



2006

How We Die: A New Prescription

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Martin Bienstock, How We Die: A New Prescription, 20 J.L. & Health 17 (2006-2007)

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HOW WE DIE: A NEW PRESCRIPTION

MARTIN BIENSTOCK*

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I. INTRODUCTION

The dawn of the twenty-first century brought with it a profound change in the way we experience death. Until the last decades of the twentieth century, our bodies died all at once: when the heart, kidneys, lungs, or brain failed, the body's other organs failed with them. Modern medicine now allows us to die in pieces, with failing organs supported or supplanted by technology.¹

Modern death is different not only biologically, but also sociologically. Until the twentieth century, death was a private event that took place in the home with the family.² It offered one final opportunity for family members and friends to engage with loving care, to forgive and ask forgiveness, and to relive life events, great and small.³ Today, death takes place mostly in the hospital, in sterile rooms full of expensive machinery, with patients who are drugged, unconscious, hooked up to machines and unable to speak—even if their bodies were still capable of doing so.

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¹See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983) [hereinafter PRESIDENT'S COMMISSION]. This phenomenon was first commented upon in this report. *Id.*

²See *id.* at 17 (“For most of recorded history . . . the ‘deathbed’ was a real place, and the dying person usually knew where he was and when it was time to assemble the family and call for the priest. . .”).

³Our literature is replete with deathbed scenes of dying with family, beginning with the Biblical Jacob's deathbed blessings of his children. *Genesis* 49:1. More recently, news reports of Jacquelyn Kennedy Onassis's leaving the hospital in order to die with her family served to highlight that it has now become exceptional and newsworthy when individuals are able to die at home with their families. See, e.g., Janny Scott, *Death of a First Lady: A Death at Home, Among Family and Friends, and Even Strangers*, N.Y. TIMES, May 20, 1994, at B10.

Doctors, lawyers, nurses, social workers, ethicists, and family members enter a complex dynamic as treatment decisions are made for the unconscious patient, and therapies are applied or refused.⁴

Approximately every ten years,⁵ a high-profile legal dispute emerges. These disputes pit families, doctors, and elected officials against each other as they seek to resolve ultimate questions of when life ends and death begins.⁶ These issues include questions of whether suffering and pain may justify the termination of patient treatment; whether actively terminating a human life is ever acceptable;⁷ and whether anyone can determine the proper role of individual autonomy when it conflicts with community values.⁸

While the debates ebb and flow, millions of ordinary families are forced to confront these issues quietly on their own.⁹ Unfortunately, current policies governing end-of-life decision-making fail these families in the most fundamental ways and fail to achieve their most basic objectives.

In the thirty years since the seminal *In re Quinlan* case, personal autonomy has been universally acknowledged as the most important value in the end-of-life process.¹⁰ A consensus has emerged that decisions at the end-of-life are the type of personal, individual choices that can only be made by the affected individual in a

⁴See PRESIDENT'S COMMISSION, *supra* note 1, at 17-18.

As medicine has been able to do more for dying patients, their care has increasingly been delivered in institutional settings. By 1949, institutions were the sites of 50% of all deaths; by 1958, the figure was 61%; and by 1977, over 70%. Perhaps 80% of all deaths in the United States now occur in hospitals and long-term care institutions, such as nursing homes. . . . But people who are dying may well find such a setting alienating and unsupportive.

Id. (quoting Lewis Thomas, *Dying as Failure*, 447 ANNALS AM. ACAD. POL. & SOC. SCI. 1, 3 (1980)).

⁵*Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990); *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *Schindler v. Schiavo*, 792 So. 2d 551, 560 (Fla. Dist. Ct. App. 2001).

⁶A decade or more separated *Cruzan* (*Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990)), *Quinlan* (*In re Quinlan*, 355 A.2d 647 (N.J. 1976)), and *Schiavo* (*Schindler v. Schiavo*, 792 So. 2d 551 (Fla. Dist. Ct. App. 2001)), each of which garnered widespread national publicity. Many other important decisions were issued along the way. See, e.g., *Cruzan*, 497 U.S. at 347 (Stewart, J., dissenting).

⁷See, e.g., *Quinlan*, 355 A.2d at 647.

⁸See, e.g., *Vacco v. Quill*, 521 U.S. 793, 805 (1997); *Wash. v. Glucksberg*, 521 U.S. 702 (1997).

⁹More than fifteen years ago, an analysis showed that 7000 legal proceedings had been brought to adjudicate end-of-life decisions. Diane E. Hoffman, *Mediating Life and Death Decisions*, 36 ARIZ. L. REV. 821 n.1 (1994). These cases, however, represent only the small tip of a large iceberg. In light of the statistics in the article by Hoffman, it is hard to imagine a family in the United States that has not been touched by this issue. *Id.* at n.3.

¹⁰See Alan Meisel, *Managed Care, Autonomy and Decisionmaking at the End of Life*, 35 HOUS. L. REV. 1393, 1397 (1999). See also the discussion at Part II, *infra*, in which the *Quinlan*, *Cruzan*, and *Schiavo* courts all agree that personal autonomy would be a compelling basis for allowing patients to make end-of-life decisions.

pluralistic society such as our own.¹¹ However, while paying lip service to the value of personal autonomy, courts and legislatures have in fact been imposing their own values and those of family members and close personal friends on the dying process. As a result, dying patients rarely take true control over the decisions in their own dying process.

