PALLIATIVE CARE IN THE U.S. HEALTHCARE SYSTEM: CONSTITUTIONAL RIGHT OR CRIMINAL ACT?

Stephen Arons
PALLIATIVE CARE IN THE U.S. HEALTHCARE SYSTEM: CONSTITUTIONAL RIGHT OR CRIMINAL ACT?

STEPHEN ARONS*

INTRODUCTION

We live in increasingly polarized times, in which science, professional expertise, pragmatism, common sense, and even human empathy are more and more becoming the acceptable collateral damage of the culture wars. The provision of healthcare—and the legal and policy contexts in which it is available—has not been immune from this corrosive process. Where once there was a rough-hewn but functional consensus governing the individual’s right to make private decisions about his or her own medical care, we now have often intemperate and ill-informed public struggle. In this new world of blind certainty, it is all too common to see family members, patients, physicians, and other healthcare workers pitted against each other, and to find that the most complex, difficult, and intimate family and individual decisions about the dying process are being transformed into grist for the political and ideological mills.

For over a quarter of a century, a general consensus has existed among physicians, healthcare experts, and biomedical ethicists that competent patients have the right to refuse unwanted medical care, even life-sustaining care, and to secure their autonomy in these matters through advance directives that become effective upon the loss of legal competence.1 Much of today’s relevant healthcare law

* Stephen Arons, J.D., Harvard University, 1969, is Professor of Legal Studies at the University of Massachusetts, Amherst. In the extended period of thinking through, researching, drafting, and editing this article, the author wishes to acknowledge the invaluable assistance of Barbara Noah, Barbara Morgan, Brynn Rovito, Lew Cohen, Kathryn Tucker, Zita Lazzarini, my colleagues on the End of Life Care Certificate Program faculty at the Smith College School for Social Work, my colleagues in the Legal Studies Department, and Maggie Solis and the rest of the able editors of the Western New England Law Review.

is based on and has reinforced this consensus. At the heart of the consensus is the principle of individual autonomy—the idea that an individual has the right to make decisions about his or her own medical care, with all that implies about one’s own sense of self, one’s values and family relationships, and one’s beliefs about the meaning of life and death.

The provision of palliative care to the terminally ill—including adequate pain management, the assistance of a physician in providing relief from other forms of physical suffering that often accompany dying, and the privacy of the doctor-patient-family relationship—is an essential element of this consensus about a person’s right to make decisions about his or her medical treatment. Palliative care is often the alternative to treatment for the terminally ill when such treatment is not available or has lost its efficacy. Palliative care becomes a necessity when a patient, exercising the right to refuse treatment or to have treatment withdrawn, decides that even life-sustaining medical intervention is no longer desired. The choice of palliative care is itself an expression of the autonomy principle in medicine. Without the availability of palliative care, end-of-life choices for many of us and our families can become not simply difficult and heart-wrenching, but impossibly cruel. This reality raises the question: what might the content of a right to palliative care be, and by what process might such a right be defined as a matter of law, medicine, and ethics?

1. See infra note 79 and accompanying text. Several of the Justices in Glucksberg observed that the provision of pain relief to the terminally ill could be a necessary part of palliative care even when such medication hastens an inevitable death. See infra notes 88 & 118 and accompanying text.
The right to refuse treatment and the availability of palliative care are inextricably intertwined. The attempt to think about one without thinking about the other is a formula for making bad law and bad policy, and for increasing human suffering. But the consensus that supports the right to make these intertwined decisions about our own medical care is now threatened. A number of doctors and nurses have been subjected to criminal accusations, malpractice suits, or investigation by medical or nursing boards for providing palliative care or for following a patient's expressed wishes to terminate unwanted life-sustaining or death-prolonging treatment. The Attorney General of the United States sought to text. When pain management involves the risk of hastening death—the rule of double effect—there is debate about its role in palliative care. That debate may encompass the practice of terminal sedation as part of palliative care. See infra notes 78 & 87 and accompanying text.

The Quill case suggests another issue in defining palliative care. Vacco v. Quill, 521 U.S. 793 (1997). In Quill, the plaintiff and other physicians in New York claimed that terminally ill patients not on life support should have physician assistance available to them just as terminally ill patients who are on life support have it available to them in easing and hastening their deaths. The Court refused to accept that equal-protection argument, calling the former physician-assisted suicide and the latter refusal of medical treatment; but this aspect of the medical and ethical issue of what constitutes palliative care is not necessarily resolved by the Court's distinctions in Quill. A number of other end-of-life palliative care practices may be more easily accepted. See Cantor, supra note 1. Palliative-care physicians have also provided some guidelines for what constitutes adequate palliative care. See, e.g., Nat'l Consensus Project for Quality Palliative Care, Clinical Practice Guidelines for Quality Palliative Care (2004), available at http://www.nationalconsensusproject.org/guideline.pdf.

Social workers, often the meditative force in family and healthcare decision-making at the end of life, have considerable experience and wisdom to impart about palliative care. See Living with Dying (Joan Berzoff & Phyllis R. Silverman eds., 2004). A number of other physician and social work organizations, ethicists, advocacy groups, legal cases, and public controversies can be read as indicating what the content of a right to palliative care—whether created judicially or legislatively—might contain. See, e.g., infra Part IV (discussing the four aspects of the attack on palliative care and on the right to refuse treatment). For a discussion of end-of-life care in general, see generally Hastings Ctr., Improving End of Life Care: Why Has It Been So Difficult? (Bruce Jennings et al. eds., 2005), available at http://www.mywhatever.com/cifwriter/content/3/files/hastings_improving_eol_care.pdf. Perhaps the most complete and useful answer to the question of what the content of a right to palliative care should include is contained in the answer to the question of what process should be employed to study, construct, and promote such a right. One of the purposes of this Article is to suggest that a multi-disciplinary, well organized, and urgent project be mounted to bring medicine, ethics, and law together in constructing a right to palliative care that would address the real needs of all of us. See infra Conclusion.

3. The term usually used is "life-sustaining" treatment; in many circumstances, treatment that sustains life is a prelude to the saving of life. But in many other cases, the growth of advanced medical technology has made that term inaccurate, for real treatment may be unavailing and advanced technology may simply prolong a painful and unavoidable death. I have added the term "death-prolonging" treatment in order
upend Oregon's Death with Dignity Act by issuing an order that would have exposed every physician in the nation to the chilling possibility of a Drug Enforcement Administration hearing about the physician's intent in prescribing Schedule II Controlled Substances Act (CSA) drugs for pain relief. The U.S. Congress and many individual state legislatures are presently considering legislation that would have the effect of chilling the practice of palliative care medicine, crimping the use of advance directives, and undermining the autonomy principle in medical care for millions of Americans. Even the principle of individual autonomy itself—the liberty that lies at the heart of constitutional democracy in America—is being deconstructed as part of efforts to promote beneficent paternalism or to advance concepts of the meaning of life held by various religious or interest groups. Perhaps the most disturbing example of this phenomenon is a section of the 2005 report of the President's Council on Bioethics, which claims that because illness often deprives patients of autonomy near the end of life, medical decisions should be made by families and physicians rather than by advance directives created when a patient is autonomous.

This Article examines the current legal status of the right of terminally ill and other patients to refuse unwanted medical treatment and to secure adequate palliative care. It discusses several legal, political, and cultural attacks on the availability of palliative care, on the principle of autonomy in advance directives, and on the right to refuse treatment. It observes that the practice of medicine and the relationships among doctors, patients, and families are increasingly politicized by these attacks. It also considers the possibility that a right to palliative care might be found in the Constitution or be created by state legislatures. Finally, the Article concludes that the legal status of these rights is more tenuous than is generally assumed and that we are in the midst of a broad effort to de-legitimize some of the most basic assumptions that Americans hold about their medical care. Tenuous liberty rights and an active cultural and political struggle have created a polarizing socio-legal flux. The strange possibility therefore exists that, in the United States, depending on the outcome of this struggle, the refusal of unwanted medical treatment and the provision of adequate pallia-

to acknowledge the reality that confronts many such terminally ill people and their families.


5. See infra note 139 and accompanying text.
tive care to the terminally ill in the future could be regarded either as matters of individual right or as the commission of criminal acts. A central theme of this Article is that only the former is acceptable in a humane democracy, and that the current conditions of law, culture, and medicine create not only the opportunity but also the need to define a right to palliative care.

Much of what follows concerns the right to refuse treatment, on the assumption that refusing or withdrawing treatment is often a necessary part of, or precursor to, palliative care. Part I uses the *Cruzan v. Missouri Department of Health* case to present the personal, cultural, and political context of a struggle over the right to refuse medical treatment. Part II discusses the legal and constitutional status of the right to refuse unwanted medical treatment, also through an analysis of the *Cruzan* case. Part III examines the right to refuse treatment in the context of providing palliative care for the terminally ill, or for those whose illnesses or conditions will cause their deaths if they decline medical treatment. It moves from the realities and legal doctrine of *Cruzan* to the discussion of end-of-life issues in *Washington v. Glucksberg* and *Vacco v. Quill*. Part IV describes and evaluates some of the main legal and policy actions that threaten the quarter-century consensus about the appropriateness of an individual controlling his or her medical treatment. The Conclusion suggests that the future of a thoughtful, effective, and ethical set of policies about the right to refuse treatment and the provision of palliative care for the terminally ill and others depends upon backing away from the overbearing self-righteousness of the culture wars and acknowledging that end-of-life decisions touch upon the most basic and intimate views of life and death in a diverse nation. The Conclusion also urges that we bring to bear upon the task of guaranteeing adequate palliative care as a matter of right, the already considerable resources of law, medicine, ethics, and our individual experiences with this unfortunately common dilemma.

I. The Right to Refuse Medical Treatment: The Context of the *Cruzan* Case

The right to refuse medical treatment, even life-sustaining medical treatment, has been a fact of legal life for over seventy-five
years. At its inception in 1914, in Justice Cardozo's opinion in the case of Schloendorff v. Society of New York Hospital, an individual was entitled to be free of unwanted and unconsented touching by a physician under the law of battery. Growing out of an intentional tort, the right to refuse medical treatment included the requirement that a patient give his or her informed consent to a medical procedure. In the last quarter of the twentieth century, the right to refuse medical treatment also found a basis in the United States Constitution, with courts referring to either a privacy interest or a liberty interest under the Fourteenth Amendment's Due Process Clause. At the core of both common law and constitutional conceptions of the right has been the principle of individual autonomy. Justice Cardozo put it this way: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." Seventy-six years later, in the Cruzan case, Justice O'Connor filled out the concept of autonomy using the language of constitutional liberty:

The State's imposition of medical treatment on an unwilling competent adult necessarily involves some form of restraint and intrusion. A seriously ill or dying patient whose wishes are not honored may feel a captive of the machinery required for life-sustaining measures or other medical interventions. Such forced treatment may burden that individual's liberty interests as much as any state coercion.

Justice Stevens went still further in his dissent in the same case: "Choices about death touch the core of liberty. Our duty, and the concomitant freedom, to come to terms with the conditions of our own mortality are undoubtedly 'so rooted in the traditions and conscience of our people as to be ranked as fundamental.'"

Cruzan v. Missouri Department of Health is the centerpiece in the development of a constitutional basis for the right to refuse medical treatment. The case magnified both the difficulty and the significance of the constitutional ruling because Nancy Cruzan, the patient involved, was in a persistent vegetative state and thus una-

10. For a brief history of the growth and legal variations of the right to refuse treatment, see Cruzan, 497 U.S. at 270-80.
11. Schloendorff; 105 N.E. at 93.
13. Id. at 343 (Stevens, J., dissenting) (quoting Snyder v. Massachusetts, 291 U.S. 97, 105 (1934)).
14. Id.
ble to contemporaneously communicate a decision about her medical treatment. A discussion of the *Cruzan* ruling and its context is central to appreciating the tenuous legal status of the right to refuse life-saving medical treatment. The depth and complexity of the Cruzan family's tragedy can only be hinted at here, but it is an important part of assessing the meaning of the constitutional doctrine in the case and the intensity of those who oppose the current consensus about the right to refuse medical treatment.

