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Suppose the Schindlers Had Won the *Schiavo* Case

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Suppose the Schindlers Had Won the Schiavo Case

ALAN MEISEL*

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I. INTRODUCTION

As the *Schiavo* case¹ became increasingly controversial, my first reaction was: "They can't do this. The law in Florida and almost everywhere else is clear that they can't." But as the litigating continued – and continued and continued, as did the legislating – the same thoughts crossed my mind that crossed the minds of so many others, who expressed their thoughts privately and publicly, in letters to the editor, radio talk shows, television news stories, Web postings, and blogs: Why not let Terri's parents take her home and care for her? What would be wrong with that? Why is Terri Schiavo's husband, Michael Schiavo, fighting her parents, Bob and Mary Schindler, tooth and nail? If he wants to get on with his life after more than a decade, that is fine. No one begrudges him that. This is a case where you can have your cake and eat it, too. Terri's parents are not merely willing, but eager to care for her. Michael can obtain a divorce and remarry.²

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1. Or perhaps more accurately, the *Schiavo* cases. The ones with which I am concerned here, those litigating substantive end-of-life law, are *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176 (Fla. 2d Dist. Ct. App. 2001), and *In re Guardianship of Schiavo (Schiavo II)*, 792 So. 2d 551 (Fla. 2d Dist. Ct. App. 2001). The *Schiavo* litigation requires a roadmap to navigate. Fortunately, there is an excellent one. See Kathy Cerminara & Kenneth Goodman, *Schiavo Case Resources, Key Events in the Case of Theresa Marie Schiavo* (2006), <http://www6.miami.edu/ethics/schiavo/timeline.htm>.

2. If Michael were to obtain a divorce, he would lose his right to inherit by intestacy

But Michael Schiavo claimed not merely to be fighting for what he thought was right, but also for what he claimed Terri wanted for herself. His position was that it was not a vindication of *his* interests that he sought, but *hers*. And he was fighting not only for Terri, but for a principle – that the wishes of patients who are unable (and never will be able) to speak for themselves be respected. This being the case, giving in to the Schindlers was not having his cake and eating it, too. It was not even a compromise. It was a sellout: a betrayal of Terri and a betrayal of a principle.

There were really two *Schiavo* cases – the private one and the public one. The private case was the dispute between Michael Schiavo and the Schindlers about whether to maintain Terri's existence in a persistent vegetative state ("PVS").³ The public case concerned Florida law and its possible effect on the law in other jurisdictions. It also concerned important principles. From Michael Schiavo's perspective, it was the principle of autonomy – the right of competent adults to refuse all forms of medical treatment and the right of incompetent adult patients to make those decisions in advance and have them carried out by their surrogates. From the Schindlers' perspective, it was the principle of vitalism – that all human life is priceless and maximum efforts must always be made to sustain it. Letting the Schindlers take on all responsibility for Terri might have sufficed in 1995 or 2000, but by 2005 the public case had taken on a life of its own. It became impossible to settle the private case without compromising principles.

In this Article, I will identify and discuss the harms that would have occurred had the Schindlers won – the harms both to Terri Schiavo in the private case and the larger set of harms to public policy in the public case. The Schindlers fought Michael Schiavo on a variety of battlegrounds – the Florida courts, the Florida legislative and executive branches, the federal courts, and eventually Congress. Had they definitively prevailed in any of these forums, the consequences for end-of-life decisionmaking would have been largely the same. Had they prevailed in Congress or even in the state legislative and executive branches, however, the consequences would have implicated issues beyond end-of-life

whatever sum, if any, remaining in the trust established by the award from the malpractice suit brought on Terri Schiavo's behalf, and her parents would inherit the sum. *Schiavo I*, 780 So. 2d at 178. However, the court concluded that there is "no evidence . . . that either Michael or the Schindlers seek monetary gain from their actions." *Id.*

3. For a recent and comprehensive discussion of PVS, see James L. Bernat, *Chronic Disorders of Consciousness*, 367 LANCET 1181 (2006). A recent study suggests that patients in a minimally conscious state, which involves less severe brain damage than a PVS, may be capable of regenerating segments of brain cells. See Henning U. Voss et al., *Possible Axonal Regrowth in Late Recovery from the Minimally Conscious State*, 116 J. CLINICAL INVESTIGATION 2005 (2006).

decisionmaking, potentially altering the balance among legislative, executive, and judicial power and between federal and state power. Separation of powers and federalism, however, are not the topics I will address.

II. THE PRIVATE CASE: WHAT IS THE HARM? WHAT IS THE PRINCIPLE?

Was the principle involved in the *Schiavo* case – at least as Michael Schiavo saw it – merely promisekeeping? Michael Schiavo claimed that he promised Terri he would never allow this kind of thing to happen to her. So to entrust her parents with her care – the same parents who proclaimed that they would prevent her death by refusing to remove her feeding tube – would have involved breaking that promise.

Who would dispute that promisekeeping is important and a value worthy of societal protection? Nonetheless, we know that not all promises can be kept – especially as time goes on and conditions change. Furthermore, even if we do not know in fact, we are at least on notice that the law does not enforce all promises. Sometimes the law does not even permit promises to be kept, evidence of which abounds in a variety of substantive legal areas. In fact, the law is frequently invoked to prevent promisekeeping.

However, assuming that Michael Schiavo made such a promise to Terri Schiavo, it might prove instructive to understand why it was requested and why it was granted. Many people say something like, “if I’m ever in that fill-in-the-blank condition, I don’t want to be kept alive like that.” They say it after visiting a sick or dying person,⁴ they say it after watching a television program about this subject, or they say it in academic or formal discussions.⁵

Why do people make such statements? There is no single reason, and sometimes more than one can be at work in a particular instance. The most obvious, perhaps, is to forestall the suffering that they expect to experience if they are “kept alive like that.” Another is that they consider existence in such a seriously compromised state to be undignified or purposeless.

People also make such statements to avoid imposing further suffering on their families, friends, and other loved ones. Serious illness can take a tremendous emotional and financial toll on those who are close to a patient. Sometimes such illness takes an additional toll on the health of others, especially if those others provide personal care for people who are living at home with a serious terminal illness over a long period of

4. See, e.g., *In re Westchester County Med. Ctr. ex rel. O’Connor*, 531 N.E.2d 607, 614 (N.Y. 1988).

5. See, e.g., *In re Storar*, 420 N.E.2d 64, 68 (N.Y. 1981).

time. But even when a dying person is in a hospital or nursing home, the emotional toll and the financial cost can be severe. Some people just do not believe it is worthwhile to extend their own lives, with a seriously impaired quality of life, at the expense of bankrupting their families financially, emotionally, or both.

There is another financial reason people make such statements, but the concern is far broader than the financial impact on their families. In fact, such concerns may more likely be voiced by people whose own resources or public or private entitlements (including health insurance and long-term-care insurance) are adequate to protect them and their families from health-induced insolvency. This objection to treatment arises from a concern about the wise use of societal, rather than individual, resources. When there are so many unmet healthcare (or other social) needs, it seems extravagantly wasteful to some to expend large sums to keep one person alive for a short time or in a seriously impaired condition. Better, they believe, that such scarce resources be spent on other people for whom the benefit will be far greater.

The first of these treatment objections does not seem to apply to a PVS patient like Terri Schiavo. What harm would treatment pose for her, a person who could perceive no pain, who could experience no suffering?⁶ Furthermore, in Terri Schiavo's case her family did not face financial insolvency because the proceeds of a lawsuit were financing her care.⁷ If Terri Schiavo had been kept alive in a PVS, it would have taken no physical toll on Michael Schiavo because her parents sought to care for her. And it would have exacted no *unwanted* physical toll on her parents because they volunteered for that duty. Keeping her alive would have meant that her husband failed to fulfill his promise, which might have imposed some emotional toll on him. But, as mentioned

6. There is virtually no responsible scientific opinion claiming that persons in a PVS can experience anything, let alone pain:

The Multisociety Task Force acknowledged the biological limitations to knowing categorically that patients with vegetative state lack all awareness or capacity for suffering or experience because one person cannot directly experience the conscious life of another. We can only interact with another person and make a reasoned judgment about their cognitive life on the basis of the quality of their responses to our stimuli. That we incorrectly deny the presence of their conscious life when it exists simply because we cannot measure it is, therefore, possible. Despite this limitation, there are compelling reasons to conclude that patients in vegetative state utterly lack sentience based on neuroimaging, evoked potential, and neuropathological data.

Bernat, *supra* note 3, at 1183. *But see* Christian J. Borthwick, *The Permanent Vegetative State: Ethical Crux, Medical Fiction?*, 12 ISSUES L. & MED. 167, 175 (1996) ("It is possible that hundreds of patients across the USA are suffering untreated pain because their physicians have relied on the Multi-Society Task Force Consensus Statement.").

7. *Schiavo I*, 780 So. 2d at 178.

above, sometimes there are overriding interests in breaking promises. And the only emotional cost to her parents would have arisen after Terri died, not if she continued living.

But this only considers others' interests. What about Terri Schiavo's interests? Some would assert a "no-interests" position – that Terri Schiavo, as a person in a PVS, had no personal interests once her cognitive faculties departed this world, leaving only her body behind.⁸ However, some believe that she had interests that survived her loss of cognitive functioning. The principle involved, simply put, is respect for Terri Schiavo's wishes.

