IMPROVING
End of Life Care

WHY HAS IT BEEN SO DIFFICULT?

Edited by Bruce Jennings,
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THE HASTINGS CENTER

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Preface

At the time of the Karen Ann Quinlan case in 1975, the law and ethics of forgoing life-sustaining treatment were terra incognita. By 1990, the Nancy Beth Cruzan case, the federal Patient Self-Determination Act, and court rulings and statutes in all fifty states had created a widely accepted framework for decision-making near the end of life. Establishing this framework is one of the great accomplishments in bioethics.

Or so goes one common story. Expanded a little, the story goes like this: Thirty years ago, awareness began to grow that the experience of dying (for the individual, for the family, and often for health caregivers) was often a horror. Sentiment began to grow behind a movement to improve end of life care, and this reform movement was based on the belief that the horror of death was avoidable because it does not reside in dying or death per se, but in a poorly managed dying. What needed to be done, the reformers saw, was to look death in the face and wrest control over dying from doctors and hospitals, with their powerful but mindless drugs and machines—virtual loose cannons that could be as burdensome for some as they were beneficial to others. If lack of control, the technological imperative, and unrelieved pain and suffering are what make dying fearful, then the key to improving end of life care is twofold: First, we should enlist the law to empower persons to dictate the terms of their own medical care at the end of life (via constitutional rights and legally authorized advance directives). Second, we should enlist medicine to improve its skill at treating pain and suffering (financing for hospice and professional education in palliative care). If we could do these two things (the reformers hoped and believed), ordinary people and their families—the intended beneficiaries of all this work—would embrace the reforms with open arms, insist on making their own medical decisions at life's end, and complete advance directives. By 1990, although work remained to be done to bring this agenda to fruition, the agenda itself, at least, was settled.

This story is partly true, and some of the reformers' vision has been realized. Today people have much more control of their medical care at the end of life, the technological imperative has been bridled to some extent, and palliative care is taken more seriously in the medical mainstream. Over 700,000 people who die each year receive hospice services for at least a short period of time before death; and roughly three-quarters of all deaths in hospitals now come after some explicit decision has been made to forgo the use of some type of potentially life-prolonging intervention. Many people are fortunate enough to die with pain kept to a minimum, surrounded by the people they love, in a setting attentive to their spiritual, emotional, and physical needs. That is progress.

But while the story is partly true, it is altogether too facile and simplistic. What progress has been made is now in danger of being undone. The framework of principles for legitimate decision-making at the end of life built by the courts, the legislatures, and in the professional and ethical literature has not been embraced—indeed, it has been rejected, at least in large part—by increasingly powerful and vocal minorities; and political support for this framework, as well as its intellectual justification, seems to be eroding. This is a critical problem. It points to flaws in both our concepts and our institutions. Important assumptions—about autonomy, quality of life, trust, family dynamics, and the motivations of professionals and laypeople—need to be rethought. Our systems of decision-making and care delivery near the end of life need to be redesigned.

The topic of end of life care came into its own during the 1990s. The decade began with the Cruzan case, the Supreme Court's first landmark ruling on end of life care, in which the Court affirmed the constitutional right to refuse life-sustaining medical treatment. This was quickly followed by passage of the federal Patient Self-Determination Act, and of durable power of attorney for health care statutes in many states, all stressing the importance of considering each person's preferences about end of life care in advance. Public education efforts to encourage the use of advance directives sprang up nationwide.

In the mid-1990s, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) rigorously documented the alarming extent to which aggressive life-prolonging measures were still

being used in situations where they were either medically futile, unwanted by patients and families, or both. Even concerted efforts to improve communication between physicians and dying patients did not stem the technological momentum of life-prolonging treatments in the country's major medical centers. Moreover, a large proportion of families reported that the patient had spent the last two or three days of life in severe, unrelieved pain. A precursor to this supplement, *Dying Well in the Hospital: The Lessons of SUPPORT*, which was published in the *Hastings Center Report* exactly ten years ago, contains a thorough discussion of this important research.

Growing fears of losing control of care at the end of life, of becoming dependent on machines, of being an emotional and financial burden to one's family, and of suffering due to inadequate treatment of pain and other symptoms—all these fears and more led to a growing grassroots movement in the late 1990s to legalize "physician assisted suicide" (PAS), or what some prefer to call "physician aid in dying." The situation was dramatized by the public defiance of the law by Dr. Jack Kevorkian, the controversial Oregon referendum that legalized PAS in that state, and the Federal Appeals Court rulings in the Second and Ninth Circuits that temporarily struck down existing state laws against PAS before the Supreme Court overturned those appellate rulings in 1997. But while it refused to strike down existing state laws prohibiting PAS, the Court also decided not to interfere with the Oregon law permitting it, and it left the constitutional door open to other states to change their laws on PAS as they saw fit. Controversy over PAS in Oregon still continues, however, as federal officials in the Bush administration have sought to undermine it through regulatory sanctions against physicians. Meanwhile, referenda to legalize PAS have failed at the ballot box in some other states. Dr. Kevorkian is currently serving a prison sentence.

Even as these controversies monopolized most media attention, a less contentious but arguably more significant long-term educational and institutional effort was under way, led by several groups seeking to improve end of life care and to address the concerns of the general public. Chief among them was hospice, which first appeared in the United States in the 1970s but which became more widely known and utilized in the 1990s. Efforts by hospitals and community groups to educate consumers concerning the use of advance directives also became widespread. Some educational programs have been aimed at health care professionals, whose formal training had often not included death and dying or palliative care. Among these programs is "Decisions Near the End of Life," created by the Education Development Center and The Hastings Center with support from the W.K. Kellogg Foundation and used by approximately two hundred hospitals in thirty states. Other educational programs focused on con-

sumers and communities were sponsored by groups such as the American Association of Retired Persons and various state-based coalitions and consortia, including the so-called community health decisions groups.

The health care professions themselves have also paid growing attention to improving the standard of practice in pain management and palliative care. A landmark Institute of Medicine study, *Approaching Death*, proposed improvements in the quality of palliative care. As the essay in this collection by Kathleen Foley reminds us, specialists in this area have long argued that basic medical education and general skill and knowledge within medicine are not sufficient to meet patient needs; pain has been systematically and persistently undertreated in mainstream American health care. New curricula for medical and nursing education have been developed and implemented; a major educational program of the American Medical Association, known as EPEC, trains physicians throughout the country in order to encourage better advance care planning with patients and palliative care skills, and the American Nurse's Association offers a parallel program called ELNEC. Other more specialized educational programs have followed suit, such as EPEC-O, sponsored by the American Society of Clinical Oncology for oncologists, and APPEAL, sponsored by the Institute to Improve End of Life Care for African Americans. In addition, Core Principals of Palliative Care have been adopted by nineteen national professional organizations to include in their teaching programs. The Veterans' Healthcare Administration has developed palliative care teams and leaders, making palliative care integral into its health care system. And the Center to Advance Palliative Care, based at Mount Sinai Medical Center in New York City, provides consultation and support for health care facilities seeking to establish palliative care consultation services throughout the country.

Finally, in the past fifteen years, many private foundations and grassroots groups have pressed for improvements in end of life care. Among the foundations notable for their efforts on end of life care are the Open Society Institute (through its Project on Death in America), the Nathan Cummings Foundation, the Mayday Fund, the National Hospice Foundation, the Hospice Foundation of America, and the Arthur Vining Davis Foundations, to name just a few. The Robert Wood Johnson Foundation, funder of the SUPPORT study, has been a leader in this effort. The Last Acts Partnership, a nationwide coalition of groups working on many fronts during the 1990s, was created under its auspices, as was the successor to Last Acts, an initiative called Caring Connections, organized by the National Hospice and Palliative Care Organization. The Robert Wood Johnson Foundation also funded several programs on innovative partnerships between providers and community groups, and numerous state-

based initiatives to reform laws and regulations and to improve end of life care. At the grassroots level, new organizations have been formed, such as Americans for Better Care of the Dying.

With all that has been accomplished, major challenges remain. The essays in this supplement explore the conceptual and systemic flaws in end of life care reform since the mid-1970s. They also offer suggestions about how to bridge the gap between, on the one hand, the legal and ethical framework now widely but not universally embraced, and, on the other, the real world of decision-making and care on the ground. Much of the conceptual reexamination has to do with concerns about the concept of autonomy, the dynamics of families, and the factors of race, class, and ethnicity (see the papers by Callahan, Burt, Dubler, Hickman and colleagues, and Meisel). Some of the papers consider possible systemic reforms that would lessen the weight placed on explicit, tragic individual treatment decisions. One possible reform is to design systems of care to satisfy the noncontroversial needs of people whose trajectories toward death follow one of the several well-known patterns (Lynn). Another is to develop better continuity of care across a longer period of time before death (Lynn, Foley). Essential to any further progress in end of life care reform is improved understanding and communication—between the hospice and palliative care communities and mainstream hospital-based medicine (Foley), between long-term care facilities and professionals (Johnson), and between disability advocates and patient's rights advocates who now find themselves unnecessarily at odds over fundamental issues such as quality of life and the adequacy of long-term care services (Asch). The concluding essay (Murray and Jennings) brings together many of the themes identified in the other papers and formulates lessons and recommendations that will help end of life care build on its successes while avoiding the repetition of past mistakes.

—Bruce Jennings

Death: "The Distinguished Thing"

by DANIEL CALLAHAN

Faced with his imminent death, Henry James is reported to have said, "So it has come at last, the distinguished thing." Distinguished? That seems an odd term to use, but James was a master at choosing the right word, and he may have seen better than most of us what death is all about. My dictionary defines "distinguished" as "having an air of distinction, dignity, or eminence." Yet there is dissent from that judgment. The late theologian Paul Ramsey contended that there could be no death with dignity. Death is too profound a blow to our selfhood, to everything good about our existence. James or Ramsey?

For at least forty years now—Ramsey notwithstanding—a massive effort has been under way to bring about death with dignity. The leading techniques have been the use of advance directives, hospice and palliative care, and improved end of life education for physicians, nurses, and other health care workers. As the *Hastings Center Report* 1995 special supplement on the SUPPORT study indicated, that effort achieved only a mixed success; a decade later, this report describes progress since then, but points to the long road for creating real and lasting improvement.

There has always been some ambiguity in that effort. James and Ramsey, for instance, seem to be talking about the meaning and place of death in human life, not about what kind of care is desirable at the end of life. Ramsey was no opponent of those efforts to improve end of life care. He objected to the sentimentalizing of death: even the best end of life care could not sugarcoat death's fundamental offense. Was he right? Unless it is possible to work out some reasonably satisfactory answer to that question, my guess is that the care of the dying will remain seriously hamstrung. I sometimes get the impression that recent efforts to improve that care are managing, perhaps inadvertently, to evade dealing with death itself, focusing instead on palliative techniques and strategies.

I want to get at the core question here—that of the appropriate relationship between the care of the dying and our stance toward death itself—by proposing some historical ways these two issues have either been blended or separated.

My point of departure is the premodern era, most plausibly described in the French historian Philippe Ariès's fine 1977 book *The Hour of Death*. He detailed "the persistence of an attitude toward death that remained unchanged for thousands of years, an attitude that expressed a naïve acceptance of destiny and nature." He called that "the tame death" and showed how it was accompanied by practices at the end of life that stressed death's public impact—the loss to the community of an individual's life, underscored by rituals of mourning that made the same point. How people died and the meaning of death were inextricably blended.

Though Ariès specified no particular time at which that long era ended, I believe it wound down in the 1950s and 1960s. By then postwar medical progress, rapidly enriched with lifesaving drugs and technologies, was in full flower and eagerly embraced. Medicine could finally do something about death, and doctors were quick to take up the new arms in a new cause, that of aggressively fighting to save lives, now a plausible effort.

No quarter was to be given. I recall in the 1960s arguing with physicians, educated in the postwar years, who told me that they had a moral duty to save life at all costs. The quality of life, the actual prognosis, or the pain induced by zealous treatment were all but irrelevant. The technological imperative to use every possible means to save life was combined with the sanctity of life principle in what seemed the perfect marriage of medicine and morality.

Then came the backlash, beginning in the late 1960s. Often bitter complaints about useless but painful treatments, about abandonment at the end of life, and about death in a cocoon of tubes and monitors, began to turn the tide.

These complaints led to reform efforts that focused on means to improve end of life care. What was left out of these efforts was a coming to grips with the meaning and place of death. What Aries had called a "naïve acceptance of destiny and nature" was put to one side—but nothing, seemingly, was put in its place.

That gap was soon filled. President Nixon in 1970 declared war on cancer and the National Institute of Health was soon on a roll. Gradually, almost imperceptibly, there emerged what I think of as the great schism in medicine. On one side was palliative care, seeking to bring back into clinical practice the relief of pain and suffering as one of the highest goals of medicine. That kind of care, as initially understood, required that both doctor and patient accept death as an unavoidable part of life. On the other side was an ever-expansive medical research drive, the sworn and well-financed enemy of death and illness of every stripe. That research drive is the implacable foe of an old-fashioned, anachronistic fatalism which held, as fixed human wisdom, that many bodily miseries, but especially death, just have to be endured. Death is now not to be accepted, but eliminated.

There is no easy way to reconcile these two faces of medicine. The research push treats death as a contingent, accidental event that can be done away with, one disease at a time. Research advocates can hardly contain their enthusiasm for the great possibilities that lie ahead. Think only of the campaign for stem cell research, with its promissory note of cures for heart disease, Alzheimer's, Parkinson's, diabetes—just about everything except athlete's foot.

That kind of zeal spills over into clinical practice. Force-fed by research turned into technology and undergirded by medical education and clinical acculturation, good medicine saves lives. It does not give up. It refuses to negotiate with death. Why should anyone accept, at least in principle, a death that researchers believe will someday be cured—any more than AIDS should be tolerated when, someday, a vaccine will work? In the meantime, innovative technologies can provide a few more days, weeks,

maybe months of life, than was possible even a few years ago. Every physician has his miracle story. Go for it!

I once asked a visibly dying friend, someone who had taught medical ethics for thirty years, why he had agreed to one more round of chemotherapy for his recurrent pancreatic cancer, leaving his mouth so full of sores he could speak only with great pain. "They talked me into it," he said. His oncologist probably talked himself into it as well. Death came quickly after that, the treatment useless. But how else to proceed, the true believer might ask, to gain the progress that is possible? If that chemotherapy trial failed, the next one may succeed; or at least the one after that one.

But is there an inconsistency in helping someone die well when death is on its way while simultaneously seeking a cure that will benefit future patients dying from the same disease? There is no logical inconsistency, narrowly understood, but there is a powerful psychological clash. It pits the value of accepting death when a particular death is unavoidable against rejecting death as a matter of principle for a research-ambitious medicine.

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It may well be that still another stage is beginning to appear. If the "naïve acceptance of destiny and nature" has been put to one side—for a time, with no other clear view of death to put in its place—such a view may now be coming into focus. It might be called the Denial of Death II, to invoke Ernest Becker's 1970s book *The Denial of Death*. By that phrase I mean not a refusal to look death in the face, to hide it away, which was Becker's point, but to incrementally whittle away at its supposed inevitability, and to return to the treatment aggressiveness of the 1950s and 1960s.

Part of this new stage is motivated by the research imperative, which is steadily gaining ground, and part by a combination of other influences, each of them more incremental than decisive in nature but, taken together, strong in their aggregate force. Let me give some examples of those influences, each of which drives a wedge between the care of the dying and the place of death in life. My evidence is, on the whole, anecdotal, and the items I note may not be all that telling; but this is what I see and hear.

The advanced edges of the palliative care movement, I have been told, have quietly been dropping the notion that its patients must have accepted death if it is to succeed in caring for them; it seems to be embracing a cautious neutrality on that point. At the same time, a new compromise with death has been proposed in some territory between acceptance and rejection: the teaming up,

Forces on the scientific side that treat death as the great enemy, not to be tolerated, and on the ideological side, seeing snares and delusions in end of life care, are creating new obstacles to caring for the dying. If we are not careful, we could reverse the progress made to improve end of life care thus far.

for instance, of an oncologist and a palliative care specialist to treat a terminally ill patient who teeters on the borderline between hope for life and acceptance of death.

Those (like myself) who are ready to accept death as biologically inevitable are being labeled either "mortalists" or "apologists." Some of us have sunk pretty low, I suppose. In this climate, abetted by industry marketing and media hype of one breakthrough after another, should we be surprised that physicians complain about inflated patient expectations, or that many patients or their families want aggressive treatment without limits when faced with death? Should we be surprised that some consider the death of Terri Schiavo, defined as simply disabled and thus not beyond the reach of medical care, as nothing less than murder? Religious conservatives and disability advocates often now team up to call into question the motives of those seeking an acquiescence in death, attributing it to moral insensitivity, to a denigration of those with diminished capacities, or to a crude desire to cut costs by eliminating the expensively burdensome. They are adding a new instability to an already complicated situation.

I do not mean to suggest that end of life care is burdened simply by medicine's profound ambivalence about death, intensified by a public that shares some of that ambivalence. No doubt advance directives have never had the impact hoped for because most people resist facing up to their eventual death (even the preparation of ordinary wills is widely neglected). Education and publicity can make a dent in the otherwise poor figures (less than 25 percent have advance directives by most accounts), but the fact that most deaths are not seen up close and occur for the most part in old age does not push the reality of death in one's face the way it once did. If you don't want to think about it, there are lots of ways to look in other directions.

No less important, it seems, is what I call the multiple variable problem. Just as health care reform in the United States is stymied by a large number of competing interests and a plethora of subversive variables, end of life care has its own excess of variables. Even with the best will in the world and advance directives (or surrogates) in place, much can go wrong: disagreements between doctor and patient, doctor and doctor, family and patient, family and doctor, hospital and medical cultures (some favorable and some cool to advance directives), and so on.

The Schiavo case illustrates the point. Had she or had she not clearly stated her desires? Who had her best interests at heart, her husband or her parents? Even if recovery was unlikely was it at least possible, and might some further treatments have made a difference? We all have our answers to those questions, but the point is that it was not hard to pick a fight. There are many cases that do not rise to the sad and unseemly level of the Schiavo fight. Many people will conclude that it is vitally important to have clear advance directives or a dependable surrogate, while others, unwisely and unhappily, seem to have concluded that there is some kind of plot afoot to do in patients in a persistent vegetative state or with other disabilities. There is no such plot (though surely some insensitivity here and there), but advance directives do not guarantee you will get what you want, only that they may increase the likelihood you will.

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The question left hanging is: How should medicine and its practitioners think about death and locate it in the human life cycle? There is no doubt that the nature of dying has changed and no less doubt that medicine has been encouraged to grab death by the throat and not to let go—even as our biology one way or another continues to conspire to bring us down. I believe Paul Ramsey was profoundly wrong in holding that there can be no death with dignity. The weakest sense of dignity in the context of dying focuses on the loss of control, that of life's trajectory leading irreversibly downhill, the body falling apart, marked by incontinence, pain, humiliation, dependence upon others for our very existence. One ceases to be the person one once was and wanted to be, with a new physical (if not necessarily psychological) identity taking its place, not one to be admired or to be proud of.

I call that "dignity" in the weak sense, not because physical identity is unimportant but because, as many survivors of genocide, starvation, death camps, and severe disability have shown, there is more to a human life than

the state of the body. The serious sense of a loss of dignity I understand to be the supposed ultimate insult that death brings to life, which was what Ramsey had in mind: I live, therefore I am.

I have never understood why someone should feel that way. Surely from the viewpoint of species welfare, death is no evil. It is a condition of constant species renewal (though I grant that species vitality does not do much for me as an individual). But death does not seem to me to be an evil if it comes at the end of a long life, one marked by a completion, or near it, of those aims that mark a full life. It is no accident that weeping is ordinarily absent at the funeral of an elderly person. Almost all of us know old people who, while still enjoying life, profess themselves ready to die and seem to mean it. It is hard to see indignity in a death marked by that acceptance. Of course there are many others, not yet old, not yet with a full life behind them, who will be ambivalent, and some will not want to give up, at least not at once. Advance directives can have an important place for them; and when they are ready to go, palliative care will usually be needed. One can only hope they will die in the hands of physicians and nurses who will understand their plight and their needs.

Considerable progress has been made during the past three decades in improving the care of the dying. But there remain some old obstacles, familiar from the start, and some that are not many years old. Physicians unwilling to give up and indifferent to patient desires are still with us, just as soon-to-be patients resistant to advance directives are still with us. There is unfinished work here to be done. Forces on the scientific side that treat death as the great enemy, not to be tolerated, and on the ideological side, seeing snares and delusions in end of life care, create the new obstacles.

How our society responds to those two forces will make a great deal of difference; if we are not careful, we could reverse the progress made to improve end of life care thus far. In the end, we die, and it is not an evil that our biology has made it so. We can and will argue about the timing and the details, about acceptable and unacceptable deaths. That is right and proper. Difficult decisions will never run out. But if we hedge our bets about the inevitability of death, waffling and dreaming—a fresh science-driven embrace of the denial of death—then we are likely to face worse lives and, when it comes, worse deaths.

The End of Autonomy

by ROBERT A. BURT

Attention to end of life care in contemporary bioethics took its initial impetus from the New Jersey Supreme Court's *Karen Quinlan* decision in 1976, and from this very beginning, there has been a disconnect between theory and reality. In authorizing ventilator removal from Ms. Quinlan, who was in a persistent vegetative state, the court relied on the principle of respect for autonomous choice. It gave no weight to the wishes of Quinlan's parents or her physicians; the only person with any legally recognizable claim was Ms. Quinlan herself. But she was in no position to make any decisions about continued use of the respirator. Before the incident that left her in a persistent vegetative state, she had never expressed any wishes about how she should be cared for if she became ventilator-dependent, and afterwards she was incompetent and had no prospect of ever regaining competence.

The court quickly bypassed the central problem in applying the autonomy ideal to her by positing that if she had been competent, she would have had a right to choose withdrawal, that she should not lose this right "merely" because she was now incompetent, and that her father could exercise this right for her, so long as he acted on the basis of what he believed to be her wishes rather than on his own view of her best interests. From its modern origins in the *Quinlan* case, then, the autonomy framework for conceptualizing end of life decision-making has had a distinctly artificial cast of mind. It is only thirty years after *Quinlan*, however, that we can now clearly see what should have been evident from the beginning: the autonomy framework in the context of end of life decision-making simply doesn't fit the facts.

This is not to deny that protecting patient autonomy in end of life care, as in all medical treatment and research, is an important principle. Nor is it to deny that disregard for patient choice has been a longstanding and unjustifiable feature of medical treatment and research. But the facts are that applying the autonomy framework in end of life decision-making has had little practical effect and much fictitious posturing. Efforts to persuade people to create and implement advance directives to protect their autonomy if they should become incompetent have essentially failed. The fictive character of these directives is revealed with special clarity in the laws of some thirty-nine states providing that where an incompetent person has not specified a health care proxy in advance, the state will make that choice itself on the premise that most people would want what the state wants for them—that is, spouse first, adult children second, and so forth.

The explanation for the failure of the advance directive movement emerged with considerable force in the early 1990s, with the empirical findings of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). This study tested the most extensive, rigorous effort that had ever been tried to assist terminally and critically ill patients and their families in making informed choices about end of life care. Notwithstanding the magnitude of this effort toward promoting choice, it produced no effective results. The SUPPORT data instead revealed—in findings that have been subsequently confirmed in other settings—that most patients and their families did not want to make decisions about their end of life care. Though

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most patients in the study were persuaded to fill out advance directives, a substantial portion of these patients and their families ignored their prior directives as death drew near. They simply did not want to talk about the reality that they were facing death; and most medical professionals returned the favor with equal reluctance to talk about dying.

