Whose Right to Die?

America should think again before pressing ahead with the legalization of physician-assisted suicide and voluntary euthanasia

EZEKIEL J. EMANUEL THE ATLANTIC MAR 1 1997, 12:00 PM ET

http://www.theatlantic.com/magazine/archive/1997/03/whose-right-to-die/304641/?single_page=true

The debate over physician-assisted suicide and voluntary euthanasia will soon reach its most important stage in this country. Last spring the Second and Ninth Circuit Courts of Appeals handed down momentous decisions striking down state laws in New York and Washington that forbid physician-assisted suicide. Although the Second and Ninth Circuit Court cases focus on physician-assisted suicide, and although there are important differences between physician-assisted suicide and voluntary euthanasia, the legal reasoning that would justify physician-assisted suicide would almost certainly extend to voluntary euthanasia. The intensity of the debate on both issues will grow during the wait for rulings this year by the Supreme Court, which has accepted the two circuit-court cases for review.

In physician-assisted suicide a doctor supplies a death-causing means, such as barbiturates, but the patient performs the act that brings about death.

In voluntary euthanasia the physician performs the death-causing act after determining that the patient indeed wishes to end his or her life.

Neither term applies to a patient's refusal of life-support technology, such as a respirator or artificial nutrition, or a patient's request that it be withdrawn; these have had ethical and constitutional sanction nationwide for years. And neither term applies to what is sometimes called indirect euthanasia, when the administration of drugs primarily for pain relief may have the secondary effect of causing death, as the physician is well aware. This practice, too, is ethically and legally sanctioned.

In formulating their decisions the circuit-court judges made a number of assumptions about the actual or likely circumstances surrounding cases of death by active intervention. Their judgments are based on misreadings of history, misinterpretations of survey data, mistaken reasoning, and simple misinformation.

Myth No. 1: It is primarily advances in biomedical technology—especially life-sustaining technology—that have created unprecedented public interest in physician-assisted suicide and voluntary euthanasia. "The emergent right to receive medical assistance in hastening one's death [is an] inevitable consequence of changes in the causes of death, advances in medical science, and the development of new technologies. Both the need and the capability to assist individuals [to] end their lives in peace and dignity have increased exponentially" (Ninth Circuit Court of Appeals).

Physician-assisted suicide and euthanasia have been profound ethical issues confronting doctors since the birth of Western medicine, more than 2,000 y ears ago. All the arguments made today to justify—or condemn—the two practices were articulated before any modern biomedical technology existed. The ancient Hippocratic Oath enjoins physicians to "neither give a deadly drug to anybody if asked for it, nor make a suggestion to this effect." The oath was written at a time when physicians commonly provided euthanasia and assisted suicide for ailments ranging from foot infections and gallstones to cancer and senility. Indeed, the Hippocratic Oath represented the *minority* view in a debate within the ancient Greek medical community over the ethics of euthanasia.

Even in America legalized euthanasia, rather than being a new issue, has been publicly debated and rejected—a fact the courts failed to mention. Modern interest in euthanasia in the ***United States began in 1870***, when a commentator, Samuel Williams, proposed to the Birmingham Speculative Club that ***euthanasia be permitted "in all cases of hopeless and painful illness" to bring about "a quick and painless death."*** The word "painless" is important: the idea of euthanasia began gaining ground in modern times not because of new technologies for agonizingly prolonging life but because of the discovery of ***new drugs, such as morphine and various anesthetics for the relief of pain, that could also painlessly induce death.*** Over the next three decades Williams's proposal was reprinted in popular magazines and books, discussed in the pages of prominent literary and political journals, and debated at the meetings of American medical societies and nonmedical professional associations. The debate culminated in ***1906***, after the ***Ohio legislature took up "An Act Concerning Administration of Drugs etc. to Mortally Injured and Diseased Persons"—a bill to legalize euthanasia.*** The merits of the act were debated for months and were covered extensively in the pages of *The New York Times*, which vigorously opposed legalization, and in medical journals. The ***Ohio legislature overwhelmingly rejected the bill, effectively ending that chapter of the euthanasia debate.***