Twenty-six year-old Nancy Cruzan was in a one-car automobile accident in early 1983, and her brain suffered twelve to fourteen minutes of oxygen deprivation before she could be resuscitated by paramedics. After nearly a month in a coma with virtually no sign of improvement, Nancy's father, Joe, and her husband, Paul Davis, signed a consent form to have a gastrostomy tube (for feeding and hydration) inserted surgically in Nancy's stomach in order to make her treatment and care easier. No Cruzan family member could have known that this was a decision that would result in seven years of litigation. As Joe Cruzan said later, "I had no idea I was signing away anybody's rights that day. I would have signed anything. We were just waiting for Nancy to wake up."

Many months of medical interventions and family attention failed to yield any sustained improvement in her condition. Nancy eventually was given a diagnosis of "persistent vegetative state" (PVS). She was permanently unconscious—unaware, unresponsive, unable to communicate, and deprived of any possibility of even the slightest recovery. Her very limited biological existence was sustained—or her dying was prolonged—by the artificial feeding and hydration tube inserted in her abdomen, and by constant care from a loving family and a devoted staff at a state-supported medical facility in Missouri. She was not terminally ill, and in fact her metabolic existence could have been maintained for as many as

15. As Justice Stevens put it, "Nancy Cruzan's liberty to be free from medical treatment must be understood in light of the facts and circumstances particular to her." *Id.* at 331.
17. *Id.* at 17-22.
18. *Id.* at 22.
19. Doctors found that Nancy had been in a persistent vegetative state (PVS) since January 11, 1983. There was some debate about the actual date of the onset of the PVS, but just before the probate court hearing on removal of the feeding tube, no fewer than five doctors agreed that the PVS was long-standing and permanent. *See id.* at 100.
thirty years. Since she was in a state medical facility, the enormous expense of maintaining her in a PVS was born by the State of Missouri.

Nancy Cruzan had had several informal conversations with friends that indicated that she would not want to be kept "alive" under circumstances such as those associated with being in a vegetative state, but she had no living will and had not appointed a healthcare proxy.20 By the fall of 1986, three and one-half years after the accident, and after the exhaustion of every medical option conceivable, Nancy Cruzan's parents (by then her legal guardians) reached the agonizing decision that her feeding and hydration tube should be removed and that she should be allowed to die peacefully in accordance with what the family understood to have been her expressed wishes. But the hospital, a state institution, would not agree unless so ordered by a court. In July 1988, a probate court found that there was sufficient evidence of Nancy's intent to warrant the removal of the feeding tube.21

At that point, the media attention, which had already been intense and intimidating to the family, became overwhelming. The question of how long Nancy Cruzan's death and the anguish of her family would be prolonged became a cultural and political cause célèbre as well as a significant constitutional contest. What had once been a most private, and in some senses, isolated family crisis, in which no person would wish to have to participate, had turned into a nationwide contest of seemingly boundless moral, political, cultural, religious, legal, and emotional significance in which indi-

20. Missouri law does not permit a living will to include the withdrawal of artificial feeding and hydration even from a person in a PVS. Mo. Rev. Stat. § 459.010(3) (2006). This led Missouri Supreme Court Judge Welliver, in his dissent in Cruzan v. Harmon, to write,

Yes, we Missourians can sign an instrument directing the withholding or withdrawal of death-prolonging procedures, but, after the Missouri amendments, "death-prolonging procedure" does not include: (1) the "administration of medication," (2) "the performance of medical procedure [sic] deemed necessary to provide comfort, care or to alleviate pain" (3) "the performance of any procedure to provide nutrition," or (4) "the performance of any procedure to provide . . . hydration." If we cannot authorize withdrawing or withholding "medication," "nutrition" or "hydration," then what can we authorize to be withheld in Missouri? The Missouri Living Will Act is a fraud on Missourians who believe we have been given a right to execute a living will, and to die naturally, respectably, and in peace.


21. A history of the case, from the trial court up to the Missouri Supreme Court, can be found in Cruzan v. Harmon, 760 S.W.2d 408.
individuals, interest groups, politicians, religious figures, and pundits of every stripe seemed to feel entitled to characterize the Cruzan family's motives and to control their actions.\textsuperscript{22}

The probate court's decision was appealed by the State of Missouri, whose Attorney General was William Webster and whose Governor was John Ashcroft. It would not be an exaggeration to note that Nancy Cruzan's life was once again taken from her.\textsuperscript{23} The Missouri Supreme Court overturned the probate court, ruling, in effect, that clear and convincing evidence of Nancy Cruzan's intentions, expressed at the time when she was legally competent, was not presented by the family's witnesses.\textsuperscript{24} The U.S. Supreme Court affirmed this decision in a five to four ruling in which Chief Justice Rehnquist wrote for the majority that "for purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."\textsuperscript{25} Still, the Court held that Missouri was constitutionally entitled to impose a rule of decision requiring clear and convincing evidence in such cases, thus sending the Cruzan family back to the local probate court to retry the issue of Nancy Cruzan's wishes. It had been seven and one-half years since an automobile accident had put Nancy Cruzan in a permanent vegetative state and the rest of the Cruzan family in a state of perpetual grieving.

A new hearing was held using the required clear-and-convincing-evidence standard and, with very little new evidence, the court once again determined, on December 14, 1990, that it would have been Nancy Cruzan's wish not to be maintained in a progressively worsening PVS by continuing medical treatment that offered abso-

\textsuperscript{22} The \textit{Cruzan} case bears similarities to the more recent case of Theresa Schiavo in the sense that an ideological and cultural public conflict seemed to supersede the private realities and values of the families; but the \textit{Cruzan} case carries a heavier weight in constitutional doctrine on the right to refuse treatment. \textit{See, e.g.,} Barbara A. Noah, \textit{Politicizing the End of Life: Lessons from the Schiavo Controversy}, 59 U. MIAMI L. REV. 107 (2004). For medical and social work perspectives, as well as legal and policy commentary, see Special Issue, \textit{The Lessons of the Terri Schiavo Case}, 4 \textit{Palliative \& Supportive Care} 411 (2006). \textit{See also} Gostin, \textit{Ethics, the Constitution and the Dying Process}, supra note 1.

\textsuperscript{23} When the case reached the U.S. Supreme Court, Justice Stevens commented on the state's motives this way: "The opposition of life and liberty in this case are thus not the result of Nancy Cruzan's tragic accident, but are instead the artificial consequence of Missouri's effort and this Court's willingness, to abstract Nancy Cruzan's life from Nancy Cruzan's person." \textit{Cruzan}, 497 U.S. at 351 (Stevens, J., dissenting).

\textsuperscript{24} \textit{See Cruzan}, 760 S.W.2d at 426.

\textsuperscript{25} \textit{Cruzan}, 497 U.S. at 279.
olutely no hope of any improvement in her condition. The State of Missouri did not appeal, and Nancy Cruzan’s artificial feeding and hydration was withdrawn by court order that day. She finished dying on December 26, 1990, but not before some of the many protestors who had gathered outside the medical facility sought to break in on the Cruzans’ bedside vigil and “rescue” Nancy with cups of water. Other protestors had circulated flyers describing Nancy as “smiling at amusing stories, weeping after visitors had left, ‘eating bananas, potatoes, and link sausages, and drinking juice’ after her accident.” Operation Rescue protestors, taking a page from their campaign against reproductive freedoms, had accused the Cruzans of being murderers. The conduct of the protestors prompted one judge to warn, in dismissing an Operation Rescue petition to extend the Cruzan family’s agony, that “further filings could be [considered] an abuse of process.”

One other matter completes the context of the doctrinal debate found in the Cruzan opinions. The Cruzan family’s tragedy began with Nancy’s accident and her rapid decline into unrecoverable unconsciousness, but it was compounded by the fact that this loving family had to contend daily with a struggle magnified by the media, delayed by seemingly endless litigation, and seized upon by interest groups whose political goals or religious convictions must have seemed to those groups important enough to justify prolonging not only Nancy’s biological existence, but also the Cruzan family’s emotional and spiritual anguish. Under these conditions, Nancy’s father Joe, though he ultimately prevailed in court, could hardly have considered the fruits of his long struggle on Nancy’s behalf to be a win. More than five years after the world of politics

27. Id. at 373.
28. Id. at 368; see id. at 367-80 (describing the protests at the hospital). The abstract issue had become so intense that the protestors completely lost any sense of the reality of the case and any human understanding of the Cruzan family’s ordeal. Colby reports that one judge became so exhausted by the protestors’ attempts to exploit the judiciary that he interrupted one protestor’s plea by saying, “I just despise people like you…” “Get out of here.” Id. at 380.
29. Many of the protestors were from outside of Missouri and plainly veterans of campaigns against reproductive freedom. The intensity of these protestors and the substance of their arguments convey a sense in Colby’s book that much more was at stake for them, and for the state’s position in the litigation, than Nancy Cruzan’s medical treatment or even the general principle of the right to refuse life-sustaining medical treatment. It was, perhaps, a single battle in a larger legal and cultural war. See generally id. at 368-80.
30. Id. at 380.
and media had lost most of its interest in the meaning of this tragedy, Joe Cruzan—having achieved a victory that secured an irretrievable loss and having been exhausted by an emotional struggle with what must have seemed like a cold and unforgiving world of culture warriors—committed suicide. His suicide is perhaps the most poignant measure of the toll that polarizing politics can take on those individuals and families who are forced by circumstances to contend with the complex spiritual and physical realities—and the ambivalent emotions—that lie at the heart of a family tragedy like the Cruzans'.

II. THE RIGHT TO REFUSE MEDICAL TREATMENT: LEGAL DOCTRINE IN THE CRUZAN CASE

A careful, contextual reading of the five opinions in the U.S. Supreme Court's five to four decision in Cruzan is both hopeful and discouraging for anyone interested in preserving the legal, medical, and ethical consensus about the right to refuse unwanted medical treatment. In fact, so varied are the contextual and doctrinal bases of these opinions—and so pointed the disagreements among the Justices—that on the whole, Cruzan adds more ambiguity than clarity to the law in this area. The two main problems with the decision in Cruzan are discussed below.

A. A Tentative Statement of a Tenuous and Poorly Described Right

Chief Justice Rehnquist delivered the opinion of the Court, concluding that there is nothing in the Constitution that forbids Missouri from adopting a clear and convincing evidentiary standard for those seeking to show that a patient in a PVS would want artificial feeding and hydration either withheld or withdrawn. In reaching this conclusion, the Court explored the putative constitutional right to refuse unwanted medical treatment, but was willing to go no further than to state,

The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions. . . .

. . . . . But for purposes of this case, we assume that the United States Constitution would grant a competent person a
constitutionally protected right to refuse lifesaving hydration and nutrition.\textsuperscript{32}

The other basis for a right to refuse medical treatment, tort law, and the requirement of informed consent, was explored at length by the Court, thereby demonstrating how much a part of American life and medicine that right has been for over seventy-five years. But the crucial question put at issue by the probate court’s holding in \textit{Cruzan} and by the Missouri Supreme Court’s reversal of that holding, was whether a constitutional basis for protecting this individual right, either as a matter of privacy or liberty, could be found. Chief Justice Rehnquist’s exploration of the lengthy history of tort law on the subject, and his shorter history of state court rulings on the constitutional basis of the right, shows a wide variety of differing approaches and considerable disagreement and uncertainty about how to understand and approach the issue of the right to refuse medical treatment. In view of this, the Court’s very tentative statement on the matter is not particularly helpful or encouraging.

