

ETHICAL AND SPIRITUAL CHALLENGES

Holding Life and Death In Dynamic Tension

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Catholic health care institutions place great emphasis on the care they render to dying patients. This has been true for centuries, from the earliest Christian hospitals, to the medieval practice of the *ars moriendi*, to Mother Theresa's homes for the dying untouchables in Kolkata.

In recent years, this Catholic affinity for caring for the dying has met a growing secular demand. Contemporary Western public interest in improved care at the end of life grew rapidly at the end of the 20th century, as manifested in the hospice movement. The originating impulses for hospice were deeply spiritual and ethical — a grassroots response to Western society's death-denying culture, to medicine's failure to employ its newfound technological prowess wisely, and against medicine's tendency to reduce patients to biological specimens. Hospice originally operated at the margins of institutionalized medicine and few physicians participated. It was largely the work of nurses and of bereaved family members.

By the early days of the 21st century, however, medicine finally had gotten the message. Although it took longer to develop in the U.S. than in other countries, palliative medicine became a recognized medical subspecialty, and hospitals began to deploy palliative care services. Catholic hospitals have been in the forefront of palliative care, seeing this work as a way both to embrace their roots and to take leadership in a new medical field.

I wonder, however, whether some of the spiritual and ethical aspects of caring for the dying are

not being lost, or at least papered over, by these latest developments. Are the totalizing, hegemonizing tendencies of medicine gradually corrupting original impulses of the movement? Is palliative care in danger of being transformed into just another manifestation of our culture's still broadly operative, if delusional, denial of death? Are these concerns just as true at Catholic hospitals as at other health care institutions? Can the deep ethical and spiritual bases of caring for the dying be identified and cultivated in the contemporary medical and social climate?

DEATH IS STILL BAD, DYING IS STILL HARD

If life is good, death is bad. Yet everything that lives must die.

These two propositions both seem obvious. Taken together, however, they grate against each other. Life is good and death is bad; life necessitates death. Nonetheless, both must always be held together in tension if we are to cultivate a proper attitude towards our own deaths or to learn how best to care for those who are dying. To deny either will distort our attitudes and our activities.

Properly speaking, these propositions are not paradoxical. Life is good while it lasts. But life



and death are always in dynamic tension. Life is a transient, finite good, and yet life always strives towards its own continuity. Life contains within itself the seeds of death while simultaneously establishing itself continually over against death. We seem naturally designed to want to live forever, but we all know that we must die. That's the core of why dying is hard.

One can attempt a false resolution of the dynamic tension between life and death in several ways. One way is by ignoring death. This is one of the most typical characteristics of our age. We live without thinking about death and act as if it were not part of reality. We glorify youth and pretend to remain young even as we age. We hide dying persons in hospitals or nursing homes. The fact that contemporary medicine is powerful enough to rescue us from premature death and can postpone the time of death reinforces the delusion that a last day will not come. Stem cells and surgery, we imagine, will save us from death's metaphysical weight. Death is regarded as a treatable disease.

Another way to attempt to eradicate the tension, however, is by denying that death is bad. This approach is becoming more common in contemporary Western culture. It seems more enlightened, but on closer analysis it should be clear that it represents just another way of denying the reality of death.

For example, one often hears it said today that, "death is a part of life." These words are offered as words of comfort, but the price of that comfort may be to obscure death's inherent badness. One also is counseled not to be afraid of death, to plan for death with legal instruments like wills and durable powers of attorney for health care, to control even what will happen to one's body after death. "Death Cafes" now encourage people to talk about death over tea and cookies. Death is presented as a controllable phenomenon — as a phase of life that professionals can help us to manage after they've inventoried our preferences.

Such approaches, however, are far too facile. The sort of control that this brand of discourse proffers before the overwhelming reality of death is almost pathetic — like spitting into a hurricane. Death is no part of life. Death is the absence of life. And if death is not bad, then life is cheap.

We need to hold the two propositions in continuous tension. Both are unassailably true, and neither ought to be denied or hidden. If life is good, then death is bad. Yet everything that lives (including us) must die.

Ethicist Paul Ramsey saw all this more than 40 years ago. In an insightful essay written in 1974 called "The Indignity of 'Death with Dignity,'" Ramsey argued that there is no dignity in death. He was quick to point out, however, that there can be dignity in dying, and dignity in caring for the dying. Death is no part of life, but dying always is. Our culture, particularly our medical culture, must learn to face the ethical and spiritual challenges presented by dying and the care of the dying.