While the modern process of dying fails to protect the autonomy of dying patients, it affirmatively places an exceptional and unfair burden on their family members. When they face shock, grief, pain, and uncertainty, family members are often called upon to make profound life-and-death decisions that they have no desire or competence to make, and they must typically make them in a foreign environment and on a moment's notice.¹²

Considering that physicians are integrally involved in end-of-life decisions, this article discusses a new paradigm that would place on physicians the responsibility to elicit from their patients the moral guidelines that would govern end-of-life decision-making. In the event a patient later became incapacitated, the physician would be responsible to apply these moral guidelines to actual treatment decisions. Part II of this article examines the central role that the ethic of personal autonomy plays in end-of-life decision-making. Part III describes how the courts have conceptually validated that ethic, while ignoring it in practice, by looking at the three seminal end-of-life court decisions of the past thirty years. Part IV examines legislative solutions to end-of-life decision-making and highlight their failings. Finally, Part V looks at a new paradigm for end-of-life decision-making, one centered on the doctor-patient relationship.

II. AUTONOMY IN END-OF-LIFE DECISION-MAKING

Generally, two competing theories seek to explain ethical decision-making in the modern era. The first, whose principal proponent was Immanuel Kant, relies on autonomy, which is the person's right to govern himself.¹³ The second relies on utilitarianism, which requires a decision that achieves the best result for society.¹⁴

Once the right of autonomy is granted, an individual has a concomitant responsibility to exercise it in a morally correct fashion, as perceived by the individual.¹⁵ Respect for personal autonomy requires letting the person make decisions for and by himself, no matter how foolish those decisions may be.¹⁶ This

¹¹See Meisel, *supra* note 10, at 1397.

¹²One solution would be to apply a "therapeutic justice" analysis to the current law governing end-of-life decision-making, attaching a central role to the real world sociological effects of current policies. Mary Beth Morrissey & Bruce Jennings, *A Social Ecology of Health Model in End-of-Life Decision-Making: Is the Law Therapeutic?*, 11 N.Y. ST. B. ASS'N HEALTH L.J. 51 (2006).

¹³IMMANUEL KANT, *FOUNDATIONS ON THE METAPHYSICS OF MORALS* 59-67 (Lewis W. Beck trans. 1959) (1785).

¹⁴See, e.g., JOHN STUART MILL, *ON LIBERTY* 3-19 (Currin V. Shields eds. 1956) (1859).

¹⁵KANT, *supra* note 13, at 59-67.

¹⁶MILL, *supra* note 14, at 9, 104.

value is enshrined explicitly and implicitly in the Declaration of Independence¹⁷ and the Bill of Rights.¹⁸ In the context of end-of-life decisions, autonomy means that individuals have the right and duty to make ethical treatment decisions for themselves.¹⁹

Utilitarianism is a competing source of ethical values. Utilitarianism seeks to create the greatest good for the greatest number of people.²⁰ In the context of end-of-life decision making, utilitarianism means that decisions should be made that are in the best interest of society.

Defining best-interest in this context, however, requires that a standard be determined as to what most benefits society. If the primary goal is to preserve scarce medical resources, then one type of decision might be made; if the goal is to preserve the sanctity of human life, then another type of decision might be made; if the goal is to reduce human suffering, then still other choices exist. In end-of-life cases, states frequently assert the sanctity of human life as a value that should be applied to end-of-life decision-making.²¹

An important difference between autonomy and utilitarianism is that autonomy stresses that the individual should make decisions, while utilitarianism focuses on the quality of the decisions that are being made.²² These competing ethical theories form the context in which important legal issues are debated and decided by the courts. Thus, for example, a state might determine that the sanctity of human life is sufficiently important that a patient's treatment should never be terminated. This utilitarian view might conflict with a particular patient's own view that she has suffered enough and that treatment should end. In that situation, the prevailing view is that the personal autonomy should prevail; right or wrong, the decision is the

¹⁷"We hold these truths to be self evident, that all men are created equal and endowed by their creator with certain inalienable rights, including the right to life, liberty, and the pursuit of happiness." THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).

¹⁸U.S. CONST. amend. I-X. Whether under the rubric of the "right to privacy" or the Due Process Clause's prohibition on the denial of liberty without due process of law, courts have concluded that respect for personal autonomy is enshrined in the Constitution. Compare *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990) (acknowledging the liberty interest in directing one's own treatment) with *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (relying on the right to privacy enshrined in the penumbra of the Constitution).

¹⁹BARRY R. FURROW ET AL., HEALTH LAW: CASES, MATERIALS AND PROBLEMS 1344-46 (5th ed. 2004).

²⁰MILL, *supra* note 14, at 3-19.

²¹*See, e.g.,* *Vacco v. Quill*, 521 U.S. 793 (1997); *Wash. v. Glucksberg*, 521 U.S. 702 (1997); *Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schindler v. Schiavo*, 792 So. 2d 551 (Fla. Dist. Ct. App. 2001); *In re Storar*, 420 N.E.2d 64 (N.Y. 1981).

²²*Cf.* KANT, *supra* note 13; MILL, *supra* note 14.

patient's to make.²³ Only when a patient's view is unknown, should the state's utilitarian views be taken into account.²⁴

Generally, personal autonomy is considered the most important ethical value underlying end-of-life decision-making.²⁵ The choice of personal autonomy as the most important value in end-of-life decision-making means that ensuring an appropriate process for decision-making is more important than ensuring that decisions are "correct."

