The Debate over Physician-Assisted Suicide: Empirical Data and Convergent Views

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The debate over physician-assisted suicide is a small part of the process of improving care for all dying patients and their families. Available data, although limited, can help clarify this narrow debate and can provide a useful context for articulation of the common ground. This paper reviews these data, which suggest that unnecessary end-of-life suffering can be considerably reduced by improving access to and delivery of palliative care and improving recognition and treatment of pain and depression in terminally ill persons. It also sets forth possible areas of common ground between the two sides in the debate. Even with the best of care, a small number of dying patients will still have suffering that cannot be satisfactorily relieved, and some of these patients will request assistance in hastening death. Terminal sedation and the voluntary cessation of eating and drinking may be legally acceptable alternatives to physician-assisted suicide for the few patients whose suffering cannot be made tolerable with standard palliative interventions. Physicians should not violate their fundamental values when faced with such patients but should make patients aware of the full range of available alternatives to prolonged, intolerable distress. Physicians have the responsibility to give comprehensive palliative care to terminally ill patients and their families throughout the dying process and to make every effort to explore, understand, and address suffering that persists despite their best efforts.

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The debate about physician-assisted suicide in the United States has been contentious. Although the U.S. Supreme Court recently ruled that there is no constitutionally protected right to physician-assisted suicide (1, 2), its decision clearly endorsed the use of intensive palliative care (3) and seemed to give a green light to experimentation at the state level so that this "earnest and profound debate" can continue. The subsequent re-passage (by 60% to 40%) of Measure 16 in Oregon (the referendum legalizing physician-assisted suicide for competent, terminally ill patients) almost guarantees that this public and professional discussion will remain center stage (4). Unfortunately, the debate in Oregon and the rest of the United States has too often been characterized by distortion of the available data and failure to recognize areas of general agreement. Although we need more information about how people die in the United States, the widely divergent interpretations of the Remmelink Reports from the Netherlands (5, 6) should make us skeptical about whether "objective" data will resolve this emotion-laden issue (7, 8). Nonetheless, organized medicine is beginning to clarify its responsibilities in the care of the dying (9–12), and the debate on physician-assisted suicide has provided both fuel and a distraction.

We believe that the convictions the opposing camps have in common may be as important as their differences, and we believe that the available data, although limited, can answer some underlying questions. Within this context, our paper has two objectives: to provide background data that help clarify the debate about physician-assisted suicide and to outline areas of general agreement about physicians' responsibility to their dying patients.

We do not attempt to resolve the controversy about whether physician-assisted suicide is ever morally justifiable, nor do we address whether legalizing physician-assisted suicide would be good public policy. Despite our efforts to remain objective, some of our biases may emerge in the framing of positions and the analysis of data. Nonetheless, we hope that this document can be a resource for those searching for common ground and understanding in the interest of better serving dying patients.

Background Data

Access to and delivery of pain treatment and other palliative measures are seriously deficient in the present health care systems in the United States (13–31). Physician under-recognition and undertreat-

See related article on pp 559-562 and editorial comment on pp 567-568.

ment of pain and depression in dying patients has been repeatedly shown (13–20), and most physicians have been inadequately trained to provide palliative care (9, 21–24). Medical students and residents are not uniformly taught about pain relief, hospice care, and communication about death and dying (24), and less than 10% of internal medicine training programs include supervision and treatment of dying patients who are receiving palliative care (24).

Forty million U.S. citizens are uninsured and thus have limited access to preventive care, emergency care, hospitalization, long-term care, and hospice. Access to care does not, however, ensure optimal management. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), which investigated end-of-life care in acute-care hospitals, where most Americans die (25), showed high rates of utilization of invasive medical technology, sometimes against a patient's expressed wishes. Fifty percent of patients who died had moderate to severe pain at least half of the time during their last 3 days of life. Solomon and colleagues (26) showed that physicians frequently recognized that they were overtreating patients at the end of life but did not know how to stop.

