Voluntary Euthanasia and the Risks of Abuse: Can We Learn Anything from the Netherlands?

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In the United States' quite volatile public debates over the legalization of voluntary active euthanasia and physician-assisted suicide, much has been made of the risk of abuse. Indeed, it was probably fears of abuse that contributed more than any other single factor to the 1991 defeat of the United States' first ballot test of legalizing euthanasia, the state of Washington's Initiative 119—despite prior state and national polls suggesting the measure would pass. Opponents of Initiative 119, which would have legalized physician-performed euthanasia or physician-provided aid in suicide when voluntarily requested by competent terminally ill patients with less than six months to live, variously claimed that the legislation would encourage greedy family members to pressure patients into choosing death, that unscrupulous physicians would kill patients who became unattractive to treat, that cost-cutting pressures from hospitals, insurers, and other institutions would force patients into death, and that race-, age-, and handicap-prejudice would take an especial toll among vulnerable groups.

These risk-of-abuse arguments, also known as "slippery slope" or "wedge" arguments, were often fortified with claims about abuse in the Netherlands, the one country which currently openly permits active euthanasia.

Nor has the discussion ceased with the defeat of Initiative 119. On the contrary, many observers are predicting that euthanasia will become *the* social issue of the next decade. If so, claims about the possibilities of abuse are likely to continue to play a very major role. Nor are they trivial: most slippery-slope arguments predict abuse on a quite broad scale, and the more flamboyant of them warn against complete moral holocaust.

While these warnings of abuse seem characteristically both alarmist and unclear, I think we must take them seriously—especially those of us who support legalization in the United States of both voluntary active euthanasia and physician-assisted suicide. This requires both the effort to discover what, in fact, is the predicted evil against which the warning is being delivered, and what is the likelihood that such an outcome will really come about. Do we fear that greedy family members will maneuver patients into choosing death? Exactly how, and how can we know whether this will come about? Do we think physicians will lose their scruples and begin to kill their patients? Why might they lose these scruples, exactly, and what were these scruples in the first place? Will wholesale "medical homicide" take place, as former Surgeon General Everett Koop warned in TV spots broadcast in Washington on the eve of the 1991 vote on Initiative 119? Will cost-conscious institutions force patients into euthanasia or into requesting means for suicide, and if so, precisely how? What forms will race-, age- and handicap-prejudice take in exacerbating this problem, and how will it be that members of such groups are especially victimized?

Some further protections against abuse have already been proposed. Undaunted by the defeat of Initiative 119 in Washington, the Hemlock Society announced that it would introduce a similar initiative in California; it has already qualified for the November 1992 ballot. The

California Death with Dignity Act would legalize voluntary active euthanasia and physician-assisted suicide under the same circumstances as Washington's Initiative 119, but would impose additional protections—the patient's request must be "enduring," there are special protections for persons in skilled nursing facilities, there are prohibitions against intimidation, inducement and tampering, provisions for psychological consultation and for the independence of physicians, stipulations that the time and place of death are to be determined solely by the patient, limitations on fees, and record-keeping requirements; furthermore, the patient is encouraged to notify his or her family.[1] There have also been various other proposals in the public media for the addition of protections to legislation legalizing euthanasia and assisted suicide; one such set of suggestions following 119, for example, would have required that aid-in-dying be performed only in a hospital, that it be performed only within the context of an established doctor-patient relationship, and that it be restricted to residents of the state of Washington.[2] Another recommended that training in pain control and terminal care be made a condition for the renewal of M.D. licenses, implying that euthanasia and assisted suicide could be practiced without abuse only if physicians were fully skilled in techniques of treating patients' pain.[3] A Dutch proposal offered early in that country's discussions of euthanasia would have required an extensive autopsy and mortality review for every patient who died by euthanasia, comparing not only the physician's diagnosis with pathologies found on examination of the cadaver but also reviewing the deliberations leading up to euthanasia.[4] Whatever the various recommendations for the addition of protections to any proposal for legalization, it is important not to treat them too lightly; on the contrary, it is crucial to try to see precisely what fears of abuse they attempt to respond to, and also how effective they might be in preventing or controlling such abuse. In general, I think it is crucial to be as clear and forthright about the issue of abuse as possible, even if one supports, as I do, the legalization of aid-in-dying.

In doing so, one must answer two central questions:

1) Will there be abuse, and if so, precisely what kind?
2) Can abuse of this sort be prevented?

It is to the second of these questions that I will be particularly attentive here. In doing so, I shall consider only the possible effects of legalizing voluntary, active, physician-performed euthanasia and physician-assisted suicide, restricted to cases in which such help is requested by competent, terminally ill patients with less than 6 months to live—that is, I shall be considering only what Initiative 119 would have legalized—but some of the arguments will clearly apply to a wider range of possible legislation as well.

Slippery-slope arguments are designed to address the first of the two questions above: *Will there be abuse, and if so, precisely what kind?* Since they are predictive empirical arguments intended to show that permitting a given practice will result in abuse, the principal strategy available to counter these arguments is to show that they fail to specify what causal mechanisms will be involved, what background precedents would permit such erosion, and so on. Thus opponents of legalization warn of abuse in the future, pointing to alleged current abuse in the Netherlands as evidence; supporters of legalization, on the other hand, reply that claims about abuse in Holland are unsubstantiated or exaggerated and that there is little reason to think abuse would occur in the United States. One cannot fear an analogue of the Nazi holocaust, supporters of the legislation argue, for example, because even though there are local excrescences of antisemitic, anti-Black, and other racially prejudiced political activity, it is inconceivable that a country with such strong guarantees of civil rights could permit a large-scale extermination program. Thus the argument moves back and forth between opponents and supporters, however erratically; but it remains an essentially empirical argument about the potential consequences of legalization.

