Still dying badly: A Christian critique

by Allen Verhey in the November 1, 2011 issue

Sometime around 1965 people became aware that the experience of dying in America was often made worse by medical experts. People began to complain that dying had been "medicalized," that it had been made a medical rather than a human event, that too often people died lingering deaths, alone in a hospital, surrounded by technological apparatus and the experts who knew how to use it rather than by family and friends who knew *them.*

But then, as at least one story goes—a story frequently told in the literature on bioethics—in 1976 Karen Quinlan's parents won their legal battle for the right to remove the respirator that was keeping Karen alive with no prospect of recovery. Subsequent court cases reinforced this right to refuse treatment. Those victories prompted reform of end-of-life care as patients wrested control over their dying away from doctors. Court decisions and subsequent public policy authorized advance directives in order to give decision making back to the patients or their representatives and honored refusals of treatment. By the last decade of the 20th century the needed reform had been accomplished, signaled by the U.S. Supreme Court's ruling concerning Nancy Cruzan—which reaffirmed the right to refuse life-sustaining treatment, including artificial nutrition and hydration—and also by the national Patient Self-Determination Act. Now people were able to die well.

There is some truth to that story about death and dying in America, but not enough to allow us to be satisfied with it. It is true that the courts and public policy have underscored the rights of patients to refuse life-sustaining treatments and have allocated decision-making power decisively to patients and their delegated agents. But one may ask whether this emphasis on autonomy and control has really remedied medicalized dying or helped people to die well.

There are reasons to be suspicious of the now-familiar story. Accounts abound of people who did not die well in spite of the acknowledgment of the rights of patients. In addition to such anecdotal evidence, a careful study was issued in the 1990s called "The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments" (SUPPORT). It found that aggressive medical treatments to preserve life were still being used even when the treatments were futile and even when the patients or families did not want them. The study showed, moreover, that many patients had suffered with unrelieved pain on their way to their deaths.

One response to SUPPORT was simply to urge ethicists to work harder to promote autonomous decisions, to get people to stipulate advance directives and to assert their rights. But a better response would have been to acknowledge the weaknesses of this emphasis on rights and autonomy as a remedy for medicalized death.

The fundamental weakness of the stress on autonomy is its minimalism. First, by attending to the procedural question about who should make end-of-life decisions, it allows us to ignore the substantive moral questions about what should be decided and about the virtues that should characterize the one who decides. Indeed, the minimalist approach can deliberately adopt a kind of agnosticism about what should be decided, treating a decision as right simply because it is freely made.

Second, the minimalism of the stress on autonomy is displayed in its negativism. The emphasis falls on not interfering with another's liberty rather than on meeting another's needs and on what we should not do to people rather than on what we should do for them. Moreover, its minimalism is manifest in the reduction of relationships of covenant to contracts between independent individuals.

It is little wonder, then, that this emphasis on rights and autonomy has not been altogether successful against the medicalization of death. It has provided an effective constraint against the physician who would run roughshod over a patient's rights, but it has not provided and cannot provide any vision of an alternative to a medicalized dying. Moreover, this emphasis on independence and control of one's own life and body displays to all who face death just how much our society despises the weakness and withering, the dependence and lack of control, that frequently accompany death. It makes us loath to die and loath to face our own dying. It is no longer always the doctors who insist on doing "everything possible" to resist death; it is now frequently the patients or their agents. The emphasis on the autonomy of patients could not nurture trust in a physician who had learned by experience some wisdom about life and morality. Instead, it has left patients to their own resources and all too frequently exposed the poverty of those resources, as well as the reluctance of many to consider their condition honestly or to have any conversation about their own dying.

But perhaps that reluctance is simply part of our culture's "denial of death." Perhaps we simply need to work harder not only to persuade people to formulate advance directives but also to end the silence that surrounds death. Perhaps we need to see death as "natural." Such was the hope of the death awareness movement.

The death awareness movement challenged the medicalization of death and insisted that death cannot be avoided. The movement is associated with figures such as Herman Feifel and Elisabeth Kübler-Ross. When Feifel wanted to interview moribund patients about their dying, hospital authorities were incensed. They regarded his project "cruel" and "sadistic." And when Kübler-Ross asked permission to interview dying patients, the response of the hospital authorities was, "Dying? But no one is dying here!" It was precisely such resistance to the acknowledgment of death and to conversation about death that the death awareness movement set out to overcome.

To some extent the movement has succeeded. Still, its success has been limited—so limited that it must still inveigh against silence and denial. Though images of death are rife on our television sets, many people remain reluctant to discuss their own death.

