



FROM BIRTH TO DEATH AND BENCH TO CLINIC

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CHAPTER 11

End-of-Life Care

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end-of-life care

by Alan Meisel

Framing the Issue

End-of-life care and its many dilemmas capture public attention when they make national news. The story often involves a family seeking a court order to remove life support from a patient who, medical experts say, is in a vegetative state with no hope of recovery. The Schiavo case in 2005 was the most recent episode, but before that it was the Cruzan case in 1990 and the Quinlan case in 1976. When the news fades, so does public attention to end-of-life decisions.

In reality, however, these decisions are omnipresent, and far more mundane than the headlines suggest. Approximately 2.5 million Americans die each year in the United States. For the nearly 70% of them who live out their final days in hospitals, nursing homes, and at home in hospice care, decisions must continually be made about what treatment to administer, what treatment to cease or withhold, what treatment to continue, and what treatment to taper off.

While the fact of death remains inevitable, its timing is often very much a function of human agency. Once it was common to speak of nature taking its course, but today it is more common to view death as a matter about which people—individuals at or near death, or their surrogates—have some control. They may forestall death by choosing heroic measures to sustain life, such as resuscitation. Or they may hasten death by forgoing treatment, or by seeking to take action to bring life to an end. Because of its profundity, end-of-life decision-making occupies center stage in contemporary American bioethics. For three decades, medical professionals and policymakers have looked to bioethicists for advice in shaping medical guidelines and laws on end-of-life care.

Focus on Autonomy

Traditionally, the ethical and legal concerns with end-of-life care have focused on the interest of patients, an interest referred to as autonomy or self-determination. Autonomy is paramount for patients who possess decision-making capacity, but it is also a major consideration for patients who lack this capacity. Their wishes must be respected by the relatives or other health care proxies who make decisions on their behalf.

According to traditional bioethical analysis, the centrality of the individual in contemporary Western society requires that adults be permitted to make their own decisions about what medical treatment they want and do not want. To do otherwise would

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HIGHLIGHTS

- Bioethics has long shaped policy concerning end-of-life decision-making, which involves numerous choices about what treatments to administer, taper off, cease, or withhold.
- Traditionally, ethicists have considered patients' wishes to be paramount.
- Patients can express their wishes for end-of-life care in advance directives such as living wills, which are legally binding in all 50 states.
- Some bioethicists now believe that other interests—such as family members' wishes—should be considered in end-of-life decision-making.
- Better brain imaging has shown important differences in disorders of consciousness that also challenge long-held ethical views on withholding treatment for persons with devastating brain injury.

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be an inexcusable invasion of individuals' interests in bodily integrity and in charting their own life plan in accordance with their own values, preferences, and interests. American law—especially twentieth-century American law—reflects and reinforces this ethical analysis.

When individuals lose the capacity to make their own medical decisions, the interest in autonomy requires that decisions be based on the wishes that these people expressed earlier in their lives. This position has been adopted into law: all states recognize the legal authority of advance directives (living wills or health care powers of attorney). It is well accepted by bioethicists and the law that oral statements made by patients—either instead of written advance directives or to supplement them—may also be useful guides in determining what medical treatments they do and do not want.

When individuals have not made manifest their decisions about medical care, the ethical and legal protocol is to implement a person's presumed wishes through a doctrine known as “substituted judgment.” Under this doctrine, a surrogate must make decisions for a patient. If the patient has not appointed a surrogate in an advance directive, close family members are ethically and legally empowered to make decisions for the patient.

Judicial deference to autonomy has been on the increase. It can be seen most clearly in cases involving Jehovah's Witnesses, who, for religious reasons, reject blood transfusions even when they are lifesaving. The trend in the 1960s and 1970s, when these cases first arose, was to override refusals of treatment. But since the 1980s the trend has been to honor them, even though doing so is predicted to cause the patient's death and may run counter to the interests of the patient, as well as the family, community, health professions, and society as a whole.

Challenging Autonomy

Some bioethicists now argue that autonomy has come to wield a kind of tyranny over end-of-life decision-making. They believe that overruling a patient's autonomy may be justified as follows.