Prominent among the dissenters from the no-interests position are Justices John Paul Stevens and the late William Brennan, who were literally just that – dissenters in *Cruzan*⁹ – and who explained their position somewhat more richly. The harm was to Terri's memory; she had an interest in being remembered as the vibrant person she was rather than as the shell of a person she had become. To perpetuate her corporeal existence *against her previously expressed wishes* was to perpetuate the former and in the process to do further harm to the latter. Speaking of Nancy Cruzan in particular – but in terms applicable to any patient in a PVS, or indeed any person who wishes to forgo life-sustaining medical treatment – Justice Stevens wrote: "Insofar as Nancy Cruzan has an interest in being remembered for how she lived rather than how she died, the damage done to those memories by the prolongation of her death is irreversible."¹⁰ Echoing these thoughts, Justice Brennan wrote: "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 suffering is protracted; the memory he leaves behind becomes more and more distorted."¹¹

Furthermore, the harm is not merely to the person whose wishes are

8. See, e.g., Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 385 (1986) ("[p]rivacy, bodily integrity, pain, and suffering could no longer matter to" a person in a comatose condition); Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 400 (1988) ("At the very least, a necessary condition for having interests would seem to be the capacity to experience pleasant and unpleasant sensations. Interests, in other words, presuppose consciousness . . ."); John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1157 (1991) ("Irreversibly comatose patients, by definition, have no interests in their present condition, because they lack the mental substrate essential to the possession of interests.")

9. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

10. *Id.* at 353 (Stevens, J., dissenting).

11. *Id.* at 320 (Brennan, J., dissenting). See generally ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* 4-58, -60, -61 (3d ed. 2004 & Supp. 2005).

disrespected. If not a present harm, it is at least a potential harm to all who wish to have their end-of-life treatment preferences honored. This group now lives with the concern (if not fear) that their wishes may at some future time be dishonored, or may only be honored through a judicial proceeding, public spectacle, or an advance directive that has all of its legal i's dotted and its t's crossed. Had the Schindlers won – had people in a PVS been required to be kept alive – this would have been a consequence.

III. THE PUBLIC CASE: *SCHIAVO'S* IMPACT ON THE LEGAL CONSENSUS ABOUT END-OF-LIFE DECISIONMAKING

In the decade and a half between the *Quinlan*¹² and *Cruzan*¹³ cases, a consensus developed in the United States about how medical decisions near the end of one's life should be made. The consensus can be summarized as follows:

- 1) competent individuals have a legal right to refuse treatment;
- 2) incompetent individuals have a right to have treatment refused for them;
- 3) end-of-life decisions should ordinarily be made in clinical settings and not courts;
- 4) close family members have the legal authority to act as surrogates and make medical decisions for patients who lack decisionmaking capacity;
- 5) in making end-of-life decisions, surrogates should apply the substituted judgment standard;
- 6) surrogates may rely on advance directives to ascertain patients' wishes;
- 7) artificial nutrition and hydration are medical treatments; and
- 8) actively hastening death is impermissible.¹⁴

The consensus grew incrementally as various healthcare professional organizations, government commissions,¹⁵ academic think

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

13. *Cruzan*, 497 U.S. 261.

14. I discuss the legal consensus at length in Alan Meisel, *The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects*, 2 KENNEDY INST. OF ETHICS J. 309, 315 (1992). See also MEISEL & CERMINARA, *supra* note 11, at 2-4 to -6.

15. See, e.g., PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* (1983) [hereinafter PRESIDENT'S COMM'N, *DECIDING TO FOREGO*]; N.J. COMM'N ON LEGAL & ETHICAL PROBLEMS IN THE DELIVERY OF HEALTH CARE, *THE NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE AND DECLARATION OF DEATH ACTS: STATUTES, COMMENTARIES, AND ANALYSES* (1991); N.Y. STATE TASK FORCE ON LIFE & THE LAW, *WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY* (1992); N.Y. STATE TASK FORCE ON LIFE & THE LAW, *LIFE-SUSTAINING TREATMENT: MAKING DECISIONS AND APPOINTING A HEALTH CARE AGENT* (1987).

tanks,¹⁶ and religious institutions¹⁷ issued reports and policy statements consistent with the summary noted above. Courts issued decisions and legislatures enacted statutes that enshrined the consensus with a degree of credibility that would have otherwise been lacking, and the public became increasingly aware of these issues through media reports and personal experience.

The consensus also grew iteratively. The courts were strongly influenced by government-commission reports,¹⁸ public-policy statements, and positions taken by professional¹⁹ and, perhaps to a degree, religious organizations. In turn, the professional and religious organizations were undoubtedly influenced by judicial decisions and perhaps by legislation. The public, too, became increasingly aware of these developments through the mass media and likely incorporated elements of the consensus in their own end-of-life decisions and those of family members. Likewise, this process served to educate the healthcare professionals involved in those decisions.

Thus, when the U.S. Supreme Court decided *Cruzan*²⁰ in 1990, its decision was largely a reflection of the consensus that was already in place. On substantive end-of-life decisionmaking issues, *Cruzan* broke no new ground.²¹ In the decade and a half since the *Cruzan* decision, the consensus has been reiterated time and time again by various

16. See, e.g., HASTINGS CTR., GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 31 (1987); NATIONAL CTR. FOR STATE COURTS, GUIDELINES FOR STATE COURT DECISION MAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES (1991).

17. 70TH GENERAL CONVENTION, ESTABLISH PRINCIPLES WITH REGARD TO THE PROLONGATION OF LIFE, J. OF THE GEN. CONVENTION OF THE EPISCOPAL CHURCH, PHOENIX, 1991, at 383 (1992), available at http://www.episcopalchurch.org/3577_60370_ENG_HTML.htm; 200TH GEN. ASSEMBLY OF THE PRESBYTERIAN CHURCH (U.S.A.), LIFE ABUNDANT: VALUES, CHOICES AND HEALTH CARE – THE RESPONSIBILITY AND ROLE OF THE PRESBYTERIAN CHURCH (U.S.A.) (1988), http://www.pcusa.org/nationalhealth/policies/policy_affirmation.htm; CATECHISM OF THE CATHOLIC CHURCH § 2278, http://www.vatican.va/archive/ENG0015/_P7Z.HTM; COMM. ON JEWISH LAW & STANDARDS OF THE RABBINICAL ASSEMBLY, JEWISH MED. DIRECTIVES FOR HEALTH CARE 3 (1994), <http://www.rabbinicalassembly.org/docs/medical%20directives.pdf>; 5 ENCYCLOPEDIA OF BIOETHICS 2708 (Warren Thomas Reich ed., rev. ed. 1995) (discussing the Muslim position); GEN. ASSEMBLY, UNION FOR REFORM JUDAISM, COMPASSIONATE AND COMFORT CARE DECISIONS AT THE END OF LIFE (1995), <http://www.urj.us/cgi-bin/resodisp.pl?file=care&year=1995>; STANLEY S. HARAKAS, CONTEMPORARY MORAL ISSUES FACING THE ORTHODOX CHRISTIANS 176 (1982). See generally A. Mark Clarfield et al., *Ethical Issues in End-of-Life Geriatric Care: The Approach of Three Monotheistic Religions – Judaism, Catholicism, and Islam*, 51 J. AM. GERIATRIC SOC'Y 1149, 1151-52 (2003).

18. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484 (Cal. Ct. App. 1983).

19. See, e.g., CODE OF MED. ETHICS § 2.22 (Am. Med. Ass'n 1994).

20. 497 U.S. 261 (1990).

21. *Cruzan* merely held that the Fourteenth Amendment permits states to adopt a clear and convincing evidence standard of proof of an incompetent patient's wish to forgo life-sustaining treatment. *Id.* at 284.

courts²² and has become increasingly well-accepted, probably even in the states in which there has been no definitive appellate court opinion on end-of-life decisionmaking. Naturally, not everyone agrees with the consensus,²³ and the consensus has included contentious aspects from the outset.²⁴ Nonetheless, these contentious aspects do not undermine the consensus' existence. Consensus, after all, does not require unanimity.

There are several important points to note regarding the consensus' embodiment in the law. End-of-life decisionmaking law is primarily judge-made law, most of which is state law. Although state legislatures (and more infrequently, Congress)²⁵ have engaged in some lawmaking regarding end-of-life matters, the task of lawmaking has been left mostly to the courts, which have reluctantly (or so they often profess) filled the breach.²⁶

Another interesting characteristic many end-of-life judicial decisions share is their comprehensiveness. Courts have frequently issued sweeping opinions that are much broader than needed to decide the issue before them. In many cases, the decisions read like legal manuals for

22. See, e.g., *Thor v. Superior Court*, 855 P.2d 375 (Cal. 1993); *In re Tavel*, 661 A.2d 1061 (Del. 1995); *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176 (Fla. 2d Dist. Ct. App. 2001). Ironically, the consensus was largely solidified before the Supreme Court's decision in *Cruzan*. Subsequent to that decision, only one state has joined the consensus. See *In re Fiori*, 652 A.2d 1350, 1357 (Pa. Super. Ct. 1995). Nonetheless, to date, no state has repudiated the consensus' main points.

23. See, e.g., Dresser, *supra* note 8, at 379 ("[B]ecause of the primacy it awards to the incompetent patient's past preferences, the substituted judgment standard joins the advance directive in facing an even greater threat to its moral authority."); Louise Harmon, *Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 61 (1990) ("The doctrine of substituted judgment allows the state to invade the bodily integrity of the incompetent without having to justify the invasion."); Rhoden, *supra* note 8, at 380 ("[C]ourts have distorted our vision of incompetent patients by downplaying the ways in which incompetent patients inevitably differ from competent ones.").

