

The Role of Guidelines in the Practice of Physician-Assisted Suicide

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Oregon has legalized and implemented physician-assisted suicide, while observers argue about the moral import of attempting to formulate guidelines; the utility any set of guidelines can have for physician practice, health care providers, patients, or families; and whether guidelines can really protect against harm or abuse. What were once theoretical questions have taken on new urgency.

The debate over the value and power of guidelines includes the following questions: What has been the experience of efforts to implement physician-assisted suicide using consensus guidelines? What goals are guidelines intended to serve? Who should formulate guidelines? What features should be reflected in any proposed guidelines to make them practical and to permit achievement of their goals? Are there any fundamental obstacles to the creation or implementation of guidelines? Is dying a process that is amenable to direction under guidelines, be they issued by physicians, departments of health, blue ribbon panels, or other regulatory bodies? This paper explores these questions as physician-assisted suicide becomes legal.

Proponents and opponents of physician-assisted suicide can agree on at least one thing: the importance of regulatory guidelines if the practice is to be legal. However, there is much disagreement about the moral import of even trying to formulate guidelines; about how guidelines can affect physician practice, health care providers, patients, or families; and about whether guidelines can really protect against harm or abuse. Questions once only of theoretical interest have taken on new urgency since Oregon legalized physician-assisted suicide.

The debate about guidelines swirls around several interrelated questions. What has been the experience of efforts to implement physician-assisted suicide using consensus guidelines? What goals are guidelines intended to serve? Who should formulate them? Can guidelines be practical? Are there obstacles to creating or implementing guidelines? Is dying a process amenable to direction under guidelines by physicians, departments of health, blue ribbon panels, or other regulatory bodies?

What Is Known about the Value of Guidelines for Physician-Assisted Suicide?

The Netherlands, where euthanasia and physician-assisted suicide are decriminalized, is the only place where guidelines have existed for any significant period. These guidelines were created by the national medical association, along with groups such as pharmacologist organizations (1–4). Americans often invoke data from the Netherlands to support their positions on guidelines for physician-assisted suicide (5–7), but there are limits to what can be learned from the Dutch experience.

Although the Dutch people value guidelines for a practice that is still technically illegal there, the force and precision of guidelines are not what would be expected were the practice legal. Dutch physicians note that many physicians do not follow guidelines (8), and formal studies have reported high rates of noncompliance (9).

How well Dutch guidelines regulate the practice of physician-assisted suicide is a matter of dispute (1, 5, 6–8, 10). Reports of euthanasia without an unambiguous request to die prompted a re-examination of prevailing guidelines. The Netherlands has

Ann Intern Med. 2000;132:476-481.

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This paper was developed by the Assisted Suicide Consensus Panel as part of the Finding Common Ground Project of the University of Pennsylvania Center for Bioethics. The paper was authored on behalf of the Panel by Arthur L. Caplan, PhD; Lois Snyder, JD; and Kathy Faber-Langendoen, MD. Members of the Assisted Suicide Consensus Panel were: Arthur Caplan, PhD (*Chair*); David A. Asch, MD, MBA; Rev. Ralph Ciampa; Kathy Faber-Langendoen, MD; Joseph J. Fins, MD; John Hansen-Flaschen, MD; Barbara Coombs Lee, FNP, JD; Franklin G. Miller, PhD; Sally J. Nunn, RN; David Orentlicher, MD, JD; Timothy E. Quill, MD; Elliott Rosen, EdD; James A. Tulsky, MD, and Lois Snyder, JD (*Project Director*). Primary clinical staff to the Panel was Jason Karlawish, MD. Additional staffing was provided by Jennifer Klocinski.

adopted more restrictive rules, with tougher reporting and witness requirements (8, 9). Studies comparing practices in 1995 with those in 1990 have found that involuntary euthanasia continues to occur at a minimally lower rate. However, many deaths with assistance are not reported to the authorities (11). Differences in the health systems and social structure between the Netherlands and the United States further complicate comparisons.