ETHICAL CHALLENGES IN CARING FOR THE DYING

Despite decades of work in the ethics of providing care at the end of life, those who are able to hold life and death in appropriate tension still struggle mightily with the ethical questions posed by caring for the dying. For health care professionals, these questions are not classroom abstractions but lived experiences. Moreover, the challenges just keep increasing. The march of medical technology only seems to magnify the moral burden of decision-making. When there were no ventila-

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tors, one never needed to decide whether it was wise to use one in a given case. When there were no implantable cardioverter defibrillators, one never needed to decide whether it was permissible to discontinue one. When there were no drugs that cost \$200,000 a year to administer, one never needed to decide whether it was truly just to prescribe one.

Those who can practice medicine, nursing and the other healing arts within the tension between life and death always will find the ethics of caring for the dying difficult. That is a good thing. In fact, the moment anyone thinks that turning

off a ventilator is like turning off a light switch, it is time to hang up the stethoscope and go home. Making good decisions about care at the end of life always will be difficult. Carrying out the right decision should be hard. If it is not, then something is amiss.

It should be a challenge to decide when it is time to forgo further life-sustaining treatments.

Helping a patient to arrive at such a decision can be a powerful experience that reverberates with all the dignity of the human. But it is never easy.

To make such a decision means that a genuine someone (a mother, or a sister, or a grandfather, or some other child of God) will die, and that is always bad, always a loss, even when the decision is right and true and just. There is dignity in such dying, and dignity in caring for such a patient, but discerning just when it is right to forgo further therapy always will involve difficult judgments. Such judgments must take account of the particulars of the individual patient and of those who love her, the nature of the disease, the way it has affected this patient, and a host of other circumstances. Clinging to life too tenaciously can represent an undignified denial of the reality of death; forgoing life-sustaining treatment too readily can represent an undignified denial of the value of life. Making the right choice can be both the product of grace and a source of grace for others. Helping a patient to arrive at such a decision can be a powerful experience that reverberates with all the dignity of the human. But it is never easy.

These challenges are amplified when the patient can no longer speak for himself. It is hard enough to help a patient navigate the currents of ethical decision-making at the end of life, but it is even harder to do so absent the patient's voice. Ethical theorists have attempted to simplify the process, turning family members into impersonal conduits for the autonomous preferences of the patient, charged with reporting what the patient would have wanted were he able to speak for himself. But studies have shown how poorly loved

ones fare in this exercise, and how stressful it is to be put in the position of helping to make life-and-death decisions for one's closest relatives and friends. The task is really far more complex. The ethical challenge for both the health care team and the family is to choose what would best promote the good of the patient as a unique person, in the context of his or her relationships, applying the patient's authentic values, known wishes and real interests, as best they can be known, to the current clinical circumstances. That is a complex undertaking and never easy. It takes time and emotional energy. The process is best begun not by asking for a substituted judgment, but by saying, "Tell us about your Dad."

Ethical theory (and the Catholic moral tradition) hold that there is no ethical difference between withholding and withdrawing life-sustaining treatment. Yet only someone with no clinical experience would fail to recognize the differential psychological impact of these two types of decisions on loved ones and clinicians. One invariably feels very closely, causally connected to the death of a patient if one switches off a drug that had been maintaining the patient's blood pressure and watches that pressure quickly drop towards zero — more than if one had decided never to start the drug in the first place. Although both decisions are human acts and both require equivalent moral justification, the psychological impact is disparate. It can be a challenge to discontinue a life-sustaining treatment, even when it is clearly more burdensome than beneficial. We need to acknowledge that. Doing the right thing can be hard.

Interestingly, it has become challenging for clinicians to render opinions about what they think would be best for the patient. The increasing emphasis that our society places on personal choice has so influenced bioethics that physicians think it immoral to advise patients at the end of life — an imposition of biased values upon the patient. I wonder, however, whether this "non-directive counseling" approach to decisions about feeding tubes and ventilators hasn't served as a convenient retreat for physicians from the discomfort they have in sharing the burden of decision-making with patients and families. Moreover, the effect of this hands-off approach is to abandon



patients to the loneliness of a rarified and unnatural zone in which they must decide their own fates alone. For 2,500 years of Western medicine, physicians could do little but render opinions. There is no reason why they cannot do so now. Clinicians ought to share their accumulated knowledge and experience and help patients by sharing the burden of decision-making and rendering an opinion. Patients are free to choose otherwise if they disagree.

SPIRITUAL CHALLENGES IN CARING FOR THE DYING

The ethical challenges in caring for the dying that I just outlined run in tandem with spiritual challenges. Broadly speaking, there are three major spiritual temptations for clinicians who encounter dying patients.

The first temptation is to medical hubris. While this is the oldest temptation afflicting health care professionals, the more powerful medical technology becomes, the greater the temptation. There always seems to be something more one can attempt to do to prolong life. If the ventilator is not supplying enough oxygen, try extracorporeal membrane oxygenation. If medicines can no longer support a failing heart, try a left ventricular assist device. If standard chemotherapy is no longer working, enroll the patient in a phase I trial. Clinicians routinely overestimate the effectiveness of their interventions, extrapolating too easily from the highly restricted population enrolled in a clinical trial reported in the literature to their own patient with 10 other comorbid conditions, who never would have qualified for the trial, and, given everything else that is wrong, will almost certainly not benefit from the treatment.