24. See *In re Conservatorship of Wendland*, 28 P.3d 151, 170 (Cal. 2001); *In re Martin*, 538 N.W.2d 399, 407-08 (Mich. 1995); *In re Guardianship of Edna M.F.*, 563 N.W.2d 485, 489-90 (Wis. 1997).

25. There are only two major federal statutes dealing with end-of-life decisionmaking: Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388 (1990) (codified as amended in relevant part at 42 U.S.C. 1395cc(f)(1) & 1396a(a) (2000)) (popularly known as the Patient Self-Determination Act), dealing with advance directives, and the 1984 Amendments to the Child Abuse Prevention and Treatment Act, Pub. L. No. 98-457, 98 Stat. 1749, tit. 1, §§ 121-128 (1984) (codified as amended in scattered sections of 42 U.S.C.).

26. Any number of courts have extended invitations to their respective legislatures to enact statutes governing end-of-life decisionmaking. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 491 (Cal. Ct. App. 1983) ("If specific procedural rules are to be adopted in this area in order to protect the public interest, they must necessarily come from that body most suited for the collection of data and the reaching of a consensus - the Legislature.").

end-of-life decisionmaking.²⁷ It is hard to divine the reasons for this trend, but one possibility is the failure of legislatures to address the matter in a comprehensive manner. Thus, judges may feel that if they do not treat the issue thoroughly, dying patients, their families, and their healthcare providers will find themselves in a legal limbo. Perhaps another reason for these broad opinions is the interest the subject provokes. Some judges seem positively enthralled by the possibility of writing a treatise on this fascinating, controversial, and knotty subject. It may be a welcome change of pace from writing about commercial disputes, personal injury, and the myriad other dry or well-trod topics that populate a judicial docket. Nonetheless, it is doubtful that the judges' willingness to hand down codes for end-of-life decisionmaking has caused the legislatures to back away from the issue. Indeed, even in those states in which there is no end-of-life appellate decision, the legislatures have stayed their hand no less than in states where the courts have had occasion to speak.

IV. SCHINDLERS' LIST, OR THE ANTI-CONSENSUS

The Schindlers' claims posed a significant challenge to a number of the legal consensus' central aspects regarding end-of-life decisionmaking. Even though the consensus' most fundamental element – namely, the right of competent patients to refuse treatment – was not at issue, the Schindlers took direct or indirect aim at the consensus. Had they prevailed, a number of the consensus' essential features would have been overturned in Florida and seriously threatened elsewhere.

A. *The Right Not to Be Treated*

The consensus' most fundamental aspect is that patients possessing decisionmaking capacity (competent patients) have a virtually absolute right to refuse medical treatment.²⁸ Decisionmaking for competent patients tends to be far less problematic than decisionmaking for incompetent patients simply because competent patients, *ex hypothesi*, can make their own decisions. Incompetent patients cannot, hence their comparable right to have a surrogate make treatment decisions in their stead. In deciding for the incompetent patient, the surrogate – like the competent patient making his or her own decision – may make a decision to decline treatment, although the surrogate's discretion is signifi-

27. See, e.g., *In re Guardianship of Browning*, 568 So. 2d 4 (Fla. 1990); *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

28. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

cantly more constrained than that of a competent patient. In any event, there is no imperative that hopelessly ill patients be kept alive under all circumstances.

Patients who have made their wishes known before losing decision-making capacity – whether through a written advance directive²⁹ or an oral statement³⁰ – have the right to forgo life-sustaining medical treatment, assuming they have done so with the requisite precision, clarity, and weight. For a patient who has not made his or her wishes known in this manner, a surrogate may make a decision on the patient's behalf to forgo treatment if the treatment is not in the patient's best interest. This ethical principle has been accepted in law in some jurisdictions – including those that require adherence to the highest standards of precision, clarity, and weight.³¹ Courts have authorized end-of-life decisionmaking in accordance with a “best interest” standard, through which the decisionmaker weighs the benefits and burdens that continued existence poses for the patient.³² Courts have been clear in condemning decision-making based on the societal worth of the patient's existence.³³

The question whether non-sentient existence (the condition of a patient in a PVS) constitutes a benefit could be debated endlessly. From a legal perspective, however, the issue has been settled since *Quinlan* was decided in 1976.³⁴ In holding that it was permissible to remove life support from a person in a PVS and allow the person to die as a consequence of that removal, the *Quinlan* court implied that existence per se is not necessarily beneficial to a non-sentient person.³⁵ Courts have uniformly – and sometimes more explicitly than in *Quinlan* – adhered to that conclusion. They do not consider “mere biological existence”³⁶ to be a benefit sufficient to warrant a determination that the person must be kept alive.³⁷ Indeed, there is even a colorable argument that being kept

29. See *infra* Part III.D.

30. See *infra* Part III.C.

31. See *In re Westchester County Med. Ctr. ex rel. O'Connor*, 531 N.E.2d 607, 614 (N.Y. 1988); *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981) (holding that if the clear and convincing standard cannot be met to show that the patient did not or would not consent to the treatment, the decision whether to treat must be made in accordance with the State's interests in protecting its citizens' health and welfare).

32. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 491 (Cal. Ct. App. 1983); *Conroy*, 486 A.2d at 1240; see also CODE OF MED. ETHICS § 2.20 (Am. Med. Ass'n 2007).

33. See, e.g., *In re Conroy*, 486 A.2d at 1232-33 (“[W]e expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others.”). See generally MEISEL & CERMENARA, *supra* note 11, at 4-70 to -71 (collecting cases).

34. *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).

35. *Id.*

36. *Barber*, 195 Cal. Rptr. at 492.

37. See PRESIDENT'S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 212 (2005), available at http://www.bioethics.gov/reports/taking_care/ (“Caring

alive under such circumstances constitutes a detriment to the patient.³⁸

Had the Schindlers won, the legal consensus on this point would have been thrown into a sea of confusion. The vitalist perspective – that life per se, even nonsentient life, is a pearl beyond price and that we must not spare any effort to maintain it, even when the person being kept alive would not have wanted to be kept alive in such circumstances or when there is no benefit to the patient to being kept alive – would have been validated.

B. *Decisionmaking Standards*

One who makes decisions for a person lacking decisionmaking capacity³⁹ (generically referred to as a surrogate)⁴⁰ must be guided by some legal standard.⁴¹ In the absence of a standard, a surrogate would wield absolute authority over decisions regarding life-sustaining medical treatment for the incompetent patient. When there is an articulated standard, however, the surrogate's discretion is circumscribed and the deci-

well for the patient does not require *always* choosing interventions that would prolong his life or delay his dying, and sometimes best care requires forgoing treatments that may sustain life at the cost of imposing undue misery or offering palliative care that accepts an increased risk of an earlier death.”); *see also* *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 331 (1990) (Stevens, J., dissenting) (“The Court . . . permits the State’s abstract, undifferentiated interest in the preservation of life to overwhelm the best interests of Nancy Beth Cruzan, interests which would, according to an undisputed finding, be served by allowing her guardians to exercise her constitutional right to discontinue medical treatment.”). *See generally* MEISEL & CERMINARA, *supra* note 11, at 4-77 (collecting cases).

38. *See Cruzan*, 497 U.S. at 310 (Brennan, J., dissenting) (“Dying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent.”); *id.* at 344 (Stevens, J., dissenting) (“Nancy Cruzan’s interest in life, no less than that of any other person, includes an interest in how she will be thought of after her death by those whose opinions mattered to her. There can be no doubt that her life made her dear to her family and to others. How she dies will affect how that life is remembered.”).

39. Traditionally such persons have been referred to as “incompetent persons,” but in the last two or three decades there has been a terminological shift toward referring to them as “incapacitated persons” or the lengthier locution of “persons who lack decisionmaking capacity.” *See generally* SAMUEL JAN BRAKEL, JOHN PARRY & BARBARA A. WEINER, *THE MENTALLY DISABLED AND THE LAW* 369 (3d ed. 1985).

40. The nomenclature in most states for such a person is a “surrogate.” However, in Florida, the statute uses the term “proxy” as the generic name for anyone who makes a decision for an incompetent patient. § 765.101(15), FLA. STAT. (2006). In most other states, proxy is used to refer to a specific kind of surrogate, namely one appointed by a patient while competent to make such an appointment. To confuse matters further, Florida uses the term “surrogate” to refer to a patient-appointed agent. § 765.101(16).

41. Although it has never been directly litigated, this is probably a constitutional necessity; the failure to have some standard could constitute a denial of due process of law. *See* 1 LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* § 1-4, at 12 (3d ed. 2000). However, this assumes that decisions of a surrogate decisionmaker constitute state action, which is not at all clear. *See* MEISEL & CERMINARA, *supra* note 11, at 2-32 to -33.

sion must conform to certain criteria – criteria implicit or explicit in the standard.

1. SUBSTANTIVE STANDARDS

The predominant standard courts and legislatures have adopted for surrogate decisionmaking is referred to as the “substituted judgment” standard.⁴² This standard, pronounced in *Quinlan*, is the decisionmaking linchpin for patients who lack decisionmaking capacity. All but two appellate courts⁴³ have accepted it as the default standard for guiding surrogates in making end-of-life decisions.⁴⁴

The substituted judgment standard has been described in a variety of ways. One complicated rendition requires that the surrogate’s decision comport with that of the incompetent patient, were he or she competent, taking into account current and future incompetency.⁴⁵ The President’s Commission supplied a much cleaner version, requiring that the surrogate’s decision correspond to what the incompetent patient would have preferred in advance of losing decisionmaking capacity had he or she given thought to the matter.⁴⁶ Put most simply, the substituted

42. See *In re Quinlan*, 355 A.2d 647, 666 (N.J. 1976).

43. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (requiring evidence of an incapacitated person’s wishes before permitting withdrawal of artificial hydration and nutrition), *questioned in In re Warren*, 858 S.W.2d 263, 265-66 (Mo. Ct. App. 1993); *In re Westchester County Med. Ctr. ex rel. O’Connor*, 531 N.E.2d 607, 613 (N.Y. 1988).