It is this argument which I would like to enter here. As I have often said elsewhere, I do not think there is any compelling argument in principle to be made against voluntary active euthanasia or physician-assisted suicide, at least in specific circumstances, and I believe that on the contrary control of one's own death as far as possible is a matter of fundamental human right. However, I also think that the warnings of potential abuse require much more sensitive and careful examination than either supporters or opponents of such legislation have generally given them. Indeed, I think it is morally responsible to advocate the legalization of euthanasia and assisted suicide only if one can conscientiously argue either that abuse would not occur or that it could be prevented, and it is on this project that I would like to embark here. Conversely, I also think it is morally responsible to oppose the legalization of euthanasia and assisted suicide, given the importance of the freedom to be suppressed, only if one can show with reasonable likelihood that abuse would occur and that it could not be prevented.

Thus either way, it is crucial to consider the issue of abuse, and this is an obligation that no party to the discussion, on either side, ought to evade; the burden of proof in establishing what the consequences of the proposed legislation would be falls, in this special case, on both sides. That persons have a basic, fundamental right to control as much as they wish and as much as is possible the timing and circumstances of their own deaths is a claim that I shall assume here,[5] but this assumption does not relieve us of the obligation to consider the risk of abuse. After all, if the risks of abuse are great enough, this may entail that even basic, fundamental rights of persons should be curtailed. If on the other hand the risks of abuse turn out to be small or if abuse can be prevented, then it is morally imperative that persons' basic, fundamental right to control as much as possible the circumstances of their own dying be legally recognized.

Will abuse occur?

While euthanasia is presumably practiced clandestinely virtually everywhere else, it is openly practiced only in the Netherlands. Thus our principal source of empirical information about the potential for abuse where euthanasia is effectively legal must come from the Netherlands. To be sure, euthanasia is not fully legal in the Netherlands; it remains a violation of statutory law, punishable in principle by imprisonment, but the lower and supreme courts have developed a series of guidelines under which euthanasia is immune from prosecution. Thus it is effectively legal and openly practiced, and it is supported by a substantial majority of public opinion. Most Dutch hospitals now have protocols governing euthanasia, and many health-care institutions, including nursing homes and hospitals, also have developed publicly stated policies concerning whether they do or do not permit the practice.

The first nationwide study in Holland on euthanasia and other medical decisions at the end of life, prepared by a commission appointed by the Dutch government (the so-called Remmelink Commission), involved detailed interviews with 405 physicians from different disciplines, a questionnaire mailed to the physicians of 7000 deceased persons, and a prospective survey in which physicians interviewed in part I gave information concerning every death in their practice (a total of 2250 deaths) during the six months after the interview. This study found that about 1.8 percent of total deaths per year in the Netherlands are the result of euthanasia with some form of physician involvement and that about 0.3 percent of deaths involve physician-assisted suicide. But it also reported that in 0.8 percent of all deaths "drugs were administered with the explicit intention to shorten the patient's life, without the strict criteria for euthanasia being fulfilled," and it is this that has been widely interpreted in the United States to mean that 1000 patients were killed against their will. While this is a clear misinterpretation of the data in the Dutch study, fair treatment of the issue of abuse must take account of both actual and conjectural evidence from Holland.

There are several further matters to be remembered in addressing the issue of abuse. First, judgments about abuse should in principle be comparative, weighing influences on choice, adjusted for the severity of outcome, against influences on other alternative choices. Would choices of euthanasia be more or less abused than, say, choices of high-risk surgery or choices to withhold or withdraw life-sustaining treatment? After all, any of these choices can lead to death, not only choices about euthanasia. Furthermore, judgments about abuse ought not to cloak judgments about outcomes: it cannot be assumed, without further argument, that—in the kind of case at issue here—influences on a choice for euthanasia are potentially abusive while influences on a choice to stay alive are not. It is also to be remembered that there is little theoretical agreement on just what constitutes abuse: is it a distortion of voluntariness, is it the violation of a person's interests, or what?

Finally, it is important to remember that the issue of whether abuse would occur is an issue about the outcomes of policy, not about idiosyncratic acts. In every society and with regard to every kind of social policy, unstable, psychopathic, or otherwise deranged individuals commit acts which clearly constitute abuses: nurses who randomly inject patients with fatal drugs, doctors who perform deliberately damaging, unwarranted operations on patients, anaesthetists who have sex with patients on their operating tables. Such outlier cases will occur from time to time, regardless of the type of policies in effect. To be sure, one ought not be sanguine about the occurrence of such cases, but the real issue is not so much whether such outlier cases will occur—they will, in any country, with or without legislation—but whether the legislation itself would permit or encourage such cases on a more frequent, more accepted, more "normal" basis. Thus, the question is whether the policies at issue—the legalization of active euthanasia and of assisted suicide—would engender an abusive pattern of practice, not whether a handful of isolated, marginal cases of abuse would occur from time to time. It is "normal" patterns of abuse that the slippery slope arguments are properly concerned with: Would family members readily and routinely manipulate patients? Would physicians generally become callous about death? Would institutions regularly force patients into euthanasia or suicide in an effort to save costs? Would prejudice against racial, age, and handicapped groups further infect these practices?

While I have no doubt that some outlier cases of abuse would occur from time to time, I do not think the general answer to these questions is yes. Nor do I think euthanasia choices would be more abused than choices of high-risk surgery or of withholding or withdrawing life-sustaining treatment. Nevertheless, I will assume the contrary for purposes of this paper, since my real concern here is whether—if such abusive patterns might be tolerated or encouraged by legalizing euthanasia and suicide—there are effective ways of preventing abuse. This is not to assume that human nature is evil or that abuse is humanly inevitable; rather, it is to assume instead that different policies and the incentives and disincentives incorporated in policy can encourage or discourage quite different patterns of practice. Thus the question is, would the legalization of euthanasia and suicide, with or without safeguards such as those proposed by Hemlock or those already in place in Holland, engender abuse? If so, what sort, and can such abuse be prevented even if it would otherwise occur?