In perhaps its broadest formulation, the United States Supreme Court described this value in the following manner:

[M]atters involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to liberty. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood where they formed under compulsion of the State.²⁶

Jurists who do not endorse an all-encompassing "right of privacy" nevertheless acknowledge that the constitutional liberty interest extends beyond freedom from physical restraint and into matters of personal choice.²⁷ These matters of personal choice include a parent's right to send a child to private school, a right to teach a foreign language in a parochial school, a right to marry, a right to procreate, and a right to use contraceptives.²⁸

But legal cases are not about abstract values. Such values, as a legal matter, may be insufficient to trump utilitarian values identified by the state unless they are expressed in some form of traditional and long-held right.²⁹ Perhaps for that reason, courts sometimes defend a person's right to terminate treatment by reference to bodily integrity.³⁰

²³See *Vacco*, 521 U.S. at 803 n.8. A competent adult patient has the right to make his or her own treatment decisions. However, some decisions may not be available to patients, as nearly all states expressly disapprove of suicide and assisted suicide. *Id.* at 805. See also *id.* at n.9. But, almost all other treatment and non-treatment choices are available as a matter of personal autonomy. *Id.*

²⁴See *Cruzan*, 497 U.S. at 261.

²⁵See TOM BEAUCHAMP & JAMES CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (Oxford Univ. Press 2001) (1979); ALBERT JONSEN ET AL., *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* (McGraw Hill 2002) (1982); Robert Swidler, *When a Patient's Prior Decision Conflicts with a Family's Current Insistence that Treatment be Provided*, 10 N.Y. ST. B. ASS'N HEALTH L.J. 75 (2005).

²⁶*Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 851 (1992).

²⁷*Id.* at 951 (Rehnquist, C.J., concurring in part and dissenting in part).

²⁸*Id.*

²⁹*Wash. v. Glucksberg*, 521 U.S. 702, 721 (1997) (limiting the liberty interest protected by the Constitution to "fundamental rights and liberties which are, objectively, 'deeply rooted in this Nation's history and traditions'").

³⁰See *id.* at 725.

Courts have long recognized that individuals have the right to bodily integrity, which is the right to control the treatment of one's own body. As Justice Cardozo once described, "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body."³¹ Thus, he held that a patient could properly make a claim in tort when her doctor surgically removed a fibroid after she had consented only to a biopsy.³²

By expressing a general moral value as a specific right to treatment, however, we risk conflating two very different rights. Patients have a fundamental right to make general, moral decisions about life and death. They have the right to say: "I do not want to live like that," "I want to fight to the end," "I do not want to be a burden," or "I want to die at home." The decisions are so personal that no one else is equipped to make the decision.³³

Patients also have the right to direct their own treatment. They have the right to accept or refuse a dizzying array of treatments that may prolong or shorten their life, increase or reduce their suffering, and interfere with or improve their enjoyment of life. These decisions are not fundamental moral decisions about life and death, but are treatment decisions that involve choices about how to express their moral views.

When patients are conscious and have decisional capacity, the right to make moral decisions and the right to make decisions about bodily integrity are one and the same. When patients lack decisional capacity, however, they may never have contemplated their current medical condition. They may have moral views, fully formed and expressed, but not medical views. In these situations, distinguishing between the values of autonomy and of bodily integrity is critical. The value of autonomy would require that treatment be consistent with the patient's moral views. The value of bodily integrity would require a hands-off approach unless the patient has made specific treatment decisions. As described in the next section, the courts' emphasis on bodily integrity rather than moral autonomy has complicated analysis of end-of-life cases.

The right assumed in *Cruzan*, however, was not simply deduced from abstract concepts of personal autonomy. Given the common-law rule that forced medication was a battery, and the long legal tradition protecting the decision to refuse unwanted medical treatment, our assumption was entirely consistent with this Nation's history and constitutional traditions.

Id. See also *Casey*, 505 U.S. at 857 (dividing liberty interests into two classes: those of intimate relationships and those of bodily integrity, and placing end-of-life decisions squarely in the category of bodily integrity).

³¹ *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (Cardozo, J.).

³² *Id.*

³³ Even absent an argument based on the value of personal autonomy, the pluralistic nature of our society compels the same result. A society that includes strict Catholics, liberal Catholics, lapsed Catholics, Orthodox Jews, reform Jews, liberal Jews, evangelicals, atheists, and secularists likely cannot reach any form of consensus on the issues implicated in end-of-life decisions.

III. JUDICIAL RESPONSE: FALSE AUTONOMY

Courts have decided three seminal end-of-life cases in the last thirty years that dealt with incapacitated patients who lacked decisional capacity.³⁴ In each case, a young woman lay comatose, kept alive by machines, with no hope of recovery.³⁵ In each case, a young woman had expressed some moral views about end-of-life decisions, if only in general and vague terms.³⁶ Also, in each case, the courts proclaimed that individual autonomy would serve as the lynchpin of its decision.³⁷ None of the three decisions, however, vindicated personal autonomy.³⁸

Instead, all three cases turned on the utilitarian values of the deciding courts. “Liberal” courts, which believe that the most important goal is to reduce human suffering, sanctioned the termination of treatment. “Conservative” courts, which believe that the most important goal is the sanctity of human life, upheld decisions to continue treatment or, more technically, found that family members had produced insufficient evidence to justify terminating treatment in the face of the State’s competing interest in favor of continuing life. Legal commentators followed suit by taking varying positions on whether and when treatment should be continued.³⁹ However, in all three cases, the patient’s autonomy was ignored.⁴⁰

In each of the three cases the patient was left in a persistent vegetative state, incapable of having awareness of anything around her.⁴¹ Karen Quinlan was twenty-two years old when, for reasons never fully explained, she stopped breathing.⁴² Nancy Cruzan was twenty-four when a car accident cut off blood flow to her brain.⁴³ Theresa Schiavo was twenty-seven when she suffered cardiac arrest due to a potassium imbalance.⁴⁴

Their postures grew fetal-like and grotesque; their joints rigid and deformed.⁴⁵ They were not dead, however, not by any definition of the term.⁴⁶ While they could

³⁴*Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990); *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *Schindler v. Schiavo*, 792 So. 2d 551 (Fla. Dist. Ct. App. 2001).

