the patient, though at the time of euthanasia the patient had become decisionally incompetent and was no longer capable of expressing his or her wishes; these ranged from a rather vague earlier expression of a wish for euthanasia, as in comments like "if I cannot be saved anymore, you must give me something," or "doctor, please don't let me suffer for too long," to much more explicit requests. (Thus, these cases are best understood in a way that approximates them to advance-directive cases in other situations.) In almost all of the remaining 400 cases, according to the Remmelink Commission report, there was neither an antecedent nor current request from the patient; but at the time of euthanasia—"possibly with a few exceptions"—the patient was very close to death, incapable of communication, and suffering grievously. For the most part, these cases occurred when the patient underwent unexpectedly rapid deterioration in the final stages of a terminal illness. (These cases are best understood as cases of mercy-killing, with emphasis on the motivation of mercy.) In these cases, the Commission's report continues, "the decision to hasten death was then nearly always taken after consultation with the family, nurses, or one or more colleagues." The Dutch do not usually term these cases 'euthanasia,' but refer to them with the separate expression, *levensbeëindigend handelen* ("life-ending treatment"); this term is often used broadly to encompass all withholding and withdrawing treatment, including, for instance, that in severely defective newborns, permanent coma patients, and psychogeriatric patients (situations in which withholding or withdrawing treatment is also done in the United States), but may sometimes involve direct termination. Many Dutch also defend these cases, though as critics point out, the danger here is that the determination of what counts as intolerable suffering in these cases is essentially up to the doctor.

There is also some suggestion—though no clear evidence—that there is also a small fraction of cases in which there is no apparent choice by the patient and in which a merciful end of suffering for a patient *in extremis* is not the issue. These cases do disturb the Dutch: these cases are regarded as highly problematic, and it is clearly intended that if they occur, they should be stopped. The Remmelink study's interviews with physicians revealed only two instances, both of them from the early 1980's, in which a fully competent patient was euthanized without explicit consent; in both, the patient was suffering severely. In the interview which was part of the Remmelink study, the physician in one of these cases indicated that under present-day circumstances, with increased openness about these issues, he probably would have initiated more extensive consultations. There is no evidence of any patient being put to death *against* his or her expressed or implied wish.

The Dutch also distinguish between procedural and substantive or material failures to meet the guidelines, regarding the latter as much more problematic than the former. They note that failure to meet the procedural requirements of the guidelines is not uncommon—for instance, according to van der Wal, only 75% of family doctors asked another doctor for a second opinion, slightly fewer that half (48%) had kept written records, and 74% had issued a death certificate stating that the death was due to natural causes. Only around a quarter had reported performing euthanasia to the Ministry of Justice, and as van der Wal points out, "cases that reveal shortcomings are hardly ever reported to the Public Prosecutor."[8] But procedural failures do not particularly trouble the Dutch; what they are alert to is cases in which euthanasia was performed against the wishes of the patient or for ulterior reasons. Neither study yielded concrete information about any such cases, though neither study denied that some such cases—"a few exceptions"—might occur.

To understand how the Dutch defend their practice of euthanasia, given the possibility of such cases, a domestic analogy may be helpful. We, like the Dutch, recognize and defend the practice of marriage: it is enshrined in our law, our religions, and our cultural norms. Among other things, we understand this practice to be quintessentially voluntary: in order to marry, the parties involved must each choose freely to do so, and their signatures on the marriage license serve to attest to this fact. But we also recognize that some marriages are not voluntary: shotgun marriages, for example, in which the groom has been threatened by the father of the pregnant bride or in which the bride sees no alternative than to marry the man who has impregnated her. Yet while we recognize that physically or socially coerced marriages do occur from time to time, we continue to defend the institution of marriage, claiming that coerced marriages aren't really central to the practice we otherwise respect. The Dutch attitude toward euthanasia is a bit like this, though coerced marriages are no doubt a good deal more frequent that problematic cases of euthanasia: it is the *practice* which is defended, not each single case that occurs within or around it. On the contrary, the Dutch seek to control these few problematic cases around the fringes—that is part of the point of bringing the practice out into the open.

3. *There are no "indications" for euthanasia.* In the Netherlands, euthanasia is understood by definition to mean voluntary euthanasia, and nonvoluntary practices, such as the 1000 cases of life-ending treatment without explicit request in no-longer-competent patients, are not grouped under this term. Nor are two additional categories of practices concerning the end of life which are treated as distinct sorts of medical decisions in the Remmelink and van der Wal reports (as they are also in the U.S.): doses of opiates intended to relieve pain but which, foreseeably, may shorten life, and discontinuations or withholdings of treatment, even when death is likely to be the outcome. But while patient choice is a necessary condition for euthanasia, it is not a

sufficient condition; the patient who requests euthanasia is not thereby guaranteed it and does not oblige a physician to perform it. Indeed, according to both empirical studies, the majority of requests for euthanasia (60-67%) are turned down.