The United States has an extensive system of hospice programs to serve terminally ill persons, provided that they have acceptable insurance coverage, are expected to live 6 months or less, are willing to forgo aggressive care, and (generally) have a primary caregiver (27–29). Hospice programs use multidisciplinary teams to both address physical symptoms and social, psychological, spiritual, and economic issues. In the United States, hospice is largely home based; few residential in-patient facilities are available. Patients who have chronic diseases with more uncertain prognoses (such as congestive heart failure, Alzheimer disease, or amyotrophic lateral sclerosis) often do not have access to hospice or similar programs (30). Only 25% to 35% of patients with cancer die in hospice programs, and most referrals to hospice are made very late in the course of terminal illness (31).

Unrelieved or unrelievable pain is not often the major or sole reason for requests for physician-assisted death (5, 6, 32, 33). Physicians report that unrelieved pain is infrequently the only reason cited by patients who request or receive physician-assisted suicide or voluntary active euthanasia. In the first Remmelink study (5), unrelieved pain was the sole reason for euthanasia requests in 5% of cases, was part of the problem in 40%, and was not reported at all in the remaining 60% (the 5% of cases were included in the 40%). The most common reasons cited were intolerance of physical disintegration, dependence, being a burden, extreme fatigue, and lack of meaning. A study of the secret practices of Washington State physicians with respect to physician-assisted suicide showed similar results (32). Studies of patients who discontinue life support, such as dialysis, also show that unrelieved pain is not usually the sole motivating factor for discontinuation (33).

Some patients who request physician-assisted death have clinical depression, but others have no definable mental or cognitive impairment (34–45). The evaluation of depression in terminally ill patients is challenging because common symptoms of terminal illness overlap with symptoms of depression, such as fatigue, sleep disturbance, poor concentration, loss of interest in normal affairs, weight loss, and preoccupation with death. Similarly, if expressing a wish to die is defined as suicidal ideation and is equated with depression by definition, then all patients who request physician-assisted death (and many of those who request that life support not be used) will be considered clinically depressed, a self-fulfilling assumption that may be inappropriate. Studies that have modified depression scales because of this potential for over-reporting still show a higher incidence of depression in terminally ill persons than in non–terminally ill controls, but the prevalence varies considerably (13% modified criteria and 26.1% usual criteria) (34, 45). Transient wishes to die are common among terminally ill persons, but relatively few patients have a clear, persistent wish to die. In one small study (43), 60% of patients with a serious, persistent wish to die met the criteria for depression, but 40% had no definable mental disorder.

A central issue in evaluating depression in a terminally ill patient is determining whether depression is distorting the patient's judgment or decision-making capacity (34, 35, 45). Clinical depression that is distorting judgment so that the patient cannot assess treatment options would preclude the patient from making any potentially life-ending decisions, whereas a person with mild symptoms of depression may retain decision-making capacity (39–41). More research and standards are needed on this critical issue.

Few systematic data are available with regard to treatment of depression in terminally ill patients. Some depressed patients will change their minds about wanting to die when their depression is adequately treated (40). Others may refuse to undergo or may be too sick to tolerate trials of antidepressant medications or psychotherapy. Psychostimulants, such as amphetamines, may have a special role in the treatment of depression in terminally ill persons (36–38), but data about their efficacy are sparse.

Palliative care can relieve most but not all terminal suffering (28, 29, 46–53). The efficacy of symptom relief in hospice programs, where a multidisciplinary team is devoted exclusively to palliation, suggests that much terminal suffering can be controlled (28, 29). Despite this success, surveys of hospice patients suggest that 2% to 35% report their pain as "severe" or "intolerable" during the last week of life (46–49). Similarly, in one report (49), 25% of hospice patients reported their shortness of breath as "unbearable" in the last week of life. Such symptoms as nausea, vomiting, and delirium are less amenable to treatment than pain is. Weakness, fatigue, and dependence, the most commonly cited reasons for wanting physician-assisted death, are often even more intractable.

Extremes of otherwise unrelievable suffering can be managed by sedation to unconsciousness (terminal sedation) (47, 50–53), a practice that is gaining acceptance among palliative care groups but is not universally accepted. The prevalence of terminal sedation is unknown, and its acceptability to terminally ill patients, their families, their physicians, other health care providers, and society has yet to be demonstrated.

