



FROM BIRTH TO DEATH AND BENCH TO CLINIC

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CHAPTER 30

Physician-Assisted Death

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physician-assisted death

by Timothy E. Quill and Jane Greenlaw

Framing the Issue

The question of whether severely ill patients are entitled to a physician's help to end their suffering by ending their lives has been debated since antiquity. The Hippocratic Oath suggested that this was outside of the physician's professional responsibilities, but even in that time there was considerable disagreement. In the modern era, there is consistent evidence of a secret practice of physician-assisted death, and the profession and the law tend to look the other way as long as it does not become public ("Don't ask, don't tell."). This secret practice was flaunted in the 1990s when Jack Kevorkian assisted in the deaths of approximately 150 patients. Although he lost his professional license in the process (he was a pathologist, not a clinician), he was not successfully prosecuted until he provided active euthanasia at a patient's request and was subsequently jailed for over eight years.

In the United States, most jurisdictions have prohibited physician-assisted death either with specific statutory provisions or judicial applications of more general statutes. There have been attempts to change the law using several methods:

- Legal challenges to the constitutionality of the prohibitions, including two Supreme Court cases heard together (*Washington v. Glucksberg* and *Quill v. Vacco*).
- State referenda; while several challenges to prohibitions on physician-assisted death failed, Oregon's Death with Dignity Act was passed in 1995 and has survived a variety of legal challenges.
- Civil disobedience, in which physicians admitted to breaking the law, thereby challenging the legal and professional systems to come to grips with the inequities of the secret practice.

Some controversy remains about what to call the practice. Common understanding of the word suicide equates it with mental illness and irrational behavior, and the medical obligation is to prevent it if at all possible. Dying patients who see their lives being destroyed by illness sometimes come to view death as the only way to escape their suffering and, therefore, as a means of self-preservation—the opposite of suicide. The Oregon Health Department has stopped calling the practice physician-assisted suicide and started calling it physician-assisted death. That is the language we use here.

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HIGHLIGHTS

- State-of-the-art palliative care should be the standard of care for treatment of suffering at the end of life. Physician-assisted death, if ever considered, should only be a last resort when such treatment has failed.
- The American public remains deeply divided on the question of whether to legalize physician-assisted death.
- Most states prohibit physician-assisted death, and most state referenda challenging this prohibition have failed.
- Two 1997 Supreme Court cases challenged the constitutionality of the prohibitions against physician-assisted death: *Washington v. Glucksberg* and *Quill v. Vacco*.
- Empirical studies in the United States show an underground practice of physician-assisted death that is not actively prosecuted as long as it is not openly discussed.
- Allowing patients to stop eating and drinking and sedating patients to the point of unconsciousness are alternatives to ease otherwise intractable end-of-life suffering.

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PHYSICIAN-ASSISTED DEATH GLOSSARY

Euthanasia – painlessly killing or permitting the death of individuals who are ill or injured beyond hope of recovery.

Voluntary active euthanasia – hastening one’s own death by use of drugs or other means, with a doctor’s direct assistance.

Passive euthanasia – hastening death by withdrawing life-sustaining treatment and letting nature take its course

Involuntary euthanasia – causing or hastening the death of someone who has not asked for assistance with dying, such as a patient who has lost consciousness and is unlikely to regain it.

Physician-assisted death – the practice of a physician providing the means for a patient to end his own life, usually with a prescription for barbiturates that the patient takes himself; sometimes also called physician-assisted suicide.

The public remains deeply divided on the question of whether to permit physician-assisted death. In most surveys, approximately two-thirds of the population of the United States approve of it as an option for terminally ill patients with intractable suffering. But when the question of legalization comes to a vote, it is usually closer to 50/50. This split probably reflects the inherent tensions in the debate. On the one hand, most people know of cases of severe suffering, even with excellent palliative care, where the need for some predictable escape is very compelling. On the other hand, there are real fears that physician-assisted death could be used as a detour that avoids effective palliative care or as a way to eliminate the suffering of vulnerable patients by eliminating the sufferer.

Physician-Assisted Death in Practice

Palliative care—including excellent pain and symptom management and psychosocial support for patients and families—should be part of the standard of care for all severely ill patients. Many studies have demonstrated a significant gap between the potential of palliative treatments to relieve suffering and actual practice, so the first step if someone were considering physician-assisted death would be to ensure that the patient is receiving the best possible palliative treatment. But there will always be a small percentage of cases where symptoms become intractable despite skillful efforts to help. Furthermore, patient suffering cannot be restricted to the physical realm and must

include psychological, social, existential, and spiritual dimensions. The medical profession acknowledges that such unacceptable suffering sometimes exists when a physician talks with a patient about stopping life supports, but when there is no life support to stop, the medical profession tends to be judgmental of both the physician and the patient about not trying hard enough with standard palliative measures. In circumstances of intractable patient suffering, there is evidence that physicians in the United States sometimes assist in patients’ deaths. This is not an easy subject for empirical research because to admit participation, a physician must admit to a crime. Nonetheless, several very imperfect studies of the practice in the United States suggest that in the majority of jurisdictions where physician-assisted death is illegal, it accounts for approximately 1–2% of deaths.

