Spiritual Issues at the End of Life: 
A Call for Discussion

by JOHN HARDWIG

When I am dying, I am quite sure that the central issues for me will not be whether I am put on a ventilator, whether CPR is attempted when my heart stops, or whether I receive artificial feeding. Although each of these could be important, each will almost certainly be quite peripheral. Rather, my central concerns will be how to face my death, how to bring my life to a close, and how best to help my family go on without me. A ventilator will not help me do these things—not unless all I need is a little more time to get the job done.

Unfortunately, however, bioethics has succumbed to the agendas of physicians. Physicians face ethical concerns about treatment decisions—when to offer, withhold, and withdraw various treatments—and treatment decisions have been the focus of bioethics as well. But the issues that most trouble patients and their families at the end of life are not these. To them, the end of life is a spiritual crisis.

Spiritual?

The word “spiritual” is ambiguous. As I use it, spiritual refers to concerns about the ultimate meaning and values in life. It has to do with our deepest sense of who we are and what life is all about. Spiritual does not imply any belief in a supreme being or in a life after this. Atheists have spiritual concerns just like everyone else.

Spiritual, then, does not mean religious. Indeed, this sense of spiritual forces us to ask, How effectively do organized religions address the spiritual needs of their members? It may be that some organized religions—or some representatives of them—serve to silence spiritual concerns at the end of life or to distract people from them.

Certainly many American churches do not talk much about death and dying. One minister confessed, “We talk a lot about what we believe comes after death. But we skip pretty quickly over dying itself, except to say to make your peace with the Lord.” Often, there are strong social and religious pressures to suppress any doubts or questions; doubts and questions are taken as a sign of a weak faith. As a result, Christians can still find that their faith gives them no guidance about how to live the final chapter of life.

What We Suffer From

People facing death suffer from an inability to find meaning in this last chapter of their lives; from a bleak, narrowly confined and abbreviated future; from inability to deal meaningfully with family and loved ones at this final opportunity; from total dependence on others; from loss of capabilities; from being turned from a contributor into a burden on others; from the indignity of being unable to take care of even basic bodily functions; from a sense that their bodies or their minds are betraying them; from being cast out of the world in which the healthy live; from guilt; from a sense of abandonment; from anger about all of this; and from isolation due to the reluctance of the healthy to broach the subject of dying.

These are all spiritual issues, or at least quickly bring spiritual questions into view. Facing death brings to the surface questions about what life is all about. Long-buried assumptions and commitments are revealed. And many find that the beliefs and values they have lived by no longer seem valid or do not sustain them. These are the ingredients of a spiritual crisis, the stuff of spiritual suffering.

Yet they are not the themes of bioethics. Some will object that they are not properly themes of ethics at all, but if they are the dominant concerns of dying patients, bio-

ethics has failed to address patients’ concerns at the end of life. This failure has ramifications throughout the discipline of bioethics.

1) Many patients show little interest in making treatment decisions. “What difference does it make?” one patient told her doctor. She was not asking: her tone and expression made it clear that any difference a treatment decision could make would not be important to her now. Advance directives and the entire theory of proxy decisions are also largely irrelevant to patient concerns at the end of life. They too focus on treatment. Indeed, it is possible that one reason so many people do not complete advance directives is precisely this irrelevance: I expect it will hardly matter to me what kind of treatment I receive when I am unable even to recognize myself or my loved ones.

Yet when patients and especially families struggle with treatment decisions, the struggle is often rooted in the questions’ spiritual dimensions.

2) Giving pain and analgesia too central a place in the care of the dying could easily distort end of life care. Relief of pain is clearly important. However, better management of pain will do nothing to ease the suffering brought on by the specter of my end, the indignity of my decline and debility, the prospect of useless and purposeless days lying in the hospital bed, the emptiness and darkness of my future.

3) Similarly, the entire discussion of physician-assisted suicide threatens to become skewed by an inordinate focus on the pain of terminal illness. Requests for physician-assisted suicide are not motivated simply by pain or fear of pain. Death is horrible not primarily because it is painful, and my fear of death is not primarily fear of pain. (I may have experienced worse pain before.) It is a spiritual crisis that motivates many requests for physician-assisted suicide.

4) Aging, chronic illness, and nursing home care are all harbingers of death. We Americans avoid them, dislike them, dislike even thinking of them partly for that reason. Of course, each brings its own forms of spiritual suffering as well.

5) Families suffer too. They face the impending loss of a loved one with the difficulty of imagining how to go on without her. Loss of a loved one is normally also a spiritual crisis: family members may well have to reshape their identities and redefine their basic commitments when their loved one is gone. Long unresolved family issues threaten to become permanently unresolvable. Family consensus often proves elusive. And the family too suffers from guilt and from a sense of abandonment. Physicians relate stories about distant family members who suddenly materialize when dad or mom is dying and vehemently insist that everything be done. The common view is that their demand for aggressive treatment is fueled by guilt and by a desire to atone for past neglect. But guilt and atonement are spiritual issues.

6) Thus perhaps many requests for futile treatment reflect the fact that patients and their families have not completed the essential human tasks of dying. The inability to “let go” may express an inability to complete relationships as much as love for a dying family member. In any case, love too requires an ability to let go, as Simone Weil somewhere reminds us: “in loving, we need to learn only how to let go; holding comes naturally.”

