Reaping the Whirlwind: The Dutch Experience with Euthanasia

by Carlos F. Gomez

Proponents of assisted suicide in the United States have used the model of euthanasia as practiced in the Netherlands to bolster their argument that this practice can be well managed and restricted to competent patients. What is becoming increasingly evident from reports and the author's own fieldwork is that the Dutch experience should serve as a cautionary tale rather than a model program. He argues that physician-assisted suicide is an inherently immoral practice which deviates substantively from the limits set on medicine by society and by the medical profession itself.

Since 1973, with the tacit consent of the courts, the Dutch have engaged in an experiment with physician-assisted suicide. Voters in California, Washington and now, Oregon, have been or will be faced with a referenda euphemistically titled, for example, "The Death with Dignity Act" or "The Humane and Dignified Death Act." Proponents of these American legislative measures, like their Dutch counterparts, argue that physician-assisted suicide ought to be part of a continuum of care offered the dying patient. This continuum ranges from hospice and palliative care at one end, to assisting in the patient's suicide at the other. I argue that physician-assisted suicide is an inherently immoral practice; that it deviates substantively from the limits set on medicine by society and by the medical profession itself.[1] To those who reject moral absolutes, and who frame their ethical arguments in terms of individual autonomy and social utility, such a position is less than compelling.

A more practical criticism of physician-assisted suicide is that it begins as an exercise in patient autonomy, but quickly evolves into medical killing of the unconsenting. Those who propose decriminalizing euthanasia argue, simply, that it should be well controlled, and that those who oppose decriminalizing the practice deny dying patients a welcome option. There are dangers, they argue, but a mature and democratic society should be able to construct public policy that enhances the autonomy of dying patients, while protecting the rights of others. And that, say the proponents, is precisely what the laws would have accomplished in California and Washington, and now, in Oregon.

Proponents of euthanasia in this country once routinely pointed to the Netherlands as a model for this sort of practice. Some segments of the Dutch medical profession have practiced euthanasia for the past two decades. Proponents of euthanasia in the United States have used the Dutch experience to bolster their argument that this practice can be well managed and restricted to patients competent to make such decisions. The experience of the Dutch—who form a human, democratic society—should give *some* assurance that this practice does not degenerate into indiscriminate killing.

For reasons I elaborate below, proponents of euthanasia in this country are now less vocal in supporting this ongoing experiment in the Netherlands, though I contend that the comparison to the Dutch on this matter is an apt one in many ways. For example, those who defend euthanasia on the grounds that patients should be able to choose the manner and time of their death echo the Dutch acceptance of euthanasia. The Dutch give such weight to patient autonomy, for instance, that political and legal institutions—such as the courts—have found other competing interests insufficient to override a request for euthanasia. Thus, claims that euthanasia lies outside the ethic of medical practice, or that it creates unjustifiable dangers for vulnerable patients, have been subordinated to what apologists for the practice call the *right* of patients to seek their end through physician-assisted suicide. A well-established sentiment in the Netherlands parallels another argument of those in California who would decriminalize euthanasia: that there is no distinction between withdrawing life-sustaining medical

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intervention during the agonal stages of a patient's illness, and killing the patient outright. Thus, the Dutch have dispensed with the term "active" and "passive" euthanasia, and use the term "euthanasia" exclusively to denote the physician's intentional administration of a lethal drug at the request of the patient.

The notion that the medical profession can safely incorporate euthanasia into accepted standards of care receives support from organized medicine in the Netherlands. The K.N.M.G. (Royal Dutch Society for the Promotion of Medicine) has advanced euthanasia as a permissible medical practice. It has not only drawn up corporate guidelines for euthanasia, but also has actively pursued legalization of the practice through the legislative and judicial branches of Dutch government. The K.N.M.G., for example, supported the Dutch euthanasia movement early on by lending institutional support in court cases to physicians under indictment for having euthanized their patients.

Thus, proponents of euthanasia in the United States are, in one sense, correct in drawing parallels between the aims of their movement and the experience of the Dutch with euthanasia. There is a rough truth to the analogy, and defenders of the practice in this country can rightly point to public opinion surveys in the Netherlands that validate the endorsement euthanasia receives from more than two-thirds of the lay public, and perhaps an even higher percentage of the medical profession. They can, moreover, point to assurances from officials in both the government and in private professional organizations that the practice is not being abused. It is argued that the Dutch experiment with euthanasia, which is now several years old, demonstrates that the practice is essentially benign, or at the very least, that it has not degenerated into indiscriminate killing. In what had, until recently, become the common reading of the situation, the Dutch and their experiment with physician-assisted suicide are noble pioneers, and the paradigm is worthy of emulation.

