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

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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 current 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 disease. In recent years, hospice programs have provided ex-
actly 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.

Nor do they ensure that the most knowledgeable, reason-
able, 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.

**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.**

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 enable 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 equation 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 Schia-vo 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 erode 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.