Types of possible abuse

Three conceptually distinct types of abuse can be identified among the scenarios that slippery-slope arguments portray: what we might call interpersonal abuse, professional abuse, and institutional abuse. Though they are conceptually distinct, we may expect that in practice they would often be closely intertwined. Although the parallels are not exact, they also invite three rather different sorts of solutions, that is, three rather different sorts of strategies for preventing such abuses from occurring.

1. *Interpersonal abuse.* Chief among the varieties of interpersonal abuse, one might expect, would be that occurring in familial situations: the resentful or greedy spouse or other family member, who maneuvers a terminally ill patient now perceived as a burden into requesting euthanasia or assistance in suicide. Such pressures might be malevolent, the product of long years of hostility; or, perhaps more likely, they might be the product of the kind of emotional exhaustion familial caregivers often experience in attending to a patient with a lengthy, deteriorative terminal illness. "All of your suffering could be over soon," such a family member might be expected to say—not seeing that much of the suffering is not so much the patient's but his or her own. Familial messages supporting euthanasia or suicide can of course be given in an enormous variety of ways, both explicit and inexplicit, verbal and nonverbal, and they can be conveyed by a single individual family member or by a family as a whole.

Familial messages favoring euthanasia or suicide can be comparatively weak, involving suggestion or even the mere raising of the idea; they can be stronger, including what we might variously call recommendation, urging, "talking into," pleading, cajoling, remonstrating, and so on; and they can be a great deal stronger, including such tactics as threats, ultimatums, lies, and so on. Not all family life is harmonious, and underlying pathology can often be exacerbated by the stresses a family member's terminal illness brings. "All right, Granny, it's time to go" is a message we can imagine being conveyed in a large variety of ways, exhibiting an entire range from the faintest suggestion to outright coercion.

2. *Professional abuse.* If family members will manipulate or pressure patients into choosing death in all the usual ways family members control each other's behavior, it can be further argued, physicians will have an even larger range of methods for doing so. For instance, they may give inaccurate diagnoses or unreliable prognoses. They may scare patients with predictions of pain. They may decline to offer adequate pain control, citing for example the risks of addiction to narcotic drugs, or offer only pain control which is sporadic or has undesirable side effects. They may refuse to offer other treatment which might produce symptom relief. They may "recommend" premature death in ways that are too persuasive for the patient to resist, or they may recommend it to the family and let the family do the persuasion. Worse still, they may learn to lean on euthanasia as a kind of medical crutch, turning almost automatically to it as the solution for every treatment problem they cannot solve; even worse, they may use it as a cover for their medical mistakes. Perhaps still worse, they will become euthanasia "enthusiasts," employing euthanasia as part of their own political programs for reforming the medical world.

To understand these claims, it is essential first to see what background assumptions make them plausible, given that it is only voluntary euthanasia and assisted suicide that would be legalized, and then only for competent, terminally ill patients with less than 6 months to live. Yet even given the comparative narrowness of this range of cases, the dire predictions so widely voiced cannot be ignored. For this reason, it is crucial to understand what is distinctive about abuse by doctors, and to some degree by nurses and other care providers as well—that is, what is distinctive about *professional* abuse in contrast to interpersonal, usually familial, abuse of the sort discussed above.

Professional abuse, understood as that range of ways in which professionals, especially physicians, might bring a patient to "voluntarily" request euthanasia or help in suicide who would not otherwise do so, can exhibit most of the features of interpersonal, domestic abuse—suggestion, urging, manipulation, and threat aimed at one person by another—but it incorporates an additional feature: the weight of professional authority. It is the physician who holds the power in the physician/patient relationship, not only because the physician has greater knowledge of the physiological processes affecting the patient and how to control them, and because the physician's social aura conveys authoritative standing to his or her role, but also because the patient is ill. Especially when it is terminal, illness can place a person in a particularly compromised position: for many patients, illness involves discomfort and pain, anxiety, fear of impending loss of one's relationships, and fear of death. Thus "professional authority" trades on two factors: the greater weight of the physician and the compromised position of the patient. Both factors invite abuse. The nurse may also be regarded as a medical authority, particularly in situations (e.g., home care) where it is the nurse who is the primary or only contact with the patient, but it is the physician whose capacity is greatest for exploiting professional authority.

Given this disparity of power in the physician/patient relationship, physicians are very well aware of their power to influence patient choices—even while preserving the appearance of obtaining informed consent. The Latinate obscurity of medical diagnosis and the overwhelming nature of too much medical information often contribute to this possibility. Thus, many physicians claim they can get patients to agree to nearly anything they propose; it is simply a matter of how the choice is framed. Just as, in the traditional example, the glass of water can be described as half empty or half full, a proposed surgical procedure with a 50/50 predicted outcome, for example, can be described as a probable success or a probable failure; a "good chance" can mean anything from a 10 or 20 percent chance of success to 80 or 90 percent. Information can be orchestrated to emphasize benefits or to emphasize risks, even when information about both benefits and risks is actually provided. Presumably, thus, physicians would find it easy to frame choices about euthanasia or suicide in similar ways: unfavorably for patients whom they wanted to discourage, but favorably for those whom they hope to maneuver into this choice. Thus, even under legislation which protects only *voluntary* choice by competent patients, it is argued, the physician could manipulate the patient into choosing death when the patient would not otherwise have chosen it or when it is actually contrary to his or her own wishes. In all these cases, the fiction that the patient has given informed consent can be preserved; what is problematic is the way in which the physician presents the information on which the patient's choice is based.