That reluctance might prompt not just a continuing lament about silence and denial but also a consideration of the weaknesses of the movement and especially of its mantra that "death is natural." One weakness of the mantra is simply that natural is such a slippery word. It means different things to different people in different contexts. Sometimes "death is natural" seems to mean nothing more than that death is inevitable. At the end of life, people die. What could be more "natural" than that? Death is simply "a part of life," to use another mantra of the death awareness movement. Death is, on this reading of the slogan, merely a biological event that is predictably and universally the end of any organism's life.

It is hard to disagree with that point, but it has little if any power against the denial of death or against its medicalization. People are unlikely to deny that death is universal, but they remain reticent to acknowledge their own death. It is not death-in-general that we have trouble comprehending and facing but death as self-involving (and self-destroying).

Leo Tolstoy made the same point long ago in his novella *The Death of Ivan Ilyich.* Ivan Ilyich could grasp the syllogism that he had learned in logic class, "Caius is a man, men are mortal, therefore Caius is mortal," but it "had always seemed to him correct as applied to Caius, but certainly not as applied to himself." Ivan resists acknowledging that he is dying. "It cannot be that I ought to die. That would be too terrible." Tolstoy's story is surely a favorite of the death awareness movement for its depiction of the silence and denial surrounding death, but the movement's mantra, at least this particular reading of it, would have had little if any power against Ivan's denial of death.

Moreover, if what the mantra means is that death is merely a biological event, then it would seem akin to the reduction of death to a medical event that the death awareness movement rightly finds objectionable. The death of a person is always something more than either a medical or a biological event. Indeed, the death awareness movement has insisted on that point. The mantra must, therefore, mean something more and other than that death is predictably and universally the end of any organism's life. But what?

Fairly early in the movement, "death is natural" was taken to mean not simply that death is a biological event but that its meaning could be found in the natural process of growth. In 1975 Kübler-Ross edited a book titled *Death: The Final Stage of Growth.* An organic metaphor is invoked to make some sense of the "death is natural" mantra. Death is said to be natural because it is, or can be, growth. Frankly, I do not find much sense in this metaphor; the claim is so counterintuitive. Death is not growth; it is the end of growing. The proper organic metaphor would seem to be that death is decay rather than growth. Death is not a part of life but the end of life, the absence of life.

It does make some sense, of course, to say that dying is a part of life and that dying can be a time of growth. But even if we take the "death is natural" theme as a way to invoke the biological metaphor to characterize dying as a time for growth, the growth metaphor in this context still seems to rely on the model of self-realization to be found in so much popular psychology. In this model, growth is not just a biological process; it is a moral ideal. Human beings should grow, should realize their biological and personal potential.

Another problem relates to the fact that every person has a wide variety of potentialities. We cannot realize them all. We need to make decisions about which to attempt to realize and which to downplay. It is clear, for example, that we have the potential to die, sometimes perhaps even an urge to die. But is that a potential we should make actual? The death awareness movement says no such thing, of course, but not because that would be inconsistent with the language of the realization of potential. Human potentialities and the possibilities of actualizing them are not an answer to our moral questions; they are among the reasons we ask moral questions.

Against medicalization, the language of growth is used to assert that one should be allowed to die one's own death. But if such language simply reasserts the emphasis on choice and autonomy so important to standard bioethics, then all the problems identified above are revisited.

Sometimes the "death is natural" mantra is a way of setting death in the context of the ecology of nature, of construing it as part of a natural rhythm of birth and death—the natural progression from spring to winter and back again. In this view, death is not just a biological event but a biological event that is part of a larger whole, part of a harmonious ecology. Little wonder, then, that the death awareness literature and many of the memoirs influenced by it often invoke images from nature as a way of coping with death. Streams rush to disappear in the lake. Birds return to the wetlands. Habitat is restored by decay. Eagles fly. And people find some transcendence over death by participation in this vast and glorious nature.

Evidently people do find some comfort and consolation in nature. But we should not exaggerate the power of the natural rhythm of birth and death, the natural progress from spring to winter and back again, to overcome resistance to the consideration of one's own death. Death remains an autobiographical event, a self-involving event, a self-destroying event. Winter leads back to spring, back to life, to be sure, but the death of a person does not lead back to the life of *that* person. *That* person is simply dead, that story is over. Ivan Ilyich's line, "It cannot be that I ought to die. That would be too terrible," still echoes from the horizon of both the sunrise and sunset of the days of our dying. And the hole in a life left by the death of a loved one is not filled by the larger whole of nature.