Thus, decades before the discovery of penicillin (1928) and the development of mechanical respirators (1929), dialysis (1945), and other life-sustaining technologies, serious public discussions of physician-assisted suicide and euthanasia took place in the United States (and also in European countries). These discussions were couched in the ***same language we use today—"patients' rights," "the relief of pain and suffering," "the loss of dignity."***

Indeed, rather than creating a perceived need for physician-assisted suicide and euthanasia, advances in life-sustaining technology should help to obviate them. ***Patients who are being kept alive by technology and want to end their lives already have a recognized constitutional right to stop any and all medical interventions, from respirators to antibiotics. They do not need physician-assisted suicide or euthanasia.***

Myth No. 2: Legalizing physician-assisted suicide and euthanasia is widely endorsed. "There is unquestionably growing popular support for permitting doctors to provide assistance to terminally ill patients who wish to hasten their deaths" (Ninth Circuit Court of Appeals).

Yes, polls show that a majority of Americans support physician-assisted suicide and euthanasia—indeed, have supported legalizing them for almost twenty-five years. But the support is neither strong nor deep. Careful analysis of the polling data suggests that there is a "rule of thirds": a third of Americans support legalization under a wide variety of circumstances; a third oppose it under any circumstances; and a third support it in a few cases but oppose it in most circumstances.

Americans tend to endorse the use of physician-assisted suicide and euthanasia when the question is abstract and hypothetical. One formulation that has been used for almost fifty years and elicits widespread agreement is "When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient's life if the patient and his or her family request it?" The question has several flaws, the most important one being that "to end the patient's life" is vague and specific neither to physician-assisted suicide nor to euthanasia. The phrase could mean simply stopping life-sustaining technologies that are keeping the patient alive, which is already legal.

Other, more carefully designed questions can elicit majority support for physician-assisted suicide and euthanasia, but only when patients are described as terminally ill *and* experiencing unremitting physical pain. Support dwindles when the public is asked about physician-assisted suicide and euthanasia in virtually any other situation. Two thirds of Americans oppose physician-assisted suicide or euthanasia when a terminally ill patient has no pain but wants to die because of concern about being a burden to his or her family, or because he or she finds a drawn-out dying process meaningless. The most accurate characterization of the survey data is that a significant ***majority of Americans oppose physician-assisted suicide and euthanasia except in the limited case of a terminally ill patient with uncontrollable pain.***

Myth No. 3: It is terminally ill patients with uncontrollable pain who are most likely to be interested in physician-assisted suicide or euthanasia. "In the case of a terminally ill adult who ends his life in the final stages of an incurable and painful degenerative disease, in order to avoid debilitating pain and a humiliating death, the decision to commit suicide is not senseless, and death does not come too early" (Ninth Circuit Court of Appeals).

The empirical studies of physician-assisted suicide and euthanasia in the Netherlands (where the practices have long been accepted), the United States, and elsewhere indicate that ***pain plays a minor role in motivating requests for the procedures.*** A 1996 update of the comprehensive and rigorous 1991 Remmelink Report on euthanasia practices in the Netherlands revealed that in ***only 32 percent of all cases did pain play any role in requests for euthanasia;*** indeed, pain was the sole reason for requesting euthanasia in no cases. A study of patients in nursing homes in the Netherlands revealed that pain was among the reasons for requesting physician-assisted suicide or euthanasia in only 29 percent of cases and was the main reason in only 11 percent. A study of physicians in Washington State who admitted to having received requests for physician-assisted suicide or euthanasia revealed that severe pain played a role in only about a third of the requests. A study of HIV-infected patients in New York found that interest in physician-assisted suicide was not associated with patients' experiencing pain or with pain-related limitations on function. My own recent study of ***cancer patients***, conducted in Boston, reveals that ***those with pain are more likely than others to oppose physician-assisted suicide and euthanasia.*** These patients are also more likely to say that they would ask to change doctors if their attending physician indicated that he or she had performed physician-assisted suicide or euthanasia. ***No study has ever shown that pain plays a major role in motivating patient requests for physician-assisted suicide or euthanasia.***

