SCHIAVO AND ITS (IN)SIGNIFICANCE

John A. Robertson*

Karen Ann Quinlan and Theresa Marie Schiavo are names tied to legal controversies over the withdrawal of medical treatment at the end of life. *In re Quinlan*[1] arose at a time when the rules for decisionmaking for incompetent patients were still unformed and inchoate. It set the framework of analysis for most of the subsequent development in the field.

Schiavo,[2] on the other hand, arose over a dispute about the application of those rules. In the end, the case of Terri Schiavo will have contributed little to end-of-life law, but it will be remembered because of the bitter battle that erupted between her husband and her parents over whether her feeding tube should be removed and the extraordinary efforts of Florida and then national politicians to overturn a judicial ruling in a pending case.

The Schiavo controversy began as a routine case of stopping treatment on a patient in a permanent coma and then metastasized into the *Bleak House*[3] of medical-legal jurisprudence.[4] Although there are many stories to tell about the case, I will focus on only two.[5] One is the state of the law concerning proxy deci-

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 Vinson & Elkins Chair in Law, University of Texas School of Law.

1. 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976).

2. *E.g. Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004); *Bush v. Schiavo*, 861 So. 2d 506 (Fla. 2d Dist. App. 2003); *In re Schiavo*, 780 So. 2d 176 (Fla. 2d Dist. App. 2001).

3. Charles Dickens, *Bleak House* (W.W. Norton & Co., Inc. 1977) (originally published 1853).

4. The comparison with Charles Dickens' famous novel is not literally true, because the *Schiavo* cases were resolved after seven years of litigation while the fictional case *Jarndyce v. Jarndyce* in the novel went on for over twenty years. However, the unending motions and petitions in the *Schiavo* cases often left the observer wondering if the litigation would ever end.

5. Other stories include Terri's history of weight problems and her attempts to deal with them; the fertility treatment that led to her cardiac arrest and incompetency; the malpractice suits growing out of those events and the distribution of the proceeds; the domestic conflicts and dramas that led to distrust between Michael Schiavo and his in-laws, the Schindlers; the oversimplifications or distortions in the media and political

sionmaking for incompetent patients. The second is what the politicization of the case by right-to-life and disability-rights groups portends about future controversies at the end and at the beginning of life.

I. LEGAL CONTEXT: QUINLAN *AND ITS PROGENY*

Both Karen Ann Quinlan and Theresa Marie Schiavo spent their last days in persistent vegetative states. Karen Ann Quinlan had lost consciousness and stopped breathing after combining drugs and alcohol at a party, which led to prolonged anoxia—an insufficient supply of oxygen in the blood.[6] After Ms. Quinlan lived dependent upon a respirator for seven months, her loving father and family requested that the respirator be removed.[7] Because the situation was new both for doctors and the law, it led to judicial reviews that culminated in a landmark 1976 decision that set the substantive norms for decisionmaking for incompetent persons in New Jersey and many other jurisdictions as well.[8]

The New Jersey Supreme Court proceeded by first finding that the State's interests in preserving life, preventing suicide, and upholding medical ethics were not sufficient to outweigh a person's common law and constitutional right to refuse necessary medical care.[9] The Court then made the pivotal move on which most later state and federal analysis hinges—the incompetent patient should not have any fewer rights than the competent person just because the patient is incompetent.[10] To prevent that disparity, the incompetent patient should be treated as if he or she were competent:

> If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, . . . then

arena; and the ways in which politicians used such high-profile events to attract support and push other agendas. There was even a story on the conservative judge who found himself at the center of a storm of controversy for applying the law. Abby Goodnough, *In* Schiavo *Feeding-Tube Case in Florida, Notoriety Finds an Unlikely Judge Presiding*, N.Y. Times A18 (Mar. 17, 2005).

6. *In re Quinlan*, 348 A.2d 801, 806 (N.J. Super. 1975).
7. *Id.*
8. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).
9. *Id.* at 663–664.
10. *Id.* at 664.

> it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment . . . as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative, this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them.[11]

In *Quinlan*, this meant that her father's decision to have the respirator removed would be deemed a reasonable approximation of what Karen would have chosen if competent or so physicians and the courts reviewing the matter might so decide.[12] Although the Court also suggested that hospital ethics committees should review such decisions,[13] neither ethics committee nor judicial review of the proxy judgment was legally required. The New Jersey Supreme Court's recognition of a substantive approach based on substituted judgment became the legal paradigm of decisionmaking in most other states.