The weakness of the Court’s statement of the liberty right is put in bold relief by Justice Brennan’s dissent, in which he commented that the Court refused to discuss “either the measure of that liberty interest or its application,” and concluded from his own extensive analysis that “if a competent person has a liberty interest to be free of unwanted medical treatment . . . it must be fundamental.”\textsuperscript{33} Justice Brennan’s discussion of the right to be free of unwanted medical treatment in tort and in related constitutional cases places the fundamental nature of the right in the context of all-too-common human dilemmas:

\textsuperscript{32} Cruzan v. Mo. Dep’t of Health, 497 U.S. 261, 278-79 (1990) (emphasis added). Justice O’Connor’s concurring opinion went a bit further:

> Requiring a competent adult to endure such procedures against her will burdens the patient’s liberty, dignity, and freedom to determine the course of her own treatment. Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual’s deeply personal decision to reject medical treatment.

\textit{Id.} at 289 (O’Connor, J., concurring). Justice O’Connor’s was the swing vote in the case.

\textsuperscript{33} \textit{Id.} at 304 (Brennan, J., dissenting). The question of whether the liberty at stake here is fundamental is central; and in this case that question is made more complex by the fact that Nancy Cruzan was not legally competent to exercise the right—fundamental or not—herself. See \textit{id.} at 321-26 (discussing the loss of decisional capacity and the clear and convincing standard of evidence).
The right to be free from medical attention without consent, to determine what shall be done with one's own body, is deeply rooted in this Nation's traditions.

The right to be free from unwanted medical attention is a right to evaluate the potential benefit of treatment and its possible consequences according to one's own values and to make a personal decision whether to subject oneself to the intrusion.

Dying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. "In certain, thankfully rare, circumstances the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve."34

Had the Court taken the measure of the liberty interest at stake and found it to have been a fundamental one, not only would the state's burden in justifying its attempt to infringe upon Nancy Cruzan's liberty have been considerably greater, but the value of *Cruzan* as precedent would also have been greater.

Justice Brennan's understanding of the right to refuse life-sustaining treatment in general—and of what was at stake for the Cruzans and for the thousands of other families with loved ones in a PVS—highlights the paleness of Chief Justice Rehnquist's understanding of these same matters. For example, the majority opinion claimed that "[a]n erroneous decision not to terminate [Nancy Cruzan's medical treatment] results in a maintenance of the status quo [and suggests that medical or evidentiary discoveries] create the potential that a wrong decision [not to terminate] will eventually be corrected or its impact mitigated."35 Justice Brennan saw a dimension that reflects the actual experience of families faced with complex and heart-wrenching decisions about artificial life support.

But, from the point of view of the patient, an erroneous decision in either direction is irrevocable. . . . An erroneous decision not to terminate life support . . . robs a patient of the very qualities protected by the right to avoid unwanted medical treatment. His own degraded existence is perpetuated; his family's

---

34. *Id.* at 305-11 (quoting *Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626, 635-36 (Mass. 1986)). The fact that end-of-life treatment issues have become more difficult and more common with the extraordinary rise of medical technology in the past half century does not lessen the historical importance of these aspects of individual liberty.

35. *Id.* at 283 (majority opinion).
suffering is protracted; the memory he leaves behind becomes more and more distorted.  

Justice Stevens put the difference between the majority's and dissent's understandings of the rights and realities of the case in still bolder relief. In describing the nature of the individual liberty at stake, Justice Stevens reasoned that just as the physical aspects of life are protected by individual liberty, "so too the constitutional protection for the human body is surely inseparable from concern for the mind and spirit that dwell therein." He noted as well that the right to refuse treatment "presupposes no abandonment of the desire for life. Nor is it reducible to a protection against batteries undertaken in the name of treatment, or to a guarantee against the infliction of bodily discomfort." After noting that the Court was willing to ignore Nancy Cruzan's best interests and to minimize important aspects of her liberty interest, Justice Stevens observed that "[t]he Court's willingness to find a waiver of this constitutional right reveals a distressing misunderstanding of the importance of individual liberty."

The strength of the Court's statement about the liberty interest at stake in refusing unwanted medical treatment was thrown into further doubt by Justice Scalia's concurring opinion. Justice Scalia's opinion considered any refusal of life-sustaining (or death-prolonging) medical treatment to be an act of attempted suicide; and he claimed that "American law has always accorded the State the power to prevent, by force if necessary, suicide—including suicide by refusing to take appropriate measures necessary to preserve one's own life." Justice Scalia supported the requirement of clear
and convincing evidence in *Cruzan*, but would have preferred to have left the whole controversy to decision by a majority of Missouri voters: "[E]ven when it is demonstrated by clear and convincing evidence that a patient no longer wishes certain measures to be taken to preserve his or her life, it is up to the citizens of Missouri to decide, through their elected representatives, whether that wish will be honored."\(^{41}\)

In view of this opinion, Justice Scalia's concurrence with the Court's assumption of the existence of a liberty interest in *Cruzan* seems disingenuous at best, and the legal value of the Court's assumption must be discounted considerably because of it. In his dissent, Justice Stevens suggested that because of the spiritual dimension to decisions such as those made by the *Cruzan* family, religious freedoms are implicated: "[N]ot much may be said with confidence about death unless it is said from faith, and that alone is reason enough to protect the freedom to conform choices about death to individual conscience. . . . Our ethical tradition has long regarded an appreciation of mortality as essential to understanding life's significance."\(^{42}\) But Justice Scalia would have none of it: "This is a view that some societies have held, and that our States are free to adopt if they wish. But it is not a view imposed by our constitutional traditions, in which the power of the State to prohibit suicide is unquestionable."\(^{43}\)

Some of these weaknesses in the Court's statement about the right to refuse medical treatment also arise because of differences in the ways in which the question before the Court is described. The Chief Justice stated that *Cruzan* was "the first case . . . squarely present[ing the question of] whether the Constitution grants what is in common parlance referred to as a 'right to die.'"\(^{44}\) This may

\(^{41}\) Id. (emphasis added). Although Justice Scalia couches this argument in terms of restraining activist judges, it is in fact an argument that there is no constitutional (as opposed to common law) right of individuals to be free of unwanted, life-sustaining medical treatment. This suggests that the state's power over what many Americans and much of jurisprudence consider fundamental to constitutional democracy is nearly unlimited. For a similar view about the power of political majorities to control family and individual life, see Justice Scalia's opinion for the Court in *Oregon v. Smith*, 494 U.S. 872 (1990).

\(^{42}\) *Cruzan*, 497 U.S. at 343 (Stevens, J., dissenting).

\(^{43}\) Id. at 300 (Scalia, J., concurring). This statement is especially problematic for the right to refuse life-sustaining treatment—or perhaps any treatment—because Justice Scalia considers such decisions to be attempted suicide. For a discussion of why the suicide formulation is "too simplistic," see Cantor, *supra* note 1, at 409.

\(^{44}\) *Cruzan*, 497 U.S. at 277. This formulation may have been useful rhetorically to the Chief Justice in *Cruzan*, but it would become problematic for him in the physi-
have been useful in arousing opposition to the claimed right. The majority opinion had also described the question as "whether Cruzan has a right under the United States Constitution which would require the hospital to withdraw life-sustaining treatment from her." This may have been useful in casting the focus of the issue away from Nancy Cruzan's decision and onto the idea that the state would be causing her death by allowing her treatment to be stopped. The Court also put the question in terms of Missouri's rule of decision, making it seem like a merely procedural question rather than one of substantive rights. Justice Brennan's dissent also makes use of a Justice's prerogative to state the question in a way that partially answers itself to his or her own liking. "The question before this Court is a relatively narrow one: whether the Due Process Clause allows Missouri to require a now-incompetent patient in an irreversible PVS to remain on life support absent rigorously clear and convincing evidence that avoiding the treatment represents the patient's prior, express choice."47

But the most telling formulation of the question in Cruzan, the one that acknowledges and is based upon the actual context of the case and of the Cruzan family's dilemma, is provided by Justice Stevens:

If Nancy Cruzan has no interest in continued treatment, and if she has a liberty interest in being free from unwanted treatment, and if the cessation of treatment would have no adverse impact on third parties, and if no reason exists to doubt the good faith of Nancy's parents, then what possible basis could the State have for insisting upon continued medical treatment?48

45. Cruzan, 497 U.S. at 269.
46. Id. at 277.
47. Id. at 303 (Brennan, J., dissenting).
48. Id. at 334 (Stevens, J., dissenting). The question of why Missouri Attorney General William L. Webster and Governor John Ashcroft intervened in the first place—of what the state's interests really were—is made more pointed when one reflects on the second probate court's finding after the Supreme Court's ruling. Using virtually the same evidence and the required clear and convincing standard, the judge ruled again that Nancy Cruzan would have wanted treatment terminated and ordered it done. Colby, supra note 16, at 359-62. After that second ruling, there was no appeal ordered by Webster or Ashcroft. Id. at 365-66. The state's interest had apparently been satisfied by the Court's right-to-life logic, not by the actual outcome of the case.
B. Misstating the State’s Interests and Accepting its Imbalanced Procedure

With even a grudging declaration that there is an individual liberty interest in refusing medical treatment, the balancing of a state’s legitimate interest in overcoming that right was central to the ruling in *Cruzan*. The Court began its analysis with a distillation of state interests in right-to-refuse-treatment cases at the state level, including “the preservation of life, the protection of the interests of innocent third parties, the prevention of suicide, and the maintenance of the ethical integrity of the medical profession.”49 The Court concluded that “Missouri reli[e]d on its interest in the protection and preservation of human life, [to justify imposing a clear and convincing evidence standard] and [that] there can be no gainsaying this interest.”50 The Court then made two arguments central to its conclusion that the state’s interest in the protection and preservation of life was more than strong enough to justify the burden that Missouri placed upon the exercise of Nancy Cruzan’s liberty interest.

First, the Court stated that the real question was one of accuracy of decision—of whether there was sufficient evidence to ensure that Nancy Cruzan’s wishes actually were that her medical treatment should be terminated if she were in a PVS.51 Here, the Court claimed that the clear and convincing evidence standard that it approved is merely a procedural safeguard designed to provide assurance of the accuracy of any finding about Cruzan’s wishes. Second, the Court reasoned that “a State may properly decline to make judgments about the ‘quality’ of life that any particular individual may enjoy”52 by acting to preserve metabolic existence no matter what the circumstances. There are weaknesses in the reasoning of each of these arguments for *Cruzan*’s elevating the constitutional status of the state’s interest in protecting and preserving life. As a result, the case becomes an exemplar of how easily the

---

50. *Id.* at 280.
51. *See id.* at 281. This question is raised by the fact that Ms. Cruzan was medically and legally incompetent to assert her own rights or to express her own wishes because she had been in a PVS for years after her auto accident. *Id.* at 266. Since she did not have an advance directive (i.e., a living will or healthcare proxy), it became necessary for her family to try to piece together what she did say and what she would have wished about her medical treatment. The State joined the struggle over her fate when her parents and co-guardians informed the state hospital director of their decision and he refused to comply without a court order. *Colby, supra* note 16, at 49-50.
52. *Cruzan*, 497 U.S. at 281.
tenuous constitutional right to refuse medical treatment can be trumped by an artificially enhanced state interest in protecting life.

As to the first argument, the majority opinion in *Cruzan* stated that Missouri recognized the right of a surrogate to terminate artificial feeding and nutrition under certain circumstances, but “it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent.”53 But Justice Brennan’s dissent pointed out that this is not a substantively neutral procedural protection, but a “markedly asymmetrical evidentiary burden” upon Nancy Cruzan’s fundamental right to refuse medical treatment.54 The clear and convincing evidence standard was applied to the question of whether Cruzan would want the life support removed, but not to the question of whether she would want the life support continued.55 Because of this imbalance, an ostensibly neutral procedural requirement had the foreseeable effect of creating a presumption that the state’s definition of *life* would prevail.