44. The Florida Supreme Court adopted this standard in *In re Guardianship of Browning*, 568 So. 2d 4, 13 (Fla. 1990), stating that “[i]n this state, we have adopted a concept of substituted judgment. One does not exercise another’s right of self-determination or fulfill that person’s right of privacy by making a decision which the state, the family, or public opinion would prefer. The surrogate decisionmaker must be confident that he or she can and is voicing the patient’s decision.” (emphasis and internal citations omitted). Of the 39 jurisdictions with surrogate decisionmaking statutes, 18 specify a substantive standard to guide surrogate decisionmaking, and most of these prescribe a substituted judgment standard. See generally MEISEL & CERMINARA, *supra* note 11, at 8-20. The only statutes that expressly require application of a subjective standard are those of Ohio and South Dakota. OHIO REV. CODE ANN. § 2133.08(D)(2) (2005); S.D. CODIFIED LAWS § 34-12C-3 (1994). However, if this standard cannot be met, Ohio permits the substituted judgment standard to be applied, whereas in South Dakota the best interest standard may be applied without first attempting to apply a substituted judgment standard. § 2133.08(D)(3); § 34-12C-3.

45. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977) (“[T]he decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decisionmaking process of the competent person.”); see also *In re Quinlan*, 355 A.2d at 664 (“The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances.”).

46. See PRESIDENT’S COMM’N, *DECIDING TO FOREGO*, *supra* note 15, at 132 (“The substituted judgment standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose.”).

judgment standard seeks to determine the now-incompetent patient's *probable* wishes concerning treatment.

The widespread acceptance of the substituted judgment standard does not however make it sacrosanct, as illustrated by its outright rejection by the New York Court of Appeals,⁴⁷ its ambiguous status in Missouri,⁴⁸ and its rejection in a limited class of cases in California, Michigan, and Wisconsin.⁴⁹ The autonomy principle depends on establishing certainty about what the patient's wishes would be if the patient were competent to express them. Some claim this principle is better honored by the "clear and convincing evidence" standard,⁵⁰ also known by its more preferable label, the "subjective" standard.⁵¹ This standard requires knowledge of the patient's *actual* wishes about treatment rather than the substituted judgment standard's determination of *probable* wishes. Under the strictest rendition of the subjective standard, the patient must have actually made a treatment decision while possessing decisionmaking capacity, that is, before the need for the decision actually arose.⁵² Furthermore, this decision must have been made in a context of solemnity and not as an offhand comment.⁵³

Under the subjective standard's strict formulation, the surrogate is nothing more than a messenger bearing the patient's prior-made decision.⁵⁴ Under a somewhat looser formulation – which brings the subjec-

47. *In re O'Connor*, 531 N.E.2d at 613.

48. *Cruzan*, 760 S.W.2d 408 (requiring evidence of an incapacitated person's wishes before permitting withdrawal of artificial hydration and nutrition), *questioned in In re Warren*, 858 S.W.2d 263, 265-66 (Mo. Ct. App. 1993).

49. These are cases involving so-called minimally conscious patients. *See In re Conservatorship of Wendland*, 28 P.3d 151, 171-73 (Cal. 2001); *In re Martin*, 538 N.W.2d 399, 407 (Mich. 1995); *In re Guardianship of Edna M.F.*, 563 N.W.2d 485, 489-90 (Wis. 1997).

50. Some courts use the term "subjective standard." *See, e.g., In re Conroy*, 486 A.2d 1209, 1229 (N.J. 1985). Other judges have used the terms "specific-subjective-intent," "actual intent," and "present subjective intent." *See In re O'Connor*, 531 N.E.2d at 616-17 (Hancock, J., concurring).

51. The term "clear and convincing evidence" standard is best avoided because it signifies an evidentiary standard rather than a substantive standard for decisionmaking by a surrogate for a patient lacking decisionmaking capacity. *See Martin*, 538 N.W.2d at 406 n.12. There are several possible evidentiary standards; besides the clear and convincing evidence standard, the common evidentiary standards are "beyond a reasonable doubt" and "preponderance of evidence." There are also a number of possible substantive standards: the subjective standard, the substituted judgment standard, and the best interest standard. Each substantive standard can be modified by one of the adjectival standards of evidence law. For instance, in theory a court could require that in order to make a particular treatment decision for an incompetent patient, there be clear and convincing evidence of the patient's actual subjective intent. *See, e.g., In re O'Connor*, 531 N.E.2d at 613.

52. *See In re O'Connor*, 531 N.E.2d at 613.

53. *Id.*

54. One exception to this may be the situation where a patient has executed a "proxy directive" naming a proxy and expressly authorizing him or her to make end-of-life decisions, but without giving specific guidance as to what those decisions should be (i.e., a healthcare power of

tive standard closer to the substituted judgment standard – the surrogate is entitled to *infer* the patient's wishes from conversations the now-incompetent patient had regarding others' treatment before the patient lost his or her decisionmaking capacity.⁵⁵

Most courts prefer the greater degree of certainty the subjective standard provides,⁵⁶ but apply a less stringent standard on pragmatic grounds – namely, that most people simply do not make the effort to articulate their wishes with the clarity and certainty the subjective standard requires.⁵⁷ In most jurisdictions, this means that the substituted judgment standard governs end-of-life decisionmaking.

Less than a handful of cases⁵⁸ have challenged the application of the substituted judgment standard to a *limited* class of cases – namely,

attorney without a living will). The New York Court of Appeals, the very same court to require the subjective standard, seems to permit this exception as well. *Id.* at 612 n.2; *see also* *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring) (“[S]uch a duty may well be constitutionally required [for a state to give effect to the decisions of a surrogate decisionmaker] to protect the patient's liberty interest in refusing medical treatments.”); *id.* at 328 (Brennan, J., dissenting) (“[T]he State generally must either repose the choice with the person whom the patient himself would most likely have chosen as proxy or leave the decision to the patient's family.”); *cf. In re Guardianship of Browning*, 568 So. 2d 4, 16 (Fla. 1990) (written designation of a proxy “establishes a rebuttable presumption that constitutes clear and convincing evidence of the patient's wishes”); *In re Howe*, No. 03 P 1255, 2004 WL 1446057, at *19 (Mass. Prob. & Fam. Ct. Dep't Mar. 22, 2004) (“The Hospital must comply with health care decisions made . . . under a health care proxy to the same extent as if such decisions have been made by [the patient.]”); *In re Peter*, 529 A.2d 419, 426 (N.J. 1987) (although the relevant power of attorney statute does not specifically authorize conveyance of durable authority to make medical decisions, it should be interpreted that way); *Pocono Med. Ctr. v. Harley*, 11 Fiduc. Rep. 2d 128, 133 (Pa. Ct. C.P. Monroe County 1990) (recognizing a duty to follow the wishes of a person holding a power of attorney assuming the power of attorney contains certain provisions). The New York Court of Appeals has even suggested that the *oral* designation of a proxy would meet the subjective standard. *In re O'Connor*, 531 N.E.2d at 612 n.2.

55. *See, e.g., In re Swan*, 569 A.2d 1202, 1205 (Me. 1990). *But see In re O'Connor*, 531 N.E.2d at 614 (holding that patient's statements made in reaction to the treatment of others do not demonstrate a seriousness of purpose necessary to satisfy the clear and convincing evidence standard).

56. Whether the subjective standard in fact provides a greater degree of certainty than the substituted judgment standard is open to question. With the substituted judgment standard, the *surrogate* must speculate about what the patient's wishes would be if the patient were able to make a decision. However, under the subjective standard, the *patient* must speculate about what treatment he or she would want under a variety of hypothetical future circumstances.

57. *See, e.g., In re Fiori*, 673 A.2d 905, 912 (Pa. 1996) (“Were [the clear and convincing] test to be applied, all of those patients who did not have the prescience or the sophistication to express clearly and unmistakably their wishes on this precise matter would not be able to have life support removed.”).

58. *See supra* note 44; *see also In re Conroy*, 486 A.2d 1209, 1229, 1231-32 (N.J. 1985) (rejecting substituted judgment standard for a minimally conscious patient in favor of a subjective standard – though a version more loosely formulated than those in other states – but holding that if subjective standard could not be met, best interest standard would be applied, which does not necessarily require the continued administration of treatment).

those involving minimally conscious patients.⁵⁹ These patients, like PVS patients, have suffered serious brain damage but to a lesser degree. Unlike PVS patients, minimally conscious patients, as the label suggests, have some cognitive functioning and some awareness of their surroundings.