³⁵*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

³⁶*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

³⁷*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

³⁸*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

³⁹Norman L. Cantor, *Déjà Vu All Over Again: The False Dichotomy Between Sanctity of Life and Quality of Life* (Rutgers Univ. (Newark) Legal Working Paper Series, Rutgers Law Sch. (Newark) Faculty Papers, Working Paper No. 22, 2005), available at <http://law.bepress.com/rutgersnewarklwps/fp/art22> (last visited June 2, 2007).

⁴⁰*See Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁴¹*See Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁴²*Quinlan*, 355 A.2d at 647.

⁴³*Cruzan*, 497 U.S. at 266.

⁴⁴*Schiavo*, 792 So. 2d at 551.

⁴⁵*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁴⁶*See Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

not “think” because they had no higher cognitive functions, their brain stems were still alive and produced various reflexive motions.⁴⁷

In each case, family members sought to terminate treatment and were opposed.⁴⁸ All three courts said they would look to the patients to determine how treatment would proceed.⁴⁹ And, in each case the court ignored or supplemented the patient’s expressed wishes, and someone other than the patient took responsibility for determining the outcome.⁵⁰

A. *In re Quinlan*

In re Quinlan was the first and most important case.⁵¹ After Karen had lapsed into a vegetative state, her father, Joseph Quinlan, at first did everything possible to keep Karen alive.⁵² Over time, however, he decided that Karen had suffered enough.⁵³ He was a devout Catholic, though, and turned to the Catholic Church for guidance before determining a course of action.⁵⁴ He discovered that the Catholic Church did not require that extraordinary efforts be made to preserve life.⁵⁵ Instead, the Catholic Church held the view that the patient had the right to decide whether to undertake such efforts, and if the patient was incompetent, the family must make that decision.⁵⁶

The Catholic Church advised Joseph Quinlan that his decision to discontinue treatment was, according to the teachings of the Catholic Church, “a morally correct decision.”⁵⁷ Consequently, Joseph Quinlan asked Karen’s doctor to terminate Karen’s life support.⁵⁸ The doctor, however, concluded that ending life support constituted a substantial deviation from medical tradition and involved ascertaining “quality of life” and, thus, determined that he would not do so.⁵⁹ Joseph Quinlan then went to court, seeking an appointment as Karen’s guardian and the express power to terminate treatment.⁶⁰

⁴⁷*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 655; *Schiavo*, 792 So. 2d at 551.

⁴⁸*Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁴⁹*See Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁵⁰*See Cruzan*, 497 U.S. at 261; *Quinlan*, 355 A.2d at 647; *Schiavo*, 792 So. 2d at 551.

⁵¹*Quinlan*, 355 A.2d at 647.

⁵²*In re Quinlan*, 348 A.2d 801, 812-13 (N.J. Super. Ct. Ch. Div. 1975).

⁵³*In re Quinlan*, 355 A.2d 647, 655 (N.J. 1976).

⁵⁴*Id.* at 658.

⁵⁵*Id.*

⁵⁶*Quinlan*, 348 A.2d at 812-13.

⁵⁷*Quinlan*, 355 A.2d at 659.

⁵⁸*Id.*

⁵⁹*Quinlan*, 348 A.2d at 812-13.

⁶⁰*Quinlan*, 355 A.2d at 655.

The New Jersey Supreme Court granted Joseph Quinlan specific authority to terminate treatment.⁶¹ The court acknowledged the responsibilities, rights, and duties of no less than five competing interests, including those of the patient, her family, her doctors, and the courts.⁶² It acknowledged that Karen had not specifically decided that she wished to die.⁶³ It also recognized that removal of the respirator would not conform to medical practice.⁶⁴ Nevertheless, the court held that Karen had a right in her person to terminate treatment and that this right could be exercised by her father.⁶⁵

The court's holding in *Quinlan* centered on the notion of personal autonomy. In authorizing her father to terminate Karen's treatment, the New Jersey Supreme Court made clear that it sought to protect Karen Quinlan's affirmative right to personal autonomy.⁶⁶ First, relying on the right to privacy said to exist within the penumbra of the United States Constitution, the court ruled that Karen had the right to terminate her own treatment.⁶⁷ This holding was entirely consistent with the rules of autonomy.

However, as the court observed, Karen could not make this decision for herself.⁶⁸ She had previously expressed distaste for continuance of life by extraordinary means in several conversations.⁶⁹ Nevertheless, the court found that those conversations were "remote and impersonal" and, therefore, could not be relied upon.⁷⁰

Consequently, the court looked to two other sources to determine Karen's will. First, the court itself determined what it thought Karen would have decided.⁷¹ As the court explained, it had "no doubt that if Karen were herself miraculously lucid for an interval," she would have decided to terminate treatment.⁷² Why "compel Karen to endure the unendurable, only to vegetate for a few measurable months, with no realistic possibility of returning to any semblance of cognitive or sapient life?"⁷³ The court's conclusion that it "knew" what Karen wanted effectively ignored her right to autonomy.