The Court sought to bolster its argument about the rule of decision by claiming that an erroneous decision to terminate life support is irrevocable, while an erroneous decision not to terminate life support does no real harm to the patient or her liberty interest.56 The weakness in this argument is a reflection of the Chief Justice’s apparent unwillingness to discuss the nature and scope of Cruzan’s liberty interest, as Justice Brennan pointed out.57 The Court also argued that a rule of decision, whether requiring clear and convincing evidence or proof beyond a reasonable doubt, was created to “‘instruct the factfinder concerning the degree of confidence our society thinks he should have in . . . a particular type of adjudication,’”58 and to distribute the risk of error in the decision accordingly. Again, Justice Brennan exposed the flaw in the argument:

In the cases cited by the majority, the imbalance imposed by a heightened evidentiary standard was not only acceptable but

53. *Id.* at 280.
54. *Id.* at 316 (Brennan, J., dissenting).
55. *Id.*
56. *Id.* at 283 (majority opinion).
57. See supra notes 33-34, 36 and accompanying text.
required because the standard was deployed to protect an individual’s exercise of a fundamental right, as the majority admits. In contrast, the Missouri court imposed a clear and convincing evidence standard as an obstacle to the exercise of a fundamental right.  

Brennan also pointed out that there are other, more even-handed and effective protections available to minimize the risks of an inaccurate decision about a patient’s wishes. The easiest example is the guardian ad litem, whose “task is to uncover any conflicts of interest and ensure that each party likely to have relevant evidence is consulted and brought forward.” The trial court employed such a guardian, but his recommendations and findings were ignored by the Missouri Supreme Court.  

The U.S. Supreme Court’s use of the procedural argument is thus misleading not only in its substance, but also in its consequences; for it masks the fact that the *Cruzan* opinion simultaneously inflates the state’s interest and “evinces a disdain for Nancy Cruzan’s own right to choose,” without admitting that it is doing either. Consequently, the strength of the *Cruzan* decision as a protection for the individual right to refuse medical treatment is rendered even lower than might appear from reading the language of the Court’s holding. It is troublesome also that the Court’s approval of the imbalanced standard of proof increases the polarization that is always present in an adversarial process. This adversarial intensity is traditionally regarded as useful to achieving truth in high-stakes cases, but it is far from clear that it will have any such effect on the very complex, emotional, and often ambivalent decisions about terminating medical treatment or seeking palliative care. In fact, it could be argued that it is just this process that encourages interest groups and others far removed from family tragedies like the Cruzans’ to seek to turn difficult and intensely private family decisions into polarizing public battles in the culture wars. The result is the politicization of the doctor/patient relationship.

---

59. *Cruzan*, 497 U.S. at 319-20 (Brennan, J., dissenting) (citation omitted). It should also be noted that the requirement of proof beyond a reasonable doubt, for example, is imposed in criminal cases in part to help rectify the extraordinary imbalance of power between the state as prosecutor and an individual defendant. In the *Cruzan* opinion, it appears that the object was to increase, rather than rectify, an imbalance of power.

60. *Id.* at 318.


The Court's second argument for the primacy of Missouri's interest in preserving life is no more compelling than its argument about the rule of decision. Its statement about Missouri's refusal to make a judgment about "quality of life" is appealing in that it resonates with disabled persons who are rightfully concerned that American society and law devalue their personhood and would deprive them of important rights if not restrained by an appropriate legal analysis of state interests and by a better-educated public. The Court's statement is also aimed at those who believe that state power at all levels is excessive and is becoming a general danger to individual liberty. But in fact the State of Missouri did adopt a particular judgment about the quality of life. It decided that no matter how painful, how divorced from awareness or responsiveness, or how much at odds with the wishes of the person whose life it is, \(^{63}\) metabolic life that would cease naturally must be preserved by medical technology—and "by force if necessary."\(^ {64}\)

Beyond the problem of the Court's somewhat disingenuous logic—its attempt to christen Missouri's interest in preserving any quality of life by artificial means as not a judgment about quality of life—there is the problem of the decision's consequences. Awarding to the state, instead of to the individual, the power to determine what life must be preserved carries with it the constitutional possibility that a state could adopt another, more nefarious determination setting out which lives must be preserved and which sacrificed. Justice Stevens put it this way:

Today the State of Missouri has announced its intent to spend several hundred thousand dollars in preserving the life of Nancy Beth Cruzan in order to vindicate its general policy favoring the preservation of human life. Tomorrow, another State equally eager to champion an interest in the "quality of life" might favor a policy designed to ensure quick and comfortable deaths by denying treatment to categories of marginally hopeless cases.\(^ {65}\)

---

63. That Missouri was determined to overcome even the most clear and convincing statement by even a competent person wishing to refuse medical treatment under certain circumstances can be seen from its living will statute, which cannot be used to refuse or terminate artificial feeding and hydration for a person in a PVS. Even had Nancy Cruzan filled out a living will making her wishes crystal clear, the State's definition of quality of life would still have trumped her individual wishes. See supra note 20.

64. Cruzan, 497 U.S. at 293 (Scalia, J., concurring).

65. Id. at 354-55 (Stevens, J., dissenting). The phenomenon to which Justice Stevens refers—patients or their families insisting upon the use of scarce medical resources to provide what the medical profession would consider "futile" treatments for a particu-
There is also the problem of the sectarian nature of the particular definition of life that is implied by Missouri’s decision about the quality of life that must be preserved by any and all means. Missouri has in effect adopted a particular Christian view and definition of life, its meaning, and nature. To many Americans, there is nothing wrong with this particular theological view of life, but under the Constitution, the state is forbidden from denying to individuals—indeed, does not have the power to deny to individuals—the right to determine these fundamental spiritual questions for themselves. As Justice Stevens put it,

In short, there is no reasonable ground for believing that Nancy Beth Cruzan has any personal interest in the perpetuation of what the State has decided is her life. . . . [I]t would be possible to hypothesize such an interest on the basis of theological or philosophical conjecture. But even to posit such a basis for the State’s action is to condemn it. It is not within the province of secular government to circumscribe the liberties of the people by regulations designed wholly for the purpose of establishing a sectarian definition of life.66

It may be argued reasonably that the majority opinion in Cruzan serves purposes opposite to many of those it claims to advance. Justice Stevens asked the fundamental question about “what possible basis” the State of Missouri could have in resisting the

66. Cruzan, 497 U.S. at 350 (Stevens, J., dissenting) (citing Webster v. Reprod. Health Servs., 492 U.S. 490, 566-72 (1989) (Stevens, J., dissenting)). Justice Stevens here referred to his dissent in Webster v. Reproductive Health Services, a case in which the Court had accepted a Missouri legislative definition of life in the preamble to a statute restricting abortion rights. Webster v. Reprod. Health Servs., 492 U.S. 490, 506-07 (1989). The strategic connection between the right to refuse medical treatment and the right to reproductive freedom is found again two years after Cruzan, in Planned Parenthood v. Casey. Planned Parenthood v. Casey, 505 U.S. 833 (1992). In writing the opinion for the Court, Justice O’Connor reviewed the standards by which the weight of a precedent like Roe v. Wade should be judged. Id. at 857 (citing Roe v. Wade, 410 U.S. 113, 152-53 (1973)). Justice O’Connor’s opinion that Roe should not be overruled included the following: “Roe, however, may be seen not only as an exemplar of Griswold liberty but as a rule (whether or not mistaken) of personal autonomy and bodily integrity, with doctrinal affinity to cases recognizing limits on governmental power to mandate medical treatment or to bar its rejection.” Id. Had Cruzan rejected outright the constitutional basis of the right to refuse medical treatment, the case could have further weakened the right to choose to have an abortion, as reaffirmed in Casey. Id.
Cruzan family and in denying Nancy Cruzan’s constitutional right to refuse treatment. He answered his own question: “The State’s unflagging determination to perpetuate Nancy Cruzan’s physical existence is comprehensible only as an effort to define life’s meaning, not as an attempt to preserve its sanctity.” Once the Supreme Court had accepted, or at least allowed to stand, the Missouri definition of life, there would be no more reason for state officials to bedevil the Cruzan family; and they did not do so.

III. FROM CRUZAN TO GLUCKSBERG: THE RIGHT TO REFUSE TREATMENT AND THE NEED FOR PALLIATIVE CARE AT THE END OF LIFE

On December 14, 1990, Nancy Cruzan’s artificial feeding and hydration tube was removed by order of a Missouri probate court, almost eight years after the automobile accident that had left her in a PVS. In the twelve days that it took her to finish dying in the hospice wing of the hospital, she received no medication or medical intervention. Because of the nature of her condition, she needed no palliative care. But every year, thousands, perhaps hundreds of thousands, of severely ill people do need palliative care as their lives end. Those in need of palliative care are most often patients who have decided to refuse medical treatment or to withdraw life-sustaining medical intervention. Medical treatment may have lost its effectiveness, the suffering caused by the treatment or the disease may have become greater than any benefit that treatment provides, or a terminally ill patient may have decided for any number of personal, spiritual, familial, or other reasons that the best course

67. Cruzan, 497 U.S. at 334 (Stevens, J., dissenting).
68. Id. at 345. Justice Stevens also argued that “[h]owever commendable may be the State’s interest in human life, it cannot pursue that interest by appropriating Nancy Cruzan’s life as a symbol for its own purposes.” Id. at 356. But it appears to have done just that.
69. Not only does the reasoning of the Cruzan majority render uncertain its usefulness in the growing struggle over the individual right to refuse medical treatment, but the highly conflicted opinions in the case also reflect and may encourage the kind of polarizing behavior that made the Cruzans’ struggle so long and painful.
70. In Justice Brennan’s dissent in Cruzan, he noted that “[o]f the approximately 2 million people who die each year, 80% die in hospitals and long-term care institutions, and perhaps 70% of those after a decision to forgo life-sustaining treatment has been made.” Cruzan, 497 U.S. at 302-03 (Brennan, J., dissenting) (citing H.L. Lipton, Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications and Outcomes, 256 JAMA 1164, 1168 (1986)). More recent studies confirm these proportions. See, e.g., LAST ACTS, MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA TODAY (2002), available at http://www.rwjf.org/files/publications/other/meansbetterend.pdf.
for whatever time they have remaining may lie not with medical treatment, but with palliative care. In any of these circumstances—whether a patient is taken off life-sustaining interventions such as respirators or artificial feeding and nutrition, refuses chemotherapy or antibiotics to treat their condition, or simply decides to let a medical condition take its course—the dying process may involve severe or intractable pain, agitation, or other forms of physical distress, loss of control of bodily functions, or any number of other symptoms that can be successfully ameliorated by a physician’s active provision of adequate palliative care.71

These facts of dying, especially the problem of severe pain at the end of life, were recognized as being of possible constitutional significance by several Justices in the 1997 companion cases of Washington v. Glucksberg72 and Vacco v. Quill.73 These cases unanimously upheld the power of a state to criminalize physician-assisted suicide, and each refused to find a fundamental individual right to hasten one’s own death. But in the process of writing six opinions articulating the reasoning of the decisions, the Justices suggest that there might be situations in which a state’s interference with a terminally ill patient’s ability to get adequate pain relief would violate—or lead the Court to discover—an as-yet unarticulated constitutional right. To get to these comments about a central aspect of palliative care for the terminally ill, the Justices had to consider the meaning of Cruzan and the constitutional status of the right to refuse life-sustaining medical treatment.74


72. Washington v. Glucksberg, 521 U.S. 702 (1997) (holding that Washington State’s law against assisting or encouraging suicide does not violate Fourteenth Amendment individual liberty interests, even as applied to competent, terminally ill patients who request physician assistance in hastening their imminent deaths).

73. Vacco v. Quill, 521 U.S. 793 (1997) (holding that New York’s statute making physician-assisted suicide a crime does not irrationally deprive of physician assistance in hastening death only those terminally ill patients who are not on life support). In Quill, the Court found no equal protection violation in a state law permitting those terminally ill who have refused medical treatment or have had life support withdrawn to receive active palliative care from a physician, but denying those terminally ill who are neither on life support nor in need of life-sustaining treatment the chance to receive the active assistance of a physician in hastening even an imminent death. Id. at 808-09.