What Is the Purpose of Guidelines for Physician-Assisted Suicide?

The first published proposals for U.S. guidelines to govern the implementation of legal physician-assisted suicide appeared in the early 1990s. The movement to create guidelines has been a key component in efforts toward legalization and has focused on how to implement a decision to proceed with physician-assisted suicide (rather than on how to decide that physician-assisted suicide is the "right" course for an individual patient). Some of the efforts have created model statutes or legislation, but most talk has focused on providing practical guidance about implementing physician-assisted suicide in an authoritative document.

Legalization is not a prerequisite for the creation of guidelines. Many who initially called for guidelines noted that physician-assisted suicide was already occurring in the United States. They argued that it would be better to have some sort of guidance for physicians rather than leaving physicians and patients to their own devices. Those favoring legalization thought that the cause of legalization would be advanced by promoting practical guidelines. This created a situation in which guidelines were often viewed as nothing more than a stalking horse for efforts to legalize physician-assisted suicide.

Jack Keivorkian's actions and advocacy brought new urgency to guideline writing efforts. Lonnie Shavelson (12) documented several cases in which he felt that persons had assisted others to die for morally dubious reasons. The popularity of books such as *Final Exit* (13) and *Last Wish* (14) made it clear that the public was interested in assisted suicide. Sherwin Nuland's book *How We Die* (15) reinforced the view that the prevailing standard of clinical care for the dying was often not what patients and their families wanted.

The inadequate state of end-of-life care became further evident in the findings of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (16, 17). It was obvious that something had to be done to standardize and improve the overall care of dying patients. If such improvements did not take place,

assisted suicide might become commonplace, without input from those most experienced in caring for the terminally ill.

Those calling for regulation of physician-assisted suicide often made analogies to the effect that law and regulation had had on the practice of forgoing, withdrawing, and withholding life support. The willingness of society to accept the cessation of ventilator use, renal dialysis, antibiotic therapy, and other life-sustaining interventions on the basis of policies, guidelines, and review by ethics committees made many believe that what had worked effectively for forgoing life-sustaining treatment could work for physician-assisted suicide (5, 18).

Finally, in several opinion surveys of the early 1990s, it became clear that many patients and physicians would consider undertaking physician-assisted suicide for reasons that experts in end-of-life care found troubling or simply erroneous (19). Those polled said that they would consider physician-assisted suicide if they were in terrible pain or had to depend on machines. This made some proponents think that regulation was essential to ensure that persons who were disabled or in pain would not prematurely seize upon physician-assisted suicide.

Who Should Write Guidelines?

Despite all the efforts directed toward guideline development, there has been relatively little discussion of who should create them. In Oregon, responsibility for guideline development fell to the Department of Health, although a medical society (20) and a blue ribbon panel also offered guidance (21). Other organized groups that have issued guidelines have tended to consist of professors and academics, with or without clinicians. Political necessity, more than expertise or clinical involvement with terminally ill patients, may have motivated these groups to formulate guidelines (22, 23). One notable exception was the Bay Area Network of Ethics Committee, which in 1997 issued guidelines to help clinicians respond to requests for assisted suicide (24). In part, these guidelines were created in response to numerous requests for physician-assisted suicide from San Francisco residents dying of AIDS.

Obviously, persons favoring legalization are most likely to write guidelines. In the few instances in which medical groups (Michigan Medical Society and New York Academy of Medicine) tried to write guidelines without previous agreement about the desirability of physician-assisted suicide, the efforts collapsed (25). Critics sometimes address the specifics of proposed guidelines but more often reject guidelines on general grounds (for example, no guidelines could ever be sufficient to prevent the

inclusion of inappropriate cases [7, 25]) or as an opportunity to engage in further debate about the general moral merits of legalization (25–27). Of interest, when proponents write guidelines, the intended audience is clinicians or public policymakers rather than the general public.