⁶¹*Id.* at 671.

⁶²*Id.* at 663.

⁶³*Id.* at 664.

⁶⁴*Id.*

⁶⁵*Id.*

⁶⁶*Id.* at 647.

⁶⁷*Id.* at 664.

⁶⁸*Id.*

⁶⁹*Id.*

⁷⁰*Id.*

⁷¹*Quinlan*, 355 A.2d at 663.

⁷²*Id.*

⁷³*Id.* More dramatic instance of this reasoning was when the court applied the same test to someone who had never been competent.

Even worse, by appointing Karen's father to be her guardian and deferring to his wishes, it abandoned even the pretense that treatment was terminated to vindicate Karen's autonomy rights. Joseph Quinlan did not seek to terminate Karen's life until he knew that the action conformed to his own religious beliefs.⁷⁴ If the Catholic Church believed that terminating treatment was a sin, he probably would not have done so. While Karen certainly has the right to rely on the views of the Catholic Church in making a decision, it is not clear why her father had that right when deciding on her behalf.

In sum, the *Quinlan* court agreed to terminate life support, not because of Karen's own beliefs, which it claimed it did not know, but because of the court's own belief system and in reliance on her father's belief system.⁷⁵ Whether or not the decision was correct, it involved perhaps the ultimate betrayal of personal autonomy: Karen's family and the New Jersey Supreme Court made Karen's decision for her and did it in her name. The court's failing in *Quinlan* can be traced to the absence of any system for converting Karen's moral views into practical treatment decisions. Absent such a mechanism, the court was forced to defer to Karen's family.

B. *Cruzan v. Director, Missouri Dep't of Health*

If the *Quinlan* court fabricated an "autonomous" decision on behalf of Karen Quinlan, then the *Cruzan* court highlighted what might happen absent such a fabrication. The facts of *Cruzan* were nearly identical to that of *Quinlan*. A young woman had made statements to a housemate that she did not wish to live if she would face life as a vegetable.⁷⁶ After the hospital treating Nancy Cruzan refused to end life sustaining treatment at the parent's request, her parents sought a court order to make them do so.⁷⁷ The primary difference between Nancy Cruzan and Karen Quinlan was the location in which each took ill. Karen lived in a state whose supreme court was willing to fabricate an autonomous decision on her behalf.⁷⁸ Nancy Cruzan lived in a state whose supreme court was unwilling to do so.⁷⁹ Unless Nancy's parents could prove by "clear and convincing evidence" her wish to terminate her life, the court was not willing to authorize the termination of treatment.⁸⁰ Similar to the *Quinlan* court, the *Cruzan* court recognized an individual's right to privacy to terminate treatment.⁸¹ But when that right had not been expressly claimed by a patient, the right could not be vindicated, unless it could

⁷⁴*Id.* at 658.

⁷⁵*Id.*

⁷⁶*Cruzan v. Harmon*, 760 S.W.2d 408, 432 (Mo. 1988).

⁷⁷*Id.* at 410.

⁷⁸*In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁷⁹*Cruzan*, 760 S.W.2d at 427.

⁸⁰*Id.*

⁸¹*Id.*

be proven by clear and convincing evidence.⁸² Thus, in *Cruzan*, the state's interest in preserving life prevailed.⁸³

If the *Cruzan* court rejected the fabricated autonomy of *Quinlan*, it also failed to vindicate the patient's autonomy in any manner at all. Indeed, not only did the court ignore the affirmative value of autonomy, but it also rejected the libertarian view that the state ought not interfere in private moral decision-making.⁸⁴ In *Cruzan*, the State of Missouri determined the course of Nancy Cruzan's treatment.⁸⁵ Regardless of whether its decision was "correct," it violated rather than affirmed the value of personal autonomy. Once again, the absence of any system for converting moral views into treatment decisions interfered with patient autonomy.

The fact that *Quinlan* and *Cruzan* have opposite outcomes, which are based solely upon the location in which they took ill, highlights the lack of autonomy in the system. In a system based on autonomy, the view of the patient is all that matters. When the makeup of the court determines the outcome, the decision is not autonomous.

C. Schindler v. Schiavo

While *Quinlan* pretended to protect personal autonomy by permitting death and *Cruzan* pretended to do the opposite, *Schiavo* presented a new challenge: different family members competing for the right to express the patient's autonomy.⁸⁶ The facts of *Schiavo* have by now become familiar to the public: a young woman unexpectedly left comatose, with only a few oral statements about how she would like to be treated.⁸⁷ In *Schiavo*, however, the family members themselves disputed what Terry Schiavo would have intended.⁸⁸

The Florida Supreme Court continued to use the language of autonomy, explaining that, "in the end, this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo's right to make her own decision, independent of her parents and independent of her husband."⁸⁹ Just as in *Quinlan* and *Cruzan*, the court here had no real knowledge of what Terry Schiavo would have done.⁹⁰ As the court freely acknowledged, the trial court considered evidence of Terry's values, personality, and her own decision-making process before making her decision for her.⁹¹

⁸²*Id.*

⁸³*Id.*

⁸⁴*Id.*

⁸⁵*Id.*

⁸⁶*Schindler v. Schiavo*, 851 So. 2d 182, 186 (Fla. Dist. Ct. App. 2003).