74. The Ninth Circuit majority had used Cruzan, along with the reproductive freedom case, Planned Parenthood v. Casey, to justify its decision that Washington State’s criminalization of physician assisted suicide violated the fundamental liberty rights of legally competent, terminally ill patients. Compassion in Dying v. Washington,
A constitutional right to refuse life-sustaining medical treatment seems to be supported by the *Glucksberg* and *Quill* decisions, at least insofar as most of the opinions in the cases suggest in one way or another that refusing treatment is not suicide and is therefore distinguishable from the physician-assisted suicide that the Court rejects. But the *Glucksberg* and *Quill* opinions continue the ambiguous status of *Cruzan* and seem to confirm its continuing weakness as a protection for the right to refuse medical treatment. In *Glucksberg*, for example, the Chief Justice reiterated his minimalist statement from *Cruzan* that “[w]e have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment.”75 He relegated a slightly stronger statement to a footnote discussion of the Court’s view about the creation of substantive due process rights: “[W]e concluded that the right to refuse unwanted medical treatment was so rooted in our history, tradition, and practice as to require special protection under the Fourteenth Amendment.”76 In *Quill*, the value of *Cruzan* as a constitutional precedent was reduced still further by describing it as primarily grounded in tort law: “[O]ur assumption of a right to refuse treatment was grounded not, as the Court of Appeals supposed, on the proposition that patients have a general and abstract ‘right to hasten death,’ but on well-established, traditional rights to bodily integrity and freedom from unwanted touching.”77

In spite of minimizing a constitutional grounding for the right to refuse treatment, there is significant discussion of the real needs of terminally ill patients to have access to pain relief and perhaps to other forms of palliative care. The suggestion that five Justices in 1997 were as sympathetic to a putative right to palliative care as they were opposed to finding a right to a physician’s assistance in hastening even an imminent death was raised by Professor Robert Burt in the *New England Journal of Medicine* four months after the *Glucksberg* and *Quill* decisions were handed down.78

---

75. *Glucksberg*, 521 U.S. at 720.
76. *Id.* at 721 n.17.
77. *Quill*, 521 U.S. at 807 (citation omitted) (quoting *Quill* v. *Vacco*, 80 F.3d 716, 727 (2d Cir. 1996)).
Burt's analysis of *Glucksberg* and *Quill* concluded that "[a] Court majority effectively required all states to ensure that their laws do not obstruct the provision of adequate palliative care, especially for the alleviation of pain and other physical symptoms of people facing death."79 Burt's analysis of the opinions of Justices O'Connor, Ginsburg, Breyer, Stevens, and Souter demonstrates that these Justices shared a sympathy for the plight of the many severely ill people not on life support who might have sought a physician's assistance in making their deaths more dignified had New York and Washington State not criminalized physician-assisted suicide. None of the Justices were prepared to find in the Constitution a right to physician-assisted suicide, but they were plainly concerned about whether any state's law unjustifiably aggravated the conditions of dying in America. Accordingly, the Justices provided a number of significant indications that state action that hinders the provision of adequate pain relief might constitute a fact pattern that would prompt the Court to announce a right to palliative care. Justice Breyer put it this way:

>[A]s Justice O'Connor points out, the laws before us do not force a dying person to undergo that kind of pain. . . . Rather, the laws of New York and of Washington do not prohibit doctors from providing patients with drugs sufficient to control pain despite the risk that those drugs themselves will kill. . . . Were the legal circumstances different—for example, were state law to prevent the provision of palliative care, including the administration of

---

79. Burt, *The Supreme Court Speaks*, supra note 78, at 1234. The brief of the United States Justice Department in *Glucksberg*, which supported the constitutionality of New York's and Washington State's statutes criminalizing physician-assisted suicide, nevertheless argued that depriving a person of humane treatment implicates a significant liberty interest. The Justice Department argued that

[the term "liberty" in the Due Process Clause, however, is broad enough to encompass an interest on the part of terminally ill, mentally competent adults in obtaining relief from the kind of suffering experienced by the plaintiffs in this case, which includes not only severe physical pain, but also the despair and distress that comes from physical deterioration and the inability to control basic bodily and mental functions.](https://www.jama.com/jamanetwork/journals/jama/article-abstract/2789339)

drugs as needed to avoid pain at the end of life—then the law's impact upon serious and otherwise unavoidable physical pain (accompanying death) would be more directly at issue. And as Justice O'Connor suggests, the Court might have to revisit its conclusions in these cases. 80

It is significant that in describing the problem of adequate pain management, Justices Breyer and O'Connor suggested that a state might not constitutionally be able to prevent doctors from providing even that pain control that might carry with it "the risk that those drugs themselves will kill." 81 It is frequently the case that for those dying persons in severe or intractable pain, a medication given to reduce the pain to tolerable levels could have the secondary effect of hastening death. The real differences between that form of palliative care and the provision of active physician assistance in hastening dying (such as that prohibited by the laws of New York and Washington State) can be difficult to articulate and troubling to some lawmakers and physicians. 82

Justice Breyer's opinion on pain relief and on the rule of double effect is all the more interesting in view of the facts and theory of the Quill case. 83 Quill was an equal-protection case in which the plaintiffs claimed that the State of New York had no constitutionally justifiable reason to treat two groups of virtually identical, terminally ill patients in such different ways. In particular, the plaintiffs claimed that New York law concerning the terminally ill


82. The medical phenomenon is called the "rule of double effect." For a discussion of the problem as it relates to the practice of palliative care medicine, see Lewis Cohen et al., Accusations of Murder and Euthanasia in End-of-Life Care, 8 J. PALLIATIVE MED. 1096, 1096-1104 (2005). Another form of relief for severe pain and agitation, terminal sedation, also blurs the line between palliative care and physician-assisted suicide, and it also troubles some physicians and policy makers. See, e.g., David Orentlicher, The Supreme Court and Terminal Sedation: Rejecting Assisted Suicide, Embracing Euthanasia, 24 HASTINGS CONST. L.Q. 947 (1997).

was arbitrary and irrational. New York permitted competent, terminally ill patients on life support to have the assistance of a physician in hastening death by withdrawing that life support and by providing the pain relief and other palliative care that is often a necessary part of easing the pain associated with the death that results from such withdrawal. At the same time, according to the plaintiffs, New York's ban on physician-assisted suicide prohibited those patients who were equally terminally ill, equally in pain, and equally competent—but who do not happen to require or receive life support—from receiving a physician's assistance in hastening death through the prescription of self-administered lethal medication. In a unanimous decision, the Court reversed the Second Circuit and found that New York's classification of these two groups of terminally ill persons was constitutionally justified.

The Court of Appeals, however, concluded that some terminally ill people—those who are on life support-systems—are treated differently than those who are not, in that the former may “hasten death” by ending treatment, but the latter may not “hasten death” through physician assisted suicide. This conclusion depends on the submission that ending or refusing lifesaving medical treatment “is nothing more nor less than assisted suicide.” Unlike the Court of Appeals, we think the distinction between assisting suicide and withdrawing life-sustaining treatment, a distinction widely recognized and endorsed in the medical profession and in our legal traditions, is both important and logical; it is certainly rational. The distinction comports with fundamental legal principles of causation and intent.84

The Court provides a lengthy analysis of the two distinctions—causation and intent—that it says underlie the reasonableness of how New York law treats the terminally ill. These arguments do seem reasonable when one defines the problem as one of distinguishing between refusing life-sustaining treatment on the one hand and requesting a physician's assistance in committing suicide on the other.85 The Quill Court was thus able to ground these distinctions

84. Id. at 800 (citations omitted).
85. In defending the distinction, Chief Justice Rehnquist points out that, “New York has acted several times to protect patients' common law right to refuse treatment.” Id. at 806. But several states are now considering legislation that would declare that, contrary to the holding in Cruzan, the provision of artificial feeding and hydration is not medical treatment and therefore cannot be the subject of a right to refuse treatment. See infra notes 97-98 and accompanying text. The weakness of this reassurance about the protections at stake here points up the importance of finding a fundamental
in the state's legitimate interests as discussed in *Glucksberg* and *Cruzan*:

By permitting everyone to refuse unwanted medical treatment while prohibiting anyone from assisting a suicide, New York law follows a longstanding and rational distinction. New York's reasons for recognizing and acting on this distinction—including prohibiting intentional killing and preserving life; preventing suicide; maintaining physicians' role as their patients' healers; protecting vulnerable people from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards euthanasia . . . .

Based on the interest in preventing suicide, the Chief Justice's opinion attempted to use the "intent" distinction to show that a doctor who prescribes self-administered barbiturates to a pain-ridden, terminally ill patient is intending something very different from that which is intended by a doctor who prescribes large doses of morphine to a pain-ridden, terminally ill patient whose life support has just been removed. But when one considers the actual circumstances of the many terminally ill, competent persons who are in great pain but cannot hasten death by refusing or withdrawing life support, the problem gets more complex. The Court's causation and intent distinctions seem both less helpful and less grounded in the realities of dying in America when one considers the ambiguous nature of physicians' and patients' options in end-of-life situations. This is where Justice Breyer's concern that no state should prevent physicians from providing adequate pain relief—even if that assistance actively hastens death—becomes significant. Justice Breyer and the other Justices whose opinions form the basis of a constitutional right to refuse life-sustaining treatment and to receive adequate palliative care.

86. *Quill*, 521 U.S. at 808. The Court's statement about permitting everyone to hasten death by refusing life-sustaining medical treatment (when so many terminally ill persons do not have this option because they are not on life support) not only begs the question of the *Quill* case, but it also reads like Anatole France's famous line, "[T]hey must labour in the face of the majestic equality of the laws, which forbid rich and poor alike to sleep under bridges, to beg in the streets, and to steal their bread." *ANATOLE FRANCE, THE RED LILY* 75 (Modern Library ed., 1917) (1894).

87. As the Chief Justice put it, "[T]he law distinguishes actions taken 'because of' a given end from actions taken 'in spite of' their unintended but foreseen consequences." *Quill*, 521 U.S. at 802-03 (citing Personnel Adm'r of Mass. v. Feeney, 442 U.S. 256, 279 (1979); Compassion in Dying v. Washington, 79 F.3d 790, 858 (9th Cir. 1996) (Kleinfeld, J., dissenting)).
of Professor Burt’s analysis have found the reality-based grey area in the bright-line legal distinctions that Rehnquist has drawn. 88

The problem with the Chief Justice’s opinion in Quill is that it seems to permit the states to criminalize some forms of end-of-life care on the basis of distinctions of physician intent and medical causation that do not respect or reflect the realities confronted by dying patients, their families, and physicians. Rehnquist’s analysis thereby unduly burdens the privacy and the flexibility of the doctor-patient-family relationship. 89 The potential benefit of Justice Breyer’s opinion is that it acknowledges these realities and leaves open the possibility that a right to palliative care may eventually occupy the grey area that the Chief Justice’s opinion insists is either black or white. The fact that Justice Breyer and others on the Court have been willing to recognize the realities of pain management and of end-of-life care reinforces the view that there may be ways to ensure that states do not interfere unreasonably with the provision of palliative care and with the concomitant right to refuse medical treatment. Professor Burt concludes his analysis by observing that

[]laws restricting the appropriate availability of drugs are, moreover, not the only aspect of state actions that obstruct adequate palliative care. As the Institute of Medicine report found, there are other obstructions, such as “mechanisms for financing care [that] impede good end-of-life care . . . .” If state legislatures refused to address such obstructive elements of their laws, or gave them only perfunctory attention, they would be guilty (in Justice Souter’s words) of “legislative foot-dragging,” . . . . Such

88. There is no need to deny the real differences (between permitting the refusal of life-sustaining medical treatment and legalizing physician-assisted suicide) in arguing that there is a grey area in which the Court’s distinctions do not in fact constitute real differences. The problem is difficult for physicians and for medical ethics as well. See Cohen et al., supra note 82. It is a problem of the relationship of doctor, patient, and family in each unique situation, not a problem of public policy. An interesting and provocative reflection on the limits of legal rule-making and the benefits of common law decision-making in this area can be found in the book Limits: The Role of Law in Bioethical Decision Making. Roger B. Dworkin, Limits: The Role of Law in Bioethical Decision Making (1996).