What does motivate requests? According to studies, ***depression and general psychological distress***. The Remmelink Report found that among Dutch patients the leading reason for requesting euthanasia was a ***perceived loss of dignity.*** The study of Washington State physicians found that the leading factors driving requests were ***fear of a loss of control or of dignity, of being a burden, and of being dependent.*** Among the New York HIV-infected patients the leading factors were ***depression, hopelessness, and having few—and poor-quality -- social supports.*** In my own study, patients who were depressed were most likely to discuss euthanasia seriously, to hoard drugs for suicide, and to have read *Final Exit*, the Hemlock Society suicide manual.

These studies highlight an important conflict between people's actual attitudes and likely medical practice. ***Many Americans say they would support physician-assisted suicide or euthanasia for patients in pain; they oppose the practices for patients who worry about being a burden, about life's being meaningless, about hopelessness. But patients with depression and psychological distress are most likely to request death; patients in pain are less likely to request it.***

Myth No. 4: The experience with euthanasia in the Netherlands shows that permitting physician-assisted suicide and euthanasia will not eventually get out of hand. "There is no reason to believe that legalizing assisted suicide will lead to the horrific consequences its opponents suggest" (Ninth Circuit Court of Appeals).

The slippery slope feared by opponents and supporters alike is the route from physician-assisted suicide or euthanasia for terminally ill but competent adults to euthanasia for patients who cannot give consent: the unconscious, the demented, the mentally ill, and children. Because the Netherlands is the one developed democracy that has experience with sanctioned euthanasia, advocates and adversaries alike invoke it to defend their points of view. What does the Dutch experience actually show?

Contemporary Dutch policy regarding voluntary euthanasia had its origins in 1973, with the case of a physician, Geertruida Postma, who injected a deaf, partially paralyzed seventy-eight-year-old woman with morphine, ending her life. The patient happened to be Postma's mother. Postma was convicted of murder but given a suspended sentence of one week in jail and one year on probation, a sentence that effectively exonerated her. A subsequent case in 1981 resulted in an agreement between Dutch prosecutors and the Royal Dutch Medical Society, under the terms of which physicians who participated in physician-assisted suicide or euthanasia would not be prosecuted for murder if they adhered to certain guidelines. The main guidelines, parts of which have been incorporated into proposals for outright legalization in other countries, are that 1) the patient must make an informed, free, and explicit request for physician-assisted suicide or euthanasia, and the request must be repeated over time; 2) the patient must be experiencing unbearable suffering—physical or psychological—that cannot be relieved by any intervention except physician-assisted suicide or euthanasia; 3) the attending physician must have a consultation with a second, independent physician to confirm that the case is appropriate for physician-assisted suicide or euthanasia; and 4) the physician must report the facts of the case to the coroner, as part of a notification procedure developed to permit investigation and to ensure that the guidelines have been followed.

It is important to recognize that despite a widespread perception to the contrary, euthanasia has not been legalized under the Dutch penal code—it remains a crime, albeit one that will not be prosecuted if performed in accordance with the guidelines. Several recent efforts in the Netherlands to overtly legalize physician-assisted suicide and euthanasia have been defeated, primarily because of opposition from Dutch religious authorities. The Dutch rules differ from what U.S. proposals (such as those embodied in a 1994 Oregon measure on physician-assisted suicide, still in the courts) would require in the following respects: they do not stipulate that a patient must be terminally ill, and they do not require that a patient be experiencing *physical* pain or suffering—a patient can be experiencing psychological suffering only.