2. EVIDENTIARY STANDARDS

The tendency to conflate substantive standards with evidentiary standards has confounded the question of which standards should guide decisionmaking for incompetent patients. Whatever the *substantive* standard is – subjective, substituted judgment, best interest, or something else – the standard must be established by some degree of certainty. As is the case in all litigation, it must be established in accordance with some *evidentiary* standard. The evidentiary standard ordinarily applied in civil litigation is preponderance of the evidence. However, in end-of-life litigation, since the question was first raised,⁶⁰ courts have rejected the preponderance of the evidence standard and applied the clear and convincing evidence standard.⁶¹

During the *Schiavo* litigation's earlier stages, the Schindlers did not challenge the substituted judgment standard as the appropriate decision-making standard. Rather, they claimed that the appropriate evidentiary standard had not been met – i.e., Terri's desire to have life support terminated was not established by clear and convincing evidence.⁶² This claim highlights the distinction between the substantive standard (substituted judgment standard) and the evidentiary standard (clear and con-

59. See Joseph T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 *NEUROLOGY* 349, 350-51 (2002).

60. See *In re Storar*, 420 N.E.2d 64, 72 (1981).

61. There is much confusion in the case law and the commentary about the difference between the substantive standard for end-of-life decisionmaking by surrogates and the evidentiary standard. A few judges, however, seem to understand the difference. See, e.g., *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 350 (1990) (Stevens, J., dissenting) ("My disagreement with the Court is thus unrelated to its endorsement of the clear and convincing standard of proof for cases of this kind. Indeed, I agree that the controlling facts must be established with unmistakable clarity. The critical question, however, is not how to prove the controlling facts but rather what proven facts should be controlling."); see also *In re Martin*, 538 N.W.2d 399, 406 n.12 (Mich. 1995); *In re Fiori*, 673 A.2d at 911 n.9 ("We note that the term 'clear and convincing evidence' in this context refers to the requirement that the individual in question must have stated in an explicit fashion the exact treatment desired were the patient to lapse into various medical conditions. The term 'clear and convincing evidence' is used more commonly, however, as a burden of proof. In that context, the standard refers to that quantum of evidence necessary for a party to establish a point.").

62. *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176, 179 (Fla. 2d Dist. Ct. App. 2001) ("Finally, the Schindlers argue that the testimony, which was conflicting, was insufficient to support the trial court's decision by clear and convincing evidence. We have reviewed that testimony and conclude that the trial court had sufficient evidence to make this decision.").

vincing evidence). Florida's Second District Court of Appeal also appreciated this distinction as indicated by the concluding paragraph of its decision.⁶³ The court first addressed the issue of whether the substantive substituted judgment standard was met and then followed with an analysis of whether it was met in accordance with the appropriate evidentiary standard – i.e., the clear and convincing evidence standard.⁶⁴ As with the substantive standard, the court found that the evidentiary standard had been met.⁶⁵

The Schindlers later seemed to change their tack; they did not, however, explicitly argue that the substituted judgment standard should be jettisoned in favor of the subjective standard. Instead, they attempted to have Terri's treatment continued regardless of what *she would have wanted*; the Schindlers implicitly challenged the *application* of the substituted judgment standard. They claimed that the subjective standard should be applied – i.e., to terminate life support there must be clear and convincing evidence that Terri actually made such a decision before losing decisionmaking capacity. If this could not be established, then the decision would, in default, be determined in accordance with the best interest standard which requires that life support be continued.⁶⁶

A ruling for the Schindlers would have meant a break with the primacy, and perhaps ultimately erosion, of the substituted judgment standard. If this alternative scenario had occurred, the Florida courts would have created a two-part precedent: (1) the subjective standard is the *de facto* standard regarding decisionmaking for PVS patients; and (2) should that standard not be met, the best interest standard is the default alternative.

63. *Id.* at 180.

64. *Id.* (“In the final analysis, the difficult question that faced the trial court was whether Theresa Marie Schindler Schiavo, not after a few weeks in a coma, but after ten years in a persistent vegetative state that has robbed her of most of her cerebrum and all but the most instinctive of neurological functions, with no hope of a medical cure but with sufficient money and strength of body to live indefinitely, would choose to continue the constant nursing care and the supporting tubes in hopes that a miracle would somehow recreate her missing brain tissue, or whether she would wish to permit a natural death process to take its course and for her family members and loved ones to be free to continue their lives.”).

65. *Id.* (“After due consideration, we conclude that the trial judge had clear and convincing evidence to answer this question as he did.”).

66. *See, e.g., In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981). There is a fundamental debate among courts about whether the best interest standard always requires that treatment be administered. The New York Court of Appeals, at least where the patient's life is at stake, seems to require continued treatment. *Id.* However, other courts have concluded that it is not always in a patient's best interest to be kept alive. *See, e.g., In re Conroy*, 486 A.2d 1209, 1231-32 (N.J. 1985); *In re Guardianship of Hamlin*, 689 P.2d 1372, 1375 (Wash. 1984) (“[N]onintervention in some cases may be appropriate and, therefore, in the ward's best interest.”). *See generally* MEISEL & CERMIGNARA, *supra* note 11, at 4-47 to -48.

C. Surrogate Decisionmaking

One of the consensus' foundational blocks is that family members are the natural surrogates for incapacitated patients. This means that when a patient can no longer voice his or her own treatment wishes and has neither left an instruction directive nor appointed a proxy, healthcare professionals are to look to close family members to determine the patient's wishes.

This rule is similar to the substituted judgment standard. That standard requires the surrogate to determine what treatment decision the patient would make if he or she possessed the requisite capacity. To make this determination, the surrogate must be knowledgeable – indeed, possess intimate knowledge – about the patient's values, goals, interests, and preferences: those qualities that are major determinants of patients' medical choices.⁶⁷ Courts that have accepted the substituted judgment standard have uniformly concluded that close family members are best equipped to make such decisions.⁶⁸ Thus, the default rule is that in the absence of an advance directive (either instruction or proxy), close family members are legally authorized to make end-of-life treatment decisions.

Because most people view both spouses and parents as “close family,” the prevailing common law rule provides little guidance for choosing between Terri Schiavo's husband and her parents as her surrogates. The end-of-life case law, however, prefers spouses over parents, although the strength of this preference is unclear.⁶⁹ Also, in Florida,⁷⁰ as in most other states,⁷¹ statutory law governs this matter, which tends to follow the case law in two ways. First, authority is conferred on close family members to make decisions for patients who lack decisionmaking capacity. Second, spouses are explicitly given a presumptive preference over an adult patient's parents.⁷² This does not mean that spouses defin-

67. See, e.g., *In re Welfare of Colyer*, 660 P.2d 738, 747 n.4 (Wash. 1983) (“In most instances, the familial relationship will strengthen, and not undermine, the guardian's best judgment in exercising the personal rights of the incompetent.”); see also *Schiavo I*, 780 So. 2d at 178 (“When a living will or other advance directive does not exist, it stands to reason that the surrogate decision-maker will be a person who is close to the patient and thereby likely to inherit from the patient.”).

68. See MEISEL & CERMINARA, *supra* note 11, at 3-50.

69. In *In re Guardianship of Schiavo (Schiavo II)*, 792 So. 2d 551, 557 (Fla. 2d Dist. Ct. App. 2001), the court remarked that “it would not appear that [the Schindlers] qualified as ‘next-of-kin,’ see § 744.102(12), FLA. STAT. (1997).” But, the court continued, “they were ‘interested persons’ who were entitled to appear in the adversary proceeding and present their viewpoint.” *Id.* See generally MEISEL & CERMINARA, *supra* note 11, at 8-8.

70. See §§ 765.401, 765.404, FLA. STAT. (2006).

71. See MEISEL & CERMINARA, *supra* note 11, at 8-8.

72. § 765.401(1)(b), (1)(d).

itively trump parents under either the statutes or the case law; rather, this merely means that spouses are presumed, absent contrary indications, to be the preferred surrogate decisionmaker. In other words, conditions may exist in particular cases that rebut this presumption.⁷³ A surrogate decisionmaker's conflict of interest can overcome this presumption,⁷⁴ and this is precisely what the Schindlers asserted during the *Schiavo* litigation. They made this assertion based on the fact that upon Terri's death, Michael Schiavo would have inherited any money remaining from the malpractice award he had obtained on Terri's behalf for the mishandling of her medical treatment, which had caused her PVS.⁷⁵

Had the courts accepted the Schindlers' view – that Michael Schiavo was burdened by a conflict of interest disqualifying him from serving as his wife's surrogate decisionmaker – the result could have set a significant precedent for disqualifying the very people who can best implement the substituted judgment standard: people who know the patient and the patient's wishes extremely well, such as the patient's spouse. Close family members will frequently have a financial conflict of interest. If that situation presumptively disqualifies a close family member from serving as surrogate, the disqualification would often remove the surrogate best able to effectuate the substituted judgment standard.⁷⁶ Thus, the effect of finding a conflict of interest would not only have signaled a shift in the balance of surrogate decisionmaking authority away from spouses in favor either of parents or of some larger family unit, but would have also further undermined the substituted judgment standard. Conversely, had the Florida courts also abandoned the substituted judgment standard, it would have seriously eroded, or possibly eliminated, close family members' traditional discretion to make end-of-life decisions for their loved ones. This would have been the case because abandoning the substituted judgment standard would have prevented close family members from applying their knowledge of what the patient would have wanted.