This situation, however, has led some observers to wonder whether there isn't a set of criteria developing for the performance of euthanasia, criteria that could in effect serve as indications. If physicians reject up to two-thirds of the requests for euthanasia, it is argued, they must be entertaining some set of criteria according to which some cases are to be accepted and others rejected—criteria other than patient choice. But if this is so, it is argued, it may invite a certain readiness to perform euthanasia whenever these criteria are met, independently of the patient's choice. The Dutch would reply by arguing that there are no positive criteria for euthanasia, but that there are however negative criteria for when it is *inappropriate* to perform euthanasia—e.g., when the request is motivated by depression or when suffering can be relieved by other means acceptable to the patient. With no positive criteria, "indications" for euthanasia—that is, factors in the presence of which the physician ought to perform euthanasia and hence ought to "see to it" that the patient accepts this recommendation—cannot develop. While some Dutch physicians say they do sometimes introduce the topic of euthanasia if the patient has not raised it, they insist that it be performed only at the patient's *request*, and not rather as the result of consent to a procedure the physician has proposed. However, whether criteria are developing—perhaps under the guise of justifications—for *levensbeëindigend handelen* is, however, another issue, perhaps the central (though not fully articulated) issue in the ongoing debate about end-of-life issues in incompetent patients, since in these cases patient choice is not possible anymore.

4. *We now know what the unreported cases are like.* In 1987, only 197 cases of euthanasia were reported to the Ministry of Justice by the physicians who performed them, as is required under the general understanding of the guidelines, and by 1990 only 454. Thus, the majority of cases have remained unreported and, hence, unexamined by the Public Prosecutor, who is to decide whether the guidelines have been met in a given case and thus whether the case is to be prosecuted. However, both the Remmelink and the van der Wal studies provide extensive detail about what these cases are like, since they explored both reported and unreported cases. According to vand der Wal, whose study included police reports among the sources of data, the reported cases and the unreported cases described by doctors in responding to the questionnaires differed with regard to procedural matters: cases which were not reported differed from those reported (for which police reports were therefore available) primarily in procedural requirements—but reported and unreported cases closely resembled each other in satisfying the substantive requirements concerning voluntariness, adequate information, the presence of intolerable suffering, and the absence of any acceptable alternatives for treatment. The number of cases reported is currently climbing rapidly, partly due to simplifying of the procedures, and is expected to reach about 1000 in 1992—that is, somewhere around half of the 1900-2300 cases.

5. *Euthanasia isn't routine or anonymous.* Especially in the U.S., euthanasia is often understood on the "It's Over, Debbie" model, derived from the notorious accounts in a 1988 issue of the *Journal of the American Medical Association* describing a sleepy resident's giving a lethal dose in the middle of the night to a young woman dying of ovarian cancer—a patient he'd never seen before, whose chart he had not actually examined, with whose unidentified companion sitting by the bed he had no communication, for whom he made no attempt to provide other treatment or better pain control, and with whom he exchanged only the briefest of words.

"Let's get this over with," Debbie said, in the midst of her pain. The resident ordered a syringe of morphine sulfate drawn and—telling Debbie only that he would give her something to "let her rest" and that she should say goodbye—killed her. In fact, "It's Over, Debbie" is a virtual compendium of all that is *not* tolerated in Holland. Euthanasia is typically performed by the patient's personal physician, not a stranger; and it is performed within the context of an extended period of consultation and care. Not only is it usually performed at home with the patient's family present, but the physician remains with the patient or in an adjoining room throughout the process. The physician takes no fee for performing the euthanasia. Nor will Dutch physicians perform euthanasia for patients from other countries with whom they have had no prior contact. Fears sometimes voiced in the U.S. concerning the commercialization of euthanasia or the development of a death trade, practiced for profit by greedy physicians, have no place in Holland. Euthanasia remains a rare event, generally presupposing a longterm relationship between physician and patient, and it involves an often substantial commitment of time with no financial reward.