My own reading of the situation in the Netherlands is more disturbing, and I argue that early reports of the Dutch situation were, at best, hastily optimistic and simplistic; at worst, they were deceptive. As the bare outlines of this experiment are fleshed out, it becomes evident that the Dutch experience should serve as a cautionary tale, rather than a model program. What purportedly began as the ultimate exercise in patient autonomy has degenerated, I submit, into the ultimate abuse in civil rights: innocent and unconsenting people are being killed in the Netherlands by physicians who are acting, so they would suggest, with the tacit consent of the courts. I base my opinions not only on my own fieldwork in the Netherlands, but on reports which are being released by the Dutch themselves.[2]

How has this situation evolved, and how has it, until quite recently, been cast in such a favorable light? Part of the answer lies in the confusing political and social complexity with which the Dutch have surrounded this practice. To begin with, euthanasia is still technically illegal in the Netherlands. Through a series of complicated landmark cases which began in 1973, however, the Dutch have created a *de facto* opening to the practice of euthanasia, which rests on the assumption that physicians will report euthanasia to public prosecutors. As the practice now stands, tolerance of euthanasia presupposes that physicians who practice euthanasia will have to give a public accounting of their actions. The intentional killing of a patient is formally a crime, and in reporting such a case to the district prosecutor (as mandated by court established guidelines) physicians must claim, not *innocence*, but mitigating circumstances; that they acted, in the words of the K.N.M.G., with their "backs against the wall." Thus, regulation of physician-assisted suicide, to the extent that euthanasia is regulated at all in the Netherlands, rests on the assumption that physicians will incriminate themselves in what is essentially an act of homicide.

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A stipulation of this sort, however, does not provide any sort of regulatory force. Most acts of euthanasia in the Netherlands go unreported and uninvestigated by public authorities. Both defenders and critics of the practice agree that the nearly two hundred cases of euthanasia reported in 1987 to the Ministry of Justice, for example, represented a tiny fraction of the total number. In my own small sample of clinical histories, public prosecutors were notified less than 15 percent of the time. Thus, those in the Netherlands who have claimed that the practice of euthanasia operates under a system of tight constraints have been offering to the rest of the world assurances which they would find difficult, if

not impossible, to substantiate. Formally forbidden, yet given wide latitude under the actual *practice* (as opposed to theory) of Dutch jurisprudence, euthanasia has insinuated itself, piece by piece, into the legal and political fabric of Dutch life.

This confusing regulatory structure has not only made it difficult to explain to the rest of the world the social and cultural context of euthanasia in the Netherlands, it has also provided fertile ground for the dissemination of misleading and inaccurate information. Proponents of euthanasia have used the uncertainty that existed to their advantage. First, the number of patients intentionally killed by physicians each year have been consistently under-represented. Because these data were based not only on mortality statistics, but on survey estimates, the tendency has been to underestimate the proportion of deaths each year due to euthanasia. In numerous articles which have appeared the past five years in the leading medical and bioethical journals, for example, Dutch apologists for the practice have suggested that euthanasia accounts for, at most, 2 percent to 3 percent of all deaths in the Netherlands. As recently as February of last year, the vice chair of the Health Council of the Netherlands (roughly the equivalent of our Institute of Medicine) asserted that more recent and extensive surveys suggested that "certainly less than 2 percent" of all deaths in the Netherlands were due to euthanasia.[3] If one were to accept these statistics, it would mean that in the Netherlands, with a mortality rate of 130,000, anywhere from 2,600 to 3,900 people die from euthanasia each year. Defenders of the practice both here and abroad use such numbers to demonstrate that euthanasia would be little more than a statistical blip—almost undetectable—on a country's already established mortality rate. But to give the Dutch estimates some perspective, one notes that if this rate of euthanasia were to take hold in the United States (with an annual mortality rate of approximately 2 million deaths per year), a "small" number of deaths from euthanasia would represent 40,000 to 60,000 people killed each year by their physicians. This number is intended by proponents of the practice to reassure.

