

Managing Conflict at the End of Life

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An interview with Dr. Bloche can be heard at www.nejm.org.

The media spectacle that surrounded the dying of Terri Schiavo is now two months past, and America's culture warriors have moved on to other battlegrounds. Much has been said about which political players won or lost and whether key voting blocs will care. But does the experience offer any useful lessons about the subject in dispute — decision making at the end of life?

There is a widespread perception that the law failed Terri Schiavo, her family, and the country by not yielding a quick, clear resolution. Cultural conservatives and others who rallied to the side of Schiavo's parents condemn the courts for failing to keep her alive. Many who backed her husband's efforts to withdraw her feeding tube urge increased use of advance directives and living wills — and safeguards against challenges to the judgment of surrogate decision makers. Both sides look to the law to set clear rules, though the two sides differ sharply on what those rules should be.

Almost forgotten in this debate, and ignored in press coverage of the Schiavo affair, is the peripheral role of law when end-of-life dilemmas arise. The law sets some limits: active killing, for example, is impermissible, and clear advance directives must be followed if they have been properly given. In most U.S. jurisdictions, suicide is unlawful, as is the assistance of physicians in self-killing. But within these bounds, end-of-life questions are almost always resolved in the private sphere, by patients, their physicians, and their family members, working with nurses, social workers, and members of the clergy.

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In tens of thousands of cases each year, patients and families handle catastrophic illness or injury without going to court. They do so with unsung courage, in the face of fear, anguish, and sometimes bitterness. Every loss of a loved one is, in part, a loss of hope — hope for healing of old rifts and fulfillment of thwarted possibilities. Anger and denial are common, especially when relationships were conflict-ridden beforehand. Cast-off parents, rival siblings, children who never measured up to their parents' expectations bring much to the bedside beyond their religious and philosophical leanings.

Anger, denial, and other nonrational influences can lock family members into warring stances over whether to treat a devastating illness aggressively or discontinue life-sustaining measures. What is remarkable, given the intensity of the feelings at stake, is how rarely such conflicts make their way to court. It is a measure of how discreetly such squabbles are handled that we know little about how often they arise. And it is a measure of people's character under this pressure that families usually come together to make these judgments or to honor the preferences their loved ones have expressed.

This is for the good: to rend families asunder at the end of a loved one's life does spiritual violence to all concerned. Within wide boundaries, we are committed to honoring patients' clearly stated wishes. This commitment not only safeguards patients' liberty and dignity; it protects against family strife when a patient's intentions are clear. When the patient's wishes are unstated and illness precludes asking about them, it is important to limit the possibilities for family conflict and lasting anger. Enabling families to mourn and move on — and discouraging them from playing out old resentments as end-of-life battles — should be a clinical and social priority.

The law can help to pursue this goal by making

it difficult for any one party to impose a decision when family members or others concerned disagree with it. Answers dictated by the law yield clear winners and losers, heightening long-term resentments and inviting further strife. A large literature suggests that solutions crafted by the parties to a conflict come with a sense of shared ownership that dampens discord.¹ By making it harder to invoke a court's final say, law can encourage conversation aimed at reconciliation or, at least, mutual accommodation. The proposition that law should promise quick, clear answers is a recipe for intensified family and social strife, since we are nowhere near national consensus on what the answers should be.

Some features of current law support the family-friendly resolution of agonizing end-of-life questions. The law's inquiry into what the patient would want when there is neither a clearly stated prior preference nor a designated surrogate decision maker is a legal fiction, since a person in a persistent vegetative state or a similarly incapacitated condition cannot formulate a preference. But this fiction sends the right moral message. It centers problem-solving conversation on something family members and friends have in common — their commitment to the patient's interests. This focus, in turn, encourages more mature handling of old wounds and resentments, even if they cannot be resolved.

Efforts to enmesh the law in end-of-life choices through detailed advance directives and the formal selection of surrogate decision makers risk stoking conflict. Advance directives cannot anticipate all scenarios, and the law's commands can crowd out benevolent feelings.² The more detailed the directive, the greater the possibilities for lawyerly argument about its application to situations that its author did not precisely foresee. Opting for a surrogate decision maker solves this problem but introduces another: selection of one person may hurt or offend others, reawakening old resentments. When conflicts seem likely, these risks are worth taking; when ties among loved ones are strong and cooperation prevails, the case for involving the law is weaker.

