

RETROSPECTIVE

## Dying and Decision Making — Evolution of End-of-Life Options

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I recently helped my father to die. He was an engineer, independent, always on the go and in charge. He began to deteriorate rapidly from an ill-defined dementing illness, and his confusion and intermittent agitation did not respond to the standard treatments that were tried. He had made his wishes clear about avoiding any prolongation of his dying, but now he had lost the capacity to make decisions for himself. Furthermore, we did not know whether his remaining life span was measured in months or years. He was unable to sleep or relax at night, despite trials of neuroleptics, antidepressants, and anti-anxiety agents. My mother was exhausted, but neither of them wanted their home to be invaded by strangers. How were we to honor his wishes and values and help him to find dignity and peace in the last phase of his life?

In the 13 years that have passed since I wrote a *Sounding Board* article about helping a patient to die,<sup>1</sup> there have been substantial improvements in palliative care for severely ill patients, particularly in acute care hospitals. Providers of palliative care

attempt to relieve uncomfortable symptoms and improve the quality of life for severely ill patients and their families. Unlike hospice care, palliative care is offered alongside the active treatment of a patient's underlying disease, regardless of the prognosis. Palliative care consultation services, faculty development programs, and a base of evidence-based knowledge have grown exponentially during this period, facilitated enormously by generous financial support from private foundations such as Robert Wood Johnson, Soros, Nathan Cummings, Greenwall, and Gerbode. Unfortunately, much of this funding is drying up, and the reimbursement systems that support clinical consultation services as well as ongoing academic activities may be too fragile to sustain these remarkable gains.

My father was initially a perfect candidate for palliative care. Given his progressive loss of memory and poor prognosis, he consented to "do-not-resuscitate" status but wanted to receive all other potentially effective treatments. Every effort was made to improve his quality of life with the use of

modern treatments for dementia, as well as symptomatic treatments for his agitation and insomnia. But each of these treatments made his symptoms worse, rather than better. I began to wonder if he would be an acceptable candidate for hospice care.

Hospice continues to be the premier home care program in the nation, but in order to qualify, patients must meet Medicare's requirements: they must have a life expectancy of six months or less and be willing to forgo all treatment directed at the underlying disease. Unfortunately, relatively few diseases fit neatly into the prognostic model that is used for the hospice program, and many patients would like to continue to receive some potentially effective treatments even when the likelihood of success is low. Therefore, less than 30 percent of dying patients receive hospice care, and those who do are often referred to hospices only when death is imminent (the median length of stay is less than one month, and many are not referred until days or even hours before they die). Hospices have made an effort to broaden their admission criteria to include some patients with advanced cardiopulmonary, neurologic, and other end-stage illnesses. Many hospices are beginning to join forces with palliative care programs, providing "hospice-like" services to patients who are continuing to receive some active treatment. However, the reimbursement systems are still being developed, and access to these expanded programs is therefore a major problem.

I called the local hospice in my father's community to see whether it would take him as a patient. Although symptom relief and comfort were our primary objectives, it was not at all certain that he would die within the next six months. Fortunately, the hospice accepted him after ensuring that we knew that he might have to be discharged if his condition stabilized. The support and guidance that the hospice provided to our family was invaluable. Furthermore, the transition helped us to acknowledge that my father was indeed dying.

Despite home hospice support and services, the expertise of a multidisciplinary team, and additional trials of medications, my father continued to be agitated and confused. He had always been physically active and in control, and somehow sitting still or lying down did not make sense to him. "I feel like I should be doing something" was his lament, and he could not be reassured that it was OK for him to

relax and be taken care of. We began to wonder what options he had at this stage.

Discussions about last-resort practices have also evolved substantially over the past 13 years. The Supreme Court decision in *Vacco v. Quill* and *Washington v. Glucksberg* in 1997 set the stage. Although the justices decided unanimously that there was no constitutionally protected right to physician-assisted suicide, they made it clear that they would not interfere with state-based efforts at legalization. The Court clearly did not dismiss the issue on moral or ethical grounds. The justices were concerned about the current inadequacies of access to and delivery of palliative care and about the absence of empirical data about the risks and benefits of legalization. Shortly after the Supreme Court decision, it opted not to hear an appeal attempting to block the implementation of the Oregon Death with Dignity Act (which had just passed by referendum for a second time); the Oregon law was thus allowed to go into effect.