⁸⁷*Schindler v. Schiavo*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001).

⁸⁸*Schiavo*, 851 So. 2d at 186.

⁸⁹*Id.*

⁹⁰*Id.* See also *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990); *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁹¹*Schindler v. Schiavo*, 792 So. 2d 551, 560 (Fla. Dist. Ct. App. 2001).

Schiavo is essentially a liberal response to the *Cruzan* decision. Faced with the possibility that “clear and convincing” proof would be required, the court simply held that such proof of Terry’s wishes existed.⁹² The fact that no more evidence of her intent existed than had existed in either of the other two cases again highlights that personal autonomy played no role in the outcome.

The *Schiavo* court recognized the deeply flawed nature of the process. As the court described it, “[i]t may be unfortunate . . . that the best forum we can provide is a judge with no prior knowledge of the ward, but the law provides no better solution that adequately protects the interests in promoting the value of life.”⁹³ Once again the absence of a mediating influence that could convert moral values into treatment decisions resulted in a denial of personal autonomy. But perhaps we can do better.

IV. LEGISLATIVE RESPONSE: FORMALIZING SUBSTITUTED JUDGMENT AND BEST INTERESTS

State legislatures have responded to the challenges posed by incapacitated patients by developing legal processes to govern decision-making. One such process maintains a focus on personal autonomy—the living will.⁹⁴ Others rely on family members to make decisions for incapacitated patients, whether through substituted judgment or a best interest test.⁹⁵

Living wills are documents signed by patients, which formalize their intentions. Living wills became popular in the aftermath of *Quinlan*. More than forty states have adopted living will statutes that permit competent adults to declare by advance directive that they do not wish to be kept alive by medical treatment in the latter stages of a terminal illness.⁹⁶ Living wills are an exceptionally blunt instrument for dealing with end-of-life decision-making. Perhaps for that reason, they are typically viewed not as a means of directing treatment, but as a means of authorizing a patient to direct that some treatments not be provided.⁹⁷

While living wills are accepted throughout the United States, some states promote the health care proxy as the primary planning tool.⁹⁸ In the event of incapacity, a health care proxy empowers someone else to be a person’s agent and to make health care decisions for him.⁹⁹ Agents are directed to make decisions in

⁹²*Id.*

⁹³*Schiavo*, 851 So. 2d at 187.

⁹⁴See FURROW, *supra* note 19, at 1344-46.

⁹⁵*Id.* at 1397-98.

⁹⁶ALAN MEISEL, *THE RIGHT TO DIE* § 11.12 (1989 & Supp. 1 1997).

⁹⁷See, e.g., *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 314 (1990). Missouri has a living will statute which specifically “allows and encourages the pre-planned termination of life.” *Id.* at 314 n.15. See also Mo. REV. STAT. § 459.015(1) (2006).

⁹⁸In New York, for example, the state’s notification document pursuant to the federal Patient Self-Determination Act (PSDA) is four pages long but describes living wills in one paragraph. See Patient Self-Determination Act, 42 U.S.C. § 1395cc (2006); N.Y. PUB. HEALTH LAW § 2981 (Consol. 2006). More than a decade ago, all fifty states and the District of Columbia adopted general durable power of attorney statutes, and more than a dozen states expressly authorized health care proxies. *Cruzan*, 497 U.S. at 292 n.3.

⁹⁹N.Y. PUB. HEALTH LAW § 2981 (Consol. 2006).

accordance with the wishes of their principals. If those wishes are unknown and cannot be determined with a reasonable effort, the agent may use his own judgment and make decisions in his principal's best interest.¹⁰⁰ The health care proxy document itself may provide for the agency relationship to terminate upon some event.¹⁰¹

Lately, some state legislatures have authorized family members or close friends to make decisions and in some cases have established a hierarchy of decision-makers within families.¹⁰² In most cases, decisions are to be made based on substituted judgment, in which family members try to make the decision that the incapacitated patient would have made.¹⁰³ In some cases, a best interest test may be employed, which the family member simply decides on the basis of what he or she thinks is in the patient's best interest.¹⁰⁴

These approaches have three identifiable flaws. First, legislative efforts to have patients express their wishes through formalized legal documents have been unsuccessful; only one in four patients has executed an advance directive.¹⁰⁵ This fact remains true despite the mandate that the federal government imposed requiring that patients be advised of their rights to execute advance directives upon admission to the hospital.¹⁰⁶ Thus, this legislative effort fails because it is simply not utilized by patients.

Second, these legislative efforts have left patients and their families dissatisfied with the end-of-life process. A systematic review of the evidence conducted by the Agency for Health Care Quality and Research concluded that only thin and

¹⁰⁰See, e.g., UNIF. HEALTH-CARE DECISIONS ACT § 5(f) (1993) (stating that if patients wishes are unknown to surrogate, the surrogate "[s]hall make the decision in accordance with the surrogate determination of the patient's best interest").

¹⁰¹N.Y. PUB. HEALTH LAW § 2985(1)(d) (Consol. 2006).

¹⁰²Most states have adopted family consent laws that authorize family members to make health care decisions in certain circumstances. See FURROW, *supra* note 19, at 1402. See also UNIF. HEALTH-CARE DECISIONS ACT § 5 (1993) (establishing such a hierarchy).