There is a second way in which professional authority can play a substantial role in shaping patient choice. Much of the interaction, as well as the legal support, for the relationship between physician and patient is based on assumptions of *informed consent*—that is, that the patient retains the right to give or withhold consent to treatment and that in making these choices the patient is entitled to adequate information about the alternatives involved. Informed consent must be explicitly documented for specific procedures, e.g. surgery; it is assumed for a wide range of minor tests and procedures involved in medical care. But reliance on informed consent also reinforces power disparities in the physician/patient role and exacerbates the weight of professional authority: in informed consent, it is the physician who proposes the specific course of treatment and the patient who gets to say yes or no. But in this arrangement, it is the physician who identifies the problem, frames any suggested solution to it, and controls how many alternative solutions are proposed. The patient cannot know whether the problem could be seen in some other way or as some different sort of problem, whether other sorts of solutions could be proposed, whether in making the choice to give or withhold consent he or she is making a choice among all the reasonable alternatives, and, sometimes, whether there really is any problem at all. The agenda is, so to speak, entirely in the control of the physician. This may of course be a reasonable arrangement for consent to medical procedures which do not raise values dilemmas, but it is hardly a defensible arrangement in the case of euthanasia. Euthanasia is, after all, a quintessential "values" issue: whether a person prefers a chance of extended life in spite of suffering or pain, or whether he or she prefers an earlier, easier end to life in order to avoid suffering and pain. If consent to euthanasia is treated in the way consent to other medical procedures is, it will be the physician's agenda, not the patient's, that is on the table for action, and to which the patient's only option is to agree or disagree. But this, of course, is fertile ground for abuse.

Furthermore, the physician's capacity to shape patient choice in euthanasia, both by selective control of information and by initial formulation of both the problem and the solution presented for consent, may be influenced not only by malevolent but also by paternalistic intentions. To be sure, there are physicians motivated by greed, prejudice, fear of malpractice action for a medical mistake, and so on. But there may also be physicians who genuinely believe that euthanasia would be in the best interests of the patient, given the pain and suffering the physician knows otherwise lies in the patient's future, and who thus may seek to influence patient choice in this direction for the patient's own sake. Of course, whether manipulation of the patient in what the physician perceives to be the patient's own interest is to be counted as abuse depends in the end on theoretical issues about the nature of paternalism and whether abuse is defined as violation of voluntary patient choice or as violation of patient interests, but the possibility of paternalistic manipulation of the patient by the physician must at least be considered among the varieties of possible abuse.

3. *Institutional abuse.* Institutional abuse will no doubt include some of the features of interpersonal abuse and also professional abuse, but it is again conceptually distinct in its central feature: it operates by narrowing the range of actual choices open to the patient. It may seem to closely resemble those forms of professional abuse in which the physician shapes the patient's choice by selectively providing information or proposing one rather than another possible course of action for consent, but it functions in a distinct way: it erects barriers so that certain choices can be made only with difficulty or cannot be made at all. It is not only that choices are shaped, but, more importantly, that only certain choices are possible, while other choices are closed off. There need be nothing clandestine about this, as there may seem to be when the physician withholds specific information or selectively emphasizes some information in order to promote certain choices; in institutional abuse, in contrast with professional abuse, the policies in question are typically open and sometimes widely known, even though they may have manipulative or coercive consequences.

What are the fears, so vocally and variably expressed in the public discussions of euthanasia? They are fears about various sorts of institutions: hospitals, nursing homes, insurance companies, the government. They are fears primarily of policies which are financially motivated, seeking to cut costs in medicine by offering less care, imposing barriers, and withdrawing certain options. They are fears that hospitals will not provide certain types of care or will provide it only to some patients, that nursing homes will let the quality of care and of institutional life deteriorate to the point where it is unbearable, that insurance companies will exclude from coverage many forms of treatment and palliation which might benefit the patient, or that they will exclude some patients from coverage altogether. They are often fears about the government, usually fears of government intrusion via restrictive policy development.

Furthermore, these fears of what might occur were active euthanasia and assisted suicide to be legalized are rooted, it is evident, in current observations of what is perceived to constitute institutional abuse already, even though such abuse cannot now openly lead to choices of euthanasia and suicide. These are perceptions of institutional abuse in a health care system which is grossly inequitable and in which costs are out of control: a health care system in which many persons have no medical insurance; in which medical insurance is often prohibitively expensive; in which some insurance policies are misleadingly and seriously inadequate; in which insurance companies proceed by "cream skimming" and experience rating for risk avoidance, selecting for coverage persons whose health risks are good and refusing coverage to those whose health risks are not; in which both private and governmental insurers evade payment by delay and by nuisance requirements concerning filing claims; in which coverage for some sorts of patients (e.g., Medicaid) is so low that they become unattractive to providers; in which some sorts of facilities (e.g. rural and ghetto clinics) are closed or never provided; and in which the general degree of evasion and virtual deception in public statements about health care is perceived to be high. Given the chaotic nature of the current U.S. health care system, in contrast to the well-developed national health provider and insurance systems in place in other industrialized nations, it is reasonable to suppose that fears of institutional abuse in the legalization of euthanasia will be higher here than in any of these other countries—and, indeed, with good reason.

Fears of institutional abuse are further exacerbated by the fact that a very substantial portion of health care expenses are spent in the last month, two months, six months of life. But while it is possible to determine which the last month, two months, or six months of life has been for a given patient only retroactively, this in general coincides with the period in which a patient is understood to be terminal—and in which, under a statute like Initiative 119, active euthanasia or assistance in suicide would be legal. Thus it is not just that the health care system is inequitable and chaotic, with costs spiralling wildly out of control, it is also that a very substantial portion of these costs are directly associated with precisely those patients for whom euthanasia and assisted suicide would first become legally available. The shorter and easier a terminal course is, the cheaper it is to cover; and the cheapest patient of all is one who chooses death now. This, of course, is a particularly inviting occasion for institutional abuse.