Although religious groups have spoken about the morality of physician-assisted suicide, none has issued specific guidelines on its implementation or monitoring (28). The Task Force to Improve the Care of Terminally-Ill Oregonians, formed to provide guidance in implementing the Oregon law, was composed mostly of physicians, nurses, and attorneys (21). No patient or consumer groups have issued specific guidelines. This is especially noteworthy given the growing interest in the spiritual and psychological dimensions of dying, as reflected in the enormous popularity of books focusing on these aspects of dying (29–35). Guidelines have mostly been seen as norms or rules for physicians, not as general principles about how Americans ought to think about, control, or implement physician-assisted suicide.

In fact, the U.S. debate about assisted suicide seems to focus on the presumption that the persons who should be most concerned about implementing assisted suicide are physicians (36). Perhaps this stance is partly fueled by the vociferous opposition to assisted suicide by organized medicine and nursing throughout the 1990s on the grounds that such behavior violates norms of professional ethics. But the centrality of clinicians as the audience for guidelines may also reflect a deeply held U.S. view that dying is a matter with which health care professionals and biomedical science must contend (15, 35).

Content of Guidelines for Physician-Assisted Suicide

A sample of the guidelines reveals consistent core content (**Table**). In examining the first set of guidelines published in a major medical journal (37), other guidelines reported in prominent publications (22–24), and state requirements (Oregon), many common themes emerge. All require the individual's informed consent for participation, and most recommend a waiting period to ensure the authenticity of a request. Most guidelines call for consent to be written and witnessed.

Guidelines that involve more physician input include references to conscientious objection. These guidelines also try to capture the importance of good physician–patient relationships with discussions of “meaningful” or established relationships. They seek to ensure that the attending physician's judgment is reviewed by another physician to pre-

vent error or even malice. More recent guidelines tend to include suggestions that independent specialists in palliative care review requests for physician-assisted suicide, that psychiatrists or psychologists be involved in assessing the competency of those making requests, and that palliative care not only be discussed as an alternative but actually be offered to a person making a request.

Recent guidelines confine their scope to the terminally ill, defined as patients with 6 months or less to live. Like the Dutch guidelines, some earlier efforts and a recent California group (38) focused on persons with incurable conditions and intolerable pain.

Critical Reactions to Proposed Guidelines

General concerns suggest that guidelines for assisted suicide will not work in U.S. society because no guidelines can limit physician-assisted suicide to particular individuals or groups and because of worries about the applicability of guidelines to the real world of clinical practice (25). A task force in New York State argued that guidelines would “prove elastic in clinical practice and law” (39). Perhaps the harshest indictment of efforts to construct guidelines comes from Callahan and White (26), who dismiss all efforts at constructing guidelines as “an elaborate regulatory facade concealing a poverty of potential for actual enforcement.”

The main reason for thinking that the slope around physician-assisted suicide might be too slippery even for the most carefully crafted guidelines is that the presumptions behind the guidelines are inherently slippery in ways that no amount of regulatory precision can fix. If physician-assisted suicide is to be limited to the terminally ill, problems arise from physicians' inability to accurately predict who is truly terminally ill. If physician-assisted suicide is to be limited only to persons who are competent, problems arise when competency and capacity are difficult to define and assess. A patient might seek to end his or her life earlier if there is a danger that competency may evaporate as illness progresses. If suffering as well as pain is truly what leads persons to support physician-assisted suicide, then the category of what counts as unbearable suffering or emotional distress is flexible enough to permit and, indeed, require, expansion beyond terminally ill patients.