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We now know that the numbers previously used in this debate are deceptively low. The Remmelink Report (so named because it was carried out under the aegis of the Attorney General of the Supreme Court, J. Remmelink), surveyed the practices of 400 physicians and reviewed the cause of death of 8,500 patients in the Netherlands. The early results of this report, which were cast in an almost uniformly favorable light by both the professional and popular press, suggested that euthanasia was a rare occurrence, and moreover, that it was "almost never" subject to abuse. Yet the raw data from the report, which haven't received the careful scrutiny they deserve, suggest a more disquieting pattern of practice.

The authors of the report chose, for unexplained reasons, not to count as acts of euthanasia instances in which physicians gave lethal doses of pain medication not with the intent of alleviating pain *per se*, but to hasten or bring about death. In other words, the intent was to kill, not to palliate. Adding these cases to the tally would bring the number of cases of euthanasia in the Netherlands to 8,100, or about 6 percent of all deaths. Perhaps most ominously, the authors of the report chose to discount an additional 1,000 cases in which physicians used other methods to bring about the deaths of patients, who, the report notes, were incapable of giving consent. The committee chose not to include these cases as acts of euthanasia because the physicians were "providing assistance to the dying," and these acts were not, therefore, considered problematic. Adding these cases—which are clearly acts of euthanasia, whether problematic or not—brings the total documented by the Remmelink Commission to 9,100, or 7 percent of all deaths in the Netherlands. A similar rate of euthanasia in the United States would result in 140,000 deaths per year as the direct and intentional result of physician intervention.

The most damaging information about this practice, however, has only recently been made public. There is now a documented case of a woman who was "morbidly depressed," yet not terminal in any formal sense of the word, whose request for euthanasia was executed by her psychiatrist. Even more recently, Dutch physicians and ethicists have admitted that children—who by definition cannot consent to this practice—are also being euthanized either at the request of parents, or at the urging of health care workers, because of a poor "quality of life." Among those with a "poor" quality of life, for example, are a two-day-old with Down's Syndrome and duodenal atresia (an intestinal malformation easily corrected surgically), whose parents, with the pediatrician's support, refused to give consent for the surgery.[4] Similar cases of children being euthan-

ized have now been documented by the Dutch themselves.[5] There are also cases of euthanasia in which the patient was comatose, and by definition, unable to give consent.[6]

It is not surprising that this practice is evolving into something much more encompassing, and in my mind, irredeemably obscene. Inhabitants of the 20th century should, by now, be acclimated to the danger of fusing professional ethics with notions of killing, however nobly envisaged at the outset. Indeed, what is surprising is not that the Dutch are euthanizing the incompetent and unconsenting, but that the rest of the world views this with such equanimity. It is even more disheartening that the Dutch example has become, in the eyes of some, not a cautionary tale, but an impetus for legislative reform. If the death of the vulnerable at the hands of their physicians is cause, not for protest, but for emulation, then the weak, the disadvantaged, the stigmatized and the marginalized had best keep themselves hidden and alert, for in the hands of this new American medical ethic, they place their lives at risk.

References

1. For two elegant and powerful arguments to this effect see Leon R. Kass, "Neither for Love nor Money: Why Doctors Must Not Kill," *Public Interest* 94 (Winter 1989): 25-46; and Albert R. Jonsen, "Beyond the Physicians Frame of Reference: The Ethics of Active Euthanasia," *Western Journal of Medicine* 149 (August 1988): 195-98.

2. See, for example, P.J. van der Maas, J.J.M. van Delden, L. Pijnenborg and C.W.N. Looman, "Euthanasia and Other Decisions Concerning the End of Life," *Lancet* 338 (1991): 669-674; and Henk A.M.J. ten Have and Jos V.M. Welie, "Euthanasia: Normal Medical Practice?" *Hastings Center Report* (March-April 1992): 34-38.

3. Dr. Elsa Borst-Eileers, presentation to Symposium on Death and Dying, University of Florida, Orlando, Florida, February 17, 1991.

4. This case is documented in Carlos Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands* (Free Press, 1991): 83-84.

5. A documentary tape, "Choosing Death," which aired in February 1993 on PBS has several scenes with Dutch pediatricians discussing cases of infant and child euthanasia.

6. See, for example, Diana Brahms, "Euthanasia in the Netherlands," *Lancet* 335 (1990): 391, for the first case reported in the English literature of an unconscious Dutch patient being euthanized by a physician.