Another aspect of the temptation to hubris is the reluctance ever to say never. Medical power comes through science, and clinicians often retreat from the inherent ambiguity of commonsense bedside reasoning into the safety of science when facing a patient's impending death. Statistics are never zero. This can tempt clinicians into saying, scientifically, "There's only a small chance," when the practical bedside judgment should be, "To a reasonable degree of medical certainty, this treatment will not work."

Hippocrates counseled centuries ago, "When the patient is overmastered by disease, do not treat, recognizing that medicine is then powerless."

Clinicians need to cultivate the virtue of medical humility before the reality of death and acknowledge that there comes a time in every case when medicine is powerless. Then they can say, with St. Paul, "In my weakness is my strength."

The second temptation is to avoidance. Health care professionals often are afflicted with a sense of failure if a patient dies, and to avoid this unpleasant emotion they sometimes stop seeing patients who are dying. Or they may feel helpless or inadequate if the patient is dying and they feel there is "nothing they can do." Or they may harbor fears of death themselves, or unpleasant memories of a loved one's death, and therefore avoid contact with the patient.

Even if medical care is not technically compromised by such avoidance, the experience of the patient is abandonment. Dying is bad enough, but dying alone is awful. Patients deserve to be accompanied through their last days by health care professionals who care, who can remind them that they are cherished as valuable members of the community, even as the bonds that tie them to the rest of us slowly dissolve.

The antidote to avoidance is the virtue of courage. It takes courage to face death and face the limits of medicine and still walk with the patient. Clinicians who do this can participate in that perfect love that the Gospel teaches will cast out all fears.

The third temptation is to triumphalism. Even experienced and well-intended palliative care

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practitioners can succumb to a false sense that they have the power to make death pretty, and falsely offer patients this "good death." Death is never pretty. It can often be beautiful, but death is never pretty. There are no pharmacological solu-

tions to the metaphysical problem of death. Suffering can (and should) be lessened where that is possible and falls within the scope of medical care, but the drive to eliminate all suffering and control the dying process can turn even well-intentioned palliative care practitioners into brutes.

Palliative care is a wonderful, long overdue development in modern medical practice. But palliative care practitioners must see themselves as servants of the dying patient, not orchestrators of a contrived vision of a “good death.” To avoid triumphalism, one needs to cultivate the virtue of temperance, not deploy palliative care treatments and services beyond the scope of medical practice or offer the false expectation that one can erase the badness of death.

Those who can hold life and death in the proper tension will take counsel from St. Peter, who instructs, “make every effort to supplement your faith with virtue, virtue with knowledge, knowledge with temperance, temperance with

endurance, endurance with devotion, devotion with mutual affection, and mutual affection with love.” Their care will be the best that medicine can offer to the dying.

CONCLUSIONS

Caring for the dying is never easy, but the rewards of doing so can be great. The ethical and spiritual challenges one must face in caring for the dying are significant. Health care professionals who care for the dying must be vigilant never to try to disguise or resolve the essential tension that characterizes their work: life is good and death is bad; there is no life without death. Good care for the dying requires the virtues necessary to live in that tension; a life of such virtue can be gloriously fulfilling.

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QUESTIONS FOR DISCUSSION

If life is good, then death is bad. Yet everything that lives must die. Death is not part of life, but is the absence of life. And if death is not bad, life is cheap. One can find dignity in dying, and in caring for the dying, but there is no dignity in death. These are propositions that Daniel Sulmasy, MD, PhD, spells out for us before discussing the ethical and spiritual challenges inherent in caring for people who are dying.

- Sulmasy points out that the technological advancements that have increased the possibility of prolonging life have also increased the ethical dilemmas such treatments may raise for clinicians and patients alike. Talk about the difference between declining a life-sustaining procedure vs. withdrawing it. What does that mean ethically at the bedside? What does it mean psychologically? Are there differences for the patient’s loved ones vs. for the clinicians?
- What do you think of the suggestion that Sulmasy makes about giving opinions to patients or loved ones? Discuss the value of keeping your experience and thoughts to yourself as opposed to sharing your personal story and guidance. If you believe giving an opinion is important, should it be offered spontaneously or only if the patient or family member asks for it?
- How do you think your ministry and clinical staff can confront what Sulmasy describes as the three most challenging spiritual temptations in caring for people who are dying — medical hubris, avoidance and the triumphalism that is the dark side of palliative care. What kinds of team exercises and conversations with clinicians, ethicists chaplains and mission leaders could guide care of the dying?

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

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