Two Responses

There are two ways to respond to this consistently confirmed reality. One way—the dominant way for the past thirty years—has been to redouble efforts to promote patient and family choice-making. The second is to turn our attention away from the autonomous choice framework in thinking about end of life decision-making. I think we would be best advised to take this second way—not to override autonomous choice, but to remove this value from the center of attention and to recast our thinking about end of life care to promote different, though not necessarily inconsistent, goals.

One lesson I draw from our failed efforts to promote individual end of life care choice-making is that this pursuit, besides having limited potential for practical effect in individual lives and deaths, also carries substantial social dangers: it is likely to yield abuses as bad as, and even directly similar to, the abuses of physician authoritarianism that the autonomy framework was intended to correct. The crucial impetus for the modern embrace of the autonomy framework for terminally ill patients was mistrust of physicians, based on a belief that they regularly disregarded the wishes and interests of their dying patients by pursuing aggressive, painful therapies with no realistic possibility of success, by withholding effective pain relief generally, and by abandoning their patients when death became patently unavoidable. The equivalent dangers in the autonomy framework arise from the practical reluctance of most people to exercise choice.

People are reluctant to exercise choice in end of life matters because of cognitive difficulties that inescapably afflict everyone in contemplating the reality of death. Proponents of the autonomy framework during the past thirty years have not ignored these difficulties; instead, they have inveighed against them. According to their preaching, we should end our "denial of death" and view it rather as a "natural part of life," to be accepted in the same way that we accept any inevitable biological given (as some say death once was seen in some prior golden age or may still be seen in some other contemporary culture).

But we avoid acknowledging this biological inevitability not simply from fear of death but from a cognitive drag on our ability to comprehend death. We may parrot the language of rational choice in comparing our fears about death with our fears about continued life in the face of illness or disability, and we may enact a convincing appearance of autonomous choice in contemplating death. But it is very difficult, at the core of our thinking, to convince ourselves that death is rationally comprehensible. Death is more than a future condition with uncertain benefits and detriments. It is more than the absence of life. It is the absence, the intrinsic contradiction, of meaningfulness. The very concept of the choice-making self, the construct on which the autonomy principle depends for its coherence, is radically unsettled—even made incomprehensible—by the actual, imminent approach of death.

A more conventional view is that some people may be afflicted with this inability to comprehend death, but some—perhaps many or even most—are not, and the task in applying the autonomy principle is to devise guidelines for distinguishing those who are and those who are not "competent" to exercise rational choice. But the difficulties in drawing this distinction are so profound and the consequences of our inevitable failure so grave that we should not put this differentiating enterprise at the center of our practices about end of life care.

The most convincing explanation for the medical abuses inflicted by the health care system on dying patients is physicians' and others' sense of the "wrongness" of death. The incomprehensibility of death readily translates into a conviction that death is a kind of grammatical error, a misfit in a world that can be rationally comprehended. In the medical lexicon, death is understood as an error to be corrected, opposed, negated. Displacing clinicians and blaming their commitment to rational mastery over death does not, however, cure the problem posed by death's incomprehensibility. Death's status as a grammatical error leads not only to medical triumphalism and the abuse of dying patients, but also to a conviction that death is "wrong" morally. Even if one can comprehend, intellectually, that some things are worse than death and that morally condemning a biological inevitability is nonsensical, nonetheless a persistent undertow pulls continuously in the opposite direction. This moral ambivalence toward death might be consciously denied. And some people may be more capable than others of rigidly maintaining this denial into the maw of death itself. But for most people, successful resistance to this moralized understanding is akin to success in refusing to think about elephants in response to a command that you must not—whatever you do, *you must not*—think about elephants.

The consequences of thinking forbidden thoughts about the moral wrongness of death are fraught with danger. If death is a moral wrong and you cannot avoid dying—indeed, if you actively embrace dying—then it follows that somebody must be punished for wrongdoing. Physicians could, of course, punish their dying patients for this transgression, and when they held a central

Death's wrongness cannot be entirely repressed; a buried sense of its wrongness will push toward expression. The challenge for social regulation of end of life care is to design countervailing schemes.

choice-making role, they did. But though they are now removed from that role, the impulse to blame has not vanished; it has simply changed structure. As the choice belongs to the individual, the punishment will be individually self-inflicted. The precise content of this punishment varies—perhaps patients' insistence on aggressive and painful, though patently futile treatments, perhaps their refusal to request effective pain relief, perhaps their embrace of premature death. But in all such cases, the abuse previously inflicted by physicians on dying patients will reappear, for the same underlying reasons, as abuse inflicted by dying patients on themselves. The ironic consequence of the autonomy principle—that decisions about death are the legitimate prerogative of no one but the dying person—is that blame, too, will attach only to the dying person, and will be attached by the dying person to himself.

The abuse of dying patients—either self-inflicted or iatrogenic—is not inevitable, however. It is only ambivalence about death—some lurking, ineradicable sense of its wrongfulness, juxtaposed against all rational arguments for its inevitability and even preferability—that is inevitable. The impetus for turning this ambivalence toward abuse is denial—not "denial of death," in the conventional sense of that cultural construct, but denial of the wrongness of death. Death's wrongness, like the expressly forbidden thought of an elephant, cannot be entirely repressed; and if it is banished from consciousness by a single-minded insistence that death is "good" or "dignified" or "accepted," the unconsciously buried sense of wrongness and guilt accompanying death will push toward expression in action. This is the dynamic by which an unacknowledged sense of wrongdoing and guilt expresses itself by wrongful action that implicitly invites condemnation, even as the action is explicitly enshrined in protestations of righteous conduct.

Countervailing Schemes

The challenge for social regulation of end of life care is to identify the circumstances in which this malign dynamic is likely to take hold and to design countervailing schemes. Reliance on patient autonomy is not an effective countervailing scheme, any more than the now-discredited reliance on physician autonomy for deciding whether and when death should occur.

The following three proposals respond to this problem:

(1) No one should be socially authorized to engage in conduct that directly, purposefully, and unambiguously inflicts death, whether on another person or on oneself.

(2) Decisions that indirectly lead to death should be acted upon only after a consensus is reached among many people. No single individual should be socially authorized to exercise exclusive control over decisions that might lead to death, whether that individual is the dying person, the attending physician, or a family member acting as health care proxy.

(3) As much as possible, end of life care should not depend on explicit decisions made at the bedside of a specific dying person but rather should be implicitly dictated by systems-wide decisions about available resources, personnel, and institutional settings—that is, by setting up default pathways that implicitly guide and even control caretaking decisions in individual cases.

The rationale for the first proposal is that the direct, purposeful, and unambiguous infliction of death leaves no psychological space for acknowledged ambivalence. Whether the infliction is carried out on oneself or on others, it demands an unambivalent claim of rightness and righteousness that is psychologically impossible and thus invites self-contradictory expressive actions.

Our current regulations for end of life decision-making do offer psychological space for acknowledged ambivalence in various ways. The rules that permit withholding or withdrawing life-sustaining care provide some comforting assurance that these actions do not in themselves inflict death because the underlying illness is the cause of death. At the same time, the logical tenuousness of this reasoning promotes conscious acknowledgment of ambivalence—that is, of the close proximity of these actions to wrongful conduct. (This protective dynamic is compellingly described by Miles Edwards and Susan Tolle in an article about removing a competent, conscious postpolio patient from a ventilator in response to his insistent request. Although rationally convinced of the moral correctness of this course, Drs. Edwards and Tolle reported nonetheless having a powerfully troubling sense of wrongdoing, of "purposeful killing."[1]) The logical tenuousness of the distinction between relieving pain and hastening death in the high-dosage administration of opioids to dying patients—the so-called "double effect" principle—has the same psychologically protective function, serving

simultaneously as permission and a warning sign about dealing with death.

The protective function of these logically tenuous rules tends to erode over time, as their routine application dulls everyone's sense of the close correspondence between permitted and forbidden conduct authorized by these rules. The clearest indication of this erosion is in the arguments put forward by advocates for physician-assisted suicide and euthanasia. These advocates insist that withholding or withdrawing life-sustaining treatment or applying the double effect principle is logically identical to purposeful, unambiguous infliction of death, and that this logical identity means that all these steps are morally equivalent and morally correct. These contemporary advocates fail to see that, far from justifying this "next step" toward purposeful killing, the plausibility of their logical claims about existing practices should raise concerns that these practices have themselves lost their function as protective expressions of ambivalence toward death.

Our guiding principle for social regulation should be that the more comfortable clinicians and patients are with actions implicating death, the more socially dangerous these actions become. Preserving these "illogical" lines between accepting and hastening death—between physician-assisted suicide and withholding or withdrawing treatment or administering high-dosage opioids—is in the service of promoting conscious awareness of moral discomfort. Eliminating this discomfort, as urged by advocates for physician-assisted suicide and euthanasia, is logical but terribly wrong—and socially dangerous because the unconsciously buried conviction of wrongdoing ultimately will express itself in eruptions of blameworthy conduct.

Toward Shared Decision-Making

My second proposal, that social regulations should not designate any single individual to exercise exclusive control over decisions that might lead to death, would require a more radical departure from existing arrangements. Forged on the anvil of autonomous individual choice, existing arrangements search relentlessly for a single designated decision-maker based on a clear-cut hierarchy of authority. The desperate intensity of this search is revealed by the state laws, noted above, that denominate proxy decision-makers even where an incompetent patient has made no prior selection. In particular, this intense search is apparent in the provision of those laws regarding multimember proxies, such as parents or children or siblings; many such laws specify that for this class of proxies, majority vote shall prevail and, in the event of tie votes, the class is disqualified from decision-making authority. The implicit goal in these laws is not simply to

find some single decision-maker but to find an unambiguous choice about life-sustaining treatment.

There is a practical imperative behind this goal because of the binary character of the decision to treat or not to treat. But honoring this imperative means suppressing the ambivalence that is likely to accompany this decision. If it is more socially and psychologically protective to acknowledge and address this ambivalence in the course of decision-making, the better course would be to amplify the opportunities for expression of differing views—thus forcing everyone's ambivalence about death-dispensing decisions toward visible acknowledgment. To accomplish this goal, provision of life-sustaining treatment must be the default option unless and until all of the affected participants (family members and clinicians) have come to a consensus about withholding or withdrawing.

When the patient is competent and prepared to make a decisive choice, the autonomy principle does properly bestow hierarchically superior authority with the patient. But even in this clear-cut case, there are other, importantly affected participants who should have some voice in the patient's ultimate decision—not a veto but a voice, a chance to talk to the patient and address and amplify the ambivalence that the decision-making patient himself is likely to feel but also likely to deny.

Beyond—or perhaps one should say, above—this psychological benefit of consultation, there is an ethical principle that demands this consultative process. The competent patient may have the ethically highest priority in decision-making; but his or her decision to continue or discontinue treatment has a powerful and lasting impact on family members and on health care clinicians. Yet their stake in the decision is ignored when we fixate on the patient's autonomous choice. Their stake may ultimately deserve less weight than the competent patient's choice; but some weight nonetheless is appropriate and can be respected by rules providing for some consultative processes.

Perhaps these consultations should be mandatory in all cases. Perhaps some exception should be made where the patient adamantly resists any consultation, but even here the patient should be required to explain his refusal to some third party. In this explanation, some degree of respect at least would be paid by the patient both to the possibility that he is suppressing his own ambivalence about his decision and that others will be powerfully affected by his decision and thus have some ethically mandated stake in it.

Where there is no competent patient or clear-cut advance directive from the now-incompetent patient, the autonomy principle provides no ethical basis for giving priority to any one among many plausibly affected parties. The practical imperative of making an unambiguous choice among binary alternatives might justify some arbi-

trarily imposed hierarchy among potential decision-makers. But this imposition should be postponed for a considerable time while the parties are forced, by their explicitly shared decision-making authority, to collaborate with one another and to explore the possibilities of a genuine consensus.

This extended consultative process cuts against the grain of current medical practice. The process is time-consuming and emotionally draining. Clinicians are not adequately compensated financially or psychologically for these costs. They are, moreover, typically not trained to engage in these consultative processes. Extended consultation with distressed family members in conflict with one another about treatment alternatives requires considerable emotional investment and resilience among clinicians. It requires, among other things, that clinicians confront their own discomfort and ambivalence about the death-dispensing decisions that are a regular part of their daily routine. The automatic, instantaneous designation of a single decision-maker—whether it is the competent patient or one family member among many to speak for the incompetent patient—permits clinicians to avoid these arduous, complicated confrontations with conflicting family members and with conflicts within themselves. This is the path of least resistance—and the path of greatest individual and social danger toward routinized, unacknowledged abuse.

My third proposal, that systems-wide default pathways should self-consciously be constructed to implicitly guide and even dictate caretaking decisions in individual cases, derives from the same psychological premises as the other proposals. Systems-wide decisions establish the context and frequently dictate the content of individual bedside decisions on such matters as allocation of resources, locus of care (home versus hospital versus nursing home), and the roles of professional and informal caretakers.

This is the lesson, for example, of the SUPPORT finding that the place of death (home versus institutional settings) did not depend on patient or family preferences. Rather, it correlated directly with the availability of institutional beds—the more beds in any region, the more likely that terminally ill patients in those regions would die in those beds. It is highly unlikely, however, that anyone involved in the systems-wide decision-making that produced more or fewer hospital beds acknowledged, even to themselves, that their decisions would have a direct effect on dying patients and would virtually dictate whether these patients died at home or in hospital. The impact of these systems-wide choices on dying people was, in an important sense, invisible to everyone—even though a moment's clear thought would have made it visible.

The same phenomenon is found in the familiar example of the psychological difference between systems-wide decisions to withhold resources for improving coal mine safety and particularized decisions to withhold rescue resources from workers trapped in coal mine accidents. In both contexts, lives will clearly be lost by withholding safety and rescue resources and, moreover, the number of lost lives is precisely calculable. But in withholding expenditures for coal mine safety, the lives lost are statistical projections; for trapped coal miners, impending deaths are made real with specific names, faces, and families. The ethical costs and psychological dangers of withholding resources from rescue are therefore much greater than for withholding preventive expenditures. Withholding rescue resources *feels* like inflicting death and is inevitably guilt-provoking, while withholding resources for preventive safety measures feels like an impersonal policy decision, in which we may easily begin to calculate that death may be socially desirable given the costs of preventing it.[2]

In making decisions about the care of dying people, we should take advantage of the psychologically protective implications of systems-wide decision-making. As much as possible, we should make systems-wide decisions in which, at the moment when the decisions are made, no specific dying person is an acknowledged target.

The three proposals have one common theme: that the focus of attention shifts away from individual choice-making autonomy in the social arrangements regarding end of life care. Because the autonomy focus has no substantive content—because it is ostentatiously silent about whether death is desirable or undesirable, but insists only that each individual should make this value choice for himself—it has served the same psychological purpose that I have criticized throughout this essay, namely, to deny ambivalence about death—to deny that death can be both attractive and repulsive at the same time, and to deny that decisions either to accept or to resist death are more fraught with possibilities of abuse when this core ambivalence is suppressed rather than acknowledged in an open and sustained way. Acknowledging this ambivalence is difficult. These difficulties have given impetus to the relentless search for a single decision-maker regarding end of life care—whether that decision-maker was the attending physician, under the old ethos of physician paternalism, or the individual patient, under the new ethos of individual autonomy. We have seen enough by now to know that the current path is not a reliable improvement over the old.

1. M.J. Edwards and S. W. Tolle, "Disconnecting a Ventilator at the Request of a Patient Who Knows He Will Then Die: The Doctor's Anguish," *Annals of Internal Medicine* 117 (1992): 254-56.

2. For an extended, illuminating discussion of this proposition, see G. Calabresi and P. Bobbitt, *Tragic Choices* (New York: W. W. Norton, 1978).

Living Long in Fragile Health:

The New Demographics Shape End of Life Care

by JOANNE LYNN

Not long ago, people generally "got sick and died"—all in one sentence and all in a few days or weeks. The end of life had religious, cultural, and contractual significance, while paid health care services played only a small part. Now, most Americans will grow old and accumulate diseases for a long time before dying. Our health care system will cleverly supplement the body's shortcomings, making it possible to live for years "in the valley of the shadow of death," fearing not only death but also all sorts of evil from the regular dysfunctions of our health care and social systems. In a sense, the great success of modern medicine has been to transform acute causes of death into chronic illnesses. Mostly, we do not spend much time or money on cures—these are quick and cheap when they are available at all. Instead, health care now involves substituting better chronic conditions and helping people to live with implacable illnesses, a few of which are stable and many of which are progressive but not life-threatening. However, each of us eventually lives with a set of conditions that are, taken together, progressively worsening and eventually fatal.

This is a very different way of coming to the end of life from that of "the old days," when people died in childbirth, of occupational hazards, of periodic epidemics, and with the first heart attack. In 1897, Sir William Osler's *The Principles and Practice of Medicine* noted that the usual adult hospitalized with diabetes would die within a month. Things have changed so much that today we don't really have the language, the categories, and the stories to help us make sense of our

situation. One hears people say, "He's not dying yet," of a person living with fatal lung cancer. Generally, that means he's not yet taking to bed, losing weight, and suffering from pain, as would be expected when dying is all that he can do. But the category is used as if one is either "temporarily immortal"—which is the usual state of human beings—or "dying," in which case the person is of a different sort, having different obligations and relationships. "The Dying" are expected to do little but wrap life up and go. But this dominant myth about dying does not fit many people. Many elderly people are inching toward oblivion with small losses every few weeks or months.

If our language does not accommodate the new reality, it is not surprising that our shared social life has not yet taken up the challenge. No characters on evening television are cracking jokes while dealing with Grandma's wandering and incontinence. No movies show the accommodations needed to live with advanced emphysema. As a patient once told me, "No one in the Bible died like this." People find little guidance when they look to our ancient texts for comfort and advice on how to live while walking a tightrope of serious illness and frailty, propped up by modern medicine.

That lack of social understanding also shows in the conceptual apparatus we have used in trying to bring reform to what happens in the last part of our lives. Remarkably, we have used the language of decision-making and law more often than that of spiritual journey and psychological meaning. In the 1970s, the issues were framed as "the right to die" or "the right to choose." The work of the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research marks a transition to the language of "foregoing life-sus-

taining treatment." At that time, widespread reaction to the suffering inflicted on patients by cancer treatments and to mainstream medicine's inattention to physical pain led to the only widely adopted change in health care delivery in the last half of the twentieth century—hospice programs. Half of Americans use hospice at least briefly before dying. However, most of the time spent living with serious illnesses that will end in death is spent not in hospice care, but in the indistinct zone of "chronic illness" that has no specific care delivery system. Most of us aspire to "healthy aging," but we should also ensure that we can "live well while very sick and dying."

In this short essay, I will lay out the framework for a promising approach to reform. First, reformers must understand some core facts about illness, aging, and disability, and the dysfunctions of the categories and language that we have inherited. Second, we should tailor service delivery arrangements to serve the three common trajectories of service needs that people tend to follow in their last phase of life. Third, we should strategize to build the political base to insist upon rapid practical change, starting with family caregivers.

Factors in the End of Life

In the recent past, a number of events have shaped the last part of life. Oregon debated and eventually accepted a process that allows physicians to assist in some deliberate suicides. Most hospitals, including all of the Veterans Health System facilities, are beginning to offer palliative care programs. New drugs and devices often add a little to the time spent living with fatal conditions but also greatly increase costs. Families still provide most of the supportive care without financial compensation, but the effects on family caregivers are becoming more obvious as their numbers, ages, and emotional and financial burdens increase.

One element that has influenced the course of reforms in care for the last part of life has been some data-driven insights from the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, or SUPPORT, enrolled more than 10,000 seriously ill patients in five hospitals from 1989 to 1994. The project initially aimed to understand and improve decision-making for these patients through better information about outcomes and better support for those making decisions. Since SUPPORT enrolled people who had one of nine serious illnesses, or were old and had a nonelective admission, a great many patients died during data collection. While the population is not representative and the data arose fifteen years ago, the SUPPORT project illuminated a number of facts that otherwise had been overlooked or had never before been substantiated. For example:

1. Many patients suffer substantially in the time before dying.

2. The patients, their families, and their professional caregivers did not see adverse symptoms or aggressive treatment as serious shortcomings of care.

3. Statistical models could accurately predict the likelihood of survival for two or for six months, both for individual patients and for groups of patients.

4. Knowing reliable predictions concerning survival did not affect patients, family members, physicians, or nurses: they continued to follow usual treatment patterns.

5. Prognoses remain ambiguous even very close to death. For example, the median person dying of heart failure today had a 50-50 chance yesterday to live another six months. Good care for the dying requires taking care of many who will live for a long time with their serious illnesses.

6. Counseling about the possible alternatives for care and encouraging decision-making that implemented patient preferences among available options had no effect upon patterns of care.

7. The course of care is much more strongly associated with the service supply and habit patterns of the local care system than with the particular preferences or prognoses of the individual patient.

Several other facts also shape the possibilities for reforms. First, despite our cultural (and perhaps our universally human) distaste for the fact of finitude, American society is gradually learning to expect disability in old age and to accept that serious illness and death are inevitable. Thirty years ago, hospital staff attempted resuscitation on nearly every person whose heart stopped. Now, only a small minority of patients, mostly those with some real chance to benefit, undergoes resuscitation. In a similar vein, the U.S. Preventive Services Task Force has started including some "upper limits" on the ages at which screening tests make sense.

Second, the costs and burdens of care are highly concentrated in the last years of life, especially when one accounts for long-term disability. One recent study found that, for those alive at age eighty-five, one-third of lifetime health costs are still ahead.

Third, knowledge about the body has been organized by disease and organ system, and claims about quality or costs of care have been organized by program and setting (nursing home or intensive care unit, for example). Those who are very sick over a substantial time before death,

Society could build care arrangements around the major patterns of decline and dying. For any population, one could estimate the care needs and arrange to have them available at the right time. This approach conceives of the challenge of end of life care as a problem of system design.

who routinely have more than one illness, and who need many care settings challenge the care system design. Instead of noticing only virtuoso medical interventions, society is beginning to value continuity and comprehensiveness, or even just reliability. Nevertheless, initial contemplation leaves one overwhelmed by the infinitely varying arrays of physiological dysfunctions, personal preferences, family situations, and other aspects of a person's circumstances as they become ill "through to death." Some have contended that the proper course requires the care system (and the family and community) to discern and create the strategies needed to support each patient's individual situation. At the least, this view contends that patients should get to choose from among available options and craft their own end of life. While this approach has substantial appeal, it entails remarkable inefficiency and quickly reaches its limits when the services that would best serve a particular patient could be available only if they served a substantial number of patients in an area.

Trajectories of Decline

This conundrum leads to the very creative interface of seeking opportunities for "mass customization," which is how most successful product or service suppliers match their goods to the needs of important subsets of their potential markets. The reform agenda has focused on crafting patient-centered care around each individual patient or, in contrast, on altering major elements of the entire care system, such as payment policy or standards for care settings. Mass customization instead aims to define manageable populations with similar needs and then engineers services that match the size of that population and its predictable needs. This endeavor has found its anchor in the observation that most people follow some fairly stereotyped courses in those last months and years. The most common three trajectories of care needs over time are these:

1. Long maintenance of good function despite known fatal illness, with a few weeks or months of rapid decline as the illness becomes overwhelming and leads to death. While many diagnoses can lead to this course, the major

cancers are the typical cause. Probably about 20 percent of Americans follow this course.