Public and professional opinion in the United States is deeply divided about physician-assisted suicide (54–66). Over the past 10 to 15 years, public opinion polls consistently show that two thirds to three fourths of the U.S. public support a more open and accessible practice of physician-assisted suicide (54–61). In the early 1990s, state referenda to legalize physician-assisted suicide were narrowly defeated in Washington State and California before Measure 16 passed in Oregon in 1994, 51% to 49%. After a series of legal challenges by opponents, the Oregon legislature forced another referendum vote that passed by 60% to 40%. Opinion polls suggest that the public sees little moral difference between physician-assisted suicide and voluntary active euthanasia. Approximately 60% of physicians favor the more open practice of physician-assisted suicide, but only about half of these physicians would be willing to participate personally (32, 61–65). Physicians in the United States are much more reluctant to participate in voluntary active euthanasia than in physician-assisted suicide (62–65).

Public opinion polls are probably confounded because the public may not adequately understand either the efficacy of palliative care or their right to refuse unwanted treatment. Similarly, the desires of healthy persons for control over the circumstances of their deaths may bear little relation to the desires and needs of terminally ill patients. In our view, public opinion alone is not a rational basis for the legalization of physician-assisted suicide (66).

Despite legal prohibition, some patients request physician-assisted suicide and some physicians secretly provide it (5, 6, 32, 58, 62–64, 67–70). Studies about physician-assisted death in the United States are based on physician self-reports of an illegal practice and are further limited by low response rates, poor generalizability, differing regional attitudes, and ambiguous question construction; thus, exact frequencies are uncertain. No U.S. physician has been successfully prosecuted for participating in physician-assisted suicide (67), but physicians may be vulnerable to disciplinary actions by medical licensing boards if they admit to the practice. Studies in the United States consistently show the existence of an underground, illegal practice that is undocumented and unregulated, lacks the benefit of second opinion, is not prosecuted, and is not rare (70). Approximately 5% of practicing physicians admit to having provided physician-assisted suicide at least once in their careers (68). A survey of Washington State physicians showed that in 1 year, 12% of respondents received a request for physician-assisted suicide and 4% received a request for voluntary active euthanasia (32). Physicians acceded to approximately 25% of these requests. A study of physicians caring for patients with AIDS in San Francisco showed that closer to 50% of these physicians had participated in at least one case of physician-assisted suicide (69).

Although many more patients request physician-assisted suicide than actually receive it, little is known about how physicians respond to such requests (5, 6, 32). According to the first Remmelink study (5), physicians in the Netherlands reported 20 000 preliminary explorations, 9000 genuine requests, and 3000 acts per year (these data are for voluntary active euthanasia and physician-assisted suicide combined). The Washington State survey (32) similarly showed approximately four requests for each act. Neither of these studies explored actual decision making, including what (if any) criteria were used to accede to or deny a request. In the United States, no data are available about preliminary inquiries by patients of their physicians' willingness to participate in physician-assisted suicide.

Several forms of accelerating death (the forgoing of life support, terminal sedation, and voluntary cessation of eating and drinking) that do not involve physician-assisted suicide are currently legally available in the United States, but little is known about frequency or about how and why physicians and patients choose among them (5, 6, 47, 51–53, 71–82). The Remmelink Reports in the Netherlands (5, 6) are the only systematic, population-based studies of end-of-life practices. They found that 17.5% of all deaths involved stopping life support. Another 17.5% were an indirect consequence of efforts intended to "alleviate pain and suffering." The practices of terminal sedation and voluntary cessation of eating and drinking were not considered in this study, so it is unclear how deaths achieved by these means, if they had occurred, would have been reported.

Life-sustaining therapy, including use of ventilators, dialysis, feeding tubes, and intravenous fluids, is regularly withheld or withdrawn in the United States (71–76). Sometimes, these actions are based on a patient's consent or request, made with the full knowledge that death will result from the decision. Some decisions may be made without full patient participation, even though the patient is mentally capable of consent (79). Still other decisions are made after the patient has lost the ability to participate in decision making (71). In such cases, little study has been done about how much the patient's prior directives, the family's assessment of the patient's wishes, the patient's perceived best interests, or other factors are used to justify the process (80).