In contrast, physician-assisted death is less common in Oregon, where for 10 years it has been legal for terminally ill patients who experience unacceptable suffering. Data collected by the Oregon Health Department show that the practice is stable and relatively rare, accounting for approximately one in 1,000 deaths. Although there were few physician-assisted deaths, there was much conversation on the topic—one in 50 patients talked with their doctors and one in six talked with their families about the possibility. We also know that pain management has improved in Oregon, hospice utilization is among the highest in the nation, and there is a statewide program to record patients’ wishes about cardiopulmonary resuscitation (Physician Orders for Life-Sustaining Therapy, or POLST).

In the Netherlands, physician-assisted death and voluntary active euthanasia have been openly permitted for over 30 years (though they were formally legalized only recently) and have been the subject of three major studies. These studies showed very stable rates of physician-assisted death (0.2–0.3%) and voluntary active euthanasia (1.8–2.5%), and increasing public reporting over time (now over 50%). The most controversial finding has been a small but persistent number of “life-terminating acts without explicit requests” (0.7–0.8%). There has been much discussion about these cases. Advocates maintain that the patients were terminally ill, that they were experiencing intractable suffering, that they had lost capacity for decision-making, and that their physicians had responded appropriately to end their suffering.

Critics suggest that these cases are clear evidence of a practice out of control. In the Netherlands, there is a cultural bias that the responsibility to respond to an individual patient's suffering outweighs the obligation to obey the law in these difficult cases ("force majeure").

Legalizing Physician-Assisted Death

Proponents and critics of physician-assisted death each have different ethical reasons to support their positions. The principal arguments for legalization are:

Patient autonomy. A patient should have the right to control the circumstances of his or her own death and to determine how much suffering is too much.

Mercy. If a patient's pain and suffering cannot be sufficiently relieved with state-of-the-art palliative care, then the physician has an obligation to do everything within his or her power to relieve that suffering, even to the point of hastening death if there are no realistic alternatives acceptable to the patient.

Nonabandonment. The physician's obligation to his or her patient and family to see the dying process through and to be as responsive as possible outweigh other obligations and restrictions in these troubling circumstances.

The principle arguments against allowing physician-assisted death are:

Wrongness of killing. Purposefully helping a patient die is categorically wrong under any circumstances; excellent palliative care does not include physician-assisted death.

Physician integrity. Physicians take a sacred oath never to knowingly harm a patient, and physician-assisted death would violate professional standards and undermine trust between physician and patient.

Risk of abuse (slippery slope). Allowing physician-assisted death poses too high a risk to vulnerable patients. Their lives could eventually be ended against their will, or when alternative approaches to relieve suffering might be expensive or the suffering difficult to treat.

Whereas most experienced clinicians admit that there are relatively rare, compelling cases that could justify physician-assisted death, there are two main empirical questions about the effect of legal-

LEGAL MILESTONES: A TIMELINE

1995

Oregon Death with Dignity Law (1995)

- Referendum passed in 1995 (52–49); challenged and repassed in 1997 (70–30)
- Permits physician-assisted death subject to meeting several criteria:
 - Terminally ill (prognosis of less than six months)
 - Mentally competent
 - Confirmed by a second opinion
 - Waiting period of two weeks

Washington v. Glucksberg and Quill v. Vacco (1997)

Main ethical arguments:

- Liberty – patients have a right to request assistance in dying; physicians should have a right to respond if within their value structures
- Equality – similarly situated patients (such as those on life supports) have the right to make life-ending decisions but not those without life supports to stop

United States Supreme Court ruled:

- No constitutionally-protected right to physician-assisted death
- Right to good pain management, even if it requires doses that could hasten death
- Potential right to palliative care

2000

Netherlands Euthanasia Law (2004)

- 30 years of policy experience
- Initially illegal, but explicitly not prosecuted if clinician reported the act and met agreed upon criteria (very predictable legal system)
- Formally legalized in 2004
- Subject of three large national studies in the context of all kinds of end-of-life practices
- Permits either physician-assisted death or voluntary active euthanasia provided these criteria are met:
 - Terminal illness
 - Voluntary consent
 - Second opinion recommended but not required
 - Documentation and reporting
 - Strong public and professional acceptance of the practices

2005

ization. Would an open, legally regulated approach make the practice of physician-assisted death safer, more predictable, and rare (as appears to be the case so far in Oregon)? Or would it erode the gains made in hospice and palliative care, making the

RESOURCES

Web sites

- www.urmc.rochester.edu/cehpc – the University of Rochester Medical Center’s Center for Ethics, Humanities and Palliative Care. Includes links, resources, and a newsletter.
- www.aahpm.org – the American Academy of Hospice and Palliative Medicine. Position statement on physician-assisted death gives background and guidelines for evaluating a request. (<http://www.aahpm.org/positions/suicide.html>)
- www.oregon.gov - the Oregon Department of Human Services’ Public Health Division maintains a gateway page on the Death with Dignity Act. Includes annual reports, reporting requirements, publications, and FAQs.

