SEVEN CAVEATS CONCERNING THE DISCUSSION OF EUTHANASIA IN HOLLAND

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As the discussion of voluntary active euthanasia heats up in the United States (indeed, I believe it will be the major social issue of the next decade, replacing abortion in that role), increasing attention is being given to its practice in the Netherlands. Proponents of the view that the United States should legalize euthanasia (as legislation being proposed by the Hemlock Society in California, Oregon, and Washington would do) often cite the Netherlands as a model of practice; opponents, on the other hand, claim that Dutch practice already involves widespread abuse and will inevitably lead to more. For the most part, these generalizations invite misunderstanding, and they often reflect only the antecedent biases of those who make them. I would like to offer a few caveats for bioethicists about to become embroiled in the discussion of euthanasia—caveats offered in the hope of contributing to better mutual understanding during the next decade, rather than to greater polarization.

- 1. There are no hard data about the practice of euthanasia in Holland.— Despite the policy that cases of active euthanasia are to be reported to the Ministry of Justice, only a very small fraction are: of the estimated annual 6,000 cases (itself a very loose estimate), in 1987 only 197 were actually reported and provide the only reliable set of data. There have been no comprehensive empirical studies of unreported euthanasia—nor, given its tenuous legal status (to be described below), is it clear how unbiased data could be obtained. Most discussions of euthanasia—both pro and con—appeal to anecdotes about specific cases, not to data covering the full range of cases.
- 2. Exaggerations are frequent.—It is also sometimes supposed that euthanasia is a routine, frequent, everyday practice in the Netherlands, a commonplace that happens all the time. On the contrary, euthanasia is comparatively rare. If the estimate of 6,000 cases a year is accurate

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(though most observers now believe this is too high, and informal estimates are being revised downward), this would represent, in a country with (in 1987) a population of 14.5 million and a total annual mortality of about 120,000, at most 5 percent of all deaths. In other words, 95 percent or more of deaths in Holland do not occur in this way.

3. Terminological differences operate to confuse the issue. - By and large, Dutch proponents of euthanasia use the term to refer only to what in the United States would be called voluntary active euthanasia. The term "active euthanasia" is considered essentially redundant and the term "passive euthanasia" meaningless. However, the Dutch also employ the term levensbeeindigend handelen (life-ending treatment) to refer to practices that result in the death of the patient but cannot be considered voluntary active euthanasia; these for the most part are confined to withholding or withdrawing treatment, for instance in severely defective newborns, permanent coma patients, and psychogeriatric patients (situations in which withholding or withdrawing treatment is ubiquitous in the United States), but may sometimes, though rarely, involve direct termination. Thus the claim that there is no nonvoluntary active euthanasia in Holland may seem to be merely analytically true. On the other hand, it is clear that claims by some of the more vocal opponents of euthanasia also rest on terminological confusion. For instance, the Dutch cardiologist Richard Fenigsen's assertion that involuntary euthanasia outside the guidelines is widespread rests on his conflating what in the United States would be called active and passive euthanasia: Fenigsen, like many others of the opposition, does not distinguish between causing death and withholding or withdrawing treatment, that is, what we call "allowing to die." In the United States, withholding or withdrawal of treatment, including respiratory support, chemotherapy, and nutrition and hydration, tends to be regarded as morally acceptable in certain circumstances even when these decisions are not made by the patient but by second parties (a view reflected in Quinlan, Saikewicz, Conroy, and to be decided again shortly in Cruzan), while, on the other hand, direct causing of death even at the request of the patient is regarded as problematic in the extreme. In Holland, the view tends to be the other way around. One suspects that much of the opposition in Holland to active voluntary euthanasia is actually opposition to passive nonvoluntary euthanasia, a practice much more accepted in this country than that one. It is often said in the United States that the Dutch are stepping out onto the slippery slope in permitting active euthanasia; the Dutch, in contrast, think it is we who are already on the slippery slope, given our readiness to "allow to die" in ways that are not voluntary on the part of the patient.