¹⁰³See FURROW, *supra* note 19, at 1402.

¹⁰⁴*Id.*

¹⁰⁵See PRESIDENT'S COMMISSION, *supra* note 1, at 241-42 (reviewing surveys showing fifteen to twenty-five percent of those surveyed gave written instructions regarding how they would like to be treated if they ever became too sick to make decisions). See also Etienne Phipps et al., *Approaching the End of Life: Attitudes, Preferences, and Behaviors of African-American and White Patients and Their Family Caregivers*, 21 J. CLINICAL ONCOLOGY 549, 551 (2003); Ben Kusmin, *Swing Low, Sweet Chariot: Abandoning the Disinterested Witness Requirement for Advance Directives*, 32 AM. J.L. & MED. 93, 107 (2006) (stating that twenty-four percent of the patients surveyed had a living will).

¹⁰⁶Patient Self-Determination Act, 42 U.S.C. § 1395cc (2006). The Patient Self-Determination Act (PSDA), passed in 1990, requires hospitals, nursing homes, hospice programs, home health agencies, and HMOs that are Medicare and Medicaid providers to give adult individuals, at the time of inpatient admission or enrollment, information about their rights under state laws governing advance directives, including: (1) the right to participate in and direct their own health care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare an advance directive; and (4) the right to get information on the provider's policies that govern the utilization of these rights. § 1395cc (f)(1).

equivocal evidence supports the conclusion that improved, advance care planning actually improves the experience for patients and their families.¹⁰⁷

Finally, other than in the case of living wills, all of these processes involve empowering persons other than the patient to make decisions on the patient's behalf. In some cases, family members are empowered to make decisions based on what they believe that patient would have preferred. In others, they are permitted to decide what is in the best interest of the patient. Even when patients state their preferences by executing a living will (or otherwise), serious questions arise as to whether physicians are even aware of their patients' preferences. One study has found that the use of specific advanced directives, such as living wills, had no measurable effect on end-of-life care.¹⁰⁸

V. TOWARDS TRUE AUTONOMY

As described above, despite widespread agreement that personal autonomy should govern end-of-life decisions, courts, legislatures, and family members regularly make decisions on behalf of incapacitated patients. This result is not entirely unexpected; the patient who has lost capacity to make decisions cannot currently be autonomous. Because the patient is not currently autonomous, substituted judgment and best interest serve at least the purpose of excluding the State from decisions it may not be competent to make. Having one's mother, brother, spouse, or partner make the most important decisions about one's life is certainly better than entrusting the decision to the state legislature or the whim of an uninformed treating physician. None of these options, however, can be said to vindicate a person's interest in personal autonomy.

One key to advancing autonomous end-of-life decision-making for patients without decisional capacity may lie in better understanding the nature of the decision that must be made. When patients still have decisional capacity, their autonomy is expressed as a treatment decision. For example, when patients are told that they have cancer, pneumonia, and an infection, doctors ask them to determine which treatment they wish to undergo: chemotherapy, artificial respiration, or antibiotics? Patients can express their moral views through a treatment decision. When patients cannot make their own treatment decisions, however, they still have the right to have their moral decisions converted to reality by a neutral and disinterested professional whose sole duty is to their patients. Those professionals are the patients' doctors.

¹⁰⁷End-of-Life Care and Outcomes, AHRQ Pub. No. 05-E004-2 (Dec. 2004), available at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf>. The report concludes that:

The usual practice of advance directives and advance care planning is supported by little reliable scientific evidence of efficacy in improving outcomes. Improved communication and planning has some tendency toward improved patient and family satisfaction, and certainly anecdotes and small series point to patient and family frustration and disappointment with seriously flawed communication. Nevertheless, high-quality research designs have not often been applied to these questions and, when applied, have shown quite modest effects, even on increasing the rate of making decisions in advance.

Id.

¹⁰⁸See Joan M. Teno et al., *Do Advance Directives Provide Instructions that Direct Care*, 45 J. AM. GERIATRICS SOC. 508 (1997).

Doctors and their patients enter a relationship that creates a responsibility to respond to medical reality.¹⁰⁹ Doctors, as part of their duties to obtain informed consent¹¹⁰ and their obligation towards patient autonomy, need to obtain express ethical guidelines from their patients that is sufficient to make all treatment decisions. Patients need to make those ethical decisions, and then, if they cannot make treatment decisions, to rely upon their chosen doctors to make informed medical choices. And families need to be left alone to assume their rightful role as supportive and loving caretakers and not be called upon to determine when their loved ones should live or die.

Identifying appropriate parameters for patient autonomy and explicitly recognizing the relationship patients enter with doctors can help create a system of dying that imposes far less on innocent family members as life draws to a close. Patients themselves would be responsible for identifying the values that would govern decisions about their bodies. Medical personnel would be responsible for implementing those decisions. And families, the real victims of today's non-system, would be freed of the burden of determining whether and when loved ones would live or die.

A system in which physicians are required to learn their patients' moral preferences, and then to make treatment decisions for them when they are incapacitated has a number of advantages. First, it would help vindicate personal autonomy. For example, in each of the three seminal cases described above, the patient had a generalized moral view of end-of-life issues. But their views had never been developed or properly expressed. By emphasizing the role of doctors to convert moral decisions into treatment decision, we create a locus of responsibility for having patients express their views in a time and manner that can definitively lead to treatment decisions.