89. The burden is “undue” because there are other ways to prevent abuses in the provision of adequate pain relief or terminal sedation. Oregon’s experience seems to indicate that careful regulation, respectful of patient-doctor privacy, can keep even physician-assisted suicide from becoming abusive—see Oregon’s Death with Dignity Act and the reports of its use since it took effect. Or. Rev. Stat. § 127.800 (West 2006); see, e.g., Or. Dep’t of Human Servs., Eighth Annual Report on Oregon’s Death with Dignity Act (2006), available at http://www.oregon.gov/DHS/ph/pas/docs/year8.pdf.
states would (in Justice Breyer's words) "infringe directly upon . . . the core of the interest in dying with dignity," which involves "medical assistance, and the avoidance of unnecessary and severe physical suffering."90

It is more than simply ironic that such perceptions about the realities of end-of-life care, and about the nature of the liberty rights that are therein implicated, should be met over the decade since Glucksberg and Quill with a wholesale attack upon both the right to refuse medical treatment and the provision of adequate palliative care.91 It may be that these attacks are a strategic political, cultural, and legal response to Cruzan, Glucksberg, and Quill. Perhaps because these cases provide only tenuous protections for constitutional rights of autonomy for the terminally ill, they present weaknesses that the opponents of these principles may be able to exploit. And perhaps because these cases also suggest that patients, families, and physicians might require constitutional protections in end-of-life decision-making, the opponents of autonomy may feel compelled to undercut the medical, ethical, and legal consensus about end-of-life care that has existed for over twenty-five years.

IV. THE ATTACK ON THE RIGHT TO REFUSE TREATMENT AND ON THE PROVISION OF PALLIATIVE CARE

There are four main areas in which political, legal, or ideological action threatens to undermine the right to refuse unwanted medical treatment and the provision of adequate palliative care. These are: (A) proposals of state laws that restrict the right to refuse treatment, (B) federal attempts to supplant state and professional judgments about what constitutes good medical practice, (C) criminal or professional charges brought against physicians and nurses engaged in palliative care, and (D) attempts to undermine the autonomy principle in end-of-life care.

In each of these areas, the effort is to influence or create government policies such that they enact the preferences of one view of end-of-life care—or of life itself—to the exclusion of virtually all others. No doubt many of these efforts are well-intentioned and accord with the beliefs of their proponents. One can be equally


91. At the same time, there has been a high-level effort to upend the one state law that legalizes and regulates physician-assisted suicide. See infra Part IV.
confident that at least at the political level, many of these efforts are engaged in with a blind certainty unconcerned about the complex realities faced by millions of American families. One result has been an increasing polarization, both of the public discourse and of end-of-life issues themselves. Another has been the weakening of the legal protections for the rights that most Americans have come to expect as part of the decades-old consensus about individual decision-making in medical care. Still another has been the politicizing of the doctor-patient relationship and the practice of medicine itself. It is not necessary to discredit the proponents’ motives in order to see how destructive these actions are in their effects. At the close of his dissent in *Cruzan*, Justice Brennan recalled this principle as articulated by Justice Louis Brandeis: “Experience should teach us to be most on our guard to protect liberty when the government’s purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well meaning but without understanding.”

A. Proposing State Laws that Restrict the Right to Refuse Treatment

The National Right to Life Committee (NRLC) has drafted a bill entitled “Model Starvation and Dehydration of Persons with Disabilities Prevention Act,” that would prohibit any surrogate, guardian, public agency, or court from discontinuing artificial nutrition and hydration for a non-competent medical patient except, “If the person executed a directive in accordance with [state advance directive statute] specifically authorizing the withholding or withdrawal of nutrition and/or hydration, to the extent the authorization applies.” In addition to establishing a presumption against a termination of this form of life support for the 80 percent of Americans who do not have advance directives, the bill empowers states to *completely* outlaw the termination of artificial feeding and hydration by adopting laws such as Missouri’s that prevent advance direct-


94. Id. § 4B. Section 4A also provides an exception if the feeding and hydration would not sustain life or would cause discomfort to the patient.
tives from controlling such termination. The model bill also empowers a wide range of persons (including certain public officials, many relatives, and even a patient's former healthcare providers) to bring a civil action for an injunction preventing the removal of this form of life support,

against any person who is reasonably believed to be about to violate or who is in the course of violating this act, or to secure a court determination, notwithstanding the position of a guardian or surrogate, whether there is clear and convincing evidence that the person legally incapable of making health care decisions, when legally capable of making such decisions, gave express and informed consent to withdrawing or withholding hydration or nutrition . . . .

During the pendency of such a civil suit, the model bill would require that the court direct that the artificial feeding and hydration be maintained. The effect of adopting this model bill could be to nearly completely block the termination of this form of life support. If such a bill affecting artificial feeding and hydration can pass and be found not to violate *Cruzan*, the door would be open to laws preventing the refusal of other life-sustaining medical treatments.

The drafting and publication of the NRLC Model Act, amended in January 2006, has not been an academic exercise. Twenty-three states have seen bills based on or similar to the NRLC Model Act introduced as of February 2006. Many of these have languished in committee or been rejected, but the effort to

---

95. See supra note 20.

96. MODEL STARVATION & DEHYDRATION OF PERSONS WITH DISABILITIES ACT, supra note 93, § 5A.

97. There is the general problem of the weakness of *Cruzan*'s constitutional holding. Moreover, Justice O'Connor's concurring opinion in *Cruzan* specifically finds that, and explains why, artificial feeding and hydration was held to be medical treatment.

The State's artificial provision of nutrition and hydration implicates identical concerns. Artificial feeding cannot readily be distinguished from other forms of medical treatment. Whether or not the techniques used to pass food and water into the patient's alimentary tract are termed "medical treatment," it is clear they all involve some degree of intrusion and restraint.

*Cruzan*, 497 U.S. at 288 (O'Connor, J., concurring) (citation omitted). Medical organizations seem to agree, but some religious organizations and leaders, including the Pope, have declared that artificial feeding and hydration cannot be considered medical treatment.

have them adopted has not waned. Three states—New York, Kansas, and Wisconsin—have considered even more restrictive end-of-life care bills that would be particularly threatening to the right to refuse treatment. While none of these has succeeded, aspects of their contents serve to illustrate the intensity of some special interest group opposition to the right to refuse treatment.

In New York, Assembly Bill 7911, introduced in May of 2005, would have required “trial by jury for decisions by a health care agent that would result in the death of an individual” except where a valid, written living will was in existence. The standard of proof in the required jury trial would have been “clear and convincing evidence.” The bill was referred to the Committee on Health and apparently died there. But the idea of submitting decisions, such as those made by the Cruzan family, to a public trial by jury would increase, unconscionably, the delays and suffering endured by families and patients, and would turn a family tragedy into even more of a media platform for the culture wars.

In Kansas, House Bill 2307 was introduced in February of 2005. An extensive revision of the state’s law regarding the powers and obligations of guardians, the proposal would have denied a guardian the power, inter alia, to consent on behalf of the ward “to the withholding or withdrawal of life-saving or life-sustaining medical care, treatment, services or procedures” except “when the guardian can prove beyond a reasonable doubt the ward’s intent, after full informed consent, to withhold or withdraw” such care at a jury trial. Justice Brennan pointed out the asymmetrical nature of Missouri’s “clear and convincing evidence” rule of decision in

---

100. Id.
101. See COMPASSION & CHOICES, COMPASSION CHOICES (2005), http://www.compassionandchoices.org/pdfs/HealthCare_Restrictions.pdf. The information for this contention has been supplemented for New York by the author. Telephone Interview with a member of the Public Information Office of the New York State Legislature, in Albany, N.Y. (Sept. 6, 2006).
104. Id.
But by requiring that proof beyond a reasonable doubt be provided at a jury trial, the Kansas proposal was so much more lopsided than *Cruzan* that it amounted to a virtual ban on the use of advance directives of any kind to carry out the will of a patient expressed when he or she was competent. This bill died in the Judiciary Committee, but it expresses a common insistence on virtual certainty in an area that is by its very nature characterized by ambivalence, ambiguity, emotional conflict, and spiritual searching.106

In Wisconsin, Assembly Bill 207 would have expanded the circumstances in which a healthcare provider would be protected against “employment discrimination” or any other legal consequences for refusing on grounds of “religious or moral belief or conscience” to participate in “[i]ntentionally causing the death of an individual who is not in a terminal condition, as defined in § 154.01(8), by withholding or withdrawing nutrition or hydration,” or “[a]n act that intentionally causes or assists in causing the death of an individual by assisted suicide, euthanasia, or mercy killing.”107 The bill, which would have virtually eliminated the right to refuse treatment and the provision of palliative care by making every healthcare worker the personal arbiter of a patient’s medical treatment, passed in the Wisconsin legislature and was sent to the Governor in October 2005. Governor James Doyle vetoed Assembly Bill 207, saying,

"This bill lets your doctor put his or her political beliefs ahead of your medical best interests. That is simply unconscionable. Medical decisions should be made by the patient and the doctor based on what’s best for the patient, not on the doctor’s political ..."

105. See supra text accompanying notes 59-62.

106. In an article seeking to justify congressional intervention in the *Schiavo* case, Steven Calabresi made the argument that the “beyond a reasonable doubt” standard should be used in any case involving the withdrawal of life-sustaining medical treatment:

*Cruzan*’s holding that Missouri was within its rights to require clear and convincing evidence before an incompetent’s hydration and nutrition is withdrawn, in a case where clear and convincing evidence of a desire to die was not found, does not establish that the clear and convincing evidence standard is the right standard to use in these sorts of cases. We are dealing here with court orders that many Americans believe involve the ending of life. Ordinarily, in end-of-life cases such as those involving heinous murderers convicted of heinous crimes, we demand proof beyond a reasonable doubt before life may be ended . . . .

Calabresi, supra note 58, at 165.

views. . . . This bill doesn’t even require health care providers to
give you a referral to someone else if they object to a particular
treatment. . . .

. . . .

Because it puts a doctor’s political views ahead of the best
interests of patients, this bill ought to be called the “unconscion­
able clause.”

B. Federal Attempts to Supplant State and Professional
Judgments about What Constitutes Good Medical
Practice

Beginning in 1997, the federal government made several at­
ttempts to use the Controlled Substances Act (CSA) to overturn
Oregon’s physician-assisted suicide law, which had twice been ap­
proved by the voters of Oregon and which remained free of consti­
tutional condemnation as anticipated by the Court’s ruling in
Glucksberg. The method chosen to overturn the Oregon law
each time, however, involved casting a chill over the practice of pal­
liative care medicine (and therefore also over the right to refuse
life-sustaining medical treatment) throughout the nation. In 1997,
certain members of Congress requested that Attorney General Ja­
et Reno use her powers under the CSA to revoke the license to
prescribe Schedule II opiates of any physician assisting suicide,
even under the Oregon Death with Dignity Act. Attorney Gen­
eral Reno concluded that the CSA did not grant her that power,
and in 1998, and again in 1999, legislation was introduced in Con­
gress that would have granted the Attorney General the power to
make judgments about the intent of doctors prescribing Schedule II
drugs. The 1998 proposal, House Bill 4006, was entitled the “Le­
thal Drug Abuse Prevention Act of 1998.” The 1999 version of the

108. Executive Vetoes of Bills Passed by the 2005 Wisconsin Legislature from Janu­
ary 3, 2005 to May 30, 2006 (Brief 06-9), Wis. BRIEFS (Wis. Leg. Reference Bureau,


110. “Throughout the Nation, Americans are engaged in an earnest and profound
debate about the morality, legality and practicality of physician-assisted suicide. Our
holding permits this debate to continue, as it should in a democratic society.” Washing­


same proposal, HR 2260,113 was entitled the "Pain Relief Promotion Act of 1999." Neither passed, and in November 2001, Attorney General John Ashcroft issued an Interpretive Rule that stated,

> [A]ssisting suicide is not a "legitimate medical purpose" within the meaning of 21 C.F.R. § 1306.04 (2001), and . . . prescribing, dispensing, or administering federally controlled substances to assist suicide violates the Controlled Substances Act. Such conduct by a physician registered to dispense controlled substances may "render his registration . . . inconsistent with the public interest," and therefore subject to possible suspension or revocation under 21 U.S.C. § 824(a)(4).114

By issuing such a broad rule, the Attorney General was not only claiming the power under the CSA to judge the intentions of physicians in Oregon who might be working within the regulations imposed by the state’s Death with Dignity Act,115 he was also opening the possibility that the Drug Enforcement Agency could investigate the intentions of any doctor in the nation who prescribed Schedule II medications for pain management.116 The State of Oregon challenged this assertion of federal power over its regulation of the practice of medicine, arguing that the CSA did not give the Attorney General the power he claimed. In hearing the case of Oregon v. Ashcroft,117 the federal district court considered numerous amicus briefs from medical organizations, ethicists, and professors arguing that the rule would have a chilling effect nationally. One brief, filed by a “Group of Physicians, Attorneys, and Professors Working in Medical Ethics,” on the appeal to the Ninth Circuit stated,

> [M]any states now, by statute, permit doctors to prescribe sedation sufficient to ensure that a terminally ill patient does not feel pain or experience suffering, even if there is a risk that enough medication to quell the pain or suffering will also be lethal. The expansive powers claimed by the Attorney General would permit him to conclude that such uses of controlled substances are

115. OR. REV. STAT. §§ 127.800-.995.
outside of "the course of professional practice" or do not serve a "legitimate medical purpose," . . . .