Of patients undergoing dialysis, 4% to 22% eventually choose to stop treatment with the full knowledge that they will die (33, 74, 75). The varying rates of discontinuance or non-use of dialysis, feeding tubes, ventilators, and other life-sustaining treatments among centers have not been well studied but may reflect cultural, socioeconomic, and geographic factors.

Terminal sedation is sometimes used to relieve suffering that cannot otherwise be satisfactorily controlled (47, 51–53). The patient is sedated to unconsciousness, usually with barbiturates, opioids, or benzodiazepines. Life-sustaining therapy is then withheld so that the patient dies of dehydration or from complications of the underlying disease. The rate at which terminal sedation is used varies from 0% to 40%, depending on the clinical site (47, 52). Some guidelines and safeguards for this practice have been proposed (52), but empirical data are lacking about the circumstances of its use and its acceptability to patients, families, or professional groups. Some instances of terminal sedation may be viewed as cases of "slow euthanasia" (81, 82).

Voluntary cessation of eating and drinking has also been proposed as an ethically preferable alternative to physician-assisted suicide because it relies entirely on the patient's action and does not require a change in the physician's traditional role (53, 77, 78). This practice is considered a form of forgoing life-sustaining therapy. Again, little is known about the frequency of voluntary cessation of eating and drinking; how it is done; or whether it is acceptable to patients, families, or health care providers.

Convergent Views

Forging a consensus about good care of the dying requires taking into account the background data outlined above. In our view, the common ground between the two sides of the physician-assisted suicide debate includes the following seven areas.

A central goal of medicine is to relieve suffering by helping people die with comfort, support, and meaning (9–12, 83–89). The role of healer in the care of the dying cannot be simply conceptualized as that of curing or prolonging life; it also involves helping the dying person and the family to make the best of the situation—physically, mentally, socially, and spiritually. A healer must respond with urgency, skill, and creativity, especially if extreme suffering occurs as death approaches. The goals and methods of management must be individualized, and each patient must be given the opportunity to define meaning and comfort in the context of his or her illness and personal values.

Comprehensive, interdisciplinary palliative care is the standard of care for persons with progressive, advanced disease for whom prognosis is limited and the focus of medical management is quality of life (9–12, 27–31, 83–90). Although palliation of symptoms should be offered at all stages of disease, it becomes increasingly important as death approaches and the goals of care shift from attempted cure or prolongation of life to emphasis on quality of life. Compared with conventional care, hospice improves quality-of-life outcomes, such as relief of pain and other symptoms, and offers psychosocial, existential, and spiritual support. Comprehensive palliative care probably costs less than conventional care in the last 6 months of life, although it is not inexpensive (30, 31, 90). All physicians who care for seriously ill patients must learn how and when to talk with patients about this approach to end-of-life care, and they should be familiar with basic approaches to symptom control and psychosocial and spiritual support. Although palliative care can be delivered in any setting, including hospitals and nursing homes, and does not require a formal hospice program, it is best delivered with the expertise and support of a multidisciplinary team. Palliative care should be made available to all dying patients as a matter of public policy.

Physicians must provide adequate pain relief according to well-established standards (9–17, 86–89). Modern pain management is generally effective, and good pain relief can usually be achieved with a minimum of side effects by using widely available practice guidelines (6–8). Nonetheless, physicians should reassure patients that whatever opioid doses are needed to relieve suffering can and will be used, even if they cause sedation or indirectly hasten death. The patient should be the final guide about whether the level of pain relief is adequate and the side effects are acceptable. Withholding effective pain relief because of unwarranted fears of addiction, tolerance, or sedation or because of legal concerns is unacceptable.

Patients have the right to refuse unwanted treatment or to stop treatment once it has been started

(9–12, 85–89, 90–94). A patient's authority over what happens to his or her body includes the right to refuse or stop any and all medical treatments, even if the patient's wish is for a hastened death. If the patient is unable to express his or her wishes, clearly stated earlier preferences should be followed. If these are unavailable, decisions should be made by surrogate decision makers according to the principle of "substituted judgment"—making the decision as it is believed individual patients would if they could speak for themselves.