To understand the pervasive possibilities of institutional abuse, we must also understand the various mechanisms by which it operates. There are, I think, three primary mechanisms which wholly or partially close off choice: direct policy stipulations, indirect policy agendas, and the use of policies which control preference. The first of these involves direct, usually overt and publicly announced policy stipulations or rules: for instance, policies or rules requiring the use of certain forms of treatment or prohibiting the use of others, covering some but not all care, and so on. But some seemingly direct policies, overt and public, may also have indirect agendas; this is the second form of mechanism by which institutional abuse can take place. Several current examples come to mind, and though they cannot now lead to legally performed euthanasia or assisted suicide, they represent the kind of indirect-agenda policy one might also expect to see if euthanasia were legal. These include the development of Diagnosis-Related Groups as a basis for Medicaid and Medicare reimbursements to hospitals: while DRG's are officially formulated and were originally announced as "averages" for care costs for specific disease classifications, they have become—quite predictably—ceilings. Similarly, the Patient Self-Determination Act, effective December 1, 1991, requires hospitals, nursing homes, hospices, home health agencies, health maintenance organizations, and other health care facilities which treat Medicaid or Medicare patients to inform patients at the time they are admitted of their right to make decisions concerning their own medical care, "including the right to accept or refuse medical or surgical treatment and the right to formulate advanced directives"[8] by signing a Living Will or Durable Power of Attorney. These facilities must also ask incoming patients if they have already made an advanced directive. This legislation seems an impressive acknowledgement of patients' rights to autonomy in health care. But it is already widely believed—predictably so—that the legislation does not simply require health care facilities to ask patients *if* they have Living Wills, but that it requires health care facilities to "see to it" that patients have Living Wills. To bureaucratic entities concerned with controlling costs in terminal care, this cannot be an unwelcome misunderstanding.

Third, some policies have the effect of making only some choices rational ones for a person in specific circumstances, even if other choices would be permitted. An example already in place, which might be thought to be particularly coercive if euthanasia or assisted suicide were legal, is the provision requiring spend-down for coverage by Medicaid: a person facing an extended period in a nursing home must exhaust virtually all his or her own funds before public assistance begins. For the person who is already terminally ill and who faces a choice between exhausting his or her legacy for a comparatively short period of additional life, versus leaving earlier but managing to leave one's legacy behind for a spouse or for children, this may not seem to be a choice at all, but a situation in which federal policies make the choice of earlier death the only really rational one. And, of course, policies such as this may trigger various forms of interpersonal abuse as well: the spouse who will be impoverished if the patient chooses to live, but left with a legacy if euthanasia is the choice, may be unable to resist innuendo, manipulation, or open coercion in the matter.

Protections against abuse

The picture of possible abuse is a grim one, particularly in a society with a chaotic health care system, but it is, I think, a real risk. Yet I also think it is possible to erect protections against such abuse that can be both stable and effective. Such protections are not foolproof, and the policies and regulations in which they are incorporated are not likely to stop those who operate outside the law in any case. Nevertheless, these protections are adequate, I believe, to prevent the kind of general, large-scale, "normal" abuse that many forms of the slippery-slope argument predict, and thus render unwarranted the large-scale limitation of patient choice that laws prohibiting euthanasia and assisted suicide represent.

These protections fall into three general categories—policies designed to protect the quality of the patient's choice, policies designed to control professional and institutional distortions of a patient's situation, and policies designed to permit the development of objective indices of abuse. Though they are to be described separately here, they will function best, of course, in concert and interactively. Indeed, I think that all or nearly all of the forms of protections described here will need to be in place to provide reliable prevention of abuse.

Policies designed to protect the quality of the patient's choice

Policies designed to protect the quality of the patient's choice must attempt to look at two things: how the patient reached that choice, and what the content of that choice is. Both raise enormous theoretical issues, requiring answers to two philosophically difficult questions, drawing on two distinct senses of the term "rational": what must one have done to have made a "well-chosen" or "rational" choice? and what characteristics must the "right" or "best" choice, that is, the "rational" choice, display? Nevertheless, we can intuitively discern choices that are badly made in the sense that they are the product of irrational thinking, inadequate information, undue outside influence, and so on; and we can also discern choices that seem to be, given the interests and values of the individual making them, simply bad choices for him or her to have made, regardless of how carefully they were considered. Of course, this raises enormous issues of paternalism, but we can nevertheless discern at least the broad outlines of "badly made" and "bad" choices. The two mechanisms discussed below attempt to protect the quality of the patient's decision in both these cases.

Psychological evaluation. Several proposals for amending the proposed aid-in-dying legislation recommend provisions for offering or requiring a psychological evaluation of the patient who requests euthanasia or assistance in suicide. Generally, such evaluations would seek primarily to identify psychopathology or other disturbances of reasoning, especially depression, which might affect the patient's capacity to reach a fully voluntary, autonomous choice; they would thus be designed to protect the patient from choosing badly. Such evaluation might routinely use standard scales of depression, such as the Beck Inventory; it might also involve interviews by the physician involved or by a consulting physician, psychologist, or psychiatrist. Such evaluation should be conducted in private with the patient, away from the influence of family members or other parties who might exert pressures of various subtle sorts. However, it cannot be too easily assumed that any evidence of depression that could be detected in this way is grounds for rejecting a request for euthanasia or assistance in suicide; depression is a natural accompaniment of terminal illness, though more pronounced in some stages of the dying process than in others, and terminal illness, while it may involve some gains in intimacy with one's loved ones, is also a period of continuing loss. The routine use of psychological evaluation adapted for other situations, especially to detect depression, ought not to impose a higher standard for decision-making than for other important decisions in life; instead, it ought to be used just to identify the clearest cases of transient, *reversible* depression which may be affecting patient choice. Thus, psychological evaluation measures used in these situations—for persons diagnosed as terminally ill, with less than six months to live—must be redesigned so that the expression of thoughts about death, considerations of suicide, or the wish to die is not interpreted as *prima facie* evidence of depression and so taken to preclude voluntary choice.