Not until 1990, a decade after the Dutch rules were promulgated, was the comprehensive and reliable empirical study done of physician-assisted suicide and euthanasia in the Netherlands which resulted in the Remmelink Report. The recent update of this report reveals that of about 9,700 requests for physician-assisted suicide or euthanasia made each year in the Netherlands, about 3,600 are acceded to, accounting for ***2.7 percent of all deaths in the Netherlands (2.3 percent from euthanasia, 0.4 percent from physician-assisted suicide).*** Nearly ***80 percent*** of patients who undergo physician-assisted suicide or euthanasia ***have cancer***, with just four percent having neurological conditions such as Lou Gehrig's disease or multiple sclerosis. The report revealed that 53 percent of the Dutch physicians interviewed had participated in physician-assisted suicide or euthanasia at some point in their career; 29 percent had participated within the previous two years. Only 12 percent of the Dutch doctors categorically refused to participate in physician-assisted suicide or euthanasia, most likely for religious reasons.

The 1996 data show small increases in the numbers of requests for physician-assisted suicide and euthanasia since 1990, but the overall changes are undramatic. The new research does indicate, however, that problems identified by the Remmelink Report have by no means been eliminated.

First, the update found that beyond the roughly 3,600 cases of physician-assisted suicide and euthanasia reported in a given year, there are about 1,000 instances of nonvoluntary euthanasia. Most frequently, patients who were no longer competent were given euthanasia even though they could not have freely, explicitly, and repeatedly requested it. Before becoming unconscious or mentally incompetent about half these patients did discuss or express a wish for euthanasia; nevertheless, they were unable to reaffirm their wishes when the euthanasia was performed. Similarly, a study of nursing-home patients found that in only 41 percent of physician-assisted suicide and euthanasia cases did doctors adhere to all the guidelines. Although most of the violations were minor (usually deviations in the notification procedure), in 15 percent of cases the patient did not initiate the request for physician-assisted suicide or euthanasia; in 15 percent there was no consultation with a second physician; in seven percent no more than one day elapsed between the first request and the actual physician-assisted suicide or euthanasia, violating the guideline calling for repeated requests; and in nine percent interventions other than physician-assisted suicide or euthanasia could have been tried to relieve the patient's suffering.

Second, ***euthanasia of newborns has been acknowledged.*** The reported cases have involved ***babies suffering from well-recognized fatal or severely disabling defects, though the babies were not in fact dying.*** Precisely how many cases have occurred is not known. One estimate is that ten to fifteen such cases occur each year. Whether ethically justified or not, providing euthanasia to newborns (upon parental request) is not voluntary euthanasia and does constitute a kind of "mercy killing."

The Netherlands studies fail to demonstrate that permitting physician-assisted suicide and euthanasia will not lead to the nonvoluntary euthanasia of children, the demented, the mentally ill, the old, and others. Indeed, the persistence of abuse and the violation of safeguards, despite publicity and condemnation, suggest that ***the feared consequences of legalization are exactly its inherent consequences.***

Third, the Boudewijn Chabot case raises a warning flag. Chabot, a psychiatrist, participated in the suicide of a depressed fifty-year-old woman in 1991. Her first son had committed suicide a few years earlier. Then her father had died. Under the stress her marriage dissolved. In May of 1991 her second son died of cancer, and less than three months later the woman reached Chabot through the Dutch Voluntary Euthanasia Society, seeking someone to help her end her life. She refused antidepressants and additional psychotherapy. She was never seen by another physician in consultation. When Chabot discussed the case with seven colleagues, at least two suggested that he not assist in the suicide. The Dutch Supreme Court ultimately opted not to penalize Chabot, reaffirming the permissibility of providing assisted suicide and euthanasia on grounds of mental suffering alone. The Amsterdam Medical Disciplinary College did reprimand him, however.