Recent news

- Jane E. Brody, “A Heartfelt Appeal for a Graceful Exit,” *New York Times*, February 5, 2008.
- Daniel Bergner, “Death in the Family,” *New York Times*, December 2, 2007.
- Charlotte F. Allen, “Back Off! I’m Not Dead Yet,” *Washington Post*, October 14, 2007.
- Darshak Sanghavi, “Helping My Father Die,” *Boston Globe*, July 3, 2007.

- Nancy Vogel, “Assisted Death Bill Fails Again in Capitol,” *Los Angeles Times*, June 8, 2007.

Further reading

- Timothy E. Quill, “Physician-Assisted Death in the United States: Are the Existing ‘Last Resorts’ Enough?” *Hastings Center Report*, September-October 2008.
- Daniel Callahan, “Organized Obfuscation: Advocacy for Physician-Assisted Suicide,” *Hastings Center Report*, September-October 2008.
- Agnes van der Heide et al., “End-of-Life Practices in the Netherlands under the Euthanasia Act,” *New England Journal of Medicine*, May 10, 2007.
- Timothy E. Quill and Margaret P. Battin, eds., *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice*, Johns Hopkins University Press, 2004.
- Susan W. Tolle et al., “Characteristics and proportion of dying Oregonians who Personally Consider Physician-Assisted Suicide,” *Journal of Clinical Ethics*, Summer 2004.
- Kathleen M. Foley and Herbert Henden, *The Case Against Assisted Suicide: For the Right to End-of-Life Care*, Johns Hopkins University Press, 2002.

environment riskier and more frightening for our most vulnerable patients, (as the cases of involuntary euthanasia in the Netherlands appear to suggest)? Since the passage of Oregon’s Death with Dignity Act, there have been a variety of attempts to legalize physician-assisted death or other means of easing patients’ suffering. Most have been unsuccessful. Referenda similar to Oregon’s were defeated in Michigan and Maine. Efforts by Hawaii, California, and New Hampshire to change the law through the legislative process have also failed. The legislative approach proved especially difficult because it led to polarized and unproductive political discussion.

An Oregon-style referendum will be on the ballot in 2008 in the state of Washington. This state had the original “death with dignity” referendum in the United States in 1991. It included both physician-assisted death and voluntary active euthanasia and was narrowly defeated. The proximity to Oregon and similar demographics make prospects for passage favorable, but by no means certain.

Last Resort Options

State-of-the-art palliative care remains the standard of care for any end-of-life suffering, and last

resort options should only be considered when such treatments are ineffective. Good palliative care services are not available in all locations; efforts to increase education and proliferation of these services are being made by medical groups, state initiatives, and patient advocates.

When considering cases of intractable suffering in the face of excellent palliative care, a more politically and ethically acceptable alternative to legalizing physician-assisted death may be to expand other “last resort” options. Prescribing medication for aggressive management of pain and other symptoms, even in doses that might unintentionally hasten death, has wide ethical, legal, and professional acceptance. This practice can be justified on ethical grounds by the doctrine of double effect, which holds that even though it is wrong to take someone’s life intentionally, it can be permissible to risk foreseeably hastening someone’s death as long as one’s intention is to relieve suffering.

Another last resort option with wide acceptance is for patients to be able to stop (or not start) any potentially life-sustaining therapy if it does not meet their goals, even if their purpose in refusing treatment is to escape suffering through an earlier death. The possibility for patients to stop eating and drinking voluntarily to escape intolerable suf-

fering is accepted by many hospices and has considerable ethical and legal support. The ethical justification for these options is that they preserve patients' right to bodily integrity—to say what happens to their own bodies.

A last resort response to some of the more complex and difficult cases is for physicians to sedate a patient to the point of unconsciousness to enable the person to escape otherwise intractable physical suffering at the end of life. Support for this practice includes the 1997 Supreme Court decision in *Washington v. Glucksberg* and *Quill v. Vacco*, which recognized the right to good pain management, even if it requires doses that could hasten death. This practice invokes the rule of double effect and the right of bodily integrity. In July 2008 the American Medical Association stated that “it is the ethical obligation of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms” at the end of life when “symptoms cannot be diminished through all

other means of palliation.”

Giving doctors and patients more open access to—and awareness of—last resort options could have several beneficial effects. One potential effect is increased opportunity to get second opinions from skilled palliative care clinicians to be sure that other, less extreme avenues to address suffering have been considered. Another benefit is reassurance to severely ill patients who fear end-of-life suffering and want to know that there are some avenues of escape that can be pursued openly and predictably. In addition, last resort options may lessen the desire and need for physician-assisted death by providing alternatives. Some patients in Oregon are choosing these alternatives even though they have access to physician-assisted death because, in some circumstances, these approaches are better able to address their particular needs. Finally, the added alternatives increase both clinicians' and society's awareness of their obligation to address intolerable suffering when it is encountered. 🌳