A patient's right to forgo life-sustaining therapy has a long tradition and wide acceptance in medical ethics and law in the United States, provided that the physician is acting in accord with the patient's wishes or best interests (92–94). To minimize suffering, patients should receive appropriate palliative care during the withdrawal or withholding of treatment (94).

Patients who request that death be hastened—by the forgoing of life-sustaining therapy, the voluntary cessation of eating and drinking, terminal sedation, physician-assisted suicide, or active euthanasia—should have their requests fully explored, and they deserve an exhaustive search for palliative alternatives (9–12, 53, 95–100). These requests should be viewed as a "cry for help," the meaning of which should be carefully explored. Requests may be a sign of unrecognized and potentially ameliorable suffering (such as pain; depression; or a psychosocial, family, or spiritual crisis) and should initiate a comprehensive evaluation and strenuous effort to relieve distress and make continued living desirable. Such an exploration should also recognize the possibility that the request is fully informed, autonomous, and a true reflection of the patient's values, given the current clinical situation. Consultation with others who have expertise in the care of the dying should be strongly considered.

Exploring such requests does not obligate a physician to accede to a patient's wishes. Indeed, physician participation in any approach to terminal care that may hasten death may be a moral act only when comprehensive palliative care is unable to relieve suffering adequately and the patient is fully informed about alternatives and consequences. Moreover, any and all such methods have the unfortunate potential to be used, intentionally or not, as a substitute for comprehensive palliative care. Prematurely participating in such options might reflect 1) a lack of familiarity with appropriate measures to relieve suffering, 2) pressures for cost containment, or 3) the strain on health care providers or families of providing complex and emotionally demanding forms of terminal care.

Even if physician-assisted suicide is justified under some exceptional circumstances, this does not necessarily mean that it should be supported as public policy (9–13, 66, 85–89). Public policy questions about physician-assisted suicide, terminal sedation, or the forgoing of life-sustaining therapy require a more complex analysis of how each type of act might be used to respond both to the infrequent dilemmas of individual patients and to the needs of the population at large, including such vulnerable groups as disabled, poor, mentally ill, and incompetent persons. Public policy decisions about physician-assisted suicide must attend to the intended and the potential unintended consequences of an open practice subject to regulation and of the current underground, unregulated, erratically available practices.

Every physician should remain committed to the skillful and compassionate care of the terminally ill throughout the dying process but should not be required to violate his or her own fundamental values (9–12, 30, 83–89, 95, 96). Any physician who works with severely ill patients is obligated to help them achieve comfort, peace, and dignity by proficiently providing comprehensive palliative care. However, physicians would not be obligated to provide physician-assisted suicide if it would violate their fundamental values, even if the practice were legalized. When a patient no longer wants to live under the circumstances imposed by illness and seeks to hasten death, the physician should explore mutually acceptable alternatives and request consultation from others with expertise in the care of the dying. If common ground cannot be established, the physician may offer to transfer care to a clinician or institution whose values coincide more closely with those of the patient.

Conclusions

The background data reviewed and the convergent views expressed suggest three conclusions: 1) Considerable end-of-life suffering can be eliminated if we do a better job of delivering palliative care; 2) unacceptable suffering can still occur in the face of excellent palliative care, and some patients who have this suffering want to escape from what they feel is an intolerable situation; and 3) as a last resort, forgoing or stopping life-sustaining therapy, terminal sedation, and voluntary cessation of eating and drinking are clinical options that may be acceptable to both patient and physician and do not require fundamental changes in the law.

The development of good public policy about physician-assisted suicide in the United States requires a national commitment to further research about end-of-life care, including clarification of how biases influence the manner in which available data are being interpreted and what questions are being asked. The debate about physician-assisted suicide, however, focuses on areas of strong disagreement about the management of a relatively small number of patients for whom even the best and most comprehensive palliative care becomes ineffective. It would be unfortunate if this debate distracted us from the broader issue of enhancing care for the majority of dying patients and their families, who could be better served by improved access to and delivery of palliative care. While the narrow policy debate about physician-assisted suicide proceeds, we must promote all currently available and legal means of ameliorating suffering at the end of life.

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