Counseling. As least until recently, most counseling available in the U.S. has been committed to the principle of suicide prevention, and would view any expression of a wish or intention to die as grounds for further treatment. In this sense, most counseling has been directive: it has been concerned to direct clients or patients towards life-affirming choices and constructive ways of resolving their problems, away from death. Furthermore, perhaps as a result of the *Tarasoff* decision, most psychologists have understood themselves to be obligated to report serious potential harm to third parties or to the patient, and hence obligated to take action (for instance by initiating involuntary commitment) with respect to a patient who reports a serious intention to commit suicide. In a large range of cases, these postures are entirely appropriate. But they are not appropriate in the circumstances at issue in terminal illness, especially if the patient has a legally protected right to euthanasia or assistance in suicide; here, what is in order instead is genuinely nondirective counseling, designed to help the patient discover whether his or her request for euthanasia or assistance in suicide is in fact a genuine one, carefully thought through, fully understood, and in keeping with his or her most basic values—that is, whether it is the "right" or "best" or "rational" choice *for this person.* Of course the request might be a "cry for help" or the product of external manipulation or other abuse, but it might also be a genuine product of the person's most considered, reflective choice. Any counseling offered ought to serve solely to differentiate these two, not to close off one set of options; if not, it is useless in these situations. Suicide-prevention centers and crisis hotlines have, I have argued elsewhere, been particularly remiss in failing to serve that proportion of the population who may find their services most valuable: persons considering suicide (or euthanasia) as a way of responding to the prospect of deteriorative terminal illness, as well as those with severe permanent disabilities or advanced old age.[9] Such persons, who take themselves to be considering a rational response to difficult circumstances, cannot avail themselves of services whose announced purpose, "suicide prevention," makes it clear that they will work to preclude such a choice, or of services whose policies require initiating involuntary commitment for persons viewed as likely to commit suicide. Rather, what is needed is counseling designed to help a patient think through the issues in "rational suicide," including requests for assistance or for physician-performed euthanasia. Such suicide-neutral counseling takes the request at face value and seeks to help the patient be sure he or she has considered all consequences, acknowledged his or her own emotions, and recognized all conflicts or affirmations of value such a choice might involve.[10] Indeed, such counseling may well serve to reduce the psychopathology of such situations by allowing more open discussion of them; but it cannot do so if it is committed to pre-shaping choice.

Continuity requirement or waiting period. Some proposals have suggested that a waiting period be required between the initial request for euthanasia or assistance in suicide and the provision of these services. The clear intent behind such proposals is to ensure that the choice is stable and enduring, rather than a fleeting, transitory response to a new setback, and hence that it is an expression of the patient's true, underlying values. Other mechanisms which might be said to provide concrete evidence of the patient's values at earlier periods in life would include such instruments as a Living Will executed before the onset of the terminal illness or at an earlier point during it; some courts have considered records of or testimony about earlier comments made by the patient concerning other persons in similar circumstances. While a short waiting period (say, 24 or 48 hours) may serve as some protection against impetuous decision-making, longer waiting periods (say, a month or two) are not only artificial but have the potential to be cruel, since they postpone that very relief the patient is seeking. Paradoxically, waiting periods may also encourage some patients to make premature requests as a way of getting into the queue early. Living Wills and Durable Power of Attorney documents need not be signed under controlled circumstances, and it is sometimes argued that they do not reliably represent a patient's true choices over time, especially since the patient may be unable to correctly anticipate his or her future situation. Despite the deficiencies of waiting periods and advance directives, nevertheless, some form of protective device designed to ensure both the stability of the choice and its consonance with the patient's own values seems appropriate—provided, of course, that it does not completely preclude any possibility for the patient to change his or her mind. Notice what is *not* recommended here as a protective device: the deliberations of a committee. These can only be deliberations about the content of the patient's choice, not the patient's voluntariness in making that choice, and I do not see that a committee decision on whether the patient may or may not end his or her life protects the quality of the patient's choice. More likely, it serves to protect the institution in which the committee is based.

Policies designed to protect against professional and institutional distortion of a patient's choices

The sorts of policies considered in this section are designed to prevent both intentional and inadvertent distortion of a patient's situation and hence a patient's choices by either the physician or other health care providers or by institutions, including hospitals, nursing homes, home care agencies, insurance companies, and governmental agencies.

Prohibition of fees. In remarks published before the vote on Initiative 119, Professor Albert Jonsen warned of a "flood of persons" who would travel to Washington in order to seek euthanasia. Other voices warned of the development of "death houses" or "euthanasia clinics," clearly drawing on the analogy with abortion clinics, and some suggested that unscrupulous physicians would offer inducements to patients to seek such services, perhaps by advertising in the public or medical media. Remote as these predictions might seem to be, there is a simple way to prevent such traffic and the institutional stimulation of such traffic: no physician or other health care provider should be permitted to charge a fee for performing euthanasia or for providing assistance in suicide, or at least no fee beyond minimal compensation for the time actually involved. Advertising such services, at least in any way more elaborate than announcing their availability, should also be prohibited. Euthanasia is not a complex procedure, if reliable information is available to the physician about methods for performing it (as would presumably be the case if the procedure were legalized), though it may be performed in comparatively slow ways that do involve extended time. At least some physicians in the Netherlands, where euthanasia is in effect legal and where medical information about methods to be used is widely available, report that they do not accept fees, even though the procedure may be performed in a hospital or in a home, and even though, at the request of the patient, the procedure is often performed in a way that involves a long, slow induction of sleep followed by coma over a period of several hours, usually to make the transition from life to death easier for the family to watch. Dutch physicians report that they expect to remain with the patient (and the family) throughout this time, though they do not take fees for it.[11] Similarly, to prohibit health care facilities from advertising and from charging fees for euthanasia or any closely related ancillary services, or from charging fees that would provide a profit over expenses, would preclude at least some incentives for euthanasia and for the development of a euthanasia "trade" or market.