Controlled substances are also commonly prescribed to relieve pain in terminally ill patients who have chosen to refuse further life-sustaining care. If the Attorney General opposes such a patient's right to refuse care, as his filing in the Schiavo case suggests, he could effectively prevent the exercise of this right by threatening to revoke the license of any physician prescribing controlled substances to ease the pain of a patient who rejects further life-sustaining support.118

The district court ruled against the Attorney General, and the ruling was affirmed by the Ninth Circuit.119 In January 2006, the Supreme Court affirmed 6-3 on the narrow ground that the CSA did not give the U.S. Attorney General the power he had claimed.120 The Court did not directly address the contention of several amici concerned about a national chilling effect on the practice of palliative care medicine or on the right to refuse life-sustaining medical treatment. Moreover, the Court did not use the case as an opportunity to expand on the suggestions contained in many of the Glucksberg opinions that any state action that unduly burdened a terminally ill patient's right to get adequate pain relief (such as that of Attorney General Ashcroft in 2001) might raise the possibility of finding a constitutional right to palliative care. The Court's only statement in this area was,

Under the Government's theory, moreover, the medical judgments the Attorney General could make are not limited to physician-assisted suicide. Were this argument accepted, he could decide whether any particular drug may be used for any particular purpose, or indeed whether a physician who administers any controversial treatment could be deregistered.121

Because the Court chose the statutory grounds for its ruling, did not reinforce the constitutional right to refuse medical treatment, and did not even make reference to the constitutional consequences of federal or state actions that deny access to palliative care, it left open the possibility of amending the CSA, as had been tried in 1998 and 1999. On August 3, 2006, Senator Sam Brown-

---

119. Oregon v. Ashcroft, 368 F.3d 1118 (9th Cir. 2004).
120. Gonzales, 126 S. Ct. 904.
121. Id. at 921.
back of Kansas introduced the Assisted Suicide Prevention Act of 2006 to do just that. The bill acknowledged that "[a]lleviating pain or discomfort in the usual course of professional practice is a legitimate medical purpose for the dispensing, distributing, or administering of a controlled substance that is consistent with public health and safety, even if the use of such substance may increase the risk of death." But it also empowers the Attorney General to prove "by clear and convincing evidence that the intent of the practitioner was to dispense, distribute, or administer a controlled substance for the purpose of assisting suicide or causing the death of a person." Thus the weakness of Cruzan's constitutional holding and the failure of the Court in Glucksberg, Quill, and Oregon v. Gonzales to strengthen the autonomy principle in medical care has left open yet another front for the continuing attack on the right to refuse treatment and on the provision of palliative care.

C. Criminal or Professional Charges Brought Against Physicians and Nurses Engaged in Palliative Care

In a 1998 article, Criminal Act or Palliative Care: Prosecutions Involving the Care of the Dying, it was reported that a search of national databases uncovered a very small number of indictments of physicians for homicide in connection with providing end-of-life care. The number of such indictments over a fifty-five year period from 1935 to 1990 was ten; but the pace increased considerably in the seven years between 1990 and 1997, when there were seven indictments. Still, the small absolute number seems inconsistent with the anecdotal reports of several physicians and medical researchers, and even a small number of convictions could be having a significant negative impact on the practice of palliative care medicine. A study was therefore initiated in 2006 to determine not only the current prevalence of prosecutions of doctors and nurses engaged in palliative care of the terminally ill, but also the condi-

123. S. 3788, § 3(2).
124. Id. § 4(i)(4).
126. Id.
tions that may have led to those prosecutions. The results of the study are at least a year away. But one example of such a case, drawn from publicly available legal literature and media coverage, illustrates how ideological and political attacks on end-of-life care options can create an atmosphere in which healthcare providers are at risk, constitutional rights to refuse treatment become ever more tenuous, and the ability to get access to adequate palliative care is reduced. At the core of all of these problems is the threat posed by the growing politicization of healthcare to the privacy of the doctor-patient-family relationship and to the integrity of the medical profession.

In January 1996, a Kansas physician, Dr. L. Stanley Naramore, was convicted in a jury trial of the attempted murder of one of his patients and of the malicious second-degree murder of another of his patients in 1992. Dr. Naramore provided palliative care to the first patient, who was suffering from end-stage cancer and was in extreme pain. He had participated in the termination of resuscitation efforts on the second, an actively dying patient. Dr. Naramore was sentenced to serve five to twenty years in a maximum security prison, and was paroled after serving six months. He lost his license to practice and his reputation; he could not maintain his family or his finances, and he could find no job. In July 1998, the Kansas Court of Appeals reversed both of Naramore’s convictions and took the very unusual step of totally exonerating him by directing a verdict of acquittal.

A number of things about the events that led up to and followed the indictments remain unclear and were not dealt with by the Kansas Court of Appeals. It appears that the family of the first patient gave consent to the palliative treatment after a thorough

---

127. The study, funded by the Greenwall Foundation, is entitled *End of Life Care: Healthcare Professionals and Subject Deaths*, and is described in an article by Lewis Cohen et al., in the *Journal of Palliative Medicine*, as being focused on medical and nursing staff who have been targeted and exonerated. We believe the prevalence of such allegations needs to be determined, a more complete understanding of the medical, social, and legal circumstances surrounding accusations should be reached, and the bioethical issues underlying end-of-life care warrant further examination. We hope to discover whether there are specific risk management strategies, public policies, or legal initiatives that can be used to meet this challenge.

Cohen et al., *supra* note 82, at 1102-03.


129. *Id.* at 213.

discussion with Dr. Naramore in the hospital chapel, but it also appears that the son of the patient changed his mind after much of the pain medication had been given.\textsuperscript{131} There were some suggestions that the hospital administrator had been hostile to the doctor and had played some role in convincing the families to turn against him.\textsuperscript{132} It is unclear why the local prosecutor went ahead with the prosecutions without first exploring the standards of medical care observed by Kansas physicians in similar cases. There were also allegations of jury misconduct contained in Naramore's appeal, and there was a claim that the trial judge should have granted a change of venue from the very small Kansas town in which Naramore practiced and from which the jurors were drawn.\textsuperscript{133} Neither of these last two issues was reached by the Court of Appeals.

What does seem clear from the available facts is that the use of the criminal process (in two medical cases involving the most complicated and emotionally difficult decisions that families and physicians ever have to make) is at least partially responsible for this miscarriage of justice. Under these circumstances, an atmosphere was created in which the jury was allowed to ignore accepted standards of good medical practice and make the defendant a lightning rod for the grief and anger that many people feel in the face of death. Personal beliefs and ideologies appear to have taken precedence over careful consideration of the facts and application of legally appropriate standards of judgment.

There was voluminous expert testimony in the case. The Court of Appeals had the benefit of several amicus briefs from physicians and medical associations, and at trial three physicians testified for the state and six for the defense.\textsuperscript{134} The convictions were reversed, and the acquittal ordered, on the basis of legal insufficiency of evidence (and with the implication that the defendant had been railroaded).\textsuperscript{135}

We have made a thorough review of the record, which includes a wealth of undisputed evidence and expert medical testimony. We find that no rational jury could find criminal intent

\textsuperscript{131} Naramore, 965 P.2d at 212, 215. A documentary about the case, hosted by Bill Kurtis, was aired by the A&E Television Networks, and pointed to some of these unresolved questions. \textit{American Justice: A Questionable Doctor} (A&E television broadcast Mar. 5, 2003) [hereinafter \textit{A Questionable Doctor}].
\textsuperscript{132} \textit{A Questionable Doctor}, supra note 131.
\textsuperscript{133} \textit{See} Naramore, 965 P.2d at 224.
\textsuperscript{134} \textit{Id.} at 219-21; \textit{see} \textit{A Questionable Doctor}, supra note 131.
\textsuperscript{135} Naramore, 965 P.2d at 224.
and guilt beyond a reasonable doubt based on the record here. When the issue is whether there is reasonable doubt, a jury is not free to disbelieve undisputed facts. What occurred here is generally known. The jury was not free to disbelieve that there was substantial competent medical opinion in support of the proposition that Dr. Naramore’s actions were not only noncriminal, but were medically appropriate.136

The court further hinted at the problem of politicizing healthcare and the practice of medicine by observing that if it had upheld a jury verdict based on ignoring an “authoritative medical consensus,” it would have “criminalized malpractice and even the possibility of malpractice.”137 In a dissent, the Chief Judge of the Court of Appeals agreed that the verdicts should be reversed, but would have sent the case back for retrial based on adequate instructions to the jury. The dissent makes clear the role that the law ought to play in protecting the provision of quality healthcare to individual patients in a time of public passions and political machinations about end-of-life care.

However, unlike the civil Pattern Jury Instructions provided in medical and professional malpractice cases, there are no criminal Pattern Jury Instructions relating to the medical and moral responsibilities of care givers for the critically or terminally ill patient, nor are there legislatively created screening panels. If care givers are now to be faced with the specter of criminal prosecution in these kinds of cases, then the legislature may want to consider requiring the appointment of panels similar to those used for medical malpractice cases prior to the filing of criminal charges.

... At the very least, in the present case, the jury should have been instructed on the physician’s duty and standard of care when treating a terminal cancer patient for pain and the recognized standard of care and measures to be taken in attempting to save a [dying] patient . . . . Since they were not so instructed, it is impossible to determine whether the jury made an assessment of Naramore’s actions, taking into consideration his role as a physician.138

The case of Dr. Stan Naramore—like the attempt of Attorney General Ashcroft to control the practice of medicine in the states, and like the ongoing state efforts to restrict the right to refuse medi-

136. Id. at 223.
137. Id. at 224.
138. Id. at 225 (Brazil, J., dissenting).
cal treatment—illustrates how the natural anguish that accompanies the death of a loved one, and the unnatural pressures that are sometimes brought to bear by interest groups bent on imposing their own sincerely held morals on everyone, can cast a pall over the practice of palliative medicine and hobble the end-of-life care that we are all someday likely to need.