In adopting the analytic paradigm etched in *Quinlan*, the easiest cases for state courts and legislatures were patients in persistent vegetative states and patients with advance directives. All states facing these questions adopted norms and procedures that allowed a proxy or surrogate decision-maker to withhold treatment, though some states were stricter than others in determining when treatment could be withdrawn or withheld.[14] The strictest states required that there be clear and convincing evidence of a prior directive or oral declaration on this issue, even for

11. *Id*. The assumption here was that not treating incompetent persons as if they were competent would harm them or treat them unfairly by subjecting them to burdens that competent persons do not face. But this conflates the question of whether we treat or withhold treatment from patients with the grounds or criteria for such decisions. Because a competent person may refuse treatment does not mean that society must treat incompetent persons as if they have made such a choice when they are incapable of doing so.

12. *Id*.

13. *Id*. at 668–669.

14. *Compare* Fla. Stat. § 765.401(4) (2004) (requiring that a surrogate's decision to withhold life-sustaining medical care be supported by clear and convincing evidence that the incompetent person would have made the same decision), *with* 755 Ill. Comp. Stat. 40/20(b)(1) (2005) (requiring a surrogate only to consult with the attending physician in deciding whether to forgo life-sustaining treatment for the incompetent person).

patients in persistent vegetative states.[15] In the case of Nancy Cruzan, another unfortunate young woman whose name became attached to a landmark right-to-die case, the United States Supreme Court ruled that such a standard did not violate her liberty and served legitimate state interests in preserving life and reducing error.[16]

The more difficult cases were cases in which the patient lacked a prior directive, but the patient was conscious and permanently incompetent, with varying degrees of dementia and ability to communicate. All states allowed treatment of conscious but incompetent patients to be withheld when there was clear evidence of a prior directive. In cases in which a directive was lacking, states varied as to whether they would allow a proxy to infer what the patient would have decided, or whether they would require clear and convincing evidence that such a prior choice had actually been made.[17]

II. FLORIDA LAW

The Florida courts and Legislature adopted a legal position consistent with *Quinlan*. Florida's first major engagement with

15. *E.g.* Fla. Stat. § 765.401(4); *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 262 (1990) (upholding the Missouri Supreme Court's decision that the state's public policy in protecting and preserving human life requires clear and convincing evidence of an incompetent person's wishes regarding the removal of life-sustaining treatment).

16. *Cruzan*, 497 U.S. at 284. For a defense of the holding, see John A. Robertson, Cruzan*: No Rights Violated*, 20 Hastings Ctr. Rpt. 8–9 (Sept.–Oct. 1990).

17. Massachusetts and New Jersey generally take a more liberal stance. *See In re Spring*, 405 N.E.2d 115 (Mass. 1980) (holding that an incompetent person, through substituted judgment on his or her behalf, may refuse medical treatment); *In re Conroy*, 486 A.2d 1209 (N.J. 1985) (holding that a surrogate decision-maker for an incompetent may direct the withdrawal or withholding of life-sustaining treatment). However, California, Michigan, New York, and Wisconsin have stricter requirements. *See Conservatorship of Wendland*, 28 P.3d 151 (Cal. 2001) (holding that conservator was required to prove by the clear and convincing evidence standard that patient wished to refuse life-sustaining treatment or that to withhold such treatment would have been in the patient's best interest); *In re Martin*, 538 N.W.2d 399 (Mich. 1995) (holding that prior statements that patient did not want to receive life-sustaining treatment did not constitute clear and convincing evidence that patient would not want life-sustaining treatment while incompetent but conscious); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607 (N.Y. 1988) (holding that mere statements do not constitute a firm and settled commitment that satisfies the clear and convincing evidence standard required to terminate artificial support); *In re Edna*, 563 N.W.2d 485 (Wis. 1997) (holding that withdrawal of life-sustaining medical treatment is not allowed unless patient is in a persistent vegetative state and decision to withdraw is in the best interest of the patient).

the issue occurred in 1984 in *John F. Kennedy Memorial Hospital v. Bludworth*,[18] a case holding that a guardian need not get court approval to execute the terms of living will of a man who was comatose and terminally ill.[19] Six years later in *In re Guardianship of Browning*,[20] the Florida Supreme Court broadened the right and added specificity. It found that a person who was incompetent and conscious rather than comatose had a constitutional right to have her previously expressed wishes, whether expressed orally or in writing, followed by a guardian without court approval.[21]

These results were then codified in the Health Care Advance Directives provisions of Florida's civil rights statutes.[22] Those statutes make clear that a person is free to make an advance directive refusing treatment, appoint a healthcare proxy, or have a family member or other act as a proxy to give effect to the wishes expressed in the advance directive when the person became incompetent. Unless challenged, a healthcare provider must comply within seven days with the terms of the advance directive or transfer care to a provider who will.[23]

If there is no living will, then the patient's spouse, adult child, parent, or designated others may make that decision.

> Any health