Documentation. A second form of protection against abuse involves extensive documentation of any procedure involving euthanasia or the provision of assistance in suicide. Such documentation, presumably to be a part of the patient's medical record, would include the medical history, the prognosis, the nature of the current problem(s), the reasons for the patient's request (both the patient's stated reasons and the physician's perceptions of the patient's reasons, if different), and a record of the physician's discussions with the patient's family, if any. Also to be included in the documentation is a clear expression of the patient's choice: not merely a signed "informed consent" to the procedure itself, but documentation of the patient's active request. This might of course take many forms—a letter, a tape-recording of the patient's voice, or witnessed statements by observers—but the central element here is documentation of the fact that euthanasia or assistance in suicide is the patient's idea, not that of the physician, the family, or the health-care facility.

As a second, equally important component, the documentation should also include a record of treatment alternatives discussed with the patient, including treatment alternatives refused by the patient as well as those accepted, forms of pain relief or symptom control offered the patient, and, also equally important, any forms of treatment potentially effective for the patient's condition but excluded from coverage by insurance policies, by the health care facility's care priorities, by governmental rationing policies, and so on. Thus these three elements of documentation serve to reflect interpersonal, professional, and institutional abuse respectively.

Reporting. The performance of euthanasia or the provision of assistance in suicide should also be reportable to an appropriate external agency. At the moment, of course, there is no such designated agency, but a number of possibilities suggest themselves: for instance, the coroner (since presumably the cause of death, euthanasia, perhaps together with the disease causing the terminal condition, would be entered on the death certificate), or the Centers for Disease Control (as a keeper of mortality statistics), or the National Institutes of Health (as a federal research agency), or Health and Human Services (as the highest level of federal bureaucracy for health issues), etc. However, the natural analog to the Dutch reporting requirement would not be immediately plausible in the U.S.; in the Netherlands, because euthanasia is technically a violation of statutory law and the guidelines developed in lower and supreme court cases serve as a defense to prosecutions for homicide, the physician is obligated to report any occasion of euthanasia to the Ministry of Justice after the fact, where it is reviewed and prosecution undertaken if the guidelines are not met. (As is well known, only a small proportion of Dutch physicians has been doing so, though this number has been increasing in recent years.) However, if in the United States euthanasia and assistance in suicide were legal under statutory law, reporting to the Department of Justice or state-level judicial authorities would not seem immediately plausible, since technically, no crime would have been committed; perhaps, however, a reporting requirement could be inserted in the authorizing law. Whatever the agency to which report is made, what is important in preventing abuse is that detailed information about cases of euthanasia be available for review; the effectiveness of this structure would clearly also be enhanced by a substantial penalty for not reporting.

Indices of abuse. Documentation and reporting of euthanasia cases makes possible what is perhaps the most important mechanism for the control of abuse and the reliable provision of protection to patients. What is central here is the possibility of retroactive inspection on a broad scale of patterns of performance of euthanasia. As in current analyses by John Wennberg at Dartmouth and others of geographical variation in surgical procedures and other statistical assessments of medical practice, the performance of euthanasia and assistance in suicide, if documented and reported, would also be open to objective review. Review, of course, could be made at all levels and for all factors reported: by individual physician, by health care facility, by insurance carrier, by type of terminal condition, by length of association between patient and physician, by types of pain control and symptom palliation provided, by types of alternative treatment denied, by age, race, gender, handicap status, and so on. Thus many quite revealing questions could readily be answered: Do some doctors provide assistance in suicide more frequently than others? Do the patients of some nursing homes request euthanasia more frequently than the patients of others? Are patients covered by some health insurance plans more frequently denied care for certain sorts of conditions, and are these denials listed among their reasons for choosing euthanasia? How often are spend-down provisions among the reasons for such choices? Do black patients "choose" euthanasia more often than white? Patients with poor educations or lower incomes more often than patients with privileged backgrounds? While such data might not always be easy to interpret, physicians who had become euthanasia enthusiasts, nursing homes providing deliberately intolerable care, and insurance companies forcing patients into euthanasia choices by refusing to cover certain sorts of care could be tentatively identified, and further examination of specific situations then conducted by the appropriate review organizations.

Furthermore, not only would analyses of such data reveal patterns of euthanasia practice and hence probable patterns of euthanasia abuse, but there is already some basis for comparative analysis of such data. The new Remmelink Commission study from the Netherlands provides the first objective glimpse of euthanasia practice in a climate in which it is widely accepted and in which it is legally tolerated: it is now known, as we saw earlier, that about 1.8 percent of all deaths in the Netherlands are the product of euthanasia and that about 0.03 percent of all deaths involve physician-assisted suicide. Additional information about these patients is also available: for example, their average age at the time of euthanasia (62 for men, 68 for women; interestingly, Dutch physicians report very few requests from older patients); their regional location (more in urban areas); and the approximate amount of life forgone (in 70 percent of cases, more than one week; in 8 percent, more than six months). Information is also available about the reasons for their requests of euthanasia: loss of dignity (mentioned in 57 percent of cases), pain (46 percent), "unworthy dying" (46 percent), being dependent on others (33 percent), and tiredness of life (23 percent). According to this study, in just over 5 percent of cases was pain the only reason. Furthermore, about two-thirds of initial requests for euthanasia do not end up as a serious and persistent request at a later stage of the disease, and of the serious and persistent requests, about two-thirds do not result in euthanasia or assisted suicide since, according to the study, physicians can often offer alternatives.[12]