The myth that excellent palliative care is incompatible with the provision of legal access to physician-assisted death as a last resort has been largely debunked by five years of data from Oregon.<sup>2</sup> Physician-assisted suicide has accounted for relatively few deaths (less than 0.1 percent per year), and more than three quarters of the patients who have died under the provisions of the act have been simultaneously enrolled in hospice programs. Patients who have chosen the option of physician-assisted suicide have been motivated primarily by loss of autonomy, loss of control of their bodily functions, decreased ability to enjoy life, and tiredness of dying. Unrelieved pain has never been the main reason, and clinical depression has not seemed to confound the decision.

Concurrently, Oregon has become a national leader in terms of excellence in palliative care. Markers of this success include high levels of referral for hospice care, prescribing of morphine, death at home rather than in the hospital, and public awareness of end-of-life options. These data will not sway anyone who has deep moral objections to physician-assisted suicide, but they have reassured many who have questions about whether the practice can be limited to competent, terminally ill patients and about the compatibility between legalized physician-assisted suicide and palliative care.

Of course, physician-assisted suicide is useful

**Table. Last-Resort Options for Responding to Intolerable Suffering.**

Option	Legal Status	Ethical Consensus	Decision Maker
Proportionately intensive symptom management	Legal	Consensus	Patient or surrogate
Stopping or not starting potentially life-sustaining therapy	Legal	Consensus	Patient or surrogate
Sedation to unconsciousness to relieve intractable symptoms	Legal	Uncertain	Patient or surrogate
Voluntarily stopping eating and drinking	Legal	Uncertain	Patient only
Physician-assisted suicide	Illegal (except in Oregon)	Uncertain	Patient only

only to mentally competent, terminally ill patients who are physically capable of independently ingesting medication. What other last-resort options might be available to patients like my father, who have different clinical circumstances and values?<sup>3</sup> The Table shows the five main options in rough order of consensus about acceptability. Accepting a proportionate risk of sedation or respiratory depression if it is deemed necessary in order to provide aggressive management for intractable symptoms and stopping or not starting life-sustaining therapies are all permissible options. Sedation to the point of unconsciousness to relieve otherwise unbearable symptoms in patients for whom death is imminent (also called terminal sedation) has had legal protection since the 1997 Supreme Court decision, although consensus in society at large is still evolving. Allowing patients who are still physically capable of eating and drinking to voluntarily stop doing so also appears to be legally acceptable but remains morally controversial. Finally, physician-assisted suicide remains highly contentious and is generally illegal outside of Oregon, although in many parts of the country, the secret practice is quietly tolerated (according to a “don’t ask, don’t tell” policy).<sup>4</sup>

Knowledge about these last-resort options is very important to those who fear being trapped in a life filled with suffering without the prospect of a timely escape. Those who know that escape is possible often feel free to expend their energy on other more important matters, and most will not need that escape if they receive adequate palliative care. A few, however, like my father and Diane, the patient I described in 1991, will end up in conditions of unacceptable suffering. Depending on

their values and the specifics of their clinical condition, they may pursue one of these last-resort options.

My father had been a staunch advocate of choice at the end of life. He had made it clear to us orally and through an advance directive that he had no interest in a prolonged period of dependency and would rather die than be placed in a nursing home. Because he had now lost the capacity to make decisions for himself, we had to decide on his behalf. Our family was certain that my father’s relentless agitation and insomnia were unacceptable to him and that the symptom-directed measures recommended by multiple consultants were ineffective. His agitation was also worsening as he became more unable to walk. In collaboration with the hospice team, his primary physician, and other consultants, we elected to try low-dose phenobarbital. To keep him comfortable, we would keep him mildly sedated. He subsequently appeared more peaceful than he had in months. He awakened periodically to exchange a few words, but he almost completely stopped eating and drinking. He died peacefully five days later.

Because my father had been very clear about his wishes while he was still mentally competent, and because our family understood how the system works and had the relevant knowledge and resources, we were able to use our fragmented health care system to provide him with comprehensive and humane end-of-life care. Most families are not so fortunate. In the past 13 years, the elements of excellent end-of-life care have become better defined; they include palliative care for all severely ill patients to maximize their quality of life as an integral part of their overall treatment plan, seamless transition

into hospice programs if and when palliation becomes the primary objective, and clarity about the availability of last-resort options if suffering becomes intolerable despite comprehensive caring efforts. I hope that in the next 13 years, these pieces can be integrated into a coherent whole and made predictably available to all Americans as part of a universal health care plan.

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3. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 1997;278:2099-104.
4. Meier DE, Emmons C, Wallenstein S, Quill TE, Morrison RS. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338:1193-201.