Welfare of the individual. At times, the autonomous decisions of patients may seem to compromise their welfare. While an individual may be capable of making decisions, he or she may be incapable of reasoning about their personal impact. Under such circumstances, one might argue that

the decisions are inauthentic—they would not serve the person's best interest as that person would have defined it, had he or she been capable of reasoning. Traditional bioethical analysis contends that there is rarely, if ever, any justification for overruling the decisions of people with decision-making capacity. If a decision seems to be uncharacteristic of an individual—inconsistent with the person's deeply held values, beliefs, and goals—then inquiring about the soundness of the person's decision-making capacity is justifiable. But once that soundness is established, often by psychiatric testing, the fact that a decision seems to run counter to the individual's welfare is not an adequate ethical or legal basis for overturning it. If someone's decisions could simply be ignored when, in the view of others, they would be harmful to the individual's well-being, autonomy would become meaningless; people would have autonomy only when their decisions comported with some external standard, which is the antithesis of autonomy.

The interests of others. The centrality of autonomy is sometimes criticized for failing to regard the individual as part of a complex network of relationships. According to this view, the interests of the person's partner, children, parents, and others who are close must be taken into account in end-of-life decisions. Decisions that prolong life can entail prolonged suffering for patients and their close family members and friends. Decisions that shorten a patient's life also have consequences for others. Aside from the grief of the survivors, such decisions can impose burdens—for example, the need to provide for a child who is still a minor. On the other hand, decisions to shorten a patient's life can also have possible benefits, such as the comfort of knowing that a loved one is no longer suffering, or an end to the stress and expense of caregiving.

Some bioethicists emphasize the importance of family and community interests in decision-making at the end of life. However, mainstream bioethical analysis rejects them as valid considerations unless the patient chooses to have them taken into account. So does the law. Although judicial decisions usually proclaim that an individual's right of self-determination must be balanced against the state's interest in the well-being of the individual's minor children, even that interest has virtually never been found to outweigh the patient's right of self-determination.

Interests of health caregivers. Relationships that dying individuals have with their medical and

LIMITS OF ADVANCE DIRECTIVES

Only about 15–20% of Americans have written advance directives such as living wills, and their usefulness has long been questioned by the physicians who must draw guidance from them. Advance directives tend to be either too general or too specific to shed light on the issue to be decided. For now, the best directives seem to be those that designate a health care proxy, but even their effectiveness is open to question. Studies show that close family members do not always have a good reading of what a patient really wants. Despite the limitations, it is better to have an advance directive than not to have one.

personal caregivers can become quite close and intense. The training, ethos, and codes of ethics of health care professionals buttress the feelings that arise from these relationships. Some people argue that permitting patients to make medical decisions that would shorten their lives could undermine the morale of health care professionals and thus their commitment to doing their utmost for every patient. Seen this way, one patient's decision could adversely affect the quality of care not just for that individual, but also for patients in general. The interests of caregivers have been invoked in a few legal cases involving patients' decisions to refuse medical treatment, but courts have not ruled that this interest outweighs a patient's right of self-determination.

Societal interest in allocation of scarce resources. Medical resources are scarce. That much is uncontroversial. But of all the reasons for overriding patients' autonomy, the societal interest in the efficient use of scarce health care resources is the most controversial. Some people believe that an individual's decision to continue medical care at the end of life must be weighed against the cost-benefit ratio. In other words, overriding a patient's desire for a particular treatment is justified if the benefits of the treatment come at too high a price, or if there is compelling evidence that the treatment will provide no benefit.

Proponents further contend that it is ethically permissible—indeed, ethically obligatory—to deny resources if they will provide little or no benefit when the cost is being borne in whole or in large part by society: by taxpayers through Medicare, Medicaid, or other government programs, or through private insurance.

Opponents of this position acknowledge the scarcity of resources, but claim that such “bedside

rationing” violates the physician's professional obligation to act solely in the patient's best interests, and that denial of treatment should be made at the policy, rather than the individual, level.

Another dilemma arises when a doctor thinks that a treatment is not beneficial, but a patient wants it anyway. Despite several dozen state supreme court opinions upholding patients' decisions to forgo life-sustaining medical treatment, there has been little discussion about what legal protection, if any, ought to be accorded a patient's wish to receive treatment that physicians do not consider worthwhile.

The law is clearer with regard to private health insurance companies and government payers for health care. Standard health insurance contracts, as well as Medicare and Medicaid policies, give these payers the right to refuse coverage for treatment deemed not medically necessary. Many patients have challenged these policies and prevailed, but the underlying principle that health insurance programs may deny payment for treatment of little or no benefit has never been seriously questioned.