One problem with the "death is natural" mantra is its denial not of death but of the wrongness of death. The sense of the wrongness of death is hard to repress. And neither the conscious repetition of the mantra nor any feigned indifference has finally much power against medicalized death. The promise of the death awareness movement—that if we just learned to regard death as natural, we could avoid a medicalized death—is unfulfilled.

Both standard bioethics and the death awareness movement give truncated accounts of the problems with medicalized death. The problems involve not just the violation of patient control or simply silence and denial but the vision of death as the great enemy to be defeated by the greater power of medicine. To be sure, death is a great enemy. It threatens to cause alienation from our bodies, separation from our communities and the eclipse of God. The ironic result of a medicalized death is that death makes good on those threats before the end of our lives by the very way death is resisted. We are not fated to have a medicalized dying, but it has a strong hold on us precisely because we recognize that life is a great good, that the threats of death are real and terrible and that medicine is a good gift of God the creator and redeemer.

Resistance to medicalized death need not deny the sadness of death, but it may require something like the Christian conviction that though death is a great enemy, it is an enemy already defeated by the God who raised Jesus from the dead and will raise us up by the same great power (Eph. 1:19). In the strength of that conviction Christians should and sometimes do both recognize the threats of death and meet those threats with attention to the dying person as an embodied, communal and spiritual being.

That recognition and a commitment to such attention gave birth to a third challenge to medicalized death, a challenge that had its roots in the deep Christian faith of Cicely Saunders, the founder of the modern hospice movement. It was her vision of a home for the dying that led to the establishment in 1967 of St. Christopher's Hospice in London. Saunders was herself a physician, and her vision was a challenge not to medicine itself but to the narrowing of its ministry to the effort to cure. Her vision incorporated medicine and its authority, joining it to care for the dying. She insisted that research-based medical treatment for pain relief should accompany attention to the psychological, social and spiritual needs of dying patients.

However innovative her challenge to medicalization, Saunders regarded her vision as solidly within the Christian tradition of care for the sick. As she said, "For a thousand years, Christian charitable institutions carried the burden of the sick and the poor—the indigent, orphans and others—amounting almost to a general national health and welfare service."

The key concept in hospice was not the rights of patients but the care of patients. To be sure, the dignity of each patient was explicitly recognized (and proselytizing was forbidden). But the relationship to patients was not seen as a contract between self-interested individuals but as a covenant and a community. And the mantra, if there was one, was not "death is natural" but Matthew 25:40: "Just as you did it to one of the least of these . . . you did it to me."

Saunders's vision was carried to the United States soon after St. Christopher's was established. Less than a decade later, in 1975, a hospice modeled on St. Christopher's opened in Connecticut. And across the country volunteers, nurses and doctors who shared something of Saunders's vision initiated programs to care for dying persons in their homes.

In 1982 Congress passed the Medicare Hospice Benefit, which provided payment for hospice services to patients older than 65 who had a prognosis of less than six months to live and who agreed to forgo therapies intended to provide a cure for their disease. Patients were entitled to the care and support of a hospice team, supervised by a physician, who would attempt to relieve pain, manage symptoms and alleviate psychological, social and spiritual stress. Gradually private insurance programs and Medicaid began to include some coverage for hospice. By 2004 there were more than 3,200 hospice programs in the U.S., caring for more than 900,000 people.

The story of hospice is quite remarkable and is replete with successes. Hospice is much to be commended as institutional support for dying well. But there are problems even with hospice. In the first place, it remains an underutilized resource. Many physicians and others remain unwilling or unable to tell patients that they are dying, and many patients remain unwilling or unable to hear the prognosis that could lead to their utilization of hospice. Silence and denial are still realities, as is medicalized death.

The underutilization prompted by silence and denial is, however, not the only problem. Ironically, there is a risk of medicalization in the hospice movement itself—not the medicalization of death, but the medicalization of suffering. The success of palliative medicine has led to great advances in pain management and to the risk of reducing suffering to pain and reducing care for the dying to the management of their pain. Dying without pain is desirable, of course, and effective pain relief makes an important contribution to the possibilities of dying well, but dying well and faithfully cannot and should not be reduced to a death without pain.

Saunders had insisted that hospice care utilize the best practices of pain relief and symptom management, but she also insisted on a relationship with the suffering and dying that was not simply a relation of professional and client but one of the kind that Martin Buber described as an I-Thou relationship, a genuine meeting of two persons in a covenantal way. She had envisioned a "home"—a building, to be sure, but also a place of warmth and welcome, a place to get comfortable with family and friends, a place to be yourself. Compassion required access to the best palliative care possible, but it also required that others just be there with and for the suffering person. Keeping company was no less a component of care, no less a key to dying well, than pain management.