2. Slow decline in physical capacities punctuated by serious exacerbations, with death often coming rather suddenly. If patients survive an episode, they may well return home without much worsening of their everyday limitations; but at some point, rescue attempts fail. Although many diagnoses can lead to this course, chronic heart failure and emphysema are the most common; about 25 percent of Americans follow this course.

3. Long-term dwindling of function, needing years of personal care. Although half of this population has serious cognitive failure as part of the disease course, half maintain cognitive function, at least when not stressed by illness. Dying often follows a physiological challenge that would have been a minor annoyance earlier in life—influenza, urinary infection, pneumonia, or a broken bone. Approximately 40 percent of Americans follow this course.

These three trajectories are roughly sequential in the ages afflicted, with fatal cancers peaking around age sixty-five, fatal chronic organ system failures roughly a decade later, and frailty and dementia afflicting mostly those who live past their mid-eighties. As science and public health more reliably prevent or delay onset of cancer, emphysema, and heart disease, the proportion of the population facing the third course will increase.

One can see how a society could build care arrangements around these three patterns, following the mass customization approach. Those facing the first trajectory need excellent medical care during the long period of good function, meshed with supportive hospice care for family and patient during the period of rapid decline. Those living with the second trajectory benefit from disease management to reduce the likelihood of exacerbations and to sustain all possible function, along with rapid intervention at the first sign of exacerbation (often in the home rather than the hospital) and good advance care planning directing the eventually overwhelming exacerbation. Those living with the third trajectory need supportive care over many years, including assistance with the ac-

tivities of daily living, housing, and comfort. The core need is to support family caregivers, although they also need reliably paid aides and institutional care. For any population, one could estimate the care needs and arrange to have them available at the right time. Patients, families, and providers would still make small adjustments to fit their capabilities and preferences, but the core arrangements for care would already be in place, rather than being patched together for the first time around each patient.

This conception of the challenge of care for the end of life as a problem of system design reflects a very different concept from "refusing life-sustaining treatment." Indeed, it is really quite different from imagining that the core problem is decision-making by patient and physician. Those remain important, but this approach does not assume that good care could arise from prudent choices by individual doctors and patients. Rather, it starts from the claim that the care system should be designed to serve the vast majority of patients "on autopilot." That is, if no one makes any particularly strong choices, still just about the right things will happen for patients because they are "built into the system" and are part of the expected pattern.

This is what happens now in obstetrics. Just a few decades ago, women had to advocate personally for the services each wanted; now nearly everyone is well-served by a care system that supports prepared labor, bonding with the baby, breastfeeding, and other desirable goals. One way to think about the reforms needed in end of life care is to aim for a care system in which almost every patient would get very close to what serves him or her and the family well, without having to advocate for himself or herself.

The Shape of a Reform Agenda

One implication of the SUPPORT findings concerning prognostication and the model involving trajectories is that we cannot build workable care systems that serve only those who will die quickly. Rather than the Medicare hospice program's approach of conditioning tailored care to the near certainty of death within six months (and thus the median survival of just a few weeks), effective restructuring of care will need to serve populations that include people who end up dying after some years, as well as those who die soon. No strategy is available, for example, that would serve most who die of heart failure without including many who live with those services for years. With most conditions, including heart failure, the timing of death is just too unpredictable to enable good services to be conditioned upon reliable short-term predictions of death.
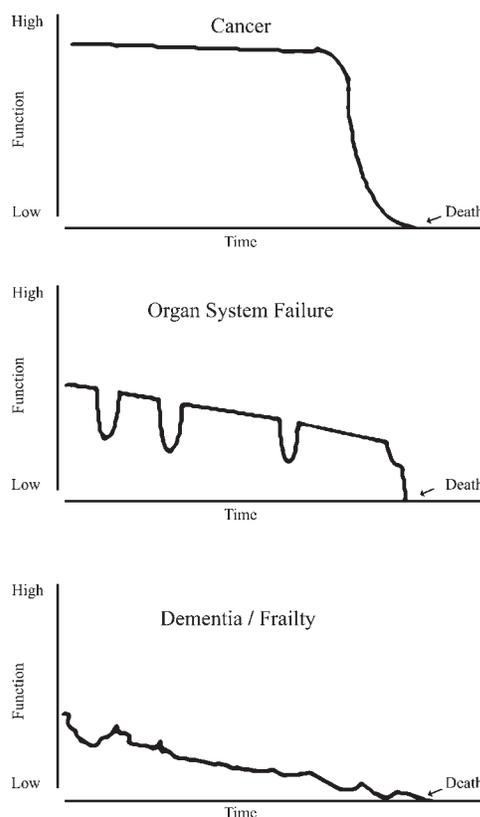

Figure I.
Three General Trajectories of Function and Well-Being over Time in Eventually Fatal Chronic Illnesses

Palliative care teams trying to achieve quality improvement often find the relevant population by asking what we have come to call the "surprise question." Instead of asking whether the person has a prognosis of some short limit (such as having a prognosis of six months, which Medicare regulations require if a patient is to qualify for reimbursement of hospice benefits), the clinical team asks, "Is this person sick enough that it would be no surprise for the person to die within the next six months, or a year?" Whether one looks a few months ahead or a year turns out not to matter much; at stake is whether the person is in a fragile enough condition that relatively minor worsening or intercurrent illnesses could spell the end of life. Some of the patients identified by "the surprise question" will end up living for years in a fragile state, and some will die soon, but all typically need the services that are priorities in the last part of life: advance care planning, comfort measures, assistance for daily activities, family support, and so forth. Whether a particular person needs this help for a few weeks or a few years, the social planning requires arranging services that can stay with the person throughout.

One might think that the concentration of suffering and costs would have led to substantial investments in learning how to serve people as they pass through that last part of life. However, investments of this sort have been very slow in coming. While the Soros Foundation's Project on Death in America, the Robert Wood Johnson Foundation, and others did invest during the last decade in building palliative care consultation in hospitals and grassroots citizen action, very few substantial demonstration projects have tested reformed care delivery, very little basic science research has targeted symptoms and disabilities, and few initiatives have started to alter the dysfunctional financial incentives that favor medical, surgical, and pharmacological interventions over reliability, continuity, and comprehensiveness.

I recently participated in a review of the state of the science underlying palliative care. The review was worded as optimistically as possible, but the science was indefensibly inadequate on virtually every issue, from measuring better and worse outcomes of care to assessing the merits of standard therapies. I came away feeling that this must have been the state of science regarding heart disease fifty years ago—when most of the "science" was expert opinion and much of it was inadequate, even erroneous. In twenty years, when the aging of the Baby Boomers doubles the number of people living with serious illness in the last years of life, society will have to focus on generating reliable science and insights about effective care. Otherwise, we are sure to make major errors and incur major inefficiencies in serving the burgeoning population.

What might make the last part of life as comfortable and meaningful as possible, at a cost that the community can sustain? Some elements of the shape of a worthy reform agenda include the following:

1. Articulate thresholds of severity of illness that are also administratively convenient for indicating the onset of serious illness expected to last to the end of life.

2. From that time on, focus on care arrangements that stay with the patient and family across time and settings and that are comprehensive across all care needs.

3. Insist on high standards of symptom prevention and relief, family support, and planning ahead.

4. Pay sustainable salaries and decent benefits for such a system's employees, and discount the costly services that have much smaller expected benefits (often, the high-tech devices or costly drugs).

5. Develop supports for family caregivers, such as health and disability insurance, respite care, and evidence that the community honors and respects their work.

6. Develop adequate supply of all of the critical components of good care—hands-on services for personal care as well as hospital care and good nursing homes as well as on-call nurses to handle crises in home care.

7. Monitor the effectiveness and efficiency of innovative approaches and deliberately replicate proven models, aiming to evolve a highly reliable, sustainable care system within a decade.

In a way, this reform would dramatically expand hospice principles of continuity, patient and family focus in priorities, and encouraging care at home. It would also build on the social supports and endurance of home and institutional long-term care. It would evade the sense that patients must give up on treatment to get good care, but would still make them unlikely to use burdensome treatments of limited value. The costs are probably not greatly different from those of our current approach, but the priorities are.

What gets in the way of doing this?

First, of course, many powerful interests have substantial investments in perpetuating the current dysfunctions. Those who lobbied for a broad prescription medication benefit under Medicare are not likely to have the same interest in lobbying for good working conditions for nursing home aides or for strategies that reduce the use of hospitals. Who could advocate for a more reasonable and balanced approach? The answer, tellingly, is that no strong industry interests are aligned with good care for the end of life. Even the professional trade associations have to look first to the best interests of their particular part of the puzzle, be it hospice programs or nursing careers.

The only group that comes to the fore as a potential powerful force for thoughtful reform is family caregivers. Almost all people have been, will be, or now are family caregivers. They—really, we—could take on an identity as a political force and demand that leadership focus upon these issues. That is a daunting claim—to take a diverse group that now has no particular self-identification, convince them that they have shared interests, and see them forge a political agenda and carry it through. Hope lies in the fact that the alternative is so distasteful—wasteful, unreliable services that also bankrupt the country and demoralize family members—and that all of us face this fate together, across the entire range of wealth and family structures.

Conflict and Consensus
at the End of Life

by NANCY NEVELOFF DUBLER

I t is hard to die in America. A process that should shield patients as they disengage from life instead leads with increasing frequency to conflict and media attention and provides an opportunity for third parties with political or self-serving agendas to feather their particular ideological and personal nests. For a few years after *Quinlan* (and before *Wendland*, *Baby K*, and *Schiavo*), it seemed as if a tentative consensus had been reached that death is not always the worst outcome. Families received support in their attempts to avoid a protracted dying for loved ones. Ethically and legally cognizable elements in end of life decisions included: the agreement of physicians about the prognosis of unlikely recovery; prior wishes of the patient related to medical treatment and quality of life; and matters of suffering. Clearly some patients and family wanted "everything done to maintain life," but if pain control were assured, many chose less invasive, more comforting interventions. But consensus is hard to achieve, and even harder to maintain, in a dichotomized society. Recent developments illustrate the truth of this proposition.

The medical-ethical climate is clearly changing and, in prominent cases, families are now demanding continued support for patients long after the patient has lost relational ability and conscious appreciation of surroundings. Moreover, these sorts of decisions appear to be part of a new political and moral agenda that sees the "right to life" as applying both to the beginning and to the end of existence. Rather than reaching a more finely honed consensus about the values and practices that undergird end of life care, conflict has come to dominate the discussion. The consequences are serious for patients, health care providers, family members, and society. Moreover, the economic costs of these ethical challenges will have a serious effect on allocation of resources in a population with an ever-increasing number of persons who are not medically insured.

Whatever consensus once existed in end of life care was based on the assumption that death is not always the worst medical option for a terminally ill, suffering, or insensate patient. But defining the worst and the best is never simple. Everyone is ambivalent about death: both the family members who confront this most singular and terrifying event, and the physicians, nurses, and others who regularly witness it. In end of life narratives, major confrontations about death often build on a history of small prior skirmishes. Increasingly, private conflict is playing out not in patient rooms and hospital corridors, but rather in the nation's courts and legislatures. Conflict about death and dying is one of the new arenas for exhibiting the political, social, and moral cleavages in American society.

Conflict is endemic in American society. We thrive on it and encourage it. We litigate civil disagreements that would have no place in the courts of other nations. The founding fathers disagreed about the underlying principles of the statehood. A largely two-party system has regularly magnified political, economic, and religious differences in pursuit of politically viable territory. Democracy is messy and unkempt; it provides a platform for voices that challenge expert opinion and insist on the integrity and wisdom of their dissenting positions. And our once emerging but apparently now declining consensus about the end of life—forged in courts and state legislatures,

A Family Illness,
by Robert Pope
By permission of the Robert Pope
Foundation.

supported by model legislation, and regulated by departments of health—is in danger of being entirely undercut by politics and the needs of the infotainment industry.

The brief period of consensus on death and dying facilitated the wide dissemination of "brain death" as an acceptable alternative to the prior understanding of death as the "irreversible cessation of cardiac and respiratory function." This change supported the development of organ donation by deceased persons. Consensus has also permitted the honing of standards for withdrawing and withholding life-sustaining care and has fostered the authority of health care agents to act on their judgment that the best interest of the patient lies in death. The growth of palliative care services and hospice programs that offer alternate, evidence-based medical care for patients at the end of life made the nascent consensus operable.

The Schiavo case reflects the fact that death is the new arena for self-serving professional and partisan preening and for potential political gain. Death stories feed the insatiable media machine, which in turn feeds the beast of dispute on the juicy red meat of dying or moribund patients. This casting of end of life care as an opportunity for conflict is a tragic development. Unfortunately, as the Schiavo case demonstrated, death may be good politics. As the case of Teron Francis illustrates, death can provide priceless media exposure. Both goals provide fodder for the American conflict mill.

Published news reports of the Francis case set out the basic narrative without divulging fresh details and violating the patient's confidentiality:

LATE-NIGHT hosp. drama keeps tragic [Bronx] boy on life support

According to [Robert] Genis [the family's attorney], the family traces Taran's [sic] illness back to April 6, when he had a terrible toothache.

He was taken to Bronx-Lebanon Hospital's pediatric dental clinic, and scheduled for root-canal surgery on April 15, the family said.

But when he showed up, in the care of two older teenage relatives, he was told the surgery couldn't be performed. His relatives weren't old enough to give permission for the procedure.

Two days later, on Sunday, Taran's toothache had developed into a blinding headache, and Marcerlyn [the boy's mother] also was feeling achy and disoriented.

By Monday, Taran was vomiting and seeing double. His mother called 911 and both were taken to Bronx-Lebanon Hospital.

In the emergency room, doctors examined Taran and told Marcerlyn the infection that had started as a toothache had traveled to her son's brain.

That's when he was wheeled away crying, "Mommy."

Rather than reaching a more finely honed consensus about the values and practices that undergird end of life care, conflict has come to dominate the discussion.

Both were admitted to the hospital and assigned to different rooms.

Soon after, Taran's doctors did a spinal tap to see if he was suffering from meningitis, said Marcerlyn's sister-in-law, Anne Marie Douglas.

"And ever since then he's been unconscious," she reported.

"They started doing CT scans, they came up negative," she said. "Then they did an MRI and found his brain was swelling."

On Tuesday, he was transferred to Montefiore.[1]

Let Teron go in peace—then demand answers

Officials at elite Montefiore, where Teron was transferred last Tuesday said yesterday that the moment the boy arrived at their facility doctors suspected he was already brain dead.

By Thursday, their suspicions were found to be correct.

"Brain death is death," Montefiore's Dr. Kathryn McVicar explained. "It is devastating to families because they have no idea what that means."[2]

TRAGIC KIN WIN
Only they can pull plug on boy: judge

Teron's family had gone to court earlier Friday [April 22] after a doctor reportedly told them they had 24 hours to grieve before the seventh-grader would be taken off life support.

Hospital officials have repeatedly denied that they planned to pull the plug on the boy—and they did so again yesterday.

"That is not our practice and not our policy," insisted Dr. Gary Kalkut, Montefiore's medical director. "Our policy is to support and accommodate the family until they come to grips with this diagnosis."[3]

Additional articles published in New York newspapers during these events further illustrate the potential for conflict fueled by media misunderstanding of medical facts that experts on end of life cases take as a given. They also illustrate the sensationalism that is at the core of much media coverage. On April 23, the *New York Daily News* reported:

> A BRAIN-DEAD BRONX teen struggled to survive with the help of a respirator yesterday as his loved ones whispered into his ear—pleading with him to beat the odds. "Jesus raised Lazarus from the dead and he will raise you," his grandmother, Lorna Douglas, 68, said lovingly to the boy. . . .
>
> "What the family really wanted was for God to be calling him," said family lawyer, Robert Genis. "If his heart stops, it stops. They just didn't want someone to pull the plug." . . .
>
> "I believe in miracles," Marcerlyn Francis said earlier through tears while caressing her son's hand. "His heart is still beating and he's warm, and I am not going to give up on him right now."

Robert Genis, the lawyer for the family, held press conferences daily. At one point, he stated that the hospital was not providing the appropriate "standard of care" because the child was not receiving antibiotics. The National Chief of Advocates for Disabled Americans, Veterans, Police, Firemen, and Families joined to lobby on behalf of care for the child.

Finally, on April 29, the *New York Times*, which had assumed a respectful silence during the conflict, ran a story under the headline: "Boy, 13, Dies After Dispute Over Life Support Is Settled." The *Times* reported:

> Teron Francis, the 13-year-old Bronx boy who slipped into a mysterious coma about nine days ago, died yesterday after his parents asked doctors at a Bronx hospital to turn off his respirator. His death ended a bitter feud between the family's lawyers and the officials of the Montefiore Medical Center over his care there.

Were this narrative merely an aberration, it might be disregarded as one more story from the New York City borough that brought you the 1970s movie *Fort Apache, the Bronx*. But this is not an event that will be without sequelae. Some were immediate. In the middle of the Teron

Francis case the sister of an eighty-two-year old patient who was brain dead stated that she would "go to court" rather than consider the implications of the determination.

The conflict surrounding the death of Teron Francis reflects public misunderstandings about medicine and the weaknesses in today's health care system. It involved a child who died from an easily remedied problem that clearly would have been addressed in a family better served by the health care system. It centered on an African American family who apparently had no relationship with a stable and trusted family physician; was framed by a lawyer who saw an opportunity for publicity; and was supervised by a judge who saw himself as Teron's protector—as the "guardian" of this patient, his ward. An insatiable media monster that saw good copy and good footage seized the story and reported on it daily.

Sources of Conflict

Quinlan, *Saikewitz,* even *Eichner* and *Storer,* occurred in a very different time in American social history. These early cases, which explored decisions to withdraw medical treatment and permit death, focused on the following questions: Who gets to decide, based on what sorts of rules, with what relationship to the known wishes of the patient, and with what possibility of review? And review by whom—family or courts, or both? Courts and state legislatures struggled honorably with these questions. They produced thoughtful opinions and legislation that grappled with developing legal and ethical concepts. They did so, however, before the advent of twenty-four-hour talk radio and twenty-four-hour cable television news, and before tabloid sensationalism. The evolution in news presentation has produced an insatiable need for new quotes and pictures and has given voice to grossly partisan and self-interested discussants whose comments, by their presentation in the media, gain credence as opinions with merit. For many listeners and viewers, hearing it on the radio or seeing it on television provides apparent legitimacy for dubious assertions.

Public misunderstanding is not likely to be the worst outcome for inaccurate reporting and melodramatic narrative. On May 8, 2005, the *New York Post* and the *New York Daily News* both ran stories that indicated that a Bronx Assemblywoman and the judge in the Teron Francis case were planning to introduce legislation to make it easier for families to contest determinations of death by medical centers. The *Daily News* reported that the presiding judge, who had attended the boy's funeral, stated, "I found myself forming a special bond with his family because we shared that terrible decision together." The article reports, "Assemblywoman Naomi Rivera (R-Bronx) said she will introduce legislation this month to make it

easier for families to contest determinations of death by hospitals until the family have had time to confirm a diagnosis." Under her draft bill, whenever a patient is declared brain dead, a family member may object to withdrawal of organ support systems and may appeal to the court for review of the underlying decision. A New York State Supreme Court Judge (in New York the Supreme Court is the lowest court of general jurisdiction) would then be required to go to the bedside, meet with all parties, and rule on whether the patient is really dead. Pending that ruling, "treatment" would have to continue. One can only hope that this draft legislation will be deflected along its path to law.

The last decade has been one of exponentially increasing conflict in medicine. The dynamics of the doctor-patient and provider-patient relationships have been deformed by the increasing focus, in fact and in the media, on the cost-containment thrust of both managed care and acute care medicine. In the ambulatory setting, physician-patient relationships have been disrupted by employer shifts in contracts demanding patient shifts in loyalty. Patients are increasingly aware of these economic inroads into medicine, whether they are actually shifted to a new provider or whether they merely experience a change in the benefit package, an increase in the copay, or a new barrier to vault on the way to second opinions or tertiary care expertise. The doctor-patient relationship has become rather crowded with discharge planners, fiscal officers, reimbursement specialists, and length-of-stay managers. There are simply more parties to any decision and thus greater potential for misunderstanding, misinformation, disagreement, and dispute.

These areas of potential dispute are often converted into actual conflicts by issues of race, color, and class. Class and race matter. They especially matter at the end of life. The last years have seen the spread of the use of advance directives. Informal surveys of audiences to whom I speak have indicated that people who have trusts and estates specialist attorneys—people with assets—always have medical advance directives executed as a part of their advance care financial planning. But in practice, in the Bronx, from the AIDS epidemic until now, care providers find that patients are almost uniformly uninterested in advance directives designed to limit care at the end of life. Patients in the Bronx, many of them persons of color, are interested in *access* to care, not in *limiting* care.

And it is not merely perceptions of unfairness and discrimination that affect the positions of patients and families. The data are crystal clear: patients of color do not receive care equal to that received by patients who are not minority. Thus it is neither paranoid nor ungrounded for patients and families of color to question whether the care they are receiving is the best that medicine can offer.

In most disagreements about care, many of which are characterized as bioethical dilemmas, effective interventions informed by techniques of dispute resolution and mediation can be found.

In its study *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, the Institute of Medicine found that "a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. This research indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services." For example, minorities are less likely to be given appropriate cardiac medications or to undergo bypass surgery and are less likely to receive kidney dialysis or transplants. They are also less likely to receive opioid analgesics. In contrast, they are more likely to receive certain less-desirable procedures, such as lower limb amputations for diabetes.

Resolving Conflict

How can medicine in general and bioethics in particular adjust its practice in this new era of politicized and polarized death? The Schiavo and Francis cases illustrate a number of propositions. First, family decision-making does not always comport with the wisdom of medicine, law, and bioethics. Second, appeals to prior patient wishes, the gold standard of surrogate choice, may not resolve difficult decisions about death. Third, private decisions may be surfaced by appeals to the media and to courts, not to mention legislatures and congress. And fourth, bioethical and legal labels may provide a platform for and encourage intellectual and emotional chaos. In these cases and in many others referred for bioethics consultation, the bioethics hook is really the entrée into a full-blown conflict that must be resolved if care is to go forward.

These cases illustrate out-of-control, irresolvable conflict. It is my premise, however, that while conflict is endemic in medicine and is exacerbated by the emotional rawness that surrounds the process of dying, it can often be recognized and managed for the benefit of families, providers, and patients. *Schiavo* and *Francis* reflect conflicts that became unmanageable as the result of personal emotional issues. But most cases of disagreement and conflict are and should be managed as a part of good medical care. Leonard Marcus captured the notion of conflict in biomedical ethics a decade ago:

By its very nature the arena of medical ethics is replete with conflict. Here principle meets practical: the burden of allotting limited resources challenges what may be a morally correct course of action; personal encounters policy; a hospital-wide procedure may not fit the unique circumstances of a particular patient; and a mixed multitude, sometimes a whole committee, ponders a question ultimately in the domain of the individual. In a health care setting, doctrines of justice and patients' rights translate into concrete decisions based on immediate reality. Although an action may directly affect one particular patient, many people affect and are affected by it, and thus may claim a secondary stake in what happens. Herein lie the ingredients for conflict.[4]

That quotation was embedded in the first attempt to structure a mediation process to guide bioethics consultation. That attempt has since been expanded and sharpened in a second edition.[5] Both of these didactic guides assume, based on the experience of a very active clinical ethics service at Montefiore Medical Center, that most calls for bioethics consultation are calls to resolve conflicts. There is generally a bioethical hook on which to hang this first request for consultation, but that hook typically constitutes 5 percent of the problem; the remainder of the issues are facets of conflict. Both works argue that dispute resolution, specifically mediation, is a proper role for bioethics consultation, for two reasons. First, mediation is one of the most efficient routes to resolving conflict. Second, and more important, mediation is the route that best respects differences in the cultures of patients, families, and health care providers.