In addition, such a system would instigate the creation of a science to end-of-life decision-making. Because decision-making now is focused on the family, no standards have evolved to help evaluate the decision-making process. Returning the medical profession to the end-of-life treatment arena will ensure that methods will evolve for translating moral decisions into treatment decisions. As these methods crystallize, the moral choices will become clearer as well, because categories of treatment will evolve that enable patients to better understand how their moral views will be converted to reality.

This system would also be compatible with the skills and interests of patients. The process of becoming so ill that one is incapacitated to the point of death is transformative; it may be impossible for a person truly to project a decision into the future that represents his or her real moral view.¹¹¹ This appears to have been the

¹⁰⁹Thus, doctors are said to have a fiduciary relationship with their patients. See Roger B. Dworkin, *Getting What We Should from Doctors: Rethinking Patient Autonomy and the Doctor-Patient Relationship*, 13 HEALTH MATRIX 235, 236 n.7 (2003). Dworkin argues persuasively that current notions of the doctor-patient relationship are conflicted, representing neither a true fiduciary relationship nor true autonomy and that doctors should instead be charged to behave towards importantly affected individuals with respect for their well-being.

¹¹⁰See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 790 (D.C. Cir. 1972); *Cobbs v. Grant*, 502 P.2d 1, 6-7 (Cal. 1972).

¹¹¹Imagine a twelve year old who takes a vow to her father to remain chaste until marriage. Is the vow meaningful when she turns fifteen? Eighteen? Twenty-one? Thirty-

justification for courts to ignore the weakly expressed wishes of Karen Quinlan and Nancy Cruzan and impose their own utilitarian views upon these women. By strengthening patients' ability to express clear moral views, while reducing the expectation that they can anticipate how they would make treatment decisions, the process can be clarified, allowing more patients to take control over their care.

Certainly, creating a new paradigm would require addressing an entirely new system of pressures. A new paradigm would require doctors and patients to reinvest in a closer and more personal relationship, a worthwhile goal in any event, but difficult to achieve in today's specialist-oriented system. Physicians with moral objections to preferences expressed by patients would need to be accommodated. Some monitoring would need to be undertaken to ensure that utilitarian values, especially financial considerations, do not infringe on autonomy. At the same time, additional medical malpractice costs would need to be avoided. These pressures are not insurmountable, however, and are worth addressing to advance a better end-of-life decision-making process.

Vesting treatment decisions with doctors while reserving moral decisions to patients may seem pathbreaking, but it is in fact merely a variation of an early court opinion in this area. In a fascinating if now-forgotten chapter of the *Quinlan* case, the New Jersey Chancery Court, a lower court that heard testimony on the case, proposed that the courts defer to physicians in end-of-life situation.¹¹²

That lower court initially declined to grant to Karen's father the authority to terminate her treatment.¹¹³ The court first held that since Karen had never specifically decided that she wished to die in these circumstances, the decision of when to terminate Karen's treatment was a medical question and not a judicial one.¹¹⁴ Family members were too personally involved to make a decision, and the courts would not interfere with a treatment decision.¹¹⁵ The decision was to be made by her doctors.

As the New Jersey Supreme Court concluded, the lower court's conclusion that the ultimate decision was medical, not judicial was clearly misguided; it is for the courts ultimately to adjudicate these issues.¹¹⁶ The court's recognition of the unique role to be played by physicians, however, contains a critical understanding. Physicians do have a unique role to play in end-of-life decisions. The role is not to decide for the patient, but it is to find a way to provide treatment that comports with the patient's wishes.

The doctor-patient relationship affords a unique opportunity to learn the patient's views in a neutral setting. Once those views are known, a physician is in a unique position to convert those views into actual treatment decisions. Unlike family and other bystanders, physicians are moral actors in the end-of-life saga; they must treat

five? It is not merely that at age twelve she is incapable of deciding, but also that at age twelve she is incapable of understanding what the choice will be when she reaches more advanced ages.

¹¹²*In re Quinlan*, 348 A.2d 801 (N.J. Super. Ct. Ch. Div. 1975).

¹¹³*Id.*

¹¹⁴*Id.*

¹¹⁵*Id.* at 819-820.

¹¹⁶*In re Quinlan*, 355 A.2d 647 (N.J. 1976).

or not treat their patients. Placing responsibility in the hands of those with a real and moral role would re-invigorate the personal autonomy interest. To the extent that our legal system is aligned with this reality, it will both improve personal autonomy and relieve families from the unfair burden of making end-of-life treatment decisions they are not equipped to make.¹¹⁷

¹¹⁷Ray D. Madoff, *Autonomy and End-of-Life Decision Making: Reflections of a Lawyer and a Daughter*, 53 BUFF. L. REV. 936 (2005). Ray Madoff, a professor at Boston College Law School, spends much of her time teaching about end-of-life decisions. *Id.* When her father became ill, she discovered the vast gulf between the world of law and the world of reality. *Id.* She discovered that a sympathetic and caring doctor was able to guide her family through end-of-life treatment decisions that, while not strictly complying with her father's health care proxy, was sympathetic to the needs of all involved. *Id.* Madoff concludes that her personal experience was that "the law" did not work very well in the real world, where doctors needed to work towards the best result, not one bound up on paper decisions. *Id.* Perhaps, she mused, this is the best system we can get. *Id.*

But, perhaps not. So long as we exclude physicians from the responsibility of discerning their patients' wills and, then, converting them to real-life treatment decisions, our laws and our reality will continue to clash at the cost of personal autonomy and family peace.