The Bioethical Silence

I submit, then, that patient and family issues at the end of life are almost entirely spiritual, for perhaps especially at the end of life, we become aware that we are spiritual beings. These would be important common denominators of our difficulties with dying, a central element in adequate care for the dying.

Why have contemporary bioethicists been so largely silent about spiritual issues at the end of life? It is partly because they have conceived of bioethics as an ethics for physicians and other health care professionals. Despite all the emphasis on patient autonomy and patient empowerment, the responsibilities on which bioethicists focus are the responsibilities of physicians and other health professionals. We have had virtually nothing to say about the responsibilities of autonomous patients, certainly nothing at all to say about how to die a responsible death.

Bioethicists’ silence may also be due partly to the fact we have been struggling to establish bioethics as a secular discipline. We badly want a place at the table in secular health care institutions. We want to speak to scientifically minded physicians and to distinguish ourselves from chaplains and other clergy.

Bioethicists have also struggled to present a unified face and a unified theory to the world of health care. A unified body of knowledge and perspective bolster our claim to professional status. Spiritual issues may well divide us. Perhaps we also fear the depth and intractability of dissension over spiritual issues, as well as the dogmatism that can so easily be aroused by it.

Finally, bioethics may be hamstrung by the contemporary assumption that ethics is solely about right and wrong conduct. However unable a patient may have been to bring her life to a successful close, it would be very odd to say she died wrong. But ethics is more than a theory of right and wrong conduct, and bioethics must surely be more. A bad death is not necessarily or even primarily a “wrong death” or the result of a series of “unethical” decisions at the end of life. A bad death is also a meaningless death, or one marked by an inability to accept one’s mortality, or one that is divisive and destructive to loved ones and families. Thus if good care for the dying is a part of bioethics, we cannot avoid these spiritual issues.

Even more basically, a discussion of spiritual issues at the end of life is central to ethics in the classic sense, in which a pivotal question is, What is the good life? Such an ethics teaches how to live, and so also how to die. I suggest a return to older traditions in which it made sense for an
ethicist to offer a manual on how to die. Such an ethics offers advice or counsel, not prohibitions and injunctions. If a label is helpful, the discussion I intend would be one part of a “eudaemonistic bioethics.”

The Care of the Dying

The theoretical silence of bioethicists is reflected in a practical neglect. Health care institutions generally do little to help patients and families deal with the spiritual issues of the end of life. At most, they provide a chaplaincy service to which such questions can be handed off. But spiritual issues must not be left to chaplains or other clergy, helpful as they often are, for that leaves unmet the spiritual concerns of those who do not share the faith commitments of the chaplains’ religions. Also, a service available only at the end of life may be too late. The spiritual suffering at the end of life may begin well before the patient is actively dying. Once, people normally got sick and died in a matter of days or weeks. Now the average American will know three years in advance what she will die of. Even a terminal illness is not always necessary; aging alone also brings with it a recognition that death is no longer remote.

Should we expect physicians to assist terminally ill patients in dealing with spiritual issues, too? There seems to be a variety of reasons not to. Aren’t physicians too focused on diseases? Aren’t the medical treatment issues themselves complicated and vexing enough? Do physicians have either the disposition or training that would enable them to help patients deal with the end of their lives? After all, physicians are reported to have an unusually high death anxiety that medical school does little to alleviate. The role of a physician is already overwhelmingly complex. Wouldn’t asking physicians also to take on the role of spiritual counselor at the end of life prove to be both unrealistic and unsustainable? Moreover, the bewildering array of unfamiliar medical specialists that patients face at the end of life would fragment any spiritual care beyond usefulness, and the cost-containment pressures that are forcing physicians to spend less and less time with any one patient perhaps effectively prohibit serious attention to spiritual concerns.

But if physicians are not suited for the job, then we ought to “demedicalize” death. We ought not put doctors in charge of the care of the terminally ill. Doctors should be “ancillary personnel,” for their expertise is just too peripheral to the concerns of the dying. The hospice movement has taken steps in that direction, but the care of a much broader spectrum of dying patients would need to be removed from the hands of physicians. Spiritual care is the core of care for the dying.

A Nonreligious, Spiritual Discussion

I believe we must move the discussion of spiritual issues at the end of life to center stage in bioethics. The discussion must be, in large part at least, an inclusive, nonreligious discussion. We need such an inclusive discussion because the spiritual needs of the unreligious must also be met. For nontheists, only a nonreligious discussion can hope to articulate the spiritual needs of a secular world. Also, for members of religious communities, only a nonreligious discussion can lay bare the concerns and mind set of our contemporary culture, revealing the spiritual issues at the end of life that even religious discussions will have to address. Further, strong religious convictions are not sufficient to ensure a good death or to endow the terminal phase of life with meaning, purpose, or validity. My eighty-eight-year-old mother is absolutely convinced that she will be reunited with her husband in heaven, but she says to me over and over again, “John, why does this have to take so long?”

Only at the end of such a discussion will we know whether there are spiritual common denominators shared by all or many of the dying. Only then will we be able to locate the pivotal differences. Only a serious effort at such discussion will determine whether we can talk with each other across the differences in our religious convictions.