D. Attempts to Undermine the Autonomy Principle in End-of-Life Care

In a 2005 report by the President’s Council on Bioethics, the following statement was made in a chapter entitled, *The Limited Wisdom of Advance Directives*, as part of an argument that the autonomy principle should be restricted or abandoned in end-of-life care:

> Not only are living wills unlikely to achieve their own stated goals, but those goals themselves are open to question. Living wills make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care.139

The report goes on to praise the usefulness of proxy directives, since proxies “serve the wise and helpful purpose” of providing care and making medical decisions on the basis of the explicit instructions they have been given. But the report concludes that one can never know one’s needs in advance and must therefore rely on decisions made at the time by loved ones. The report praises the directive a patient might give a proxy and the role of the proxy as caregiver and participant in making decisions for patients who have become unable to make their own. But, unlike Justice O’Connor’s opinion in *Cruzan*, the report does not suggest that the healthcare proxy’s decisions, or those of another guardian or surrogate, should be regarded as determinative. Justice O’Connor sees that it is lib-

---

erty at stake: “[T]he Court does not today decide the issue whether a State must also give effect to the decisions of a surrogate decisionmaker. . . . In my view, such a duty may well be constitutionally required to protect the patient’s liberty interest in refusing medical treatment.”

In effect, if not in intent, the President’s Council report lays a philosophical and policy foundation for diminishing the constitutional importance of the liberty interest that the *Cruzan* Court was at least reluctantly willing to articulate. In doing this, the report relies heavily on an article published in 2004 by the Hastings Center, *Enough: The Failure of the Living Will*. The Hastings article takes, among others, an economic view of the value of individual liberty in end-of-life care decisions. The authors claim that “[i]n an attempt to extend patients’ exercise of autonomy beyond their span of competence, resources have been lavished to make living wills routine and even universal. This policy has not produced results that recompense its costs, and it should therefore be renounced.”

There are, of course, practical problems with advance directives just as there are problems with medical decisions made for those who come to the last stages of their lives without having left any instructions or appointed any proxies to carry out their treatment wishes and look after their welfare. One of these problems, referred to in both the President’s Council report and the Hastings article, is that only about 20 percent of Americans execute advance directives of any sort. Some commentators have lamented the low rate of adopting advance directives and the psychological and philosophical dilemmas of a competent person’s deciding what he or she will value when no longer competent. These problems are

---


142. *Id.* at 31.

143. The well-known SUPPORT study provided resources that might have increased the percentage of people with advance directives, but to no avail. *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591, 1591 (1995); see also President’s Council on Bioethics, supra note 139, at 55 (concluding that advance directives will not solve societal problems related to care decisions because only a minority of Americans create them); Fagerlin & Schneider, supra note 141, at 32 (noting that “without considerable intervention approximately 20 percent” of people complete living wills).
then cited to justify declaring not only advance directives but also the autonomy principle itself to be on life support.

In a 1998 book, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*, law professor and physician Carl Schneider suggests that the autonomy principle at the end of life is an empirically ineffective expression of hyper-rationalism. Schneider argues that the evidence of actual end-of-life decision-making points to the fact that in many circumstances physicians are likely to make better decisions than severely ill patients who want only to be taken care of competently. But in a review of the book, Professor George Annas takes issue with Schneider's assessment of how to approach the role of autonomy:

I am with those who believe, unlike Schneider, that patients continue to have too little, not too much, autonomy. . . . I agree . . . that more is at stake than just autonomy and that many choices patients have are illusory and hollow. The central question is not whether patient autonomy should be taken seriously: liberty is a basic human right and is nowhere potentially more compromised than when we are sick. The question is how we can build a medical care system that routinely respects human rights and human dignity as the fundamental constituents of life.145

The consequences of the medical and legal debate over autonomy are far-reaching. In an article entitled *The End of Autonomy*, Professor Robert Burt concludes that the difficulty of being rational about what is essentially irrational (one's own death), and the importance (to patients, families, physicians, and public policy) of maintaining an ambivalent attitude about end-of-life decisions, both support the policy conclusion that an entirely new path should be chosen for regulating end-of-life decisions.

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 unset-

---

tled—even made incomprehensible—by the actual, imminent approach of death.146

The President's Council report and the other policy and scholarly explorations raise interesting philosophical issues and policy problems, but viewed in the context of current law and of political struggle over end-of-life care, they are very problematic. To say, for example, that living wills or other explicit advance directives lack validity because they are used when a person is no longer autonomous is to deny, in effect, the personhood of the maker of the living will. The whole idea of an advance directive is to preserve one's dignity, one's values, and one's liberty into a time when they are dwindling—to use one's capacities while they are fully functional to plan for a time when they are not. There are, of course, many changes of mind, unforeseeable circumstances, and new developments that might influence how an advance directive would be used or how a surrogate might evaluate a patient's previous expressions of will. But the difficulty of so doing is part of the human condition, part of the mystery and the anguish of end-of-life decision-making. These realities cannot be banished by any formula for care of the terminally ill or any regime of decision-making about dying; and the attempt to do so can only reduce the personhood,147 which advance directives in particular, and the autonomy principle in general, are meant to preserve.

There are two other basic problems with these subtle and not-so-subtle attacks on the autonomy principle. First, one has to consider the alternatives to the present tenuous regime of constitutional law. The President's Council report, for example, praises the role of family and of loved ones in making end-of-life decisions. The reality of healthcare politics—as illustrated by culture wars fought over the right to refuse treatment—is that the state or some

146. Robert A. Burt, The End of Autonomy, in Hastings Ctr., supra note 2, at S9, S10. Burt offers three “countervailing schemes” for the social regulation of end-of-life care designed, he claims, to avoid the “malign dynamic” that prevails now and that prevailed before the advent of the autonomy principle. Id. at S11. For another deeply humane but equally dark discussion of the philosophical and psychological realities of our ambivalence toward death, see Robert A. Burt, Death is That Man Taking Names: Intersections of American Medicine, Law and Culture (2002). See also Cruzan v. Mo. Dep't of Health, 497 U.S. 261, 351 (1990) (Stevens, J., dissenting); supra text accompanying note 42.

147. Justice Stevens' observation in Cruzan is apposite: "To deny the importance of . . . [what Nancy Cruzan loses by having medical treatment continued against her wishes] is in effect to deny that Nancy Cruzan has interests at all, and thereby to deny her personhood in the name of preserving the sanctity of her life." Cruzan, 497 U.S. 261, 353 (Stevens, J., dissenting).
interest group, and not the family, will wind up making these decisions. To engage in philosophical debates about the nature of personhood, or the question of "whether the experience of old age with dementia will still seem valuable to a future self" may mask the struggle or it may provide a comfortable haven for speculation about the mysteries of life; but it cannot stop the politicizing effect of the culture wars upon end-of-life care. The realities of law and politics explored in this Article suggest, moreover, that de-legitimizing the autonomy principle may be the last action needed to undermine the medical, ethical, and legal consensus on individual liberty in decision-making about end-of-life care.

The other basic problem with the attack on the autonomy principle is that much of this discussion is so profound. At the discussion's core are questions about the meaning of life, death, and the nature of the Self. It is a discussion fundamental to the ways in which we understand our world and define our relationships to each other, to the state and to the spiritual plane of existence. Differences of belief and of opinion about these elements of the human condition are matters of conscience. As such, they are as important a part of individual liberty and as much deserving of constitutional protection as are the freedoms of religion enumerated in the First Amendment. It is precisely the power and depth of these competing ideas—and the conflict that inevitably ensues when government takes sides in the competition—that should convince us that the autonomy principle is not simply useful in end-of-life care decision-making, it is essential. Justice Stevens put the matter clearly in his dissent in

148. As Justice O'Connor put it, "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 were they formed under compulsion of the State." Planned Parenthood v. Casey, 505 U.S. 833, 851 (1992).
149. See President's Council on Bioethics, supra note 139, at 83.
150. The philosophical debate is an interesting exploration of difficult problems of end-of-life care decision-making. It is easy to lose sight in these discussions of the fact that the United States Constitution is based upon philosophical decisions and political theory that are grounded in the Enlightenment. It is possible that the debate over end-of-life issues may become not only a means to undermine the consensus on patient autonomy in medical care decisions, but a threat to the basis of other individual liberties as well. To explore some of the philosophical debate, see Michael Quante, Precedent Autonomy and Personal Identity, 9 Kennedy Inst. Ethics J. 365 (1999); Rebecca Dresser, Dworkin on Dementia: Elegant Theory, Questionable Policy, Hastings Ctr. Rep., Nov.-Dec. 1995, at 32, 32-38; Ronald Dworkin, Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom (1993).
Our duty, and the concomitant freedom, to come to terms with the conditions of our own mortality . . . are essential incidents of the unalienable rights to life and liberty endowed us by our Creator. . . . [N]ot much may be said with confidence about death unless it is said from faith, and that alone is reason enough to protect the freedom to conform choices about death to individual conscience. We may also, however, justly assume that death is not life’s simple opposite, or its necessary terminus, but rather its completion. Our ethical tradition has long regarded an appreciation of mortality as essential to understanding life’s significance. It may, in fact, be impossible to live for anything without being prepared to die for something.151

CONCLUSION

This review of the Supreme Court cases and of some of the political controversies involving the right to refuse life-sustaining medical treatment and the provision of palliative care suggests that the constitutional rights and the autonomy principle at stake are tenuous, perhaps even unreliable. It also suggests that the ideological and cultural attacks upon these rights are becoming strong, even virulent. The effect has been the politicization of end-of-life healthcare in general, and an undermining of doctor, patient, and family privacy and of the integrity of the medical profession in particular. This last—the politicization of medical practice and of the relationship of doctors to their patients and their families—is a great irony. For among the state interests that the Court has found to be legitimate and important is not only the protection of life but also the ethical integrity of the medical profession, with all that implies not only about easing suffering but also about maintaining the trust and privacy central to the doctor-patient relationship.152

At the same time, there are hopeful signs for the maintenance and enhancement of the quality and dignity of medical care for the terminally ill. Several Justices of the Court have written opinions that indicate not only that they understand and empathize with the

151. Cruzan, 497 U.S. at 343 (Stevens, J., dissenting).
152. Washington v. Glucksberg, 521 U.S. 702, 731 (1997). This state interest includes the idea that the state should protect medical ethics partly in order to secure the conditions of trust between doctor and patient upon which the proper functioning of the entire healthcare enterprise depends. To politicize the relationship between patients and their doctors is hardly to support the trust upon which good decision-making by them depends. It appears, then, that in some cases the state has been using one legitimate interest—the protection of life—to undermine another legitimate state interest—the effectiveness and integrity of the medical profession.
heartaches and struggles of families and patients faced with the need for palliative care, but also that they see the logic of using the liberty protections of the Constitution to secure individual autonomy, family, patient, and physician privacy and the availability of palliative care. Public opinion is clearly and overwhelmingly opposed to the meddling of government and of special interest groups in the private dilemmas of families such as the Cruzans and the Schiavos. The philosophers and advocates of medical paternalism and of religious hegemony are still in the minority. There is potential, therefore, to extend the protections for, and resist the attacks on, end-of-life care by working towards the creation of a comprehensive right to palliative care for the terminally ill and for those who refuse medical treatment.

The creation of a right to palliative care—which might be articulated judicially on the state or federal level or through legislation at the state level—would be a complex matter. Such a right would have to be based on the evaluation of many questions about end-of-life care and refusal of medical treatment like those raised by the cases and controversies discussed in this Article. The process used for recommending the content of a right to palliative care would have to be multi-disciplinary and apolitical, providing ways to take into account the experiences of ordinary Americans and the many forms of professional, academic, and policy expertise already contained in the literature of medicine, social work, ethics, and law. Most important, the work would have to be undertaken by persons who understand that individual autonomy and doctor-patient privacy in making end-of-life decisions are fundamental parts of liberty, and that this liberty must be secured against the politicization and polarization that has characterized so many of the battles in a growing culture war over death and dying in America.

153. See supra note 2 for an outline of some of the substantive issues about the nature of palliative care that would have to be addressed. It might be said that the evaluation of the law and politics of palliative care contained in this Article begins and ends with an urgent call for the construction and adoption of a right to palliative care for the terminally ill, but that it does not prescribe in detail what such a right should contain.

154. Unfortunately, experience has shown that the President's Council on Bioethics might not provide such an apolitical forum. See supra note 139.