D. *Advance Directives*

Had the Schindlers prevailed and had the Florida courts adopted the subjective standard for end-of-life decisionmaking cases, there would have been profound implications for advance directives, even if limited

73. See MEISEL & CERMINARA, *supra* note 11, at 8-13 to -19.

74. See MEISEL & CERMINARA, *supra* note 11, at 3-96 to -100.

75. See *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176, 178 (Fla. 2d Dist. Ct. App. 2001).

76. See, e.g., *In re Welfare of Colyer*, 660 P.2d 738, 747 n.4 (Wash. 1983) ("In most instances, the familial relationship will strengthen, and not undermine, the guardian's best judgment in exercising the personal right of the incompetent.").

in application to PVS patients. In principle, the subjective standard can be applied in the absence of a written advance directive.⁷⁷ In practice, however, the absence of an advance directive that provides instructions regarding future treatment⁷⁸ makes the application of the subjective standard much more difficult. Under the subjective standard, clear and convincing evidence must exist of the now-incompetent patient's *actual* subjective treatment wishes, as opposed to what treatment he or she *would* have wanted if able to speak. Because, *ex hypothesi*, the incompetent patient is unable to express his or her wishes, the patient must have actually made a treatment decision before losing decisionmaking capacity in order for the subjective standard to be satisfied.

Under this standard, the degree of specificity with which the patient must have contemplated the present situation is not entirely clear. For example, if such a standard had been required in the *Schiavo* case, would it have been necessary for Terri Schiavo to have said, before losing decisionmaking capacity, "if I am ever in a persistent vegetative state being kept alive by a *feeding tube* with virtually no hope of recovery, I want the feeding tube withdrawn"? Or would less specificity have sufficed, for example, "if I am ever in a persistent vegetative state being kept alive by *life support*, I want the treatment withdrawn"? Or would even less specificity have sufficed, for example, "if I am ever being kept alive by life support *with virtually no hope of recovery*, I want the life support withdrawn"? Or if she had directed the termination of life support if she were ever in a PVS, would this statement apply if she were in a *minimally conscious state* instead? Would the term "life support" have been construed to include a feeding tube?

Courts have yet to pose and answer these questions with much precision, and hence it remains unclear what degree of specificity is required. What is clear, however, is that the subjective standard requires a greater degree of specificity than the substituted judgment standard. An excellent example is the *O'Connor* case from New York.⁷⁹ In *O'Connor*, the record was replete with evidence of conversations the patient had had over a number of years with friends and relatives about her abhorrence of the notion of prolonging the dying process through

77. See *In re Westchester County Med. Ctr. ex rel. O'Connor*, 531 N.E.2d 607, 612 (N.Y. 1988); see also *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring) ("[It] may well be constitutionally required [for a state to give effect to a surrogate's decisions] to protect the patient's liberty interest in refusing medical treatment."); *id.* at 328 (Brennan, J., dissenting) ("[T]he State generally must . . . repose the choice with the person whom the patient himself would most likely have chosen as proxy . . .").

78. An "instruction" directive, popularly referred to as a "living will."

79. *In re O'Connor*, 531 N.E.2d 607.

medical means.⁸⁰ Nonetheless, the New York Court of Appeals refused to find that she had authorized the termination of a feeding tube before losing decisionmaking capacity because

there is nothing, other than speculation, to persuade the fact finder that her expressions were more than immediate reactions to the unsettling experience of seeing or hearing of another's unnecessarily prolonged death. Her comments – that she would never want to lose her dignity before she passed away, that nature should be permitted to take its course, that it is “monstrous” to use life-support machinery – are, in fact, no different than those that many of us might make after witnessing an agonizing death. Similarly, her statements to the effect that she would not want to be a burden to anyone are the type of statements that older people frequently, almost invariably make. If such statements were routinely held to be clear and convincing proof of a general intent to decline all medical treatment once incompetency sets in, few nursing home patients would ever receive life-sustaining medical treatment in the future. The aged and infirm would be placed at grave risk if the law uniformly but unrealistically treated the expression of such sentiments as a calm and deliberate resolve to decline all life-sustaining medical assistance once the speaker is silenced by mental disability.⁸¹

Whatever the requisite degree of specificity may be, the validity, and thus the probative value, of the patient's statements are significantly enhanced if those statements have been committed to writing in an instruction directive. While no rule of law would have required an instruction directive (unless the Florida Supreme Court had explicitly established such a requirement) had the Schindlers prevailed, a populace fearful that its wishes would be ignored would certainly have been handed a substantial incentive to execute instruction directives.

That might not be a bad thing. Many have bemoaned the low advance-directive execution rate for years.⁸² Instruction directives may, however, create as many problems as they solve. There probably would

80. *Id.* at 614.

81. *Id.*

82. Figures from 2005 polls range from about 30% to about 40%. Compare *Poll: Keep Feeding Tube Out*, CBS NEWS, Mar. 23, 2005, <http://www.cbsnews.com/stories/2005/03/23/opinion/polls/main682674.shtml> (33%), and Linda Lyons, *Last Wishes: Half of Americans Have Written Wills*, GALLUP POLL NEWS SERV., June 7, 2005, <http://www.galluppoll.com/content/?ci=16660&pg=1> (40%), with *Washington Post-ABC News Poll: Schiavo Case*, WASH. POST, Mar. 22, 2005, http://www.washingtonpost.com/wp-srv/politics/polls/polltrend_032205.html (42%). This is a dramatic increase from the 20% or lower level in the early 1990s. See PEW RESEARCH CTR. FOR THE PEOPLE & THE PRESS, REFLECTIONS OF THE TIMES: THE RIGHT TO DIE 9 (1990), <http://people-press.org/reports/pdf/19900610.pdf>. A study based on government data from the mid-1980s found a living will completion rate of less than 10%. Laura C. Hanson & Eric Rodgman, *The Use of Living Wills at the End of Life: A National Study*, 156 ARCHIVES INTERNAL MED. 1018, 1018 (1996).

not have been a *Schiavo* case if Terri Schiavo had executed a directive stating, "if I'm ever in a persistent vegetative state and am being kept alive by a feeding tube, and if I don't recover after one year, I want the feeding tube removed, and I want to be allowed to die peacefully." Under these circumstances, even if there had been a *Schiavo* case, the likelihood that it would have become the circus it became would have been remote. But if Schiavo's advance directive had stated, "I never want to be kept alive by extraordinary treatment," or, "if I'm ever in a persistent vegetative state, I don't want to be kept alive by extraordinary treatment," or even, "if I'm ever in a persistent vegetative state and do not recover after one year, I don't want to be kept alive by extraordinary treatment," the question would have remained whether a feeding tube was "treatment," let alone "extraordinary treatment." In that situation, it is unlikely any of the actors in the *Schiavo* matter would have reacted differently from the way they reacted absent an instruction directive. Other imprecise instruction directives would have likely produced similar results. Thus, some courts may require precise instruction directives, and there are an alarming and possibly infinite number of ways to create imprecision.

If the applicable law required that an instruction directive provide precision, another kind of difficulty arises because such instruction directives essentially eliminate discretion. In other words, the greater the degree of precision required, the less discretion a surrogate has to make a decision in circumstances that vary from those contemplated in the instruction directive. It is highly unlikely that this is a desirable outcome in end-of-life decisionmaking, a process in which many unanticipated variables exist. Of course, if life per se is a pearl beyond price, and if it is better to err on the side of keeping a person alive when what he or she wants is uncertain, then this is a desirable outcome. This is not, however, the outcome that the legal consensus has sanctioned for three decades. If public opinion polls are correct, this is also not the outcome that most people want for themselves.⁸³

Would a *proxy directive* eliminate the problems posed by decision-making under the subjective standard? Or more precisely, does an advance directive that appoints a proxy but does not give instructions about future treatment satisfy the subjective standard? No case has yet

83. See David W. Moore, *Three in Four Americans Support Euthanasia*, GALLUP POLL NEWS SERV., May 17, 2005, <http://www.gallupoll.com/content/?ci=16333&pg=1> ("When it comes to being 'in a persistent vegetative state with no hope of for significant recovery,' 85% of Americans say they would want to have their life support removed."); *Poll: Keep Feeding Tube Out*, *supra* note 82 ("In general, 73 percent say if a patient is in a coma with no brain activity, a close family member should have the right to tell the doctor to remove the feeding tube and let the patient die.").

decided this question, though at least two have addressed it in dicta, both concluding that a proxy directive will suffice.⁸⁴ This conclusion is not necessarily consistent with the subjective standard's rationale, which is to ensure that a decision made for an incompetent patient will effectuate that person's *actual* wishes. Allowing a surrogate – even one the patient selects – to make a decision, possibly without any actual knowledge of the patient's wishes, is seemingly at odds with the *subjective standard* because it permits the surrogate to exercise the kind of broad decision-making discretion usually associated with the *substituted judgment standard*. Thus, if under the aegis of the subjective standard a surrogate (albeit a patient-designated surrogate) is permitted to exercise an equal degree of discretion as a surrogate operating under the substituted judgment standard, has any change really been worked in the law? Indeed, in this scenario it is unclear whether any difference between the substituted judgment standard and the subjective standard exists. Instead, this seeming inconsistency appears to create an incentive for patients to appoint a healthcare proxy if the patient wishes to avoid drafting an instruction directive that addresses every conceivable treatment contingency.

Thus, another outcome of a Schindler victory in the *Schiavo* case would have been increased uncertainty about the need for an advance directive and about what kind of advance directive to create. Reliance on either an oral directive or a proxy directive in a subjective standard state invites the risk – far more so than in a substituted judgment standard state – that one's wishes will be ignored. On the other hand, reliance on an instruction directive runs the risk that it will provide no guidance or misleading guidance.

E. Tube Feeding

Terri Schiavo was kept alive by a feeding tube. After a decision was made to allow her to die, terminating tube feeding ultimately led to Terri's death. The question whether to terminate tube feeding first arose in a litigated case in 1983⁸⁵ and has been the subject of frequent litigation,⁸⁶ despite the Supreme Court's approval in *Cruzan* in 1990 and considerable controversy in academic and professional literature concerning

84. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring) (“[It] may well be constitutionally required [for a state to give effect to the surrogate's decisions] to protect the patient's liberty interest in refusing medical treatment.”); *id.* at 328 (Brennan, J., dissenting) (“[T]he State generally must . . . repose the choice with the person whom the patient himself would most likely have chosen as proxy . . .”); *In re O'Connor*, 531 N.E.2d at 612.