Information of this sort would provide an initial basis for comparison of U.S. experience with a country in which two relevant characteristics are different. First, the Netherlands is a country in which the practice of euthanasia is widely and generally accepted, both by patients and by physicians; thus, it is a country in which the incidence of euthanasia is, presumably, not distorted by severe social discouragement. Second, it is a country in which the practice of euthanasia is uncoerced by financial considerations on the part of the patient (the Netherlands has an effective national health insurance system which provides all residents with extensive care in the hospital, nursing home, and at home); thus, it is a country in which patient choice is not constricted in at least one way common in the U.S. Thus, the Dutch experience can provide tentative expectations about what our own experience might be were euthanasia accepted and were it not affected by financial considerations; though of course this is a highly conjectural strategy, examining the practices in the Netherlands can at least initially provide very rough, informal guidelines for scrutinizing our own practice. If we suppose for example that, despite differences between Dutch and American culture, somewhere around 1.8 percent is the "normal" percentage of persons dying who would choose to do so by euthanasia when that alternative is socially accepted and when it is not coerced by financial considerations, and that a tiny additional fraction would choose physician-assisted suicide, we then have an easy measure for suspecting abuse in our own society. Are, say, 10 or 20 percent of terminally ill Medicaid patients choosing suicide, but not such a high number of privately insured patients? Thirty or 40 percent of the uninsured? About one-fourth of Dutch AIDS patients die by euthanasia; is the proportion higher among AIDS patients here? Is "pain" the reason for which a large proportion of patients are said to have chosen euthanasia? Since this is the primary reason for only 5 percent of Dutch patients choosing euthanasia, we might well suspect foul play—or its medical and bureaucratic variations, like deliberate neglect or refusal to provide adequate symptom control—if the rates in the U.S. were much higher. Of course, these figures can hardly be treated as rigid norms, and certainly not as either quotas or ceilings; but they can give us some idea of what we might expect were we to permit the practice here, and what would be wildly out of bounds. This is not to assume that the Dutch have got it right, so to speak, and that abuse never occurs in the Netherlands; but inasmuch as there is no documented evidence that abuse is occurring (other than very rare "outlier" cases), it is reasonable to begin with Dutch experience as a guide to what, if all went well, we might expect in the U.S. To be sure, these proportions might change as social attitudes change, and would no doubt increase if acceptance for self-determination in dying were to grow; they may of course also change in the Netherlands. And these proportions would of course change dramatically if Robert Kastenbaum's well-known prediction were to come true, that suicide will become the *preferred* mode of dying because it enables a person to control the time, place, and circumstances of doing so. Thus statistical analysis cannot by itself identify patterns of abuse without some further analysis of social values and trends; but it is nevertheless adapted to identify variations in pattern within a culture and across institutional and geographic lines. What the data from the Netherlands now tell us is that we should expect that euthanasia would be quite infrequent—less than 2 percent of all deaths—and that the reasons for which patients choose it do not have to do only with pain. Of the various mechanisms for protecting against abuse, it is the possibility of potential public exposure, incurring the risk of further legal action, that provides the most secure protection, provided of course the penalties for not reporting are substantial as well. It is true that many of the slippery-slope arguments warn of abuse on a vast scale, but they forget that we can easily put in place expert methods for detecting and thus preventing it.

As I said earlier, I think it is the moral responsibility of those who favor legislation to show how abuse can be prevented; I also think it is the moral responsibility of those who oppose legalization to try to show that abuse will occur and that it can be prevented in no other way. The burden of proof in this immensely important, sensitive area falls on both sides, and neither side can be certain of its predictions about the future. However, the present does provide us with a good deal of evidence for thinking clearly and specifically about just what sorts of abuse we might expect and what sorts of abuse can be prevented, and I think the weight of the argument falls in favor of recognizing patients' rights to self-determination: even if abuse might otherwise occur, there are sophisticated, effective ways to prevent it, and the right in question is too fundamental to suppress without compelling reason. I have no doubt but that abuse could occur; in fact, all the forms of potential abuse elaborated here already occur in our current choices about death—that is, in choices of withholding and withdrawing treatment, the only forms of control over death legally permitted in the United States. Because these sorts of choices about death are less conspicuous than choices about euthanasia and assisted suicide, they are less subject to review and control via the various mechanisms identified here. Indeed, I think the open, legal practice of voluntary active euthanasia and physician-assisted suicide will have not only the morally important effect of leading to recognition of a wider range of what I believe to be fundamental rights, but, insofar as it will require us to erect protections against abuse, the practice of euthanasia will also prod us to develop much stronger protections for the kinds of choices about death we already make in what are often quite casual, cavalier ways.

References

1. *The California Death With Dignity Act,* California Civil Code Title 10.5, Initiative.

2. Edward Larson, "Washington State: the Nevada of Death?" *Seattle Times*, October 1991.

3. Robin Bernhoft, M.D., "Should Aid-in-Dying Be Allowed? No." *Seattle Times*, October 27, 1991, p. A21.

4. The proposal was put forward by F. I. Meijler, a cardiologist at the University of Utrecht, in 1984. See Carlos Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands*, New York: Free Press, 1991, p. 96, citing Teresa Takken.

5. This does not, however, entail that love-sick teenagers have a fundamental right to suicide or that one ought not intervene to prevent the suicide of a person who is depressed. For an extended discussion of how a right to suicide can be fundamental but not entail these conclusions, see my "Suicide: A Fundamental Human Right?" in M. Pabst Battin and David J. Mayo, *Suicide: The Philosophical Issues* (New York: St. Martin's Press, 1980), pp. 267-285.

6. Reported in English in Paul J. van der Maas, Johannes J.M. vanDelden, Loes Pijnenborg, and Caspar W. N. Looman, "Euthanasia and Other Medical Decisions Concerning the End of Life," *The Lancet* 338: 669-74 (September 14, 1991).

7. *Ibid.*, p. 671.

8. Public Health and Welfare, 42 section 1395cc(f)(1)(A)(i).

9. See my brief note, "Suicide Prevention Centres Fail the Elderly," *Current Awareness Bulletin* of the Suicide Information and Education Centre (Calgary, Canada) 3:3 (Summer 1988).

10. For specific recommendations concerning how to conduct such counseling, see my paper "Rational Suicide? How Can We Respond to a Request for Help?" *Crisis* [Journal of the International Association for Suicide Prevention] 12:2 (1991).

11. Source: personal interviews in the Netherlands, September-October 1988; 1989; 1990.

12. Van der Maas et al., *op cit.*, p. 673.