Emerging Policy Issues

Although there is a consensus in law and clinical medicine about many of the ethically difficult issues in end-of-life decision-making, recent developments demand attention from public policymakers and legislators.

Palliative care. The realization that patients' control over their dying needs to include adequate relief of pain has led to increased education of doctors about palliative care. It has also led to laws and medical policies that permit the use of palliative medications even if it unintentionally hastens death. In 2008, the American Medical Association adopted a policy supporting the use of sedation to the point of unconsciousness at the end of life in the rare circumstances when palliative measures are ineffective.

Physician-aided dying. The debate over the legalization of physician-aided dying may be heating up again with a referendum to legalize it on the Washington state ballot in 2008. It has been legally practiced in Oregon since 1997, with diminished public controversy and—all but the most stalwart opponents would agree—a great deal of success (see chapter 30, “Physician-Assisted Death”).

Persistent vegetative state. Advance directive

RESOURCES

Web sites

- www.abcd-caring.org – Americans for Better Care of the Dying. Includes news from the field, policy tools, and links.
- www.caringinfo.org – Caring Connections. Resource page includes glossary of terms and brochures on several topics in end-of-life care.
- www.growthhouse.org – Growth House, Inc. Includes RSS feed, fast facts, online reports, bookstore, and blogs on end-of-life care.
- www.pbs.org/wnet/onourown/terms – Companion Web site for the *On Our Own Terms: Moyers on Dying* series. Includes video from the series, resources, patient and community tools, and a glossary.
- www.medicaring.org – the Palliative Care Policy Center. Includes free PDF downloads of reports and monographs on end-of-life care and news from the field.

Recent news

- Timothy Gower, “Fatal Flaw,” *Boston Globe*, March 9, 2008.
- Nicholas Bakalar, “Antibiotics Questioned in Care at Life’s End,” *New York Times*, March 4, 2008.
- Rob Stein, “Devices Can Interfere with Peaceful Death; Implants Repeatedly Shock Hearts of Patients Who Cannot Be Saved,” *Washington Post*, December 17, 2007.
- Jan Hoffman, “The Last Word on the Last Breath,” *New York*

Times, October 10, 2006.

Further reading

- Margaret P. Battin, “Terminal Sedation: Pulling the Sheet Over Our Eyes,” *Hastings Center Report*, September-October 2008.
- Gerald S. Witherspoon, “What I Learned from *Schiavo*,” *Hastings Center Report*, November-December 2007.
- Joanne Lynn, Ekta Chaudry, Lin Noyes Simon, Anne M. Wilkinson, and Janice Lynch Schuster, *Common Sense Guide to Improving Palliative Care*, Oxford University Press, 2007.
- Bruce Jennings, Gregory E. Kaebnick, and Thomas H. Murray, “Improving End of Life Care: Why Has It Been So Difficult?” *Hastings Center Report Special Report*, November-December 2005.
- Joseph J. Fins, “Rethinking Disorders of Consciousness,” *Hastings Center Report*, March-April 2005.
- Angela Fagerlin and Carl E. Schneider, “Enough: The Failure of the Living Will,” *Hastings Center Report*, March-April 2004.
- Joanne Lynn, *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*, University of California Press, 2004.



See relevant legislation in appendix

legislation frequently cites persistent vegetative state as a reason for forgoing life-sustaining treatment. But recent developments in neuroscience have made it clear that this condition is not the unitary phenomenon it was once thought to be. Devastating brain injuries exist along a continuum. Some people who appeared to be permanently vegetative were then found, based on brain imaging, to have a surprising amount of brain activity, perhaps raising the hope that their condition may improve. This new insight into the brain raises the difficult question of whether life-sustaining medical treatment must be maintained for such persons in the absence of clear and convincing evidence in an advance directive that they would not want to be kept alive in such a condition (see chapter 4, “Brain Injury”).

Denial of treatment. Perhaps the issue people

least want to talk about may prove to be the most important because it is closely bound up with larger issues of health care reform. That issue is the denial of some forms of medical treatment at the end of life because of the belief that they provide little or no benefit and consume scarce health care resources—in other words, rationing (see chapter 17, “Health Care Costs and Medical Technology”). Current practice by physicians, hospitals, and health insurers is sometimes to resist providing such treatment initially, but eventually to yield in the face of pressure from families. This practice is unlikely to change, unless there is a national consensus, embodied in legislation, that limits the medical treatment that will be paid for by private and government health insurance to that which has been proven, if not cost effective, then at least effective. 🌳