Unfortunately, a generic spirituality has replaced Saunders's commitment to the Christian faith. Some, of course, regard this not as a problem but as an advance, as a necessary adjustment to the religious pluralism of American society (and perhaps as a requirement of government funding). Religious differences are a significant issue for hospice. To its credit, hospice did not deliberately adopt a perspective that set aside a person's faith (or religious beliefs or spirituality) in favor of scientific objectivity. It recognized that in dying as in living, we are surrounded not only by puzzles but also by mystery. And at the depths and heights of our lives and at the ends of them, there is the Ultimate Mystery, which many call God. There is no escaping this mystery.

Of course, the world is full not only of mystery but also of different ways of naming it. But name it we must if we are to begin to interpret its presence and to relate it to senses of dependence, gratitude, remorse, hope and responsibility. One way or another we learn to name the Mystery, and the way we live and die is a response to the Mystery so named. There is no purely rational foundation for talking about the Mystery any more than there are purely rational ways for talking about morality. There is no religious Esperanto any more than there is a moral Esperanto, no universal language for talking about either the Mystery or morality. That's the first problem with the sort of generic spirituality adopted by hospice.

Hospice has adopted a generic spirituality that refuses to name the Mystery because it seeks to respect religious and spiritual diversity. But generic spirituality can have an ironic result; it is not finally hospitable to difference. When spirituality is reduced to a lowest common denominator, to something like "the Ultimate Mystery," then the ways in which it is named can be trivialized. Or worse, spirituality can be reduced to an internal and individual search for meaning. Then particular religious communities and their practices can be regarded as less relevant to the dying than this individual quest for meaning.

I am a Christian. I know of no other way to talk faithfully about the Mystery at the heart of our world than as a Christian. Of course, it is easy to be presumptuous here, easy to claim to know too much. Even so, as a Christian, I dare to claim that all our responses to Mystery are in fact responses to the God whose story is told in scripture.

One can do worse, I think, than to name the Mystery wrongly. One can respond to the Mystery—even if it is named rightly—by ignoring it. One can deny or suppress the senses evoked by it. Even those who can name the Mystery rightly can still be guilty of refusing to trust and to honor God. They can—and sometimes do—regard God as the enemy of God's own work. More often, they turn the Mystery into a giant puzzle. And more often still, they domesticate the Mystery, rendering the inscrutable not only scrutable but also serviceable to their own projects, to their own communal or individual causes. Those who know enough to say, "Lord, Lord" can still be guilty of domesticating God, drafting God into the service of this army or that one, into the service of this ecclesiastical organization or that one, or into their own service. But the Mystery resists—and a commandment prohibits—the effort to domesticate God. The domestication of the Mystery is the second problem with the sort of generic spirituality adopted by hospice. It virtually sponsors the domestication of the

Mystery, regarding it as therapeutic or as helpful, even if it is a helpful fiction. It is rendered another opiate.

Emphasizing the individual's internal quest for meaning and undercutting the role of particular religious communities, this generic spirituality is too easily co-opted by notions of individual autonomy advanced by the patient rights movement. But it can also be co-opted by the death awareness movement when the spirituality assumed by the mantra that "death is natural" is regarded as somehow transcending religious differences.

At the beginnings of hospice a list of its stakeholders would have included the Christian church. Now it is less than clear that the Christian church would be included. Nevertheless, the Christian community does have a stake in care for the dying. Saunders's vision should be enough to remind us of that. Hospice remains a movement in which many Christian doctors, nurses, social workers, chaplains and volunteers can and do fulfill their vocations. Many Christians die well and faithfully with the help of hospice. The Christian community's stake in the care of the dying may also suggest, however, both support for new hospice programs, self-consciously and deliberately formed in accord with Saunders's originating vision, and—more important—a refusal simply to surrender death and dying to medicine, or to abandon its proclamation that death has been and will be defeated by the great power of God, or to leave the task of ministry to the dying to hospice.

I grant that some progress has been made against the medicalization of death since the Quinlans had to fight to take their daughter off a respirator. But the challenges have not yet been joined to credible alternatives. It is easy, when dying goes badly, to blame the doctors, but it is not their responsibility to teach people how to die well and faithfully. That challenge belongs to the communities of faith. They have the resources and the traditions to re-form our vision of death, to teach people how to die well and faithfully and how to care well for the dying. It is time for the churches to rise to that challenge, to begin again to apprentice people in the art of dying well and faithfully.

This article is adapted from Allen Verhey's book The Christian Art of Dying, *just published by Eerdmans.*