6. *The Dutch see the role of law rather differently.* Not only is Dutch law a civil-law rather than common-law system, not only does it contain the distinctive Dutch doctrine involving practices which are statutorily illegal but *gedogen* or tolerated by the public prosecutor, the courts, or both (such practices include not only euthanasia, but also prostitution and the possession and use of limited amounts of soft drugs), and not only does it involve very little medical malpractice activity, but the Dutch also tend to see law as appropriately formulated at a different point in the evolution of a social practice. Americans, it is sometimes said, *begin* to address a social issue by first making laws and then challenging them in court to fine-tune and adjust them; the Dutch, on the other hand, allow a practice to evolve by "tolerating" but not legalizing it, and only when the practice is adequately controlled—when they've got it right, so to speak—is a law made to regulate the practice as it has evolved. That the Dutch do not yet have a law shaped to accommodate their open practice of euthanasia may not show, as some have claimed, that they are ambivalent about the practice, but perhaps rather that they are waiting for the practice to evolve to a point where it is under adequate, acceptable control, at which time it will be appropriate to revise the law. Earlier and recent attempts to pass such a law have failed to satisfy enough parties (especially the Christian Democrats) within the Dutch coalition governments, but some observers still think that their will be greater agreement before long, reflecting the end of the debate and the emergence of social consensus. Of course, some commentators see the delicate balance in which the practice is technically illegal under Dutch law but protected from prosecution by Dutch court decisions as a desirable bulwark against abuse, but others still argue for a more comprehensive revision of the

statute, amending the penal code and spelling out in the Medical Practice Act the conditions under which a physician would not be prosecuted.[9] Full legalization, they argue, is crucial to providing legal security for both physicians and patients.

7. *The situation isn't getting worse; it's getting better.* Many of the foreign commentators have interpreted those cases of which the Dutch are not proud and do not wish to defend as evidence that the Dutch are indeed sliding down the slippery slope, moving from sympathetic cases of voluntary euthanasia to morally indefensible, broaderscale killing motivated by such matters as impatience, money, or power. They cite several celebrated outlier cases involving gross violations of the guidelines, such as an infamous nursing home case in which nurses administered euthanasia to a group of terminally ill, mentally disturbed cancer patients when a physician refused to do so, and the cases the Remmelink Commission report identified as falling outside a strict interpretation of the guidelines. The recognition that there are cases of *levensbeëindigend handelen* not counted as euthanasia contributes to this view. Furthermore, several commentators—especially Carlos Gomez and John Keown—have argued, the Netherlands' legal and other protections against future abuse are wholly inadequate.

But the Dutch themselves see things in quite a different way: they see bringing euthanasia and related practices out into the open as a way of gaining control. For the Dutch, this is a way of identifying a practice which, in the Netherlands as in every other country (including the U.S.), has been going on undercover and entirely at the discretion of the physician. It brings the practice into public view, where it can be regulated by guidelines, judicial scrutiny, and by the collection of objective data. It is not that the Dutch or anyone else have only recently begun to practice euthanasia for the dying patient, nor is this a new phenomenon in the last decade or so; the Dutch, rather, are the first to try to assert formal public control over a previously hidden practice and, hence, effectively to regulate it. Both open public discussion and the development of formal mechanisms such as guidelines and hospital protocols are seen as crucial in developing a social consensus, understood and accepted by both physicians and patients, about what can be permitted and what not.

As with the first seven caveats, these next seven also point to differences between the U.S. and Dutch health care climates that are often unnoticed in discussions of euthanasia. Until these differences are incorporated into both sides of the debate, it is unlikely that Americans will ever fully understand why the Dutch support their practice of euthanasia, and conversely, it is unlikely that the Dutch will understand why the Americans are so ambivalent about its legalization or why Americans are so likely to distort the Dutch practice.

Notes

1. Published as "Seven Caveats Concerning the Discussion of Euthanasia in Holland" in *Perspectives in Biology and Medicine* 34(1):73-74(Autumn 1990), and in the *Newsletter of the American Philosophical Association Committee on Philosophy and Medicine* 89(2):78-80 (Winter 1990). I'd like to thank Hans van Delden, M. D., and Loes Pijnenborg. M. D.. for comments on these additional points.

2. Paul J. van der Maas, Johannes J. M. van Delden, Loes Pijnenborg, Caspar W. N. Looman, "Euthanasia and other Medical Decisions Concerning the End of Life: An investigation performed upon request of the Commission of Inquiry into the Medical Practice concerning Euthanasia," published in full in English as a special issue of *Health Policy* 22(1+2)(1992), Amsterdam: Elsevier Science Publishers, and in summary in *The Lancet* 338 (Sept. 14, 1991) 669-674.

3. Gerrit van der Wal, "Euthanasie en hulp bij selfdoding door huisartsen," Academisch Proefschrift, Rotterdam: WYT Uitgeefgroep, 1992, English summary available.

4. The study is being conducted by John Poole and John Griffiths.

5. The study is being conducted by Chris Carlucci and Gerrit Kimsma.

6. Else Borst-Eilers, M.D., paper delivered at the conference "Controversies in the Care of Dying Patients," University of Florida, Orlando, Feb. 14-16, 1991.

7. Incorporated in the English summary in *The Lancet*, van der Maas, et. al., p. 671.

8. van der Wal, English summary, p. 150.

9. J. K. M. Gevers, "Legislation on euthanasia: recent developments in the Netherlands," *Journal of Medical Ethics* 18(1992): 138-141.