A statement by Else Borst-Eilers, the Dutch Minister of Health, raises ***concerns about how euthanasia will come to be viewed once it is routine: "There are situations in which the best way to heal the patient is to help him die peacefully, and the doctor who in such a situation grants the patient's request acts as the healer par excellence."*** The logic of understanding voluntary euthanasia as "healing" ***begins to justify using euthanasia for children, the incompetent, the mentally ill, and others who are suffering or who we imagine are suffering in some fashion***. As we have seen, there is a very strong tendency among people who are healthy to extrapolate from the suffering of others in ways that those who are in fact suffering would not countenance.

Many in favor of legalization urge caution in applying the experience of the Netherlands to the United States, citing the many significant geographic, cultural, and political differences between the countries. The differences suggest, though, that the kinds of departures from agreed-upon procedures that have occurred in the Netherlands are likely to be even more commonplace in America. ***Whatever the emerging cultural, ethnic, and religious diversity of the Netherlands, it pales in comparison to the raucous diversity of the United States.*** And the Dutch have relative income equality, whereas ***income inequality in the United States is among the greatest in the developed world.*** Such diversity and inequality make it harder to share norms and to enforce them. The Dutch are also a law-abiding people who view government social supports, interventions, and regulations as legitimate. America is a land founded on opposition to government, where candidates for office campaign against government legitimacy. If the law-abiding Dutch violate their own euthanasia safeguards, what can we expect of Americans?

In the Netherlands physician-assisted suicide and euthanasia are provided in the context of universal and comprehensive health care. The United States has yet to provide such coverage, and leaves tens of millions effectively without health care. Paul van der Maas, the professor of public health who conducted the two Netherlands studies, has said that in the absence of health-care coverage he would be loath to permit euthanasia in the Netherlands, fearing that pressure might be brought to bear on patients and doctors to save money rather than to help patients.

What, then, should be U.S. policy regarding physician-assisted suicide and euthanasia? Magazine and television stories about patients who want to end their suffering by means of physician-assisted suicide or euthanasia help to reinforce the seemingly inherent link between pain and such interventions. As an oncologist I have often personally cared for patients who suffer despite all available treatment. Only the callous and insensitive would deny that in such cases physician-assisted suicide or euthanasia can offer obvious benefits -- can end a life that is worse than death.

But these cases distort the picture. The question is not about whether intervention is right for this or that particular patient. ***In any given case it may be the ethical thing to do, whatever the law says—and should be done. The question confronting the United States is one of policy: Should we broadly legalize physician-assisted suicide and euthanasia? We must not be swayed by a few—or even a few***

thousand—wrenching cases in which such intervention seems unequivocally right.

Most of the patients interested in physician-assisted suicide or euthanasia will not be suffering horrific pain. As noted, ***depression, hopelessness, and psychological distress are the primary factors motivating the great majority.*** Should their wishes be granted? ***Our usual approach to people who try to end their lives for reasons of depression and psychological distress is psychiatric intervention—not giving them a syringe and life-ending drugs.***

Legalizing physician-assisted suicide and euthanasia, some argue, would not benefit only those who eventually made use of these procedures; it would also provide "psychological comfort" or "reassurance" to millions of other Americans, who would know that if they were dying and things got really bad, they could end their lives. However, the one study we have—the Boston study mentioned previously—shows that ***for every cancer patient who is likely to be reassured by a discussion of physician-assisted suicide or euthanasia, another patient finds that such a discussion would decrease his or her trust in the care being provided.***

Whatever the benefits of legalized physician-assisted suicide and euthanasia, they must be measured against the dangers of legalization. In considering dangers we must consider more than potential violations of safeguards, although the Dutch experience indicates that the danger is real. (It is hardly surprising that, according to surveys, those who are most opposed to physician-assisted suicide and euthanasia include those most likely to experience abuse and coercion: the old, the less well off, and minorities.) For instance, how would legalization affect our society's already tenuous commitment to providing quality health care for the millions of people who die every year?