4. Legal claims are misleading, either way.—Many American observers of the Dutch practice of euthanasia are tempted to claim that euthanasia is legal in Holland; others insist that it is not. Both are right—but only

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partly so. Killing at the request of the person killed is a violation of the Dutch penal code, punishable by imprisonment; however, several lower court decisions, supported by a Supreme Court decision and reflected in the policies of the regional attorneys-general, have held that when euthanasia meets a certain rigorous set of conditions it may be defended under a plea of force majeure and so is not subject to prosecution. These conditions include:

- a) Euthanasia must be voluntary; the patient's request must be well considered and enduring.
- b) The patient must have adequate information about his or her medical condition, the prognosis, and alternative methods of treatment.
- c) The patient's suffering must be unbearable, in the patient's view, and irreversible.
- d) It must be the case that there are no reasonable alternatives for relieving the patient's suffering that are acceptable to the patient.
- e) The physician must consult with a second physician whose judgment can be expected to be independent.
 - \hat{f}) Euthanasia may be performed only by a physician.
- g) The physician must exercise careful and due care in reviewing and verifying the patient's condition as well as in performing the euthanasia procedure itself.

Is euthanasia legal or illegal? It is a violation of the statute but cannot be prosecuted if it meets these guidelines. This circumstance entails that euthanasia cannot be excused in advance; it is to be reported to the police and investigated after the fact, though if it is determined that the guidelines have been met, the case will not be prosecuted. This delicate legal status surely accounts for a great deal of the underreporting, but it is also seen by many observers as a deterrent to abuse. Nevertheless, the delicate legal status of euthanasia in Holland is often misunderstood by outside commentators and would be difficult to replicate in the American legal system.

5. The institutional circumstances of euthanasia in Holland are easily misunderstood.—While American observers of Dutch euthanasia risk misinterpreting many features of this practice, a particularly frequent error arises from failing to appreciate differences in health-care delivery systems and other social institutions in Holland and the United States. While in the United States virtually all physician care is provided in a professional or institutional setting—an office, clinic, care facility, or hospital—in the Netherlands most primary care is provided in the patient's home, or in an office in the physician's home, by the huisarts or home physician. That the physician typically lives in the neighborhood and makes frequent house calls when the patient is ill provides not only closer, more personal contact between physician and patient but also an unparalleled opportunity for the physician to observe features of the patient's domestic circumstances, including any family support or pressures that might be relevant in a request for euthanasia. While euthanasia

sia is sometimes performed in hospitals, and many hospitals now have protocols for doing so, the majority of cases, it is believed, take place in the patient's home, typically after hospitalization and treatment have proved ineffective in arresting a terminal condition and the patient has come home to die. In these settings, euthanasia is most often performed by the physician who has been the long-term primary care provider for the family, and is performed in the presence of the patient's family and others whom the patient may request, such as the visiting nurse and the

pastor, but outside public view.

6. The economic circumstances of euthanasia in Holland are also easily misunderstood.—Holland's system of national health insurance provides extensive care to all patients, including all hospitalization, nursing home, and home care, and the services of physicians, nurses, physical therapists, nutritionists, counselors, and other care providers, both in institutional settings and in the home. Americans who raise the issue of whether some patients' requests for euthanasia are motivated by financial pressures or fear of the effect of immense medical costs on their families are committing perhaps the most frequent mistake made by American observers: to assume that the choices of patients in Holland are subject to the same pressures that choices of patients in the United States would be. While there may be some change in the national health insurance system in Holland in the near future, at present cost pressures on the system as a whole are met by rationing and queueing, not by exclusion from coverage or increased costs to patients. The costs to oneself or one's family of an extended illness, something that might make euthanasia attractive to a patient in the United States, are something the Dutch patient need not consider.

7. Differences in social circumstances often go unnoticed.—In American discussions of euthanasia, considerable emphasis is placed on slipperyslope arguments, pointing out risks of abuse, particularly with reference to the handicapped, the poor, racial minorities, and others who might seem to be ready targets for involuntary euthanasia. Holland, however, exhibits much less disparity between rich and poor, has very much less racial prejudice, has virtually no uninsured persons, and has virtually no homelessness. These differences underscore the difficulty both of treating Holland as a model for the United States in advocating the legalization of euthanasia and also of assessing the plausibility of slippery-slope arguments opposing it.

There are a great many other differences between the United States and Holland that pose further risks of misinterpretation and misunderstanding; however, because these two highly sophisticated, industrialized, modern nations resemble each other in so many ways—including the general forms of their economic systems, their common cultural roots in the European Enlightenment, their sophisticated medical care

systems, and so on—these differences often go unnoticed. The seven caveats mentioned here are only a few of the principal cautions that should be exercised in entering this discussion; as the issue of euthanasia becomes more pressing in the United States, we will do well to look much more carefully at the practices in Holland than we have perhaps been accustomed to doing. In doing this, our principal problem is to detach ourselves from the antecedent biases we bring to this issue and to examine these Dutch practices and the reasons for them with comparatively objective eyes.