One way to respond to these concerns is to note that guidelines alone will never be sufficient to control the practice of physician-assisted suicide. As is true of any rule-based practice, room must always be left for discretion and judgment. Bad people will not be stopped from doing unethical things just because rules exist. However, good people can be trusted to make reasonable accommodations in light

Table. Guidelines for Implementing Physician-Assisted Suicide

Who Developed the Guideline (Reference)	Title of Guideline	Disciplines Involved	Year	Areas Addressed in Guideline
Heilig et al., for the Bay Area Network of Ethics Committees (24)	"Physician-Hastened Death: Advisory Guidelines for the San Francisco Bay Area from the Bay Area Network of Ethics Committees"	Medicine, public health, and nursing	1997	Patient characteristics (must be terminally ill, defined as <6 months to live; competent; not depressed; and making voluntary request); physician requirements (palliative care made available, consultation procedure, informed consent process, death certification); role of family
Baron et al. (23)	"A Model State Act to Authorize and Regulate Physician-Assisted Suicide"	Medicine, law, philosophy, ethics, and economics	1996	Patient characteristics (>18 years; terminally ill, defined as <6 months to live); physician requirements (palliation offered, counseling, consultation, documentation, presence at death, conscientious objection option); family role; and legal issues (confidentiality, monitoring or enforcement, and liability)
Coleman and Fleischman (25)	"Guidelines for Physician-Assisted Suicide: Can the Challenge be Met?"	Medicine and law	1996	"Unguidelines"—evaluate existing guidelines and conclude that, despite good intentions, guidelines will not be able to limit physician-assisted suicide to narrowly defined circumstances
Drickamer et al. (19)	"Practical Issues in Physician-Assisted Suicide"	Medicine	1997	Areas of physician skill and knowledge required (understanding of patient motivation, mental states, difficulties in prognostication), role of family and of other providers, methods available for physician-assisted suicide, and effects on patient-physician relationship
Miller et al. (22)	"Regulating Physician-Assisted Death"	Medicine, philosophy, ethics, and law	1994	Patient characteristics (competent, terminally ill, voluntary), request for prerequisites (palliative care offered and judged unsatisfactory), regulatory requirements and protections, and consultative and monitoring mechanisms (palliative care consultants and committees)
Quill et al. (37)	"Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide"	Medicine	1992	Patient characteristics (incurable condition, severe and unrelenting suffering, incapacitated), physician requirements (established relationship, conscientious objection option, documentation requirements, consultation process)
Task Force to Improve the Care of Terminally-Ill Oregonians (21)	"The Oregon Death with Dignity Act: A Guidebook for Health Care Providers"	Medicine, law, nursing, pharmacy, public health, social work, hospice, state agencies, and health systems	1998	Guidebook to implement the Oregon Death with Dignity Act: patient characteristics (voluntary request, >18 years, resident of Oregon, and terminally ill [<6 months to live]), physician requirements (disclosure, process for rescinding requests, conscientious objection), and legal elements (immunity and reporting or monitoring by the state)
Young et al. (38)	"Report of the Northern California Conference for Guidelines on Aid-in-Dying: Definitions, Differences, Convergences, Conclusions"	Medicine, ethics, nursing, law, and religion	1997	Patient characteristics (terminal illness, defined as incurable condition with intolerable, irremediable suffering as defined by patient; capacity, voluntary decision, and other decision-making prerequisites); consultation and palliative care requirements; role of family; role of ethics committees, role of institutions, and special concerns raised by managed care

of rules. Many decisions in medicine are based on decisions about terminal illness, competency, and criteria for unbearable pain or suffering; thus, it will not suffice as an argument to say that because these concepts are vague and have fuzzy borders, they cannot be used to guide practice. Precision is important, but no rules—be they for the courtroom, athletic competitions, operation of motor vehicles, or physician-assisted suicide—can be precise enough to eliminate all gray areas and the need for prudent judgment.

The real core of the slippery-slope objections to guidelines is the cost of making a mistake. If persons who do not fit the paradigm commit suicide, then what moral judgment should be made about this practice and those involved in it? For many Americans, erring on the side of physician-assisted

suicide when competency is in doubt or a prognosis of terminal illness is uncertain might prove tolerable if pain and suffering were clear. However, if suffering, terminal illness, and competency are uncertain, the moral assessment of rules that would permit errors in these circumstances would be far more harsh. Both critics and proponents of physician-assisted suicide need to address their positions about mistakes more clearly.