Providing the terminally ill with compassionate care and dignity is very hard work. It frequently requires monitoring and adjusting pain medications, the onerous and thankless task of cleaning people who cannot control their bladders and bowels, and feeding and dressing people when their every movement is painful or difficult. It may require agonizing talks with dying family members about their fears, their reflections on life and what comes after, their family loves and family antagonisms. ***Ending a patient's life by injection, with the added solace that it will be quick and painless, is much easier than***

this constant physical and emotional care. If there is a way to avoid all this hard work, it becomes difficult not to use it.

Broad legalization of physician-assisted suicide and euthanasia would have the ***paradoxical effect of making patients seem to be responsible for their own suffering.*** Rather than being seen primarily as the victims of pain and suffering caused by disease, patients would be seen as having the power to end their suffering by agreeing to an injection or taking some pills; refusing would mean that living through the pain was the patient's decision, the patient's responsibility. ***Placing the blame on the patient would reduce the motivation of caregivers to provide the extra care that might be required, and would ease guilt if the care fell short. Such an easy, thoughtless shift of responsibility is probably what makes most hospice workers so deeply opposed to physician-assisted suicide and euthanasia.***

There is one final matter to consider: the possibility that euthanasia not only would be performed on incompetent patients in violation of the rules—as an abuse of the safeguards—but would become the rule in the context of demographic and budgetary pressures on Social Security and Medicare as the Baby Boom generation begins to retire, around 2010.

Once legalized, physician-assisted suicide and euthanasia would become routine. Over time doctors would become comfortable giving injections to end life and Americans would become comfortable having euthanasia as an option. Comfort would make us want to extend the option to others who, in society's view, are suffering and leading purposeless lives. The ethical arguments for physician-assisted suicide and euthanasia, advocates of euthanasia have maintained, do not apply to euthanasia only when it is voluntary; they can also be used to justify some kinds of nonvoluntary euthanasia of the incompetent. Euthanasia would come to be seen as "one end of a spectrum of caring for dying patients," as the philosopher and euthanasia defender Dan Brock writes. "When viewed in this way," he goes on, "it will be difficult to deny euthanasia to a patient for whom it is seen as the best or most appropriate form of care simply because that patient is now incompetent and cannot request it."

Advocates of physician-assisted suicide and euthanasia urge legalization for reasons of compassion, but there is no guarantee that the reasons offered in 1997 would remain the justification even a few years ahead, under different social and economic circumstances. The confluence of ethical arguments, medical practice, demographic and budgetary pressures, and a social ethos that views the old and sick as burdens would seem capable of overwhelming any barriers against euthanasia for incompetent patients.

The proper policy, in my view, should be to affirm the status of physician-assisted suicide and euthanasia as illegal. In so doing we would affirm that as a society we condemn ending a patient's life and do not consider that to have one's life ended by a doctor is a right. This does not mean we deny that in exceptional cases interventions are appropriate, as acts of desperation when all other elements of treatment—all medications, surgical procedures, psychotherapy, spiritual care, and so on—have been tried. P***hysician-assisted suicide and euthanasia should not be performed simply because a patient is depressed, tired of life, worried about being a burden, or worried about being dependent.*** All these may be signs that not every effort has yet been made.

By establishing a social policy that keeps physician-assisted suicide and euthanasia illegal but recognizes exceptions, we would adopt the correct moral view: the onus of proving that everything had been tried and that the motivation and rationale were convincing would rest on those who wanted to end a life. Such a policy would recognize that ending a life by physician-assisted suicide or euthanasia is an extraordinary and grave event. To recognize a legal right to physician-assisted suicide or euthanasia transforms the practices into routine interventions that can be administered without the need for a publicly acceptable justification. Doctors who end patients' lives would no longer bear the burden of having to prove the appropriateness of their action, if called upon to do so, but could simply justify their action as a legally sanctioned procedure.

Advocates for legalization might find a policy that permits exceptions to embody a double standard. But crafting a social policy in this way would also embody what we know: ***not all cases are the same, and among the millions of Americans who die each year there are morally relevant differences that cannot be captured in an inflexible rule. We must ensure that moral judgments are made in individual cases, and that those who make them will be accountable before the law.***