Resort to the courts by warring family members to try to narrow the acceptable range of end-of-life

choices on religious grounds is more worrisome. The clinical options at issue in the Schiavo litigation — removing the feeding tube and allowing a patient with a devastating brain injury to die or continuing tube feedings and embarking on an almost certainly futile therapeutic course — were both within the range allowed by ethics and law. To their credit, the judges who heard the case declined to narrow this range. The escalation of a family dispute through fiery religious references represented an attempt to reduce the latitude allowed by law. A Florida bishop's op-ed piece invoked “the passion of Terry Schiavo,” and some insisted that, to God, stopping tube feedings is murder. The attempt failed, but the incendiary language set a new standard for family divisiveness at the end of life.

What, then, are the lessons of the Schiavo affair for the management of end-of-life conflict? First, we should keep in mind that the affair represented an extraordinary exception: the over-

whelming majority of such cases are handled privately, by patients, family members, and caregivers. We should take pride in this fact and not overstate the problems to be solved.

Second, the overarching goal of courts, clinical caregivers, and others with a say in end-of-life disputes should be to pursue private, family-friendly accommodation within the wide limits set by law. Caregivers should, of course, defer to advance directives and to properly designated surrogate decision makers. They should, moreover, encourage patients to make their end-of-life preferences known to those closest to them, preferably through standardized means. But in so doing, caregivers should assert themselves gently: to push too hard for a living will or advance directive is to put patient trust at risk, particularly in this era of escalating worry about pressure to cut costs.

In addition, caregivers should encourage conversation about end-of-life questions among patients, family members, and others who are closely involved. And when the clinical picture takes a catastrophic turn and a patient can no longer formulate preferences, caregivers should give high priority to detecting hints of discord. At the first sign of tension, physicians, nurses, and social workers should

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become active listeners in search of smoldering feelings that might give rise to conflict.

If and when conflict erupts, end-of-life choices shouldn't be treated as purely ethical questions, divorced from the regrets and resentments involved. Psychiatric and social-work consultation should be part of the management plan, and mediation merits study as an approach. Mediators' methods of listening, exploring parties' needs, reframing problems, and proposing solutions have been well honed in work with divorcing couples, estranged business partners, and others in life-transforming crises.³ These skills are well suited to the work of guiding warring family members toward agreement on end-of-life choices for their loved one.

At times, physicians, and even insurers, become parties to these conflicts. Financial incentives, real or perceived, can shape positions and sow distrust. Cost-control strategies that engage caregivers in covert rationing can have toxic effects,⁴ particularly when medical futility is at issue. Our national unwillingness to acknowledge the conflict between efforts to limit medical spending and insistence on all possibly beneficial care worsens this toxicity. Good mediation technique can help to clarify misunderstandings, soften anger, and ease irrational distrust. But it cannot finesse contradictions that, as a country, we refuse to face.

For the last six years of Terri Schiavo's life, Robert Lynch, the local Catholic bishop, tried unsuccessfully to meet with her parents and husband to reach a solution through mediation. As their personal struggle became an international spectacle, Lynch broke with the Church hierarchy by refusing to side with the parents. Instead, he called on "both sides [to] step back" and to try for "a heroic moment of concern for the feelings of each other."⁵ In a public appeal that was ignored by all sides, he said: "The legacy of Terri's situation should not be that of those who love her the most, loathing the actions of one another."⁵ Schiavo's legacy has turned out to be worse than he feared. After her death, her parents and husband continued to battle — over access to her remains.

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3. Dubler NN, Liebman CB. Bioethics mediation: a guide to shaping shared solutions. New York: United Hospital Fund of New York, 2004.

4. Bloche MG. Trust and betrayal in the medical marketplace. *Stanford Law Rev* 2002;55:919-54.

5. Roman Catholic Diocese of St. Petersburg, Florida. Statement of Bishop Robert N. Lynch. February 28, 2005. (Accessed May 19, 2005, at <http://www.dioceseofstpete.org/content.php?P=119>.)

Patients in a Persistent Vegetative State — A Dutch Perspective

Inez de Beaufort, Ph.D.

He is 31 years old now — Henk-Jan, the son of Gerard and Ineke Stinissen. He is the son Ineke Stinissen never knew. In 1974, as the result of a dramatic medical error that occurred during emergency cesarean delivery, she was left in a persistent vegetative state. Through most of Henk-Jan's life, his mother's condition and treatment have been matters of an emotionally fraught public controversy.

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In 1985, his father sought publicity — in a television program called "How Long Should Dying Last?" — for his view that his wife's artificial nutrition and hydration should be stopped. In 1987, he went to court to demand that the nursing home stop the feeding. On January 9, 1990, it was finally discontinued, and Ineke Stinissen died 10 days later. Behind these few facts lies a long, sad story that has been widely debated in the Netherlands. Why stop the feeding? Why not? Why now? The questions echo today, in the wake of the recent case of Terri Schiavo.