Having highlighted a case in which conflict exploded, let me describe a case in which conflict abated. The core issue in this case was that the family of a capable patient was interfering with his ability to provide ethically adequate directives to the team and blocking him from receiving information he had a right to know.[6]

The case came to my attention when the team in the Medical Intensive Care Unit (MICU) called for a bioethics mediation because the staff felt that the family was preventing them from having a much-needed discussion with the patient about his future care. In particular, they felt that this patient, who was alert and aware and had recently been removed from a ventilator, needed to be involved in the decision about whether he would ever be placed back on a ventilator. They stated that his two sons,

who were loving and devoted and stayed with the patient most of the time, were very opposed to having any discussion that might upset their father.

A meeting with the care team in the MICU—physicians, nurses, and social workers—made clear that the patient was very sick, with a history of recovered melanoma, carcinoma of the colon for which surgery had been performed, and a series of cardiac problems that the patient's cardiologist thought had "likely been addressed to the maximum medically." After meeting with the team, I met with the sons and explained that the team felt obligated to have some discussion with their patient about what sort of care he would want in the future. The sons exploded, saying this was unacceptable. I said we would do nothing until we had all agreed on what should happen. After much discussion about the patient and what a terrific person and dad he had been, I asked how it would be if I opened a discussion with him with three questions: Do you want to discuss your future care with me? Would you want me to talk to your sons about future care? and Do you want to have this discussion without your sons being present? The team felt we needed to ask the patient, as he had just been extubated, whether he would want to be intubated again if he should require it medically. Finally, as there was no health care proxy, I would ask whether he would like to appoint one of his sons as his health care agent.

Both of the sons were very concerned that the discussion not indicate that the care was hopeless and that he was dying. They indicated that they realized how sick their father was, but that they wanted him to retain hope. They described him as an independent and proud person who needed hope to go on. I described studies that indicated that when family members try to shield the patient from bad news, the patient usually knows the worst, and the silence is often translated into feelings of abandonment. We negotiated how I would begin the discussion with the patient and arrived at a format that seemed comfortable for everybody.

I then reintroduced myself to the patient. The patient was clearly very weak and tired. I began by asking him who he would want to make decisions for him if he were not able to make them himself. Would he want his sons to do so? He answered, "Sure." I asked him if Sam, the older, should be first, and Harry next in the decision order. He said that was great. The sons said that their dad had never wanted to sign anything, and I assured them that we had heard his statements and would place this discussion in the chart. I asked the patient whether, since he had recently been extubated, he would agree to be intubated again if the doctors thought he needed to be. He said, "I would think about it." The sons said they, too, would think about it. That appeared to use up the patient's focus

and energy. Full-blown conflict regarding whether to "tell Dad" receded.

Mediation in this case worked with the sons to craft an approach to their father that they could tolerate, if not embrace. The mediation prevented the bifurcation of family and staff. It was labor intensive, requiring two hours, but it provided clarity going forward. A short answer, enshrining the capable patient's consent and condemning the sons, would have created full-blown confrontation. At the end of life, short answers are inappropriate; only essays will do.

Generic notions of culture direct our attention to universal attributes of human behavior and to clear legal rules and ethical principles. Local culture takes into account family idiosyncrasy and the care provider's history and refers to those complex systems of meanings that are created, shared, and transmitted by individuals in particular social groups. Local culture directs our attention to diversity, difference, and particularity. Patients and family members share cultures that are based in ethnic group identification, religious affiliations, and shared emotional and family history. When these diverse patient cultures encounter the abstract notions of medicine, the specific created practice of the institution, and the individual educational and social backgrounds of the medical professionals, conflict and disagreement are likely to occur. Very often what a bioethical analysis does is to privilege ideas that are the basis for academic exploration and analysis. This approach favors the dominant medical culture. Mediation, by contrast, parses those closed systems of analysis and intelligence and requires respect for the unarticulated values and preferences of the particular patient and family. The messy structure of a democratic society demands that the principle of "respect for persons" be actualized by a process that ferrets out and helps to amplify the silent value commitments of patients and family members.

The Schiavo and Francis cases are instances in which conflict was fueled by medical reality, fanned by self-serving professionals, and in *Schiavo*, sustained by American political divisions. In most disagreements about care, however, many of which are characterized as bioethical dilemmas, effective interventions informed by techniques of dispute resolution and mediation can be found. In most instances of patient care, there are medical options from which to choose. The choice is directed not exclusively by medical determinants, but far more by issues of religion and personal values. These techniques of dispute resolution can be mastered and put at the ready for conflicts as they emerge, rather than waiting for them to become intractable.

Bioethics mediation is a process in which the mediator facilitates a discussion between and among the parties to the conflict. This person comes fresh to the facts of the

case, impartial to the situation of the case, uninvolved in the prior treatment decisions in the case, and unallied with any party in the particular disagreement. The mediator helps the parties to identify their goals and priorities and to generate, explore, and exchange information and options. The mediator identifies styles and patterns of communication and is alert to the differentials of power and authority that inevitably infuse medicine, especially provision of acute care. Bioethics mediation combines the clinical substance and perspectives of bioethics consultation with the tools and techniques of the mediation process in order to:

- identify the parties to the conflict;

- understand the stated and latent interests of the participants;

- level the playing field to minimize disparities of power, knowledge, skill, and experience (to the degree possible) that separate medical professionals from the patient and family;

- search for a common ground, especially one that is time sensitive;

- ensure that the consensus reached is a "principled resolution," in light of legal rights and ethical scholarship; and

- follow up to be sure that the agreement reached has sufficient structural supports to become the reality of care.

This process, which is itself a part of the product, differs dramatically from articulated proscriptions for bioethics consultation. Many clinical ethics professionals state that this process describes, in large measure, what they do in the hurly-burly of their consultations. Nonetheless, the value added from articulating these guidelines and adhering to their notions of evenhandedness is that it provides greater rigor in bioethics consultation and a commitment to the essay answer, not the selection among multiple brief, seemingly principled choices.

Mediation is especially suited to conflicts at the end of life because time is of the essence; deciding not to reach a decision is not an option. Medical decisions, especially those about life and death interventions, have their own rhythm. The juggernaut of care is likely to roll forward but for the sort of explicit, time-sensitive decisions that mediation can facilitate. In addition, mediators are optimists, and they often enter scenes where staff are discouraged and dispirited. Optimists are useful guides, especially when they can teach about the process and the norms, act as a reference point for new literature, and function as a mentor in the mores and culture of the institution. Most important, mediators translate doctor-speak into language that is accessible to patients and family members, and they help to amplify nonmedical voices.

Not all cases can be mediated. Some, like that of Teron Francis, explode before the care team realizes there is a conflict. Others, like *Schiavo*, are fueled by such deep levels of distrust and fanned by such strong advocates for absolutes that intervention will likely fail. But for many end of life conflicts, mediation can provide a process to assist in the formation of a care plan that meets the needs of the patient and family and respects professional commitments. Moreover, as principled bioethics confronts multicultural contexts, feminist ethics, and narrative ethics, mediation may help to close the gap between individual rights and interests and notions of the public good. As an open, collaborative, problem-solving intervention, it is particularly suited to addressing care at the end of life, which is increasingly caught in a national political web of conflicting interests.

Conflict in life is inevitable. Conflict in health care, given the stakes and the context, is endemic. Conflict in end of life decisions is sad and potentially destructive for surviving family members. Skilled providers who are committed to managing, not banishing, disputes can help to tame some conflicts. Medical providers must acquire the skills of dispute resolution to counteract the effects of politics and media on the stories of life's endings.

1. D. Montero, D. Buffa, and A. Kranes, "Late-Night Hospital Drama Keeps Tragic Bronx Boy on Life Support," *New York Post*, April 23, 2005, 4.

2. A. Peyser, "Let Teron Go in Peace—Then Demand Answers," *New York Post*, April 26, 2005, 7.

3. D. Buffa and M. White, "Tragic Kin Win: Only They Can Pull Plug on Boy: Judge," *New York Post*, April 26, 2005, 7.

4. N.N. Dubler and L.J. Marcus, *Mediating Bioethics Disputes* (New York: United Hospital Fund, 1994).

5. N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions* (New York: United Hospital Fund, 2004).

6. All identifying material in this case has been changed to protect the privacy of the patient and his family.

Hope for the Future:
Achieving the Original Intent of Advance Directives

by SUSAN E. HICKMAN, BERNARD J. HAMMES, ALVIN H. MOSS, AND SUSAN W. TOLLE

The development of new, life-prolonging medical technologies in the 1970s aroused concern among Americans about the indiscriminant use of aggressive, life-prolonging treatments. Highly public cases such as those of Karen Ann Quinlan and Nancy Cruzan drew attention to the importance of end of life care planning for healthy adults. Advance directives were developed as a way for people to retain control over their medical care by specifying their treatment values and choices and by naming someone to make medical decisions once they were no longer able to do so. Over the past several decades, it has become clear that statutory advance directives alone have not been as successful as originally hoped in giving patients control over their end of life care. However, the initial goal of advance directives was laudable and is worth preserving. Promising new models have evolved from practice and research that move us closer to achieving the original intent of advance directives.

Most traditional advance directives, such as statutory living wills and surrogate appointments, were created by legislative processes that set specific requirements about content and established rules regarding their use to define the rights of adults to forgo medical treatment, to protect providers who honor these decisions, and to appoint an authorized surrogate decision-maker. Statutory living wills are a tool for patients to express preferences about medical treatments that can be used if a person is no longer able to make his or her own decisions. These documents typically focus on potentially life-prolonging treatments in a very limited set of circumstances, such as when a person is faced with "imminent death regardless of treatment" or is in a "persistent vegetative state." In most states, a person can also designate a surrogate to make decisions in the event the patient loses decisional capacity. Depending on state law, a surrogate may be called a health care proxy or agent, medical power of attorney, or durable power of attorney for health care.

Limitations of Traditional Advance Directives

Despite the hope that traditional advance directives would ensure that patient preferences are honored, numerous studies have found that only a minority (20 to 30 percent) of American adults have an advance directive and that these documents have limited effects on treatment decisions near the end of life, though more recent research suggests use may be higher at the end of life. In addition to a low completion rate, there are many reasons why traditional advance directives are less successful than originally hoped. These reasons include the following:

(1) The focus is often on a patient's legal right to refuse unwanted medical treatments, reflecting the legislative origins of traditional advance directives. Those who complete such documents generally do not receive assistance in understanding or discussing their underlying goals and values.

(2) The instructions given in these documents and the scenarios provided for discussion are generally either too vague to be clear (for example, "If I am close to death") or too medically specific to be helpful in com-

mon clinical situations (for example, "If I am in a persistent vegetative state").

(3) Vague instructions result in conversations that produce equally vague expressions of wishes such as "Do not keep me alive with machines" or "Let me die if I am a vegetable."

(4) Once advance directives are completed, planning is typically considered finished. A systematic effort to re-open the conversation as a person's health declines is rarely made. The only repeated question that a patient might hear is, "Do you have an advance directive?" as required by the Patient Self-Determination Act.

(5) Traditional advance directives are seen as a right of the patient, with little attention given to routinely integrate planning into the clinical care of patients.

(6) Traditional advance directives are based on the assumption that autonomy is the primary mode of decision-making for most people. However, many people in the United States, particularly those from non-Western cultures, conceptualize the broader social network as the basis of treatment decisions, not the wishes and needs of the individual. Patients may also choose to delegate their autonomy to a family member, religious leader, or others, and defer discussions about prognosis and treatments for cultural or other reasons.

(7) In selecting a surrogate, a patient authorizes someone to speak on his or her behalf; however, advance directives typically do not include directions for the surrogate or health care professionals about treatment preferences unless special instructions are also provided. Additional information about values and goals is important to assist surrogates in decision-making during stressful times.

(8) Some patients may wish for their surrogates' or families' interests to be taken into account in decision-making rather than expecting the surrogate to base decisions solely on the wishes of the patient using a substituted judgment standard. Research suggests that many patients do not expect surrogates to rigidly follow their traditional advance directives, but rather intend for surrogates to exercise judgment to determine the course of care when there is insufficient information available or for extenuating circumstances.

In response to the difficulties with traditional legalistic advance directives, clinicians and researchers have developed new models that preserve the original goal of advance directives while addressing their shortcomings. One well-known example is "Five Wishes," a document that incorporates a surrogate appointment with a range of wishes about medical, personal, spiritual, and emotional needs (www.agingwithdignity.org). Five Wishes offers advantages over traditional advance directives because it covers a range of issues typically not found in statutory living wills or health care power of attorney documents, such as how comfortable a person wants to be or how he or she wishes to be treated if unable to speak for him or herself. Five Wishes meets the legal requirements for advance directives in thirty-seven states and the District of Columbia. Unfortunately, there are no published research studies to support the efficacy of Five Wishes in guiding surrogates and health care professionals or in ensuring that wishes are honored.

"Let Me Decide" is a recently developed Canadian program with empirical data to support its effectiveness (www.newgrangepress.com) The program was studied in a randomized, controlled trial of 1,292 residents at a group of regional nursing homes and hospitals in Ontario. Residents and their family members had an opportunity to document a range of health care choices regarding levels of care, nutritional support, and cardiopulmonary resuscitation. The program was implemented systematically and nursing home staff received training in how to integrate the advance directive into clinical care. Results indicate that the intervention group had a higher prevalence of planning. Additionally, plans were more specific, residents were less likely to die in the hospital, fewer resources were used, and families were more satisfied with the process than were family members in the control facilities using more traditional advance care planning.[1]

In La Crosse, Wisconsin, "Respecting Choices" began in 1991 as part of a community-wide care planning system (www.gundersenlutheran.com/eolprograms). Local health care systems developed institutional policies to ensure that written advance directives were always available in their medical records when needed. Components of the program include staff education about the program and advance care planning; clearly defined roles and expectations of physicians; training for advanced care planning facilitators; routine public and patient engagement in advanced care planning; clinically relevant advance directives incorporated into clinical care; and written protocols so that emergency personnel can follow physician orders that reflect patient preferences. Quality improvement projects were undertaken to measure outcomes and to improve parts of the system when they did not perform in the way intended.[2]

A study of the Respecting Choices program evaluated La Crosse County deaths over an eleven-month period (524 in all). Eighty-five percent of all decedents had some type of a written advance directive at the time of death; 96

percent of written plans were found in the medical record where the person died; and treatment decisions made in the last weeks of life were consistent with written instructions in 98 percent of the deaths where an advance directive existed. Decedents with written advance directives were also significantly less likely to die in the hospital (31 percent versus 68 percent, p=0.001). Respecting Choices is now being implemented by more than fifty-five communities and organizations in the United States and Canada and is being piloted nationwide in Australia.

One of the most studied systems of advance care planning and documentation is the "Physician Orders for Life-Sustaining Treatment" paradigm, originally developed in Oregon (www.polst.org) and complementary to Respecting Choices (in fact, the Respecting Choices program strongly advocates use of the POLST paradigm to document physician orders in the out-of-hospital setting). The POLST form is designed for patients with serious illness and advanced frailty. The centerpiece of the program is the POLST document, a brightly colored medical order form that converts patient treatment preferences into written medical orders based on a conversation among health care professionals, the patient, and/or surrogates about treatment goals (see figure 1). The form transfers with patients across care settings to ensure that wishes are honored throughout the health care system. The POLST form is an example of an actionable advance directive that is specific and effective immediately. In a prospective study at eight nursing homes, residents whose POLST forms included a do not resuscitate (DNR) order and an order for comfort measures only were followed for one year. None received unwanted intensive care, ventilator support, or cardiopulmonary resuscitation.[3]

In contrast to the varied out-of-hospital DNR orders used around the country, the POLST paradigm provides patients the opportunity to document treatment goals and preferences for interventions across a range of treatment options, permitting greater individualization.[4] Research suggests that the POLST form accurately represents patient treatment preferences the majority of the time[5] and that treatments at the end of life tend to match orders.[6] A majority of nursing homes and hospices in Oregon use the voluntary POLST Program, and POLST is widely recognized by emergency medical services.[7] At least thirteen states have adapted versions of the POLST program, including Oregon, Washington, West Virginia, Utah, and parts of Wisconsin, New York, Pennsylvania, North Carolina, New Hampshire, Tennessee, and Michigan, reflecting a high degree of acceptance by health care professionals. Each state has made minor alterations to the document to accommodate local regulations and statutes. A National POLST Paradigm Task Force formed in 2004 to support national growth of the program.

Elements of Successful Advance Directive Programs

The newer, more successful, clinically based advance directive programs share key elements: a facilitated process, documentation, proactive but appropriately staged timing, and the development of systems and processes that ensure planning occurs.

First, successful advance directive programs are not limited to the content or rules relating to legal documents. Instead, an individualized plan is developed through a process of interaction with the patient that is specific not only to the patient's values and goals, but also to his or her relationships, culture, and medical condition. Advance care planning should focus on defining "good" care for each patient, rather than on simply listing the right to refuse treatment or promoting individual autonomy. A skilled facilitator can enhance advance care planning by engaging those who are close to the patient so that they understand, support, and follow the plans that are made. The process permits shared or delegated decision-making depending on the beliefs and preferences of the patient. Facilitators should encourage patients and surrogates to discuss how much leeway a surrogate has in decision-making.

Second, for advance directive programs to be implemented successfully as a patient moves between different treatment settings, documentation of wishes, goals, and plans is essential. This documentation should include the identity of a designated surrogate. Ideally, this documentation would be in the form of actionable advance directives that direct treatment with specific medical orders reflecting a patient's current treatment preferences—in contrast to traditional advance directives that address preferences in hypothetical future scenarios. To be truly effective, the actionable advance directive form must be standardized and recognized throughout the broader health care system, and it must provide clear, specific language that is actionable in all settings to which a patient might be transferred. The power of actionable advance directives is most completely realized in a system in which all institutional entities that interact with the patient (health care personnel in emergency medical services, emergency departments, hospitals, nursing homes, hospices, home health care, and others) recognize the actionable advance directive form and are authorized to follow its written orders.

Third, successful advance directive programs also require proactive but appropriately staged timing: some discussion should anticipate health care decisions, but much of it must be revisited as the patient's prognosis becomes known. For an otherwise healthy patient, the presumption is that the treatment goal is to return to his or her prior state of health. Individuals who fit this description do not need an advance directive to guide initial treat-

ment. However, healthy adults can benefit from the process of advance care planning to prepare for sudden, severe illness or injury. Healthy adults should appoint a trusted family member or friend to serve as a health care surrogate who can act as a strong advocate in the event that they are unable to speak for themselves. Healthy adults should also discuss with their surrogates whether and when a permanent loss of neurological function would be so bad that the goals of medical care would change from prolonging life to providing comfort, and

Figure 1. Sample POLST Form from Washington State

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they should address the degree of leeway that they grant to the surrogate.

In people with advanced chronic disease and frailty, planning should expand to include discussion of changing treatment goals. Success rates for interventions decline as disease and frailty progress, and patients' evaluations of the desirability of interventions often change in the face of this new reality. Patients and families look to health care professionals to initiate conversations about end of life care planning, and it seems most relevant to broach the topic in the context of a limited prognosis. Once the prognosis has been discussed, health care professionals (but not necessarily physicians) trained to facilitate advance care planning discussions can help guide patients so that plans are specific not only to the patient's experiences, values, and goals, but also to the patient's health condition, culture, and personal relationships. This planning should focus on treatment goals in scenarios likely to occur in the course of that person's chronic disease. Completion of an actionable advance directive may be particularly helpful at this time.

Finally, perhaps the most crucial elements of more successful advance directive programs are policies, procedures, and teamwork within each part of the health care system that ensures advance care planning and implementation occurs. Plans need to be clear and should reflect the individual's values and goals. Plans should be updated over time and available when needed; whenever possible, plans should be honored. A successful model requires the establishment of systems at many levels to achieve these goals. Health care organizations can create policies and procedures to assure that any written plan is available when needed. The roles and responsibilities of different health professionals must be clearly defined so that each person knows his or her part and can perform it. Furthermore, optimal performance of each player's role benefits from periodic assessment, which requires that health organizations conduct quality improvement initiatives to ensure that the implemented system achieves the desired outcomes. Organizations should be prepared to gather the necessary information to improve the system when and where it falls short.

For advance directives to be effective, they need to be integrated into each part of the system of care, including emergency medical service protocols and regulations. State statutes vary regarding traditional advance directives, surrogate appointment, and other relevant factors, such as emergency medical technicians' scope of practice. Therefore, state end of life coalitions consisting of key stakeholders (emergency medicine, long-term care, hospice, nurses, physicians, and health lawyers, among others) may need to identify and overcome state-specific regulatory, legal, and cultural barriers to the implementation of optimal advance care planning.

The original intent of advance directives to enable patients to retain control over their terminal care once they lose decision-making capacity was not fully achieved through the use of the traditional advance directives. New, more successful models address the limitations of the traditional models yet remain true to the concept's original intent. The key elements of these new models are advance care planning in a system with specially trained personnel; highly visible, standardized order forms that are immediately actionable; proactive, appropriately staged timing; ongoing evaluation and quality improvement.

For these new models to be used more broadly, systems to implement them will need to be established in each state and within every health organization. These systems need to ensure that traditional and actionable advance directives are written at the appropriate time, that they are recognized, and that they are honored. Given the initial success of these models, it is reasonable to believe that the original goal of advance directives—to ensure respect for patients' treatment wishes at the end of life—can and will be more completely realized in the future.

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Recognizing Death while Affirming Life:

Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?

by ADRIENNE ASCH

Early in 2005, a real-life drama and two acclaimed films engaged the nation in discussions of issues that had been a staple of the end of life field for over twenty-five years. Terri Schiavo's medical condition resembled that of Nancy Cruzan, whose family had succeeded in convincing the United States Supreme Court to remove her feeding tube. Hollywood's *Million Dollar Baby* and Spain's *The Sea Inside* reminded many of the Broadway play and movie, *Whose Life Is It Anyway*, in which a sculptor, like the boxer and the diver of the contemporary films, chose death over life with disability. The powerful reactions to these motion pictures, the controversy over the Schiavo case, and, in Boston, a public dispute between a leading hospital and a patient's family over the withdrawal of life support, underscore our urgent need to reform how Americans deal with life-prolonging or life-ending decisions.

Sometimes the media, the public, and professionals in end of life treatment and policy frame the debate in terms of "quality of life" versus "sanctity of life," but this casting oversimplifies the story and neglects critiques from people who share many values espoused by the end of life movement but nonetheless oppose some views that pervade the field. A sensitive decision-making process and sound conclusions demand weighing several factors: what gives life meaning and value for a particular individual; what circumstances or setting would permit the ill, disabled, or dying patient to derive comfort and fulfillment in existing relationships, experiences, or activi-

ties; whether a presumed decision-maker should ever be replaced by another person in the patient's life; and whether any factors other than patient and family preferences should influence life-ending decisions.