85. *Barber v. Superior Court*, 195 Cal. Rptr. 484 (Cal. Ct. App. 1983).

86. See MEISEL & CERMENARA, *supra* note 11, at 6-79 to -82.

end-of-life decisions. Simply stated, the opponents of tube feeding termination claim that it denies the ordinary sustenance we would provide to any person, and thus a moral obligation arises to continue the feeding.⁸⁷ Others claim that denial of tube feeding is a cruel, painful, and barbaric way for a person to die.⁸⁸ Nonetheless, the virtually unanimous judicial position, including that of the U.S. Supreme Court,⁸⁹ has been that tube feeding is *artificial* nutrition and hydration and is a *medically* administered way of keeping people alive, and as such it is subject to the same rules of continuation or termination as are other forms of medical treatment.⁹⁰

There is substantial evidence that death by dehydration is not necessarily a painful or even an unpleasant way to die,⁹¹ especially for peo-

87. Edward J. Furton, *On the Death of Terri Schiavo*, 30 *ETHICS & MEDICS* 3 (2005), reprinted in *THE CASE OF TERRI SCHIAVO* 247, 249 (Arthur L. Caplan et al., eds., 2006) (“We do not take food and water away from people simply because they suffer diminished cognitive ability. All of us need food and water to sustain life. The fact that these are administered via a plastic tube is no more relevant than the fact that you and I use plates, utensils, and cups. These too are ‘artificial’ means of preserving life.”).

88. *E.g.*, WESLEY J. SMITH, *FORCED EXIT* 50 (1997) (citing interview with Dr. William Burke) (“A conscious person would feel it [dehydration] just as you or I would. They will go into seizures. Their skin cracks, their tongue cracks, their lips crack. They may have nosebleeds because of the drying of the mucus membranes, and heaving and vomiting might ensue because of the drying out of the stomach lining. They feel the pangs of hunger and thirst. Imagine going one day without a glass of water! Death by dehydration takes ten to fourteen days. It is an extremely agonizing death.” (italization omitted)); see also *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626, 641 n.2 (Mass. 1986) (Lynch, J., dissenting in part) (“Removal of the G tube would likely create various effects from the lack of hydration and nutrition, leading ultimately to death. Brophy’s mouth would dry out and become caked or coated with thick material. His lips would become parched and cracked. His tongue would swell, and might crack. . . . At some point within five days to three weeks his major organs, including his lungs, heart, and brain, would give out and he would die. The judge found that death by dehydration is extremely painful and uncomfortable for a human being. The judge could not rule out the possibility that Paul Brophy could experience pain in such a scenario. Paul Brophy’s attending physician described death by dehydration as cruel and violent.”).

89. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990).

90. AM. NURSES ASS’N, *COMPENDIUM OF AM. NURSES ASS’N POSITION STATEMENTS* 97 (1996) (“Medically provided nutrition and hydration should be distinguished from the provision of food and water. Food and water given to patients by mouth is the usual means of providing nutrition to patients. There are, however, situations in which nutrition can only be provided by artificial means. The provision of nourishment and hydration by medical means (i.e., through tubes inserted into the stomach, intestine, or blood vessel) is qualitatively different from merely assisting with feeding.”); CODE OF MED. ETHICS § 2.20 (Am. Med. Ass’n 2007); Bd. of Dirs., Am. Thoracic Soc’y, *Withholding and Withdrawing Life-Sustaining Therapy*, 144 AM. REV. RESPIRATORY DISEASE 726, 726 (1991); Exec. Bd., Am. Acad. of Neurology, *Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient*, 39 *NEUROLOGY* 125, 125 (1989).

91. L. Ganzini, *Nurse’s Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death*, 349 *NEW ENG. J. MED.* 359 (2005); Robert M. McCann et al., *Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration*, 272 *JAMA* 1263 (1994); H. Roeline et al., *Discomfort in Nursing Home Patients with Severe Dementia in Whom*

ple who are already severely debilitated because of a life-threatening condition.⁹² If it does produce any unpleasant symptoms, medical personnel can control the symptoms in a variety of ways.⁹³ Furthermore, when a person is in a PVS, there are no painful or even unpleasant side effects because people in a PVS are incapable of perception.⁹⁴ Family, friends, and other third-party observers' suffering as a result of watching someone die from dehydration is an irrelevant *legal* concern. The unpleasant aspects of dehydration that may disturb family members, such as cracked oral and nasal passages,⁹⁵ can be attended to with proper nursing and hygienic patient care.⁹⁶

Had the Florida courts found that a PVS patient's death from dehydration is impermissible, it would have signaled an unprecedented retreat by an appellate court from the position that artificial nutrition and hydration is a form of medical treatment and therefore may be withheld or withdrawn on the same basis as all other medical treatments. Such a ruling's reach would have been profound. If it were impermissible to withdraw feeding tubes from PVS patients – patients who can perceive nothing – *a fortiori* it would also be impermissible to remove feeding tubes from patients with a lesser degree of incapacity who might actually experience dehydration's purported negative effects. It is not clear

Artificial Nutrition and Hydration Is Forgone, 165 ARCHIVES OF INTERNAL MED. 1729 (2005); R. Viola, G. Wells & J. Peterson, *The Effects of Fluid Status and Fluid Therapy on the Dying*, 13 J. OF PALLIATIVE CARE 41 (1997).

92. McCann et al., *supra* note 92, at 1265 (“We found that patients with terminal illness can experience comfort despite minimal if any intake of food or fluids. . . . Those patients able to communicate consistently reaffirmed our hypothesis that lack of food and fluids sufficient to deplete losses did not cause them suffering, as long as mouth care was provided and thirst alleviated with sips of water. In fact, in nine instances, patients experienced abdominal discomfort and nausea when they ate to please their families.”); *see also* Roeline et al., *supra* note 92, at 1733.

93. *See* Phyllis Schmitz & Merry O’Brien, *Observations on Nutrition and Hydration in Dying Cancer Patients*, in BY NO EXTRAORDINARY MEANS: THE CHOICE TO FORGO LIFE-SUSTAINING FOOD AND WATER 29, 36 (Joanne Lynn ed., 1989) (“To provide reassurance and ensure understanding, we review with the family the comfort techniques and hydration measures we envision using. These include frequent mouth care and body lotioning. If the swallow reflex is intact, we will administer small amounts of water, often using a small syringe. Vaseline will be applied liberally to keep lips moist and a room humidifier will be used.”); McCann et al., *supra* note 92, at 1263 (“In all patients, symptoms of hunger, thirst, and dry mouth could be alleviated, usually with small amounts of food, fluids, and/or by the application of ice chips and lubrication to the lips. Comfort care included use of narcotics for relief of pain or shortness of breath in 94% of patients.”).

94. *See* McCann, *supra* note 92, at 1265.

95. *See* Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 641 n.2 (Mass. 1986) (Lynch, J., dissenting in part).

96. *See, e.g.*, Sharon Jackonen, *Dehydration and Hydration in the Terminally Ill: Care Considerations*, NURSING FORUM, July-Sept. 1997, at 5, 11; Louise A. Printz, *Is Withholding Hydration a Valid Comfort Measure in the Terminally Ill?*, GERIATRICS, Nov. 1988, at 84, 85-86; Paul C. Rousseau, *How Fluid Deprivation Affects the Terminally Ill*, RN, Jan. 1991, at 73, 76.

where the logic of such a ruling would lead. Perhaps forgoing ventilator support, for example, should be prohibited because breathing is a basic, natural function. And what about blood circulation? Or renal blood cleansing? These, too, are treatments undertaken to sustain a patient.

This also raises the old problem of withdrawing versus withholding treatment, long ago thought to have been resolved by the conclusion that there is no morally, and no legally, relevant difference between the two.⁹⁷ If it is no longer permissible to terminate artificial nutrition and hydration unless there is clear and convincing evidence that the patient, before losing decisionmaking capacity requested termination, would physicians become more reluctant to initiate tube feeding for fear that they would be compelled to continue it? If that were the case, then patients who might otherwise survive would die simply because of the difficulty in predicting who will benefit from a feeding tube. In cases like Terri Schiavo's, where the brain injury progresses to a PVS, predictive ability regarding the utility of inserting a feeding tube becomes all the more difficult. This is exacerbated by the relabeling of medical treatments with charged words like "sustenance."

State laws prohibiting the termination of artificial nutrition, hydration, and other forms of medical treatment would be of questionable constitutionality. Even if the label were changed, the provision of food, water, oxygen, or blood purification without the patient's authorization, either directly or through a legally authorized representative, would constitute a restraint on liberty, thus invoking the Fourteenth Amendment's protections.⁹⁸

V. BEYOND THE CONSENSUS: INAPPROPRIATE USE OF HEALTHCARE RESOURCES

Had the Schindlers won, there might have been other undesirable social consequences, apart from the legal consequences. One such consequence concerns the appropriate use of healthcare resources.

People in a PVS do not recover. That is what the "P" in PVS stands for – persistent. Persistent does not mean maybe persistent, kind of persistent, or temporarily persistent. It means lasting, unrelenting,

97. See, e.g., *In re Conroy*, 486 A.2d 1209, 1234 (N.J. 1985). See generally MEISEL & CERMINARA, *supra* note 11, at 5-13 to -14.

98. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 288 (1990) (O'Connor, J., concurring) ("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." (internal citations omitted)).

and enduring.⁹⁹ Continuing to provide life support to PVS patients, including artificial nutrition and hydration administered via a feeding tube, requires the efforts of an array of healthcare professionals and their assistants including physicians, nurses, nutritionists, and others. This means that scarce healthcare resources, both human resources and financial resources, are devoted to caring for patients whose improvement is unlikely. Although their organs, except their brains, can be functionally maintained, they will never again be sentient beings. Compelled care to patients who can never derive any conscious benefit only contributes to the stress, disillusionment, and demoralization of an increasing number of healthcare workers.

A Schindler victory might have led to profound increases in financial costs for the healthcare system. Healthcare resources are finite and providing additional resources to certain patients necessitates withholding resources from others. For example, hospitals and nursing homes sometimes run out of beds, and staffing levels are often stretched thin. At least of equal significance is the fact that being required to keep PVS patients alive could, over time, entail providing significantly more resources to an increased number of people who lack the ability to benefit from those resources.¹⁰⁰

Had the Schindlers won, the number of similar situations and their attendant costs would certainly have risen, though it is impossible to estimate the extent of this increase. The increase would depend on numerous factors including, but not limited to, the decisions that patients make in advance directives, the latitude that surrogates would have in making decisions in the absence of instruction directives, and what deci-

99. *But cf.* Voss, *supra* note 3 (study suggesting that patients in a *minimally conscious* state, which involves less severe brain damage than a PVS, may be capable of regenerating brain cell segments). However, given the length of time that Terri Schiavo was in a PVS, it was virtually certain there was no chance of recovery. See Karen Kaplan, *As Man Lay in Coma-Like State, His Brain Was Busy Rebuilding*, L.A. TIMES, July 4, 2006, at A23 (“Neurologists believe that the longer a patient remains in a minimally conscious or persistent vegetative state, the lower the chances for recovery.”). The fact that Terri Schiavo was in a PVS with no hope of recovery was subsequently confirmed by her autopsy. See JON R. THOGMARTIN, DIST. SIX MED. EXAM’R OFFICE, REPORT OF AUTOPSY FOR THERESA SCHIAVO (2005), available at http://www6.miami.edu/ethics/schiavo/pdf_files/061505-autopsy.pdf.

100. The number of individuals in a PVS in the United States is unknown. In 1983, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research observed that at that time, “[t]he only prevalence survey available estimates that Japan has about 2000 permanently unconscious patients in long-term care, which, if the prevalence were the same (and if differing definitions of terms did not cause substantial error), would imply less than 5000 at any one time in the United States.” PRESIDENT’S COMM’N, DECIDING TO FOREGO, *supra* note 15, at 178 n.15 (citations omitted). A more recent estimate is that there are between 10,000 and 25,000 adults and between 4,000 and 10,000 children in a PVS in the United States. Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (First of Two Parts)*, 330 NEW ENG. J. MED. 1499, 1503 (1994).

sions surrogates would actually make if they in fact had the discretion to do so. If we were considering only Terri Schiavo, these costs would not be so intolerable. But if *Schiavo* and its progeny had set a different precedent, a multitude of similar cases would occur over time.

It is unlikely that these increases in healthcare cost would be significant in relation to the United States' total healthcare costs. Nonetheless, in a system where healthcare costs already represent a significant proportion of the gross domestic product¹⁰¹ and where about one of every six individuals lacks health insurance,¹⁰² providing additional treatment for more patients who cannot perceive the fact that they are alive and who will never improve cannot possibly be the best use of those resources. Some people would assert that this use of resources would play a valuable and symbolic role in demonstrating our societal commitment to life. But commitment to mere existence, instead of commitment to providing medical treatment to those who can benefit from it, may be an important symbol of societal values gone astray.

VI. CONCLUSION

Now that the dust has settled from the *Schiavo* case, it is easier to see it for what it is. *Schiavo* should serve as a reminder of how end-of-life issues can bitterly divide families and thus as a reminder to engage in advance end-of-life planning. This reminder's strength will unfortunately wane with the passage of time, as it did after *Quinlan*, *Cruzan*, and all the other high profile end-of-life cases. *Schiavo* should serve as a reminder that end-of-life cases are best dealt with in the clinical setting, where the patient and family's privacy can be maintained, out of

101. Cynthia Smith et al., *National Health Spending in 2004: Recent Slowdown Led by Prescription Drug Spending*, 25 HEALTH AFFAIRS 186, 186 (2006).

102. CTRS. FOR DISEASE CONTROL & PREVENTION & NAT'L CTR. FOR HEALTH STATISTICS, U.S. DEP'T OF HEALTH AND HUMAN SERVS., SERIES 10, NO. 229, SUMMARY OF HEALTH STATISTICS FOR THE U.S. POPULATION: NATIONAL HEALTH INTERVIEW SURVEY, 2004, at 7, 37 (2006), available at http://www.cdc.gov/nchs/data/series/sr_10/sr10_229.pdf ("Among persons under age 65 years, 173 million (69%) had private health insurance, 30 million (12%) had Medicaid, and 41 million (17%) were uninsured."). One of the ways of measuring the overall success or failure of the United States healthcare system is to look at the 31 other countries that rank ahead of the United States in infant mortality rates, despite our per capita expenditures being higher. WORLD HEALTH ORG., WORLD HEALTH STATISTICS 2006, at 37 (2006), available at <http://www.who.int/whosis/whostat2006.pdf>; Gerard F. Anderson et al., *Health Care Spending and Use of Information Technology in OECD Countries*, 25 HEALTH AFFAIRS 819 (2006) ("In 2003, U.S. health spending per capita was \$5,635, almost two and a half times more than the comparable median for OECD [Organization for Economic Cooperation and Development] countries (\$2,280 per capita)."). Perhaps a more precise ranking is that of the CIA, which ranks U.S. infant mortality at 48th in the world. See CIA FACTBOOK, RANK ORDER – LIFE EXPECTANCY AT BIRTH (2007), <https://www.cia.gov/cia/publications/factbook/rankorder/2102rank.html>.

the media's glare and the craving for grandstanding by politicians that the media can generate.

Had the Schindlers won the *Schiavo* case, the legal consensus about end-of-life decisionmaking would have suffered serious setbacks, if it had not been sent into total disarray. In the first instance, that would have only been the *legal* consequence, but legal consequences inevitably have social consequences, sometimes widespread. A victory for the Schindlers would have increased the uncertainty about how certain surrogates need to be about incompetent patients' wishes. It would have also added to the uncertainty among physicians and other healthcare professionals about decisionmaking for incompetent patients who have warring family factions. It would have strengthened the need for advance directives while adding uncertainty about whether a proxy directive is adequate or an instruction directive is required, too. And it would have made it even more difficult than it already is to resist the pressure to accept tube feeding in patients for whom it will do nothing more than prolong the process of dying.¹⁰³ And all of these consequences would have increased the likelihood that end-of-life decisions would end up in litigation rather than being resolved in the clinical setting, thereby turning private tribulations into public trials.

From a legal perspective, the *Schiavo* case is pure anticlimax because after all the litigation and legislation – not to mention fighting, and shouting, and even shoving – it did not work any changes in the law.¹⁰⁴ History will view it as another in a series of high profile cases in

103. The impact of a ruling that erodes or overturns the consensus position that tube feeding is a medical procedure that may be forgone in accordance with the same standard and procedures as any other medical procedure would be especially significant because of the large number of elderly and demented nursing home patients who have feeding tubes. See Susan L. Mitchell et al., *Clinical and Organizational Factors Associated with Feeding Tube Use Among Nursing Home Residents with Advanced Cognitive Impairment*, 290 JAMA 73 (2006) (more than one-third of severely cognitively impaired residents have feeding tubes).

104. See Maya Bell, *Governor Abandons Feeding-Tube Efforts*, ORLANDO SENTINEL, Apr. 13, 2006, at B7. In many other states, bills were introduced to amend statutes to make it more difficult to terminate artificial nutrition and hydration by requiring an advance directive specifically requesting its termination. Most of these bills were not enacted. One exception is the North Dakota advance directive statute, where in order to forgo artificial nutrition and hydration, either the patient must have executed an advance directive to that effect or "the attending physician has determined that the administration of nutrition or hydration is inappropriate because the nutrition or hydration cannot be physically assimilated by the principal or would be physically harmful or would cause unreasonable physical pain to the principal." N.D. CENT. CODE § 23-06.5-09.6 (2005). The constitutionality of such a provision is questionable. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 287 (1990) (O'Connor, J., concurring). Another type of statutory change was affected in Louisiana in which the surrogate decisionmaking statute was amended to prohibit a spouse from acting as the patient's surrogate if the spouse is cohabiting "with another person in the manner of married persons." LA. REV. STAT. ANN. §40:1299.58.2(14) (2006).

which the consensus – the legal consensus, the clinical-professional consensus, indeed the societal consensus – about end-of-life decisionmaking further solidified.

The consensus developed by small steps before the *Schiavo* case, and it will, in time, be seen as just another small step. *Schiavo* is a small step in a rejection of vitalism and a reaffirmation of end-of-life decisions based on one's own values as expressed by a formerly self-determining person. It is another small step in the rejection of enslavement to medical technology and the acceptance of the inevitability of death. *Schiavo* is, in the final analysis, a reaffirmation of the consensus on end-of-life decisionmaking. Had the Schindlers won, it would have been otherwise.