The other major source of concern about guidelines is feasibility. Physicians sometimes have difficulty diagnosing and managing mental illness, depression, and delirium (40). In addition, they often have not had long-term relationships with their patients. Time and lack of expertise can limit physicians' ability to engage in philosophical rumination or spiritual reflections with patients. Is it appropri-

ate to ask physicians to ensure that family or financial pressures have not coerced patients into asking for physician-assisted suicide? Should physicians be asked to overcome their own moral reservations about suicide when cost pressures and new modes of health care delivery are building more and more walls between physicians and patients? It may also be unfeasible to offer persons alternatives to physician-assisted suicide, such as hospice or home care, in the context of U.S. health care (20). Because many patients lack insurance and others live in areas where services are scarce or culturally insensitive, no set of rules can compensate for the absence of decent basic health care for the dying.

In addition, the absence of an infrastructure for providing oversight to dying patients in the United States also limits the feasibility of guidelines. Relatively few physicians and nurses are skilled at palliative care; thus, developing committees of specialists to monitor clinical practice could prove daunting.

Other Concerns

Most guidelines are written by people who approach the issue of dying from the perspective of health care providers or those involved in law and regulation (21). This may be necessary in some ways, but it contributes greatly to the sense that these guidelines are disconnected from the patient's and family's world of illness, suffering, and dying and that the guidelines serve providers and payers more than patients. Guidelines appear to deal less with trust and collaboration between providers and patient than with the provision of legal indemnification (4, 41). It would be interesting to see the guidelines about physician-assisted suicide that would be written with contributions by persons living with serious illness and the family members, friends, or partners of patients who have recently died. Medical and legal groups emphasize issues that greatly differ from the messages sent about the meaning and significance, pace and pattern, lessons, and morals of dying contained in popular books, movies, plays, and television programs (31, 35, 42).

Many Americans turn to religious or spiritual frameworks to guide them through dying, but these voices are rarely reflected in current guidelines. It is striking that the guidelines often refer to the need for certainty about diagnosis, autonomy, and competency rather than to issues of dependency, relationships, timing, stigma, guilt, symbolism, cultural practices, funeral arrangements, money, and other matters of overwhelming concern to patients and their families (43).

Medicine is often criticized for dehumanizing dying, and the extant guidelines exhibit these same problems. It appears that regulation is fueled by

providers' desire to avoid error and escape liability and lawyers' desire to ensure that the law does not permit physician-assisted suicide to lapse into murder. Concerns about what constitutes a good death (15, 31, 32, 44–47) are not well-addressed.

Although crucial to good end-of-life care, pain control and the role of palliative care specialists (16, 47) have been neglected aspects of health care in the United States. That is beginning to change, however. They have played a role in more recent guidelines. But good pain control and palliative care are not true alternatives to patients who seek a right to physician-assisted suicide in order to control the manner and timing of death.

Those who oppose legalization have emphasized the importance of better pain control and better palliation as alternatives. But patients who face death may not be troubled by the prospect of pain (as was the case for the persons who committed suicide with physician assistance in the first year of the Oregon law's implementation [48]). More often, they are troubled by the potential for loss of dignity as they define it, isolation, loneliness, fear, anxiety, the expectations of others, the desire not to cause sorrow or to be a burden for family members and friends, and what will happen to loved ones after death. Many do not wish to die with their minds fogged or unconscious. These matters and views of what a good death requires are not addressed by the ample provision of pain-controlling medications, but they are crucial in articulating the guidance needed to bring about a good death (4, 27, 35).

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Grant Support: The Walter and Elise Haas Fund and the Wallace Alexander Gerbode Foundation supported the development of this paper and the Finding Common Ground Project on Assisted Suicide.

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