Evolving Views of End of Life and Disability

In the years since the 1976 case of Karen Ann Quinlan, much greater weight has been given, both in law and the culture at large, to informed consent; to the experiences, views, and needs of patients and families in the medical encounter; to respect for patient autonomy and family decision-making; and to the quality, not merely the preservation, of an individual's life. These beliefs have meshed well with the efforts of feminists and other marginalized groups to equalize the power relations between doctor and patient, and they have also supported twenty-first century cultural norms of self-fulfillment, self-determination, and control over one's destiny. These ideals should have promoted an alliance between end of life reform, the emerging scholarship of disability studies, and the movement for disability rights and equality. Unfortunately, many scholars and practicing health care professionals have failed to grasp crucial insights of disability scholars or activists. Despite the common cause of disability scholars and activists with those in the end of life movement around maximizing self-determination and giving more respect and authority to patients in their encounters with medicine, the end of life movement has sharply differed with disability theorists and activists in understanding how illness and impairment affect quality of life.

Thanks to the sustained efforts of scholars, clinicians, and grassroots citizen groups like Compassion in Dying,

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When data reveal that the fear of burdening others is of greater concern to patients who seek suicide than concerns about finances or physical pain, how can we know the decision to end life is not a response to the patient's fear that she is disliked, distasteful to, and resented by the very people from whom she seeks support?

both clinical practice and case law recognize that ill or dying patients and their intimates often are concerned about their experiences and relationships during whatever time they have left to live, not merely with how long they might be maintained by medications, feeding tubes, and breathing machines. Disability activist and lobbying groups such as Not Dead Yet or Americans Disabled for Attendant Programs Today (ADAPT) also espouse the goals of creating and maintaining opportunities for ill, disabled, or dying people to enjoy fulfilling, meaningful relationships, activities, and experiences for however much time they will live. Compassion in Dying and Not Dead Yet differ in their policy and practice goals for two reasons: they focus on different kinds of paradigm cases, and they have profoundly different understandings of how illness and disability affect life's meaning and rewards. The typical case for the misnamed "right to die" movement is an elderly man or woman in the final stages of an inevitably terminal illness, who will soon die regardless of how much medical treatment is invested in his or her last days or weeks. The case that fuels the disability rights movement is that of a relatively young person with a disability, who could live for several years with the condition, but who instead asks to die—as in *Million Dollar Baby*, and as in many real-life cases.

Although mainstream reformers have criticized the way professionals often dealt with patients and their families, the mainstream has too often accepted medicine's view that illness and disability inevitably diminish life's quality. In contrast, disability theorists and activists point to research demonstrating that people with physical, sensory, and cognitive impairments can and do obtain many satisfactions and rewards in their lives. When people with illness and disability report dissatisfaction and unhappiness, they link their distress not to physical pain or to reliance on medications, dialysis, or ventilators, but to those factors that also trouble nondisabled people—problematic relationships, fears about financial security, or difficulties in playing a valued work or other social role.

Disability theorists and activists endorse the growth of hospice, palliative care, pain relief, and greater attention to the psychological and social needs of patients and their loved ones; however, they argue that endorsing treatment withdrawal from people simply because their health or

their capacities are impaired undermines the goals of human dignity, patient self-respect, and quality of life. Such goals are best achieved by helping people discover that changed health status and even impaired cognition need not rob life of its value. Respect for self-determination and human dignity entails a commitment to fostering the activities, experiences, and relationships that enrich an individual's life by finding techniques and resources to use those capacities that remain. In the case of Elizabeth Bouvia, a woman disabled by cerebral palsy and painful arthritis who sought aid in dying, the California Court of Appeals supported her request to end her life by focusing on her limitations, pointing to her physical immobility and her need for assistance with tasks like eating and toileting. Although the court described her as "alert" and "feisty," it also characterized her as "subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness." The 1996 court decision that supported physician-assisted suicide in *Washington v. Glucksberg* was filled with similar portrayals of life with impairment: it referred to people who are in a "child-like state" of helplessness, as exemplified by physical immobility or by their use of diapers to deal with incontinence.

The disability critics of the California court decision revealed an entirely different side to the Elizabeth Bouvia story. They focused on her remaining capacities and on the social and economic problems that contributed to her isolation and depression. Educational discrimination had prevented her from using her mind; she had been denied the full amount of personal assistance services that would have enabled her to stay in the community; and her depression, which stemmed from serious family problems, would have been immediately treated in a nondisabled person who had attempted suicide.

Many of the disability theorists and activists who protested the court decisions in the Bouvia case—and in the similar Michigan case of David Rivlin, who became quadriplegic and sought death rather than remaining in a nursing home—have very similar physical conditions but entirely different life circumstances. By recruiting paid or volunteer personal assistants, they live in their own homes by themselves or with family and friends. They are in the community, not in institutions. They hold jobs, engage in

Curtain, by Robert Pope
By permission of the Robert Pope Foundation.

volunteer activities, visit friends, go out to dinner or the movies, and generally participate in ordinary family, civic, and social life. Wheelchairs do not confine; they liberate. Voice synthesizers aid communication for people who can no longer speak. Diapers or catheters are akin to eyeglasses. Using the services and skills of a personal assistant who helps them get into and out of bed, eat their meals, or travel to their next appointment is no more shameful or embarrassing than it is for a nondisabled person to work closely with an administrative assistant or to value the expertise of a mechanic, plumber, or the magician who restores data after a computer crash.

Fortunately, some respected mainstream scholars have acknowledged that societal tolerance of death for people who could live for months or years with disabilities stems from misunderstanding, fear, and prejudice. Excerpts from one clinician-philosopher's recent reflections demonstrate a new receptivity to the disability critique of typical end of life practice and policy.

> I am now embarrassed to realize how limited was the basis on which I made my decisions about David Rivlin. . . . [T]here was no medical need for Rivlin to be effectively incarcerated in a nursing home. If Rivlin had been given access to a reasonable amount of community resources, of the sort that other persons with disabilities were making use of at the time, he could have been moved out of the nursing home and probably could have had his own apartment. He could have been much more able to see friends, get outside a bit, and generally have a much more interesting and stimulating life. . . . If we look at a case one way, it seems that the problem is the person's physical disability. If we shift our view, we realize that the problem is not the disability, but rather the refusal of society to make reasonable and not terribly expensive accommodations to it.[1]

In his 1979 book *Taking Care of Strangers*, Robert Burt exposed the common discomfort of health care professionals in the presence of patients with very significant impairments: "Rules governing doctor-patient relations must rest on the premise that anyone's wish to help a desperately pained, apparently helpless person is intertwined with a wish to hurt that person, to obliterate him from sight." Speaking of a burned and very disfigured patient, Burt contended: "He is a painful, insistent reminder to others of their frailty, an acknowledgement that, in the routine of everyday life, is ordinarily suppressed. Others cannot avoid wishing that he, and his unwanted lesson, would go away. He cannot avoid knowing this of others and wishing it for himself."

Toward Further Change

These insights should prompt clinicians and policymakers to question how truly autonomous is anyone's wish to die when living with changed, feared, and uncertain physical impairments that lead to anguish and to interpersonal struggles with the very professionals, family members, and friends who are assumed to be supports in a time of trouble. The spirit of such observations illustrates the danger of relying on a simple notion of patient autonomy when deciding to withdraw life-sustaining treatment.

Consider this case from the end of life literature, reported by M. Edwards and Susan Tolle: Their patient—conscious, alert, with mobility impairments that had lasted for forty years—had recently developed breathing problems that necessitated use of a ventilator, which rendered him unable to speak. Finding this increased disability intolerable, he sought death, and family, professionals, and the hospital ethics committee concurred with his autonomous wish. Edwards and Tolle proposed a seven-step procedure to assure themselves that such an aided death is acceptable. Absent from their analysis is any exposure to

or contact with people who have more than two weeks of experience living as ventilator users. The case description provides no information on how effectively this patient was communicating (whether by writing, pointing to letters and words, or using a communication technology). It contains no information about whether this man's decision was affected by concerns over how his relationships with family and friends might be changed by his different means of communication. Presumably these clinicians knew that nonvocal but conscious and responsive individuals have been able to interact in family and work settings. One wonders why these clinicians did not urge such means upon this patient before acceding to his pleas for death rather than life without speech. He may have been psychologically abandoned by his family and clinicians when he most needed their energy, resourcefulness, and imagination to help him devise a new way to express himself.

The most recent report on the workings of Oregon's law on physician-assisted suicide offers yet another illustration of social rather than medical issues at work in requests for assisted dying. The most frequently cited reasons for seeking to die stemmed from loss of enjoyable activities, loss of autonomy, and loss of dignity. Yet these were mentally alert individuals who should have been aided by professionals and their own social networks to discern that autonomy and dignity can reside in self-expression, in determining what activities to pursue, and in obtaining the assistance to undertake them. This reframing of autonomy and dignity is urgently necessary as a way to restore self-respect and pride to people who feel shame at needing physical or emotional help from those around them. Have they lost their own ability to provide love, support, friendship, and guidance to their families and friends, and if so, what professional psychological help might let them regain those capacities? Or have they lost their connections to the social world, and so been denied a way to give and to receive help and support?

For people living with disabilities, the data on Oregon's assisted suicides provokes concern. One can respect individual choice but worry that the Oregon data, like the case involving ventilator withdrawal, graphically support Burt's reflections on the ambivalence of health care professionals and families toward people with significant disability. When these data reveal that fear of burdening others is of much greater concern to patients who seek suicide than concerns about finances or physical pain, then how can professionals and families know that the supposedly autonomous wish to end life is not a response to a patient's deep fear that she has become disliked, distasteful to, and resented by the very people from whom she seeks expertise, physical help, and emotional support? And when we learn that divorced and never-married individuals are twice as likely as married or widowed people to use

physician-assisted suicide, we must ponder whether a single dying person feels especially alone and abandoned. It is probably the rare friend who has the time, energy, or willingness to make a sustained, reliable, and deep commitment to live through another's illness and death. Once the severely disabled, ill, or dying person is seen as "other"—as different, not quite in the human and moral community, even past friendship and familial bonds—social bonds can diminish. To anyone with the capacity to perceive the difference between warmth, toleration, and coldness in how he or she is treated by others, the thought of days, months, or years of life subject to resentful, duty-filled physical ministrations may be a fate worse than death, akin to imprisonment and solitary confinement. What needs to change is not the patient's physical or cognitive situation, but the emotional and interpersonal environment; that environment can change only when professionals lead the way to supporting the capacities and and thereby affirming the humanity of severely ill and imminently dying people.

Once we have understood the disability community's concerns about cases involving alert people with physical, but not cognitive and affective disabilities, we can better understand the reaction to the unfortunate case of Terri Schiavo. By the time her husband sought to withdraw her feeding tube, all the medical experts were certain that she had not even minimal cognitive capacity or consciousness. Schiavo's supporters in the disability community were almost certainly mistaken about her potential for interaction or responsiveness, and they may have done damage to their efforts to join with others seeking to reform treatment of disabled or dying people. Yet the apprehension in the disability community, apprehension about societal indifference and neglect, is more understandable after reviewing a few of the many instances in which law, medicine, bioethics, and government programs failed to help traumatically disabled patients discover the financial, technological, social, and psychological resources that could sustain them and provide the opportunity for rewarding life. When people with relatively intact cognitive and emotional capacities are neglected, neglect is even more likely for those with greatly diminished cognitive and emotional function.

Although the intense court reviews of Schiavo's situation consistently confirmed her PVS diagnosis, professional literature contains scattered information on patients who were misdiagnosed as being in that state and were consequently denied rehabilitation and treatment from which they might have benefited. Some misdiagnosed patients have limited ability to respond meaningfully to others; this diagnostic error cost such patients between one and four years of interaction with people and the world around them. It is rare for courts or scholars to champion continued treatment for cognitively impaired

Advance directives should help people imagine not only what physical changes may occur, but also what social, technological, and financial resources they might require to maintain themselves after the onset of serious illness and disability.

people who might still enjoy some level of life satisfaction and human interaction.[2]

The disability equality perspective on end of life and treatment withdrawal cases described here should demonstrate that the alliance of disability studies and disability rights with the evangelical religious groups is more apparent than real. Disability critics of much health care practice share more with end of life reformers who seek to promote an emphasis on respect for the dignity and capacities of people facing illness, disability, and death. Like these reformers, they seek the means for maintaining dignity and capacity; the aptly named Not Dead Yet strives to convince people with disabilities, their families, and their health care providers that people can still find satisfaction and quality in their lives. The president of Not Dead Yet clearly articulated the ways in which disability opposition to life-ending decisions is truly a quest for quality, rather than sanctity, of life:

> The far right wants to kill us slowly and painfully by cutting the things we need to live, health care, public housing and transportation, etc. The far left wants to kill us quickly and call it compassion, while also saving money for others perhaps deemed more worthy.

> [W]e also have an attitude about disability that diverges from the mainstream. . . . Frankly, I think that's why we were deliberately excluded from the last decade of policy making conducted off the public radar screen, why the right-wing-left-wing script was so important . . . no matter how untrue and exclusionary.[3]

These comments lead to a case with disturbing implications for mainstream discussions of patient autonomy, family decision-making, and professional obligation. Barbara Howe, a seventy-nine-year-old woman with amyotrophic lateral sclerosis, using a ventilator, was being treated at Boston's Massachusetts General Hospital. Howe's daughters and grandchildren visited her consistently. Howe had indicated that she wished to stay alive as long as she could appreciate family visits and had named one of her daughters to serve as health care proxy. In March of 2005 she was thought to be conscious and alert but was unable to speak or to show responses through any facial or bodily movements. Yet the hospital sought to remove Howe's daughter as her health care proxy and to discontinue ventilator support. After legal wrangling, a re-

portedly reluctant daughter agreed that ventilatory support could be withdrawn on June 30 (Ms. Howe died while still on ventilatory support before that date).

Although the details of Howe's case are not yet and may never become public record, the published reports give considerable basis for concern. If case law and mainstream end of life practice are to continue their adherence to patient autonomy, health care proxy decision-making, and rights to receive as well as rights to forego life-sustaining treatment, they should question the basis on which the hospital staff sought to end treatment in the face of expressed wishes of patient and family to continue that treatment. On what basis did staff feel that the treatment was inhumane since the patient had requested that she be kept alive regardless of pain if she was appreciating her family's visits? Did the hospital staff have reason to believe that it knew the patient better than did her family because the staff was with her for many more hours every day? Was the staff experiencing the kind of pain and ambivalence Burt describes in the presence of a conscious yet unexpressive woman with complete physical paralysis? Did the hospital, like the hospital in the 1991 case of Helga Wanglie, believe that continuing to provide expensive treatment no longer served either the patient or the public good? Was stewardship of resources an unstated but serious concern, and should it become a legitimate public concern? If end of life practice and law answer yes, as they well may need to do, the field will have to rethink its almost unquestioned championing of patient autonomy and family decision-making if those autonomous or proxy decisions are to maintain, rather than to forego, expensive life-sustaining treatment.

The stories of Helga Wanglie and Barbara Howe clearly reveal the need for end of life reform to re-examine the possibility of setting limits to its own commitments to patient autonomy or family decision-making in the face of public resource constraints. This issue could lead to even more division between the mainstream end of life field and the disability theorists and activists who seek both a shift in an understanding of "quality of life" and a distribution of resources to individuals who need physical, medical, and social support to maintain a life with dignity and meaning.

Next Steps

This largely absent disability perspective could profitably enliven the world of end of life reform. The post-Schiavo reaction, with its renewed calls for advance directives for all Medicare patients, should encourage bioethicists to redesign the current forms, which ask people only about which interventions they do and do not want. Instead, the forms should describe the various medical scenarios that might occur in certain situations and encourage people to consider what they would or would not want done in each instance. Which physical and cognitive capacities can they imagine losing and still find life rewarding? What activities do they envision as essential for life satisfaction? These educational documents should help people imagine not only what physical changes may occur, but also what social, technological, and financial resources they might require to maintain themselves after the onset of serious illness and disability. Recognizing how difficult it is for anyone to project herself into a radically different situation, the end of life field has moved away from advance directives and instead endorsed family decision-making and health care proxies. Indeed, many families will accurately gauge their loved one's desires, whether for continuing or ending life-sustaining treatment; nonetheless, widespread discomfort in the face of physical and cognitive changes in a spouse, parent, sibling, or friend suggest that even intimates may fail to appreciate the rewards and satisfactions remaining in their loved one's life. I would therefore suggest that revamped advance directives and drastically revised educational materials continue to be indispensable in helping us out of the end of life care morass.

End of life reform and society generally have never successfully confronted the rationing question; neither has the disability rights movement or the field of disability studies. Groups like Not Dead Yet bring an invaluable perspective on disability to end of life conversation, and they need to be sought out as we search for progress in reforming end of life practice. Activists from Not Dead Yet and ADAPT, as well as disability scholars from philosophy, psychology, health economics, and other disciplines, need to participate regularly in the mainstream conversation; they need to help determine criteria for allocating national resources among all the many health, disability rights, environmental, and social justice problems we face. They also need to be recruited for hospital and hospice ethics committees, and they need to train physicians, nurses, and social workers in new ways of understanding life with disability. The events of this year demonstrate how desperately the disability perspective needs to become part of the conversation rather than being excluded from it.

At the end of life, facing decline and death, these "disability issues" are issues for everyone—learning how to affirm and celebrate what gives life meaning and simultaneously acknowledge loss of capacity and eventually loss of life itself.

Acknowledgement

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3. D. Coleman, testimony before the Subcommittee on Criminal Justice, Drug Policy and Human Resources of the Committee on Government Reform of the U.S. House of Representatives, *Oversight Hearing on Federal Health Programs and Those Who Cannot Care for Themselves: What Are Their Rights, and Our Responsibilities?* April 19, 2005.

Making Room for Dying:

End of Life Care in Nursing Homes

by SANDRA H. JOHNSON

People are dying in nursing homes. This may sound like a clarion call for a new wave of nursing home policing; instead it is a statement of a simple fact that we must embrace. Over 20 percent of older Americans meet their deaths in a nursing home, and 30 percent of all persons dying in hospitals have been transferred there from nursing homes just a few days earlier.

Understanding that people die in nursing homes—and *should* die in nursing homes, just as they should be able to die at home—ought to drive us to improve their care. The literature is already rich with case studies and demonstration projects undertaken by nursing homes to improve care of the dying. Broader change requires a shift in culture and a reframing of the issues. Contemporary standards for nursing home quality and the accepted framework for end of life decision-making have inadvertently placed obstacles in the path of good care for the significant proportion of older people who will spend their final days in a nursing home.

Enriching the Ideal for Nursing Home Care

The cornerstone of contemporary nursing home quality standards has been the unequivocal repudiation of the related beliefs that nursing homes are way stations for the dying elderly and that decline is inevitable for nursing home residents. Instead of being resigned to inevitable decline, regulators and professionals are committed to maintaining, if not improving, the physical, mental, and social health of nursing home residents. This hard-won expectation of active support for maintenance and growth rather than mere caretaking has directed nursing homes toward a more engaged and less fatalistic care model. This change is good, in part because the nursing home industry, regulators, and caregivers have become alert to substandard care that had once hidden behind routine acceptance of physical and mental decline.

These rehabilitative, health-promoting expectations, however, may have unintentionally produced a death-denying culture within the nursing home. Regulations impose standards that assume that physical, mental, and emotional decline are signals of deficiencies in care unless demonstrated to be otherwise. Physical changes commonly associated with dying, such as weight loss, have thus become signs of failure, rather than a normal part of dying, and so trigger requirements that the facility justify its care. Because nursing home administrators are highly sensitive to regulatory risk and avoid situations that may attract the attention of regulators, the regulatory emphasis on positive indicators of health can discourage them from providing good care to a dying resident. This dynamic is revealed, for example, by the fact that imminently dying residents are often transferred to hospitals so their deaths will not occur in the nursing home and require that care be defended. Failure to accept the indicators of decline that naturally occur in dying may also be reflected in the emphasis on tube feeding for nursing home residents. Thus, the rehabilitative expectations, captured and reinforced in regulation, skew nursing home care models away from care of the dying.

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Before nursing homes can improve end of life care, dying will have to find its place in the nursing home culture. For nursing homes, a shift in culture necessarily involves paying attention to regulation and to the providers' reactions to regulation as well as to other behaviors that create and maintain a culture. Culture and regulation go hand in hand in the nursing home environment because of the pervasive scope of nursing home regulation, the enforcement orientation of regulators, and the intense risk aversion of nursing home administrators. Efforts to make room for the dying patient require a review of standards and adoption of changes to facilitate the appropriate level and type of care for them. Some have argued, for example, that changes in the mandatory Resident Assessment Index could more readily encourage nursing homes to provide better palliative care. Such efforts should not require nursing homes to abandon their mission of health promotion, however. Palliative care models view support of the dying as active, positive, and promoting of health and human values, even as agressive medical interventions aimed at cure are relinquished. In addition, both hospices and nursing homes engage in the most intimate forms of care, and this shared experience can form a meeting ground between what are now often viewed as separate approaches to care.

The challenge is to encourage the regulatory system to accept the process of dying, with its accompanying physical and mental deterioration; to exercise restraint in the use of interventions, including inquiries, that would otherwise be pursued; and to do so without creating a shield for neglect. Nursing homes are plagued by a reputation for neglect and abuse, but gearing the entire system to account for the bad apples can inadvertently have the effect that all homes provide less than optimal care for the dying. Unintentional adverse effects are a problem for any health care regulatory system, of course. They can occur whenever health care professionals make decisions in patient care that are motivated not by the best interests of the patient, but by the provider's fear of litigation or scrutiny by a regulator. Nursing home administrators often try intensely hard to avoid doing things that would trigger regulatory scrutiny because part of their professional obligation is to manage legal risks. This has a very deep effect on patient care because the administrator has a profound influence on patient care in the nursing home (as compared to other health care settings). Such decisions therefore raise ethical issues concerning the duties of health care providers, including administrators, to patients, not only to the facility. While administrators have a professional obligation to protect the facility, ethical duties to residents' well-being supersede their management responsibility. Because of their influence on care, administrators cannot defer that ethical obligation to professional caregivers.

Of course, the nursing home culture consists of more than the regulatory environment. If the nursing home culture is to make room for dying, the incremental patterns that maintain that culture will have to be addressed. Publicly marking the death of a resident by more than redistributing clothing or reassigning the "bed," expressions of sympathy to other residents and to family, and bereavement support for staff can be significant in creating a culture that responds to the reality of death. Paying attention to culture also broadens the focus to include the community of caregivers in the nursing home. Often, direct caregivers and residents in a nursing home differ in terms of race and ethnicity, socioeconomic class, and culture. If culture is taken seriously, the clashes in expectations and values that occur between residents and caregivers—and often between the professional and nonprofessional staff—can be addressed as larger questions rather than as individual conflicts with uncooperative caregivers.

Adjusting the Framework for End of Life Care

Improving the quality of care for the dying in nursing homes is not solely a matter of nursing home culture and regulation, however. It also requires adjusting the general framework for end of life decision-making to better account for the nursing home context.

One important characteristic of the dominant legal and ethical framework for end of life care is the drive to the crucible—a concentration on the cases that place fundamental values in stark contrast and thus highlight intractable moral conflict. The paradigm case in the end of life debate—whether nutrition and hydration should be provided for a person in a persistent vegetative state—has persisted as *the* test case for the moral and legal questions for decades. But testing principles and decisions against this paradigm can thwart progress in improving care for the dying. By focusing squarely on issues that are more commonplace, both in terms of incidence and in the sense of shared values, nursing homes can improve the lives of those who will die in their facilities. Rosalie Kane argued that long-term care should emphasize what she termed "everyday ethics"; similarly, the well-being of individuals living and dying in the care of nursing homes is better served if we focus on the routine rather than the extreme.

If nursing homes have a distinctive case in which key ethical issues are embedded, it is the decision whether to transfer the dying resident to a hospital. Unnecessary hospitalization of nursing home residents when death appears imminent is both a symptom of, and scaffolding for, the culture that denies death and thus impedes the most appropriate end of life care.

Studies indicate that hospitalization when death is imminent does not provide the resident with better treat-

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ment. Rather, such transfers can impair good care because the hand-off to a new care team can result in absent or unclear transfer orders for pain and symptom management, disruption of care plans developed with the resident or the family, and the disturbance of moving to an unfamiliar location. Reducing the incidence of unnecessary hospitalizations can improve care of the dying significantly in the nursing home without facing a stalemate over the moral values of human life and human caring.

A second "common" issue is improvement in pain and symptom management. Unrelenting pain can interfere so completely with thought, self-awareness, emotional engagement, and social relationships that it can rob the individual of the experience of being human. But pain is badly undertreated in nursing homes; studies report that 30 to 80 percent of residents receive inadequate pain management. Pain management may be undercut by regulations intended to avoid excessive use of pharmaceuticals, especially those that affect awareness. Efforts to improve pain management confront a tendency on the part of health care providers and family members to underestimate pain in the elderly, as well as the tendency of the elderly to underreport pain for fear of being a burden. Assessing pain in people with cognitive impairment requires intense effort. Improving pain management will not grab the headlines or fuel the debates that withdrawal of nutrition and hydration does, but it is the foundation for compassionate care for the dying.

Food and water—including medically provided nutrition and hydration—carry symbolic weight, but especially in the nursing home setting. Nutrition and hydration, and the nutritional status of the resident, are a core measure of adequate or deficient care. Deficiencies in diet and hydration are commonly viewed as the root cause of substantial physical and mental impairments and of injuries ranging from bedsores to mental confusion. Poor food service and inattention to encouraging fluid intake are, in fact, key indicators of poor nursing home care.

Nutrition and hydration in the nursing home are also icons of the ethic of care. The better nursing homes, for example, understand the social and emotional power of eating. Despite the focus on health promotion, sometimes the primary goals of nursing home care, especially for the

families, are to keep this person safe, to keep her warm, and to keep her fed.

Tube feeding is not the same as eating, however. Its sole justification is that it maintains the physical health of the patient. When tube feeding does maintain physical health, there can be a battle over whether continuing or stopping is moral or immoral. Increasingly, however, evidence indicates that a common intervention for tube feeding in nursing homes—percutaneous endoscopic gastrostomy (PEG)—does not reduce the risk of pneumonia or infection and may not reduce the risk of bedsores. This new knowledge presents a challenge, or opportunity, analogous to earlier efforts to reduce the use of physical restraints in nursing homes. The two developments are similar in that the common practice was supported by a "common knowledge"—restraints keep residents safe and PEGs keep them healthy—that has proven mistaken. As with restraints, new knowledge about the negative effects of medically provided nutrition and hydration should reduce recourse to tube feeding, even when the nutritional intake of patients appears inadequate, while strengthening rather than rejecting the values that support feeding.

The battleground of medically provided nutrition and hydration for the PVS patient is fought ferociously because there is disagreement over the meaning of life and the meaning of care. In contrast, the most significant nutrition and hydration issue in the nursing home for end of life care may now present a question of fact rather than contested value. Unless this common practice is uncoupled from its association with the crucible of the provision of nutrition and hydration to the patient in PVS, the shared values that support its reduction in use will not be recognized.

Questioning the Assumptions

Different states have varying normative and legal frameworks for decisions concerning medical care at the end of life. Furthermore, actual practice often differs significantly from the principles established in the law and in the ethics literature. In practice, for example, health care professionals, families, and patients may bring more nuance to the situation than either the law or the ethics literature can encompass.

Listening, by Robert Pope
By permission of the Robert Pope Foundation.

Three fundamental assumptions in the current structure for end of life decision-making are particularly ill-suited to the nursing home environment. These are the concepts that "end of life care" is synonymous with "care for the dying," that the patient is the only person whose autonomy or well-being has moral significance, and that there should be a presumption in favor of life-sustaining treatment.

Legal, ethical, and clinical decision-making at the end of life still bear the mark of their original emphasis on the significance of terminal illness. The moral and legal distinction between terminally ill individuals and others certainly has been modified somewhat; however, the status of "dying" still has significant connotations. More important, it assumes a recognizable process with a beginning that is as clearly defined as its end.

For nursing home residents, the dying process is often subtle and incremental. Is *this* pneumonia or *this* infection the one that signals imminent dying, or will treatment restore the patient to her previous health status? The problem of recognizing the onset of dying may be an even more serious problem among patients with dementia, who constitute a significant population in nursing homes. According to one study, only 1.1 percent of residents with advanced dementia were identified by clinicians as having a life expectancy of less than six months, while 71 percent of those same patients actually died within that timeframe.

The problem of identifying the beginning of the dying process or categorizing a patient as "dying" is not only one of medical uncertainty. It is, rather, evidence of a lack of language and even a lack of concepts for this stage of human life, even though it is a stage typical of so many nursing home residents. The problem of defining when someone can be labeled as "dying" is also a manifestation of the denial of death and the fear that accepting a broader "end time" will cause individuals to be neglected and devalued. Unfortunately, when aggressive interventions are pursued or when palliative care is withheld until one is labeled as "dying," individuals and their families do not receive optimal care and support.

The dominant structure for decisions at the end of life, however we define that period, single-mindedly focuses on the well-being and autonomy of the patient, but this too is a mistake; family members are not merely adjuncts to the patient. Family members bear significant burdens in the long-term care of an individual, even when that individual is housed in an institution. These family members can experience significant physical, emotional, and financial stress at levels that adversely affect their own health, especially when they are older or are physically vulnerable themselves. Their concerns and well-being should be recognized as morally significant. Requiring that families be singular and unflinching in their devotion to the patient's best interest not only demands the humanly impossible but provides an insufficient moral accounting of the situation.
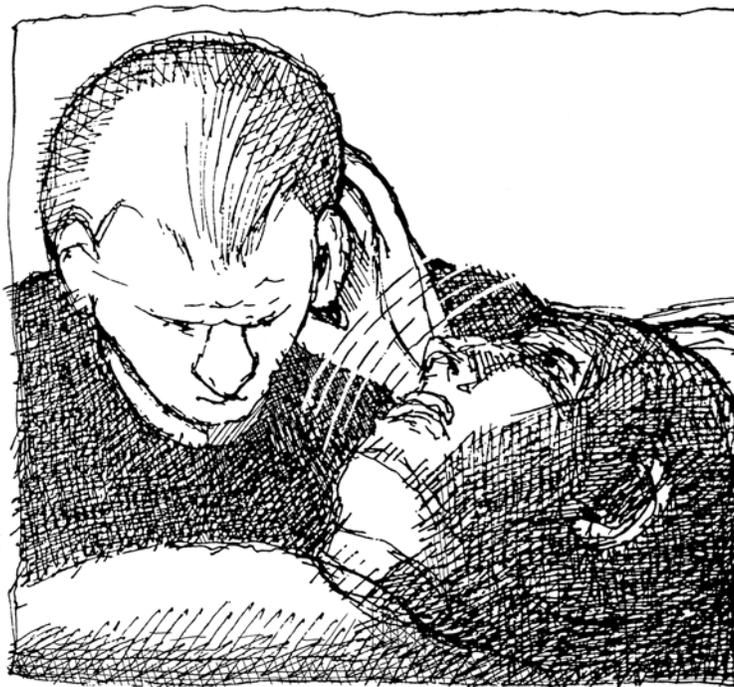
The moral status of paid caregivers in a nursing home, professional and nonprofessional alike, should not be denied. Their voice also belongs at the table for what they can contribute to understanding appropriate care for a particular resident. Researchers have found that nursing home staff use family terms to describe their relationship with residents and view themselves as protective and caring and intimate with the residents—sometimes more so than actual family. Compensated paraprofessional caregivers engage in the most intimate care of the resident over weeks, months, or years. Even though they are often paid less than people working at other, less demanding positions, their commitment to caring is evident on a daily basis.

The autonomy and well-being of family members who bear the burden in the care of a dying person are morally significant, despite cases in which family members are callous, distant, and opportunistic. Similarly, compensated caregivers should be recognized as moral agents and their voices should be considered in decision-making about in-

Allowing individuals to choose life-sustaining treatments over those that relieve pain or promote function, but putting the burden on them to do so, would show respect for pluralism, freedom, and individuality without imposing excessive burdens on individuals or their families.

dividual patients even though there may be conflicts in values and culture, and even though there are cases where compensated caregivers are neglectful or abusive. Such is life; although the "exceptions define the rule," general practice should not be determined by the worst cases. Bringing the conflicts and differences to the table may enrich our understanding of the best way to care.

Finally, the legal structure currently defers to individual choice regarding life-sustaining treatment. Legal standards defer to individual choice out of respect for the pluralism and freedom that lead us to disagree on the "one right thing" to do and out of fear that any diminution in the commitment to prolong life would result in a devaluation of human life, or that any community effort to identify appropriate care would destroy personal liberty. Deference to individual choice places confidence in the inherent value of individuation even though identifying the choices of incompetent individuals presents serious and familiar difficulties. It is also a deference that weights the scale significantly in favor of medical intervention. Thus the medical intervention holds a favored position, not the individual's life history and values or the more complex goals of care.

With advances in palliative care as a discipline and with increasing expertise in relieving suffering, it is time to consider whether the presumption in favor of life-sustaining treatment should be changed to a presumption in favor of care that provides comfort, relieves suffering, or promotes activities of daily living. Stating the presumption in that fashion would bring the goals of palliative care to the forefront and put life-sustaining medical interventions in proper perspective. People do vary in their preferences and convictions. Allowing individuals to choose treatments that do not relieve pain or promote function but putting the burden on them to do so would support respect for

pluralism, freedom, and individuality without imposing excessive burdens on individuals or their families when the choice is merely unclear.

This essay necessarily speaks about nursing homes and nursing home residents in general terms. Not all nursing home residents are alike, however; and not all nursing homes are the same. Some nursing home residents are alert and engaged; others are in various stages of dementia; some are insensate. Obviously, the goals of care for dying nursing home residents and the expectations for nursing homes will have to account for these variations. The term "nursing home" itself is a catch-all phrase sometimes used indiscriminately for many different levels of long-term care. Even among skilled nursing facilities there is significant disparity in how ill and disabled residents are, and this, too, will influence appropriate care models.

The quality of nursing homes also varies considerably. This essay leaves the problem of policing the bad apples largely on the shelf. Although it is a significant problem, the design and implementation of a regulatory system has to follow the identification of appropriate goals and standards for quality of care rather than the goals and standards developed for purposes of enforcement. At the very least, these two perspectives need to be in dialogue and perhaps in tension; one arm of the effort should not exclude the other.

Advocates for nursing home residents and those nursing homes in the leadership of best practices have worked hard to dismantle the stereotype of the nursing home as a warehouse for those who are declining into death. This work needs to be protected. However, once dying is recognized as an undeniable part of living—including living in a nursing home—it is clear that the ideal of health promotion will have to embrace care for the dying.

The Past and Future
of Palliative Care

by KATHLEEN M. FOLEY

A national dialogue is now in full flower on how to advance palliative care and expand hospice services in the United States. Driving this discussion are concerns about an aging population, the changing trajectory of illness, advancements in high-tech life support systems, limitations in health care resources, and issues surrounding patient autonomy and the right to a dignified death. The public concern has been magnified by media attention to the legal, ethical, and moral issues surrounding end of life care—withholding and withdrawing care, Kevorkian's advocacy for assisted death, Oregon's legalization of physician-assisted suicide, and health care professionals' support for futility decision-making. In the last fifteen years, the convergence of the hospice and palliative care movements reflects a growing response by a wide range of stakeholders to improve the quality of living for patients and families with serious chronic illness.

Hospice care in the United States began as a grassroots movement to improve the quality of dying for patients at home. It has evolved into a fully funded entitlement program providing care to more than 50 percent of Americans who die of cancer and to approximately 20 to 30 percent of those who die from other chronic diseases. Health care professionals have fostered the more recent palliative care movement, which aims to improve the care of the seriously ill and dying in the hospitals and nursing homes where more than 55 percent of Americans die. The two initiatives share a common philosophy and goal—to improve the quality of life for patients with serious, chronic illness, and for their families as well.

A tipping point in the history of these movements and in public and professional discussions about end of life care came with the publication of the SUPPORT study, which validated widespread concerns among the public and health care professionals about the barriers and challenges to providing humane, compassionate care. This pivotal two-phase study of almost 10,000 patients in five major American hospitals revealed serious limitations in the care of patients with life-threatening illness. Patient and family communication with health care professionals about care at the end of life was poor, the cost of care depleted some family's life savings, and half of patients experienced moderate to severe pain in the last three days of life. Interventions to address communication and pain management were not successful. This study, coupled with surveys of public attitudes and beliefs and focus group discussions, led to a growing consensus that significant barriers—organizational, institutional, educational, and economic—had to be overcome before end of life care could be improved. Three reports from the Institute of Medicine frame the problem and provide solutions by offering evidence-based recommendations to address the field's most challenging issues: the lack of professional education and knowledge on end of life care, and the need to develop and expand hospice and palliative care services to hospitals and nursing homes, where the majority of Americans die. These reports represented the first time the IOM had specifically addressed care of the dying.

If we build a field of palliative care, will they come? Americans really do see dying as a second choice. The challenges going forward are to define the domains of palliative care and model a program that provides continuity of care throughout the trajectory of illness.

The Hospice Movement

The United States has had a rich tradition in providing hospice care for the terminally ill at home. Initially an advocacy movement, hospice responded to the public's concern about the overmedicalization and institutionalization of care of the dying. In 1975, the first free-standing hospice opened in Connecticut, modeled after the innovative program of Dame Cicely Saunders at St. Christopher's Hospice in London, the 1967 birthplace of the modern-day hospice movement. The movement resonated with a growing number of charismatic nurses, physicians, and volunteers who started community hospice programs to care for the dying at home. Initially, this grassroots effort, with its community-based, home-centered care programs, operated outside the traditional hospital-based health care system, as a parallel initiative for those with terminal illness. By 1982, it had sufficient political and social force to successfully lobby Congress for the passage of the Medicare Hospice Benefit, whose reimbursement formula focused on home-based care and has defined hospice care in the United States.

The Medicare Hospice Benefit is an entitlement program for patients over the age of sixty-five who have a prognosis of less than six months. Under the Medicare benefit, at least 80 percent of care must be provided in the patient's home. A multidisciplinary team of nurses, social workers, and counselors, supervised by a physician, provides care and support to the patient and loved ones. Respite care (to relieve family caregivers) and inpatient admissions (for symptom management) are available for limited periods. This home-based model allows patients to die at home while receiving expert pain and symptom management, psychosocial support, and spiritual care; follow-up bereavement support for family members is provided following a patient's death. To be eligible for the Medicare benefit, patients must agree to forgo active therapies such as chemotherapy.

As of 2004, more than 3,200 hospice programs in the United States were caring for more than 900,000 Americans. Approximately 40 percent of adult Americans whose death includes a preceding period of dependency receive hospice care; up to half of U.S. hospice patients have a noncancer diagnosis. Depending upon the community, 50 to 90 percent of cancer patients receive hospice care before their death. Pediatric hospice services may be inte-

grated into adult programs or function as independent services. Both private insurance plans and Medicaid support hospice programs to a varying degree.

While the American hospice movement developed, the Cancer Unit of the World Health Organization (WHO) spearheaded efforts to focus attention on the needs of cancer patients worldwide for appropriate symptom management, particularly pain relief. Beginning in 1982, the Cancer Unit of the World Health Organization created an expert panel to develop guidelines for the relief of cancer pain and the integration of the philosophy and concepts of hospice care into all national cancer control programs. The World Health Organization chose the term "palliative care" rather than "hospice care" as the umbrella term to describe such care when a multinational expert panel concluded that the term "hospice care" might be misinterpreted in some translations.

Balfour Mount first used the term palliative care in Canada in 1975. He sought to integrate end of life care into the existing Canadian health care system, rather than to create a parallel health care program of freestanding hospices. His leadership and stature clearly influenced the WHO's decision to adapt this term, which was not confined to representing either a reimbursement scheme or a care setting. Inpatient palliative care units developed throughout Canada, with home-based hospice care integrated much later into its home care program.

WHO published its first definition of "palliative care" in 1986 and a revised version in 2002 (see Figure 1). The current definition reflects an evolution in thinking about the role of palliative care in modern society. The definition emphasizes that palliative care should be provided throughout the continuum of a patient's illness and that it should focus not only on treating suffering but on preventing suffering, in keeping with the role of palliative care as a public health approach to managing chronic diseases. WHO has advocated palliative care's integration in international strategies for cancer patients, for care of the elderly, for children, and for patients with HIV/AIDS. WHO recently published two monographs, *The Solid Facts of Palliative Care* and *Better Care of the Elderly*, to better inform policy-makers who are interested in integrating palliative care in national health strategies.

WHO's definition has been controversial because it describes an "approach," a word that some palliative care ad-

vocates have argued demeans the field. The debate continues over the scope of care and the vision of palliative care programs. David Clark's history of the development of hospice and palliative care points out that more than eighty countries have well-developed programs that reflect very different origins, settings, organization, and reimbursement.

In the United States, the major impetus for the expansion of palliative care has come from a wide range of stakeholders but has been led predominantly by health care professionals, organizations, and foundations that push for the need to transform the culture of dying. The Robert Wood Johnson Foundation and the Project on Death in America provided over $300 million over the last ten to fifteen years to advance the integration of palliative care into the American health care system. Many other nongovernmental and governmental organizations have contributed to this effort.

Integrating Hospice Care and Palliative Care

It is the confluence of these events, an enormous and defined need, philanthropic leadership, professional leadership, and public awareness that catalyzed the multiple stakeholders interested in advancing the varied aspects of end of life care to build the field of palliative care. Yet the expansion of palliative care was initially viewed as a threat to the hospice movement's dominant role in end of life care. A subtle but perhaps more serious concern was that the developing field of specialist palliative care and palliative medicine might further medicalize care of the dying and be antagonistic to the very values and traditions for which hospice had evolved to counteract the medicalization of death. Fueling this tension was the reality that palliative care, which is based in hospitals and led by physicians and nurses, appears to be "academic" and "evidence based," with the potential to create a two-tier system for end of life care.

These tensions are currently openly debated and discussed. Britain—with its system of academic palliative care units, freestanding hospices, and home-based hospice care; its academic- and hospital-based development of palliative care; and its recognition of palliative medicine as an official medical specialty—has experienced an expansion of hospice services rather than a contraction in their role or importance and offers a model of care. Palliative care units in Britain are fully integrated and financed in the National Health Service, whereas freestanding residential hospice programs receive only 30 to 50 percent of their support from the government, requiring them to raise up to half of their funds from charitable organizations. The fact that palliative care units were NHS funded has clearly influenced the growth and development of palliative medicine as a specialty.

In the United States, newly developed palliative care units are now being financed through hospital operating budgets and physician payment for the diagnostic and the medical services provided. Palliative care unit programs at the Cleveland Clinic and M.D. Anderson Cancer Center have pioneered this inpatient model. An attempt to develop a palliative care DRG—a "diagnosis related group," a classification of treatment options that facilitates official recognition and insurance coverage—has so far failed to gain momentum, but it remains a policy option as palliative care programs and hospitals expand and palliative medicine in the United States achieves specialty status. In part, the push for the DRG may have been introduced too early, before there was sufficient capacity in the field and a sufficient number of palliative care units to test its validity and usefulness.

The future of palliative care is perhaps best described in the recently published *Clinician Practice Guidelines for Quality Palliative Care* by the National Consensus Project. This document represents a major collaborative effort between palliative care and hospice professionals to define the field of palliative care in a way that is responsive to the needs of its various stakeholders. *Clinician Practice Guidelines* describes palliative care as a continuum of care based on patient and family needs, care setting, and illness trajectory; as patients transition in the course of their illness, their care goals may change, and their requirements for pain and symptom management may vary. Hospice care is one component of palliative care. The hospice concept is introduced early in a patient's illness to facilitate patient

and family understanding of hospice's role and to emphasize that it is an integral and appropriate choice.

The chief challenge to the full utilization of hospice and palliative care lies in patients' willingness to hear the information about options for care when they have serious symptoms or are dying, and in health care professionals' willingness and ability to provide the information empathetically and effectively. Growing evidence shows that patients and families want this information and that health care professionals, specifically physicians, are being trained to deliver it.

Recognizing the need to expand and redefine services, numerous hospice organizations and major professional organizations have changed their names, adding either "hospice" or "palliative care," in order to bring both within their ambit. Such organizations include the National Hospice and Palliative Care Association, the American Academy of Hospice and Palliative Medicine, and the Hospice and Palliative Nursing Association. In moving forward, the collaboration of the leading organizations to foster, share, nurture, and retain the traditional values of hospice remains a challenge. Political, economic, and competitive forces can easily derail ongoing attempts to bridge the gaps between hospice's leading role in home-based care for the dying and the need for institution-based care (hospitals and nursing homes) to provide symptom management and continuity of care for those with life-threatening chronic illnesses.

Other challenges concern the ability of hospices to reach patients. Over the last ten years, the median length of hospice stay has dropped to twenty-two days, and one-third of patients die within seven days of admission. This means that hospices often provide "brink of death" care rather than having the opportunity over several months to prepare patients and families for death. The NIH State of the Science Consensus Panel recently argued that the Medicare Hospice Benefit severely limited the quality and quantity of care to patients who could benefit from such care but are excluded by the current eligibility criteria, which are based on prognosis rather than on functional status and burden of illness.

The wide range of expensive supportive therapies that are available to patients who are dying, ranging from blood supply products to nutritional support to high tech drug delivery devices, challenges the financial viability of hospices, which are dependent on a per diem rate. Hospices vary in providing such therapies because of differences in their patient census and philanthropic support.

Financial support for inpatient palliative care units appears to be growing, with evidence that these units may both improve the quality of care and reduce the cost of care for seriously ill patients by controlling the costs of drugs and services provided to dying patients. Such cost shifting and cost reduction are clearly incentives for hos-

pitals to develop such units or palliative care consultation teams.

Lastly, efforts to expand hospice and palliative care services to minority populations remain complicated by concerns about lack of available services, diverse cultural norms, and an overwhelming concern that such care limits access to high tech care. Yet some success has been achieved in developing innovative hospice programs in prisons to address the special needs of dying inmates.

Institutional Progress

Competition to enter the hospice market is growing, with the emergence of for-profit hospices who provide a range of services from simple home care to palliative care consultations to hospice care. This focus on the business end of end of life care may affect the quality of care and the traditional values so integral to the hospice mission.

The creation of national standards, the increasing professionalization of the field, and the development of a specialty in palliative medicine are essential components of the process for fully integrating palliative care into the U.S. health care system. These initiatives all focus on defining the scope of palliative care practice and the specific training, curricula, and qualifications of health care professionals who provide palliative and hospice care services.

There is increasing attention in medical schools, nursing schools, schools of social work, and pastoral care educational programs to incorporate palliative care as an educational topic. At the graduate level, a series of consensus documents have outlined the "Core Principles of Palliative Care" now adopted by nineteen national professional organizations for inclusion in their professional teaching programs as a specific subspecialty. Curricula for various medical and surgical subspecialties as well as for certain diseases such as cancer, HIV/AIDS, geriatrics, pediatrics, and surgery are available. The Veterans' Health Care Administration (VA), where one in seven Americans receives care, has developed an expansive initiative to support and sustain the development of palliative care teams and leaders, making palliative care integral to their health care system.

Many national organizations have developed programs to train health care professionals. Examples include the American Medical Association's program for practicing physicians, EPEC, as well as two targeted programs, EPEC-O, sponsored by the American Society of Clinical Oncology for oncologists, and APPEAL, for minority professionals, sponsored by the Institute to Improve End of Life Care for African Americans. Multiple pediatric palliative care curricula have been written, along with ELNEC, a sophisticated nursing curriculum, and a re-

cently published compendium on the role of the social worker in end of life care.

There is reason to be optimistic that the professionalization of the field is progressing. To date more than two thousand physicians have been certified by the American Board of Hospice and Palliative Care, and more than ten thousand nurses and nursing assistants are certified by the Hospice and Palliative Care Nursing Association. More than forty-two physician fellowship training programs in palliative care are now offered nationwide, and twenty are certified as having qualified to train fellows in clinical competency in palliative care. Similar fellowship programs are developing in nursing and social work.

The American Board of Hospice and Palliative Care is in the process of applying for specialty status and has defined its scope of practice, curricula, and certification process. A growing number of endowed chairs in palliative medicine have been established, and the first endowed chair in palliative care nursing was recently announced at the University of Oklahoma.

Yet a recent work force development study reveals that there remains a significant demand for palliative care expertise. One strategy to encourage support for expanding the capacity of the work force for palliative care is the Palliative Academic Career Award, a proposed federally funded initiative to develop leadership in the field modeled on the Geriatric Academic Cancer Award.

Based on data accumulated by the Center to Advance Palliative Care (CAPC), Diane Meier has demonstrated that interest is growing in the development of palliative care services in hospitals throughout the United States. CAPC plays a major role in providing technological and substantive expert advice to hospital administrators as well as to palliative care physicians and nurses on the organization, economics, and marketing aspects of developing palliative care services and consultation programs within hospitals.

CAPC has demonstrated that palliative care programs provide economic benefits to hospitals while also improving the quality of care for patients and families—essential components for encouraging hospitals to consider initiating and institutionalizing such programs.

At the same time, a series of initiatives has been launched to foster hospital- and hospice-based initiatives that will bridge the gap in services, enhance care, and support hospice teams that provide palliative care consultations to hospitalized patients. Data from the National Consensus Project point out that one-half of hospice programs are now closely allied to academic hospital programs. Bridging the gap between acute care hospitals and hospices is an important component in developing a model of continuity of care for patients with serious life-threatening illness.

If we build a field of palliative care, will they come? Americans really do see dying as a second choice. The challenges going forward are to define the domains of palliative care and model a program that provides continuity of care throughout the trajectory of illness. Demonstration projects now underway in cancer centers that provide simultaneous hospice care and cancer therapy will give needed evidence of the benefit, costs, and quality of such an integrated system and provide the financial and policy implications for changing the benefit. Additional demonstration projects have been proposed for patients with chronic cardiac disease and neurodegenerative diseases; their outcome will influence future policy reform.

The future of palliative care will be determined in part by its integration into mainstream health care. Fortunately, this integration is already occurring in bridging programs between hospices and hospitals. To date, 20 percent of American hospitals (1,100) have developed palliative care units and/or consultation teams. Increasingly, palliative care is identified as part of quality medical care. For example, the American Cancer Society has recently published a palliative care book, *Focus on Care*, that outlines the role of palliative care as an aspect of quality cancer care. A greater openness to talking about end of life issues and care options—exemplified by this book—seems to be facilitating a consumer advocacy movement.

One last example of progress in hospice and palliative care is the National Institutes of Health's two State of the Science meetings that have outlined research with a rich potential to advance the field and have recommended that the research be a high priority for further funding. Only 1 percent of all NIH funding currently supports research on the major symptoms—pain, nausea, and dyspnea—that dramatically impact quality of life and chronic illness.

All of these efforts to advance hospice and palliative care have been slow and incremental and have engaged a broad range of stakeholders, from health care professionals to policy-makers, patient advocacy groups, and governmental agencies, foundations, and insurers. Institutionalizing educational and policy reform and demonstrating the economic consequences and quality aspects of palliative care are the hurdles to overcome.

Americans are increasingly aware of the importance and opportunities for care that emphasizes their quality of living and reduces needless suffering. Such information is transforming their perspectives on choices and options for care and will lead to the full integration of hospice and palliative care into the health care system. The confluence of a grassroots consumer activism for choice, care, and quality with health care professionals who are focused on reclaiming their professionalism offers an optimistic future to improve care for this vulnerable population.

The Role of Litigation in End of Life Care:
A Reappraisal

by ALAN MEISEL

We live in a society permeated by litigation. That this is so hardly needs mention; there are reminders all around us. It sometimes seems, however, that we have lost sight of the limits of litigation as an instrument of change—both social change and individual change. Lessons abound of litigation that has not brought about the anticipated benefits—school desegregation and police misconduct in interrogations, to mention only two long-standing historical examples. Yet when a new problem arises clamoring for resolution, we frequently ignore the past lessons. Perhaps litigation is addictive. We know that it will not solve all of our problems, but despite our intellectual understanding, our will is overborne.

The problems posed by end of life decision-making are but one more example. Since 1975, people wishing to forgo life-sustaining medical treatment or their families have relied on the judicial system to solve a problem that undoubtedly has a legal component, but that might have been resolvable outside the courts. In 1975, it was the Quinlan case; today it is the Schiavo case, a contemporary *Bleak House*, spawning a mini-industry of litigation—endless rounds of essentially the same arguments made in different courts (and sometimes the same courts) through different (and sometimes the same) lawyers.

The lesson of *Schiavo*, if not of its five score or more predecessors, is this: our assumptions about litigation—that it provides a resolution to individual and social prob-

lems, that this resolution is final and uncontestable, and that there are no other last-resort mechanisms for resolution—are largely unsustainable. But then again, that is a rational conclusion, and addiction is not a rational process.

Limits of Litigation

Perhaps it is inevitable that end of life cases end up in court. Just consider the situation of the first prominent case to do so—the case of Karen Ann Quinlan. Here was a young woman in what her doctors said was a state of unconsciousness from which she would never emerge. Although not dead, her parents believed—as did most people—that her life was over. From time immemorial, when this has occurred, we have buried or burned our dead. But Ms. Quinlan's doctors—for a variety of more or less understandable reasons given the era in which these events occurred—would not, in effect, permit this to happen. Her parents were denied the opportunity to mourn their loss in a culturally and what their Catholic religious advisors considered to be a religiously appropriate way.

They had two choices: accept this affront to their values, their beliefs, and their dignity, or fight it. They fought it as long as they could through conventional means, but when those ultimately failed, they could continue to fight only by resorting to litigation. Litigation, however, has several limitations that ultimately make it a very unsatisfactory weapon in the armamentarium of solutions to end of life disputes.

Jurisprudential limits of litigation. In the litigation of end of life cases, like many other kinds of cases, the bat-

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The lesson of *Schiavo* is this: our assumptions about litigation—that it provides a resolution to individual and social problems, that this resolution is final and uncontestable, and that there are no other last resort mechanisms for resolution—are largely unsustainable.

tle does not end the war. In all cases, the judicial decision, strictly speaking, applies only to that case. Everyone other than the parties to the case is entitled to ignore the decision—indeed, to defy it—with legal impunity. What happens in fact is far more complex than either uniform acquiescence or uniform defiance. Every litigated case in which an opinion is written by the court—and sometimes several opinions are written (there were four in *Cruzan*)—raises far more questions than it answers. This results from two factors.

First, litigation attacks problems piecemeal. Courts only answer questions they are asked, and litigants only ask questions that must be answered for the resolution of their particular dispute.

Second, this is not quite true. Courts write opinions that are sometimes quite discursive, and this has certainly been characteristic of end of life cases, where opinions sometimes exceed one hundred pages. However, every opinion is made up of two parts: holding and dicta. The holding of the case is the only part of the case that, strictly speaking, is law. The holding constitutes the answer (or answers) to the question (or questions) presented by the parties to the court. All the rest is, as the lawyers say, *obiter dictum*—"A judicial comment made while delivering a judicial opinion, but one that is unnecessary to the decision in the case and therefore not precedential (although it may be considered persuasive)."[1] Thus, although certain limited parts of a court's opinion are law, the remainder of the opinion gives guidance about how the law *might* develop in the future. Reliance on this guidance is at one's own risk.

Thus, while the case before the court is resolved once and for all, there is a lack of finality in a broader sense. New cases that arise, no matter how similar, may have slight factual differences that dictate a different legal outcome. No one can foresee all the issues that might arise in the future and all of the convoluted twists and turns they might take. This is why judicial opinions, apart from the holdings, are not binding. Judges do not want to decide issues they are not compelled to in part because real facts bring issues into sharper focus.

Practical limits of litigation. Litigation adds trial to tribulation, both literally and figuratively. There are all sorts of costs, and in advance they are incalculable. Litigation is expensive and emotionally draining (sometimes unimaginably so), primarily because it is also time-con-

suming—so time-consuming that in many end of life cases the patient expires before the litigation does.

And in the end, litigation is a blunt instrument for the resolution of disputes. It can fine-tune a resolution only to a limited extent. In end of life cases, the parties are left with a pronouncement—treatment may be terminated, must be terminated, or must not be terminated—and they are left to pick up the pieces of shattered human relationships—among family members, among health care professionals, and between family members and health care professionals. Acrimony is beyond the scope of litigation to repair.

Practical limits of implementing case law. High-profile end of life cases are well publicized. People who need to know about them—primarily health care professionals—learn about them from a variety of sources, and the holdings in these cases become part of the lore of clinical practice. However, the judicial opinions are often complex, and as the information gets passed along, it gets simplified, and sometimes oversimplified, and sometimes distorted, as in a children's game of "telephone."

Even experts can succumb to reductionist tendencies and lose sight of the subtleties. Lawyers may be inclined to obscure the subtleties in order to enhance the case's comprehensibility.

Even if clinicians really understand the law, they need to be able to apply it to actual clinical situations. An intellectual understanding of the law—even a recognition that one is faced with a clinical situation to which the law applies—does not come close to assuring compliance with it. Resistance to applying the law can arise from nonrational sources. If the law in question is in conflict with a professional's strongly held values, resistance to applying it can be a serious impediment to behavioral change. Nor will courts' pronouncements that the legal principles they are enunciating square with the ethos of the health care profession's guarantee that clinicians will adopt and abide by those professional views.

Costs and dangers of an agenda defined and driven by litigation. It is hard to imagine a world in which medical technology could have developed to the point that it has without creating the ethical dilemmas that it has. And given the pervasive nature of law in our society, it is equally hard to imagine that law would not have played a role in addressing these dilemmas. Assuming that legislatures will act reluctantly, if at all, to remove or mitigate them,

sometimes there is no choice but to resort to litigation. Other mechanisms for dispute resolution usually meet their match when the trump card is the possibility of legal sanction.

Litigation undeniably resolves individual cases, although the costs of doing so can be high. Judicial opinions have also brought a measure of clarity to the end of life decision-making process and thus the end of life for untold numbers of patients and their families, sparing them both the trauma of a prolonged and burdensome dying process and the added trauma of litigation.

The legally driven agenda has not been cost free, however. In addition to the costs to the individuals involved in litigated cases, there are costs to society at large—and to particular subgroups.

External imposition. One significant cost of litigation has been felt by health care professionals—and, most likely, predominantly by physicians. First, litigation can make the parties feel imposed upon from outside. Second, physicians may feel that they have been imposed upon by what they regard as a rival profession, with the subtlety being lost that it is judges, not lawyers, who make law, and with the further lost subtlety that judges are merely carrying out their socially sanctioned role. Third, and perhaps most important, this outside imposition has often conflicted with the ethics, ethos, customs, and deeply held values of the health care professions, or at least of individual clinicians.

The result has been a certain demoralization of health care professionals, who resent being told what to do and how to do it, particularly since professionals traditionally have some measure of control over their own work. To top it off, the courts have usually insisted that what they are asking of health care professionals is *not* inconsistent with the ethics of the medical profession, when in fact it probably is—or at least *was*, in the earlier years. And in any event, it is sometimes inconsistent with the personal values of individual health care professionals.

Nonmajoritarian law-making. Litigation has another drawback: the courts are a somewhat unusual law-making entity in a democratic society because they are often nonmajoritarian. In resolving ordinary disputes, this is rarely a matter of much contention, but when courts settle issues that are part of a much larger and contentious social debate, they are sometimes subjected to criticism on the grounds that the issue would better be resolved by legislatures—in part because legislatures are majoritarian institutions, and in part because legislatures can engage in the kind of fact-finding that is thought to provide a more comprehensive, rational, and socially acceptable outcome. Indeed, courts themselves have frequently pointed out in end of life cases that although they must decide the issue before them, it would be better if a comprehensive resolution were prescribed legislatively.

Law-making by elites. One of the consequences of judicial law-making is that the resulting law is imposed by elites. Further, in the end of life context, the *content* of the law has been significantly shaped by elites—medical, policy, even religious elites. Courts have relied on the opinions of academic physicians, for example, in recognizing the existence, meaning, and implications of the permanent vegetative state. The dominant judicial view that artificial nutrition and hydration is no different from forgoing any other kind of medical treatment has been influenced in significant part by the views of both religious and medical elites. And the larger consensus about forgoing life-sustaining treatment has been significantly shaped by the report of a presidential commission whose staff was drawn largely from academia.

It is not, however, the elites upon whom the impact of the law usually falls on a day-to-day basis. It is physicians and other health care professionals who play little or no role in developing the law and who may not even be aware of, let alone subscribe to, the views of their professional organizations or their professional leaders. It is the pastoral clergy of all denominations who counsel patients and their families, often at the bedside, at or near the end of life, who also play little or no role in shaping the views to which they supposedly subscribe, and again who may not even be aware of them or of their nuances. It should not be surprising, given these facts, that the law is so foreign to—and thus resisted by—the troops in the field

Assumptions about quality of life versus vitalism. Finally, the judicial consensus that has developed around end of life decision-making has been based on a reasonable, but nonetheless questionable, assumption. The assumption is that, at or near the end of life, people prefer dying a peaceful, nonmedicalized death to eking out a few additional days or weeks or months sustained by high-tech medical interventions. Put another way, the assumption is that the quality of a person's existence is always relevant in determining what medical treatment should or should not be administered.

Patients in the litigated cases certainly have expressed a preference—either contemporaneously or through an oral or written advance directive—for quality of life to be a determinative factor in how they die. And perhaps this preference is shared by most people. But it is not what everyone wants. A vocal proportion of the population, growing ever more vocal, believes that life per se is a pearl beyond price and must be preserved at all costs regardless of the burdens that might be imposed by life-sustaining medical treatment. (This set of beliefs, known as "vitalism," has given rise to what are popularly called "futility cases.") Another vocal segment of the population believes that the quality of life ought to be irrelevant to the decision whether to administer or forgo life-sustaining medical treatment, and that to withhold or withdraw such treat-

We must try other means of social change. However, in the current climate, if the goal is to preserve the consensus about end of life decision-making, it may turn out that what we need is not an alternative to litigation, but a smarter litigation strategy.

ment constitutes discrimination on the basis of disability and devalues the lives of the disabled.

Law that deals with high-profile, emotionally charged issues is certain to meet some resistance from those who feel its impact the most. But when that law is developed in the way end of life law has—sometimes inconsistent with the norms of health care professionals, predominantly nonmajoritarian, under the influence of elites, and based on assumptions that may be less widely shared than is often assumed—it is virtually certain to meet resistance. Perhaps it would have met resistance even if it had developed primarily through legislation, but in a legislative forum, opposing points of view might have more readily been expressed and had more impact on its development.

A Contemporary Litigation Agenda

Despite these reservations, litigation will almost certainly not be abandoned in the end of life context as an instrument either of dispute resolution among interested parties or of efforts to effect social and legal change. With respect to dispute resolution, the conditions that initially gave rise to the use of litigation to resolve end of life disputes remain unchanged. Thus, when one's back is to the wall, as it was in *Quinlan*, the only socially acceptable alternative in our society, other than walking away, is to litigate. And this is a good thing, because when this alternative is unavailable (or is available but unknown), people sometimes resort to force or violence.[2]

In terms of larger social change, other options exist. First, alternative means of effectuating change are sometimes available—with efforts to enact legislation or to convince administrative agencies to promulgate regulations and enforce existing ones prime among them. In the wake of *Schiavo*, state legislatures may be more willing to enact broad legislation for end of life decision-making. However, as the sages say, be careful what you wish for. If legislative change is forthcoming, in the immediate aftermath of *Schiavo* it may roll back the consensus that has been carefully and deliberatively crafted over the past thirty years.

Failing legislative or administrative solutions—or because such solutions may attempt to roll back the consensus—litigation may continue to be the change agent of choice. What should its goals be? Assuming the effort is to effect change in the law—not merely to answer a narrow question—these are the current priorities:

Signing more states onto the consensus. Given that the legal consensus about end of life decision-making is under attack from vitalists, disability rights groups, and opponents of forgoing artificial nutrition and hydration, efforts need to be made to strengthen the consensus. In some states this means merely getting the supreme court to articulate what everyone assumes to be the law: the right of competent patients to forgo medical treatment and the right of incompetent patients to have close family members make these decisions for them. In half of the states, these fundamental principles have not yet been articulated in case law, and to the extent that they are recognized in advance directive legislation, they are frequently hedged with significant exceptions. For example, some advance directive statutes limit the effectiveness of an advance directive if the patient is pregnant or if the treatment in question is a feeding tube.

Clarifying ambiguity. Another important—and related—goal is to urge courts to clarify some ambiguous areas of seemingly settled law. One pressing example is the meaning of the "clear and convincing evidence" standard. Everyone called on to apply this standard—including lawyers—needs to understand that "clear and convincing evidence" refers to a standard of proof (an evidentiary standard), not to a substantive standard by which surrogates are to be guided. What is crucial is that "we view the clear and convincing evidence standard not as a decision-making standard, but as an evidentiary standard of proof that applies to all decisions regarding termination of treatment, regardless of the decision-making standard employed."[3]

Grounding the law in state constitutions. The decisions of state courts are subject to nullification by state legislatures unless the judicial decisions are grounded in the state (or federal) constitution. Thus a primary goal of any litigation agenda must be to anchor the consensus firmly in state constitutional law. This has happened only occasionally in the past, most notably (and most ironically, in light of *Schiavo*) in Florida. Not all states have constitutional provisions that lend themselves to such an effort, but many do.

Beyond autonomy. The concept of autonomy has played a central role in the legal development and analysis

of end of life decision-making. It has been so dominant that it has sometimes been stretched beyond the breaking point. Although some have questioned this dominance, for the most part these have been lost voices in the wilderness. Perhaps it is time to forge a litigation agenda that urges courts to rethink the role that autonomy should play, especially in comparison with two competing values—economic justice and the interests of other concerned persons.

Justice. One of the more contentious issues—and an issue that legislatures are unlikely to take on—is the question of how to address the economic realities that affect all medical decision-making, but especially decision-making at the end of life. End of life litigation has had only brief and episodic contact with this issue in the guise of the so-called futility cases. Even though we are engaged in a forthright public debate about escalating health care costs (which have now priced more than forty million Americans out of the health insurance market), about the unsustainable costs of Medicare, and most recently about the explosive growth in Medicaid costs (which threaten to overwhelm state budgets and severely curtail the resources available for other essential social needs), we still ignore this reality when we address end of life medical care. To address it better will require an increased awareness of the role that justice might play in end of life decision-making.

Interests of health care professionals. Just as justice may need to be introduced into the debate as a counterbalance to autonomy, there has been a paucity of attention paid to the interests of health care professionals and families in end of life decision-making—except to the extent that courts have almost uniformly rejected these considerations as not worthy of consideration because they are antithetical to patient autonomy. Considerations of professional interests have arisen when health care professionals object to judicial orders permitting the termination of medical treatment because they feel morally compromised by participating in the termination. The usual resolution of such cases (there is only a smattering) is for the patient to be transferred to the care of others who share the patients' views. But this does not fully address the issue. Consideration needs to be given not only to the moral sensibilities of health care professionals, but also to

the many people who care for terminally ill patients but who are not usually thought of as professionals, such as aides and orderlies. This is especially true in long term care facilities, where strong emotional bonds are perhaps more likely to develop between caregiver and patient.

Family interests. Similar attention—a fortiori—needs to be paid to interests of the patient's family, which, like caregivers, should be defined more in terms of social realities than formal relationships. There are relations by blood and by marriage whose interests, given their past and current relationship with the patient, are not particularly strong, and there may be others—friends and domestic partners—who have no legal relationship to the patient but who have a strong social relationship. Crafting law that gives consideration to the interests of these individuals is a daunting task, but to ignore them completely is unjust and can give rise to the kinds of conditions that created and perpetuated the conflict in *Schiavo*.

Avoiding Litigation, and Doing It Better

The moral of the tale is consistent with what is known of litigation in other spheres: litigation has significant limits as an instrument of systematic social change. While it would be naïve to advocate that litigation not continue, we must try to use other means of social change. Perhaps we need to pay more heed to judges' pleas that legislatures address end of life issues. Our first priorities might be better statutes on advance directives—such as the adoption of the Uniform Health Care Decisions Act—and on the use of adequate treatment of pain. However, in the current climate, if the goal is to preserve the consensus about end of life decision-making, it may turn out that what we need is not an alternative to litigation, but a smarter litigation strategy.

1. *Black's Law Dictionary*, 8th ed. (2004).

2. See S. Miles, "Taking Hostages: The Linares Case," *Hastings Center Report* 19, no. 4 (1989): 4; *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990).

3. *In re Martin*, 538 N.W.2d 399, 406 n.12 (1995). See also *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 350 (1990) (Stevens, J., dissenting).

The Quest to Reform
End of Life Care:
Rethinking Assumptions and Setting New Directions

by THOMAS H. MURRAY AND BRUCE JENNINGS

The United States Supreme Court decision in the case of Nancy Beth Cruzan, *Cruzan v. Director, Missouri Department of Health*, was a landmark in law concerning decision-making near the end of life, but it was not the end of social controversy. The Court established the constitutional right to refuse medical treatment—even life-prolonging medical treatment— but it did not settle the moral question of how and when this legal right should be exercised, nor did it lessen the gap between the theory of how end of life decisions should be made and the practice of how such decisions actually are made at the bedside.

Twenty-five years after *Cruzan*, end of life care is a nexus of cultural and political conflict. The mass media's aggressive pursuit of discord, coupled with various interest groups' use of the Internet to amplify divergent points of view, fuel the polarization of the issue. Sifting out accurate, responsible medical information and opinion from unfounded or exaggerated claims has become exceedingly difficult. Although conflict and rhetoric ran high in the 1980s as the Cruzan case moved through the courts, that episode seems almost calm compared to the spectacle unleashed in 2005 by the sad case of Terri Schiavo.

In this essay we aim to synthesize and discuss many of the insights and arguments contained in the preceding papers. We also draw a series of lessons—"recommendations" seems too precise and definitive a word for the cur-

rent state of play in this field—about where the movement to reform end of life care should head.

Before turning to specifics, one general observation is in order about the type of discourse that should be the norm in the end of life care reform movement. Advocacy must ground its ethical arguments in the best and most objective understanding of medical facts available. It is also essential that this movement remain dynamic, flexible, and open to new ideas and to conversation with new voices. Reasoned discourse, pragmatic improvement, and respect for civil rights and human dignity must be the hallmarks of end of life care reform in the years ahead.

How Far Have We Come?

Between the *Quinlan* decision in 1976 and the *Cruzan* decision in 1990, something like a consensus emerged, at least in the law. But end of life decision-making remains far from ideal. Many people die today while still in pursuit of unrealistic, futile hopes for cure; many deaths leave surviving family members and loved ones feeling regret as well as grief and loss. Dying becomes the object of conflict, within families or between family and health professionals. People die, not in the familiar surroundings of home or a good nursing facility, but in an ambulance, emergency room, or intensive care unit. Equally troubling is the fact that many people still die in severe pain—not because pain cannot be treated or managed (that is very rare), but due to lack of physician training, unnecessary regulatory red tape, and financial barriers to access to hospice and palliative care services.

What has gone wrong and continues to go wrong? Three themes in answer to this question resonate in the essays collected here.

We sometimes seem to act as though dying were solely the concern of the dying person. The fact is, we die, as we live, in a web of vital and complex relationships.

For one thing, most people would prefer not to stare death in the face—at least not their own. Consider people with a life-limiting illness who retain decision-making capacity. Some of them resist enrolling in a hospice program until very late, for it requires that they forgo nonpalliative (curative) treatments, and it feels like giving up hope. (For their part, doctors don't really know when to recommend hospice enrollment, and they don't want to feel as though they are abandoning their patients.) Some don't execute an advance directive, or, if they do, they have not talked to their health care proxy (or the rest of their family) about their wishes and values in enough detail to provide useful guidance. Then there are those critically and terminally ill people who have lost decision-making capacity; even more uncertainty and trouble arise in their cases. A majority of these do not prepare any type of advance directive. Even when they do, however, there is no guarantee that either the named proxy or the attending physicians will adhere to it.

Moreover, what was widely believed to be the consensus on how to make decisions at the end of life is not today—and perhaps never was—universally shared. People living with disabilities are sensitive to the discrimination that works against them in our society. When it comes to end of life care, advance directives, and decisions to forgo life-sustaining treatment, they worry that an able-bodied perspective on the quality of a life marked by severe impairment and dependency is likely to be biased against continued treatment and life. A similar bias may color the advance directives of still healthy individuals fearful of future disability. Those who believe in the sanctity of life object in principle to decisions that may hasten death (and especially to the discontinuation of artificial nutrition and hydration). Also, in our diverse and pluralistic society, many racial and ethnic minority communities have long found the consensus on end of life treatment foreign to their way of thinking about death and dying, medical care, and family relationships. For those who have struggled much of their lives to obtain access to health care, discussions about refusing life-sustaining treatment are hard to fathom. Such discussions make them mistrust the motives of doctors and hospitals who broach the subject.

Finally, and perhaps most troublesome, is the realization that this consensus is based on several profound misconceptions and oversimplifications:

• *Our approach to end of life decision-making has been excessively rationalistic.* The system of end of life care works best for those who plan ahead for their terminal illness, and it does not always work well even for them. Most Americans find planning for their own deaths exceedingly hard to do. The number of people who prepare advance directives (or even property wills) remains small. The consensus, on the other hand, assumes that people are able and willing to acknowledge their own mortality along with the limits of what medicine can promise.

Furthermore, such attitudes toward future planning and control do not travel well across cultures and traditions within our increasingly pluralistic society. The words in durable powers of attorney for health care can be translated into other languages, but the concepts in them may remain incomprehensible. Is there only one universal paradigm of responsibility or virtue in the face of death? Are planning and decision-making to spare oneself from certain types of treatment necessarily the most appropriate response? Or might one's attention be directed elsewhere, toward one's faith or toward concern to protect family from being burdened?

• *Our approach to end of life decision-making has been excessively individualistic.* For the past thirty years, patient autonomy has been the cornerstone of our approach to decisions near the end of life. Framing end of life care as first and foremost an issue of privacy (as the *Quinlan* court in New Jersey did in the wake of the landmark Supreme Court privacy cases, *Griswold v. Connecticut* and *Roe v. Wade*) casts dying as primarily a matter of civil liberties. But this approach underestimates the social power of medical science and technology on the one hand, and the cultural meaning of death and dying (such as the norms and responsibilities of family members as caregivers) on the other.

The end of life is not the best time to wage battles on behalf of autonomy. Caring, family solidarity, mutual respect, love, and attentiveness to the dying person are the qualities most needed then. If anything, the consensus about patient autonomy has been rather distrusting of families and tends to make them morally invisible in the official dying process. They become empty conduits of the patient's wishes. Mothers and fathers, brothers and sisters, lose their long relationships with the dying person and become "surrogates" or "proxies"—cold terms connoting an impersonal role.

In order to improve end of life care, liberation of the patient from heavy-handed medical paternalism is a necessary but far from sufficient accomplishment. Law, ethics, and policy must also come to grips with the fundamentally communal and public—not private—issues of mortality and meaning. We sometimes seem to act as though dying were solely the concern of the dying person. The fact is, we die, as we live, in a web of vital and complex relationships. What happened in life, and what happens in dying, is shaped by and shapes those relationships.

• *Our approach to end of life decision-making has been based on what may be a misdiagnosis: we have assumed that inappropriately aggressive and unwanted treatment at the end of life is fundamentally a problem of prognostic uncertainty and poor communication.* In fact, as the SUPPORT study demonstrated, physician behavior is not altered significantly by addressing uncertainty and poor communication alone. These are elements of the personal interaction between physician and patient. The fundamental problem with end of life care, however, may be structural and institutional in nature. In the modern acute care hospital, virtually everything is oriented toward using life-sustaining equipment and techniques, not toward forgoing them. The informal culture of specialty medicine, the reward system, the institutional pressures faced by family members, the range of choices people in extremis are being asked to make—each of these factors and more make up a system that is remarkably resistant to change.

Lessons Learned: Muting Challenges and Charting A New Course

How then might we go about changing the system? Doing so will require a forceful response to three challenges.

The first challenge is to health policy broadly defined. We must educate and motivate health professionals, adapt institutions, and realign financial incentives so that, in Joanne Lynn's words, "just about the right services will be in place and just about the right things will happen for patients, because they are 'built into the system.'" As Lynn notes, distinct trajectories of dying can be identified for large populations of patients. Each of these trajectories poses its own challenges for patients and families, health care institutions, and policy-makers. And each of these trajectories requires a well-adapted caregiving system with different types of medical and psychosocial services offered at different times.

The second challenge is to reach across color, class, disability, and moral convictions to create a new consensus on care at the end of life that takes into account feelings of mistrust and lived experiences of unequal treatment. This will not be an easy task, but one imperative is clear: the circle of people engaged in forging the consensus must be enlarged. People with disabilities, people with strong religious beliefs about the sacredness of life, and people who feel left out by mainstream medicine must become part of the conversation. There is also reason for hope. Ideological differences are likely to dwindle in significance when people confront the lived realities of suffering patients, grieving families, and compassionate caregivers.

The third challenge may be the most difficult. We must rebuild, reinforce, and reinterpret our laws, institutions, and practices around the acknowledgment that dying is an interpersonal affair, that it is not undergone strictly by individuals. Hospice does this; it creates space for families and intimate friends to be close to the dying person, and it recognizes the emotional needs of those people. The durable power of attorney for health care can likewise be understood in this light; health care proxy decision-makers can and should take into account the dying person's concerns for those whose lives will be affected by the patient's death. In the inventory of final concerns for many dying persons, taking care of loved ones—who must cope with their own grief and conflict, and move on with their lives—counts for as much, and perhaps more, than finding interventions that may extend life.

If we focus on these challenges, what specific practical steps can be taken to put end of life care on a new and better course? There are again three areas of thinking and practice that we believe should be singled out for special attention: (1) our approach to end of life care delivery systems; (2) our approach to advance directives and surrogate decision-making; and (3) our approach to managing conflict and disagreement.

1. We should approach end of life care from more of a policy- and population-based perspective, not simply from a clinical one.

Thus far, the ethical/legal consensus on the appropriate framework for end of life care has focused so much on empowering patients that it has not noticed the extent to which it also burdens them and their families with an excessive menu of detailed and often bewildering clinical choices. Instead of focusing on how to accommodate the idiosyncratic decisions of individual patients one at a time, as it were, we should ask what needs dying persons generally have, and how we can design a health care delivery system that will meet most of those needs for most people, most of the time.

An epidemiologically well-grounded approach to the design of end of life care systems would avoid two inappropriate extremes that are now all too common—on the one hand, a virtually automatic do-everything-possible, "full court press" approach, and on the other, an approach that requires family members to micromanage a recurring series of life-threatening complications within an underlying progressively degenerative and incurable chronic dis-

ease. In recent years, hospice programs have provided exactly this kind of system, and palliative care is extending this approach so that it can be used for longer periods in the patient's care and can allow palliative treatments to supplement reasonable attempts at disease-modifying and life-extending medical treatment.

2. We should reevaluate advance directives and surrogate decision-making.

This reevaluation will have a number of facets, and advance directives will be understood differently when a less individualistic, more family-oriented and systemic approach is taken in end of life care.

2(a). Advance directives should be more adequately and routinely factored into information and decision-making systems that physicians are comfortable with.

Hickman and colleagues discuss ways of doing this. Their recommendations include the development of new kinds of treatment orders and documentation, electronic record keeping, and the like. Quality improvements such as these are taking place throughout medical care, and there is no reason in principle that they cannot be helpful in end of life care as well.

2(b). The appropriate role of family members in such cases should be more easily accommodated.

Without abandoning the important legal strides that reinforce a competent person's right to refuse unwanted interventions, our end of life care system should learn from the voices assailing it. The weakest link in the consensus has always been the problem of how to translate the right of a competent person to refuse life-extending treatment into a right exercised by someone else on behalf of a person who no longer has decision-making capacity.

Consider first treatment directives, or what traditionally have been called "living wills." Even when someone has the wisdom and prescience to execute a treatment directive, doubt and conflict can arise. The problems are legion. We rarely foresee in accurate detail the circumstances of our dying. A typical living will may direct that if the patient is in condition *a*, *b*, or *c*, then treatments *x*, *y*, or *z* should not be imposed. But what if the patient's actual clinical condition does not quite fit any of the categories envisioned? How are clinicians or surrogates to divine what the patient meant when writing, "I don't want
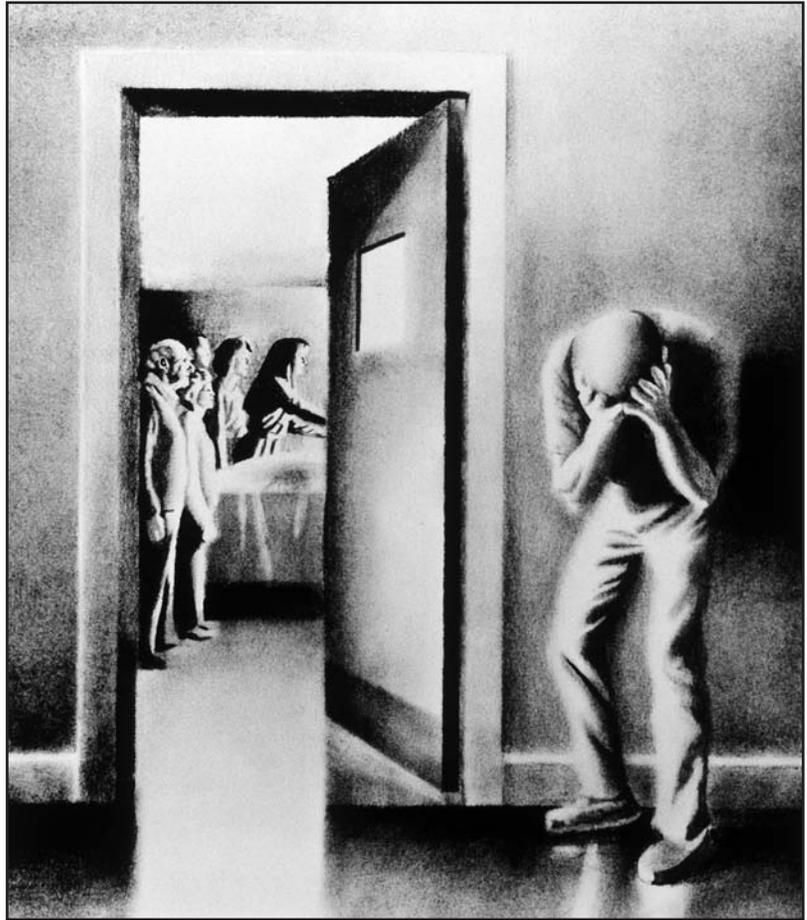
to be a vegetable?" What if the treatment modalities rejected (or embraced) when the living will was composed several years ago are now outmoded and new treatment options, with different risks and benefits, have taken their place?

Durable powers of attorney for health care or "proxy" appointments are more supple, but have their own problems. Appointing another person to speak for you seems a sounder strategy, but even that can be open to dispute. Sure, Sam and Mary had been married for thirty-seven years when Sam appointed Mary his health care proxy, but that was six years ago, before they began fighting incessantly.

More than thirty states have taken a different approach to coping with the limitations of advance directives in the form of a law listing family members and friends who would be authorized to make decisions for a person without capacity. These individuals are typically listed in priority order, and health care providers are supposed to turn to them in that order. Such statutes are helpful as far as they go, and they are preferable to the legal limbo into which persons without advance directives now fall in many states. But they do not go far enough. They do little or nothing to avoid conflicts within families, of course.

Culture needs time to catch up with end of life law. The next decades should be a time of education and soul-searching discussion in communities and at kitchen tables, as well as in health care settings.

Nor do they ensure that the most knowledgeable, reasonable, and truly caring person is selected to be the surrogate.

Finally, this approach and these so-called "family decisions" statutes dodge the genuinely difficult question that procedural solutions have so far evaded: what substantive standard should govern end of life care decision-making? Put differently, it is necessary to decide which treatments are objectively beneficial and in the best interests of the patient, and which are not. We have avoided serious engagement with this thorny question for as long as we can. We should avoid it no longer.

As the contributions by Asch and Burt in particular remind us, many are now challenging not only the practicality of advance directives, but also their validity. Should a healthy or able-bodied person be permitted to make a decision that will be binding later in life, when he or she may be impaired or disabled? Is there sufficient continuity of values and preferences over time to be confident in following the perspective of the earlier self? What do the notions of self-determination (autonomy) and best interests really mean, particularly if the life-prolonging treatment in question is not clearly futile? Many advance directive statutes and many of the legal standards articulated by the courts appeal to these concepts without sufficiently examining how problematic they can be in actual end of life situations.

These are fundamental ethical and philosophical issues that do not lend themselves well to new court decisions and legislation. We do not favor laws that would require the provision of artificial nutrition and hydration for all patients in a persistent vegetative state, for instance. Nor do we favor laws, such as one in Texas, that permit health care providers to determine that further life-extending treatment for a patient is futile and unilaterally to decide, even if family members disagree, that the treatment should be discontinued. New laws that would either require or forbid certain types of life-sustaining treatments, no matter what, are not what is needed now. At best they would be premature and imprudent; at worst, tyrannical and unjust.

Before we get more law, we need more deliberation, debate, and moral wisdom from the mechanisms of communication and education in our society. Learning how to analyze in a substantive way what the best interests of the dying patient actually are in a given case is one way to

more fully accommodate the role of all family members in the decision-making process.

2(c). Surrogates named in advance directives and other family members should be given adequate information, counseling, and support.

In recent years, national efforts to encourage and implement the use of advance directives in end of life medical care have concentrated on making individual patients aware of their rights under the law and on ensuring that both health care agents and other surrogate decision-makers (such as family members) have information about the patient's medical condition and about the patient's prior wishes and values. Not only have these two objectives proved more difficult to fulfill than was anticipated; in and of themselves, they have proven to be insufficient to produce ethically responsible and responsive surrogate decision-making. In building a system of surrogate decision-making for end of life care, we need to go beyond these traditional objectives in significant ways.

We need to place more emphasis on education, counseling, and support for health care agents and other family members to improve their capacity to play this role and to improve the quality of the decisions they make. Agents are thought to be preferable to written treatment instructions (living wills) because an individual on the scene has the flexibility to exercise judgment and to interpret the patient's wishes and values in light of specific and sometimes rapidly changing information about the patient's condition, treatment options, and prognosis. Written instructions cannot have these qualities of flexibility and judgment. But while we seem to expect these skills in agents and surrogates, we have done little or nothing to study the environmental conditions in the health care setting that are most conducive to them, nor have we developed protocols of education, counseling, and support aimed at enabling surrogates to engage in good decision-making. In short, we have thus far focused almost exclusively on how to *empower* agents to make decisions; we must now also begin to address how to *enable* them to make good decisions.

Moreover, hospitals and other health care facilities have an institutional and systemic responsibility and role to play in enhancing proxy decision-making. This is not to say that individuals and families do not have a responsibility to prepare for these decisions on their own initiative. They do. But up to now, the institutional side of the equa-

tion has been relatively neglected. More research and assessment tools are needed to study current institutional practices and to improve them in the future. Health care professionals must become more knowledgeable about, and sensitive to, the special needs of surrogates and the special burdens of the surrogacy role. To improve the quality of support that agents and surrogates receive, we must learn to draw on many disciplines, including medicine and nursing, but also ethics, pastoral counseling, social work, and other sources of expertise about the full range of cognitive and emotional work surrogate decision-making entails.

Surrogacy is both a cognitive and an affective task. It involves potentially complex factual information, values, and deep-seated emotions. While it is—and should be—focused primarily on the wishes, values, and best interests of the patient, the decisions a surrogate makes redound to affect the surrogate himself or herself (and the entire family) as well. Families and surrogates need to have a framework within which that information has meaning and which validates their own past relationship with the patient and their own sense of themselves as loving, caring, responsible people faced with life-and-death decisions in the midst of shock, loss, possibly guilt, and grief. To see surrogacy as simply an information processing task is to miss most of its human angst and drama. And yet that is the approach that many health care facilities have taken, implicitly or explicitly, by the paucity of resources they provide to agents and surrogates, by the nature and style of communication offered to them, and by the low priority most institutions give to multidisciplinary counseling and support.

3. When conflicts and disagreements arise within families, independent mediation and conflict resolution services, including pastoral counseling, should be readily available in health care institutions.

No strategy meant to allow people to control what happens to them after they can no longer speak for themselves is immune from dispute. Instructions must be interpreted; relationships evolve. From the point of view of the law, when a competent person says yes or no, we presume she means what she says. Besides, when the consequences of a decision to refuse medical treatment fall most directly on the one making the decision, that strikes us as respecting both liberty and justice.

Granted, even this seemingly clear case can quickly become murky. People's motives can be obscure, even to themselves. A refusal of treatment may be a thinly disguised question to one's family: Am I too great a burden on you? If not, please urge me to hold on. We know that many people fear that their pain will not be treated, that loneliness and indignity will mark their end.

And families can disagree. Sometimes, as in the Schiavo case, their differences are sharp and enduring enough to lead them to the courts. But litigation is a very blunt instrument that inflicts painful wounds. As Alan Meisel eloquently notes, "Acrimony is beyond the scope of litigation to repair"—especially acrimony built up over years or decades of complex family dynamics. Nancy Dubler's pioneering program in mediation and similar efforts described in her paper are heartening examples of a less painful alternative.

From Legal to Cultural Change

There can be no doubt that we are learning how to improve care near the end of life. Equally without doubt is the fact that we still have a long way to go. Important progress has been made since 1976, when Karen Ann Quinlan and a new generation of effective mechanical respirators forced us to pay attention to hard choices. Progress has been made even since 1990, when the Supreme Court's decision in the case involving Nancy Beth Cruzan affirmed the constitutional right to refuse life-prolonging medical treatment. Despite this progress, too many Americans still receive poor end of life care and die unnecessarily bad deaths. They and their families must contend with a lack of information, misunderstandings, restrictive policies, and financial stress. They die with inadequate palliative support, inadequate compassion, and inadequate human presence and loyalty, in fear, anxiety, loneliness, and isolation. They die in ways that efface dignity and leave bitter memories.

Further progress in improving end of life care does not depend primarily on enacting new laws or regulations. Existing laws in most states will work, if we let them, and, if anything, end of life care reform in the past has been excessively driven by the law. Culture needs time to catch up. The next decades should be, we believe, a time of education and soul-searching discussions in communities and at kitchen tables, as well as in health care settings. And as we shift from legal to cultural means of change, so too should we move from a focus on procedure and process to a focus on the substantive arguments and values that tell us what to decide, not just how to go about deciding. We must talk about what we dare not name, and look at what we dare not see. We shall never get end of life care "right," because death is not a puzzle to be solved. Death is an inevitable aspect of the human condition. But let us never forget: while death is inevitable, dying badly is not.

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World Health Organization, *Cancer Pain Relief and Palliative Care* (Geneva, Switzerland: World Health Organization, 1990).

World Health Organization, *National Cancer Control Programs, Policies and Managerial Guidelines* (Geneva, Switzerland: The World Health Organization, 2002).

The organizations and websites listed below provide information that may be useful to those wishing to explore end of life care issues more fully. As with any such listing, the content and reliability of this information may vary. This listing is for informational purposes only and does not imply endorsement of these organizations or their materials.

Aging with Dignity
www.agingwithdignity.org

American Academy of Hospice and Palliative Medicine
www.aahpm.org

American Bar Association Commission on Law and Aging
www.abanet.org/aging

American Hospice Foundation
www.americanhospice.org

Americans for Better Care of the Dying
www.abcd-caring.org

Caring Connections
www.caringinfo.org

Center to Advance Palliative Care
www.capc.org

Center for Practical Bioethics
www.practicalbioethics.org

Completing a Life
http://commtechlab.msu.edu/sites/completingalife/index.html

Dying Well
www.dyingwell.com

Growth House, Inc.
www.growthhouse.org

The Hastings Center
www.thehastingscenter.org

The Hospice Foundation of America
www.hospicefoundation.org

National Center for Ethics in Health Care
www1.va.gov/vhaethics

National Hospice and Palliative Care Organization
www.nhpco.org

On Our Own Terms: Moyers on Dying
www.pbs.org/wnet/onourownterms

The Palliative Care Policy Center
www.medicaring.org

Physician Orders for Life-Sustaining Treatment
www.polst.org

Promoting Excellence in End-of-Life Care
www.promotingexcellence.org

Supportive Care of the Dying: A Coalition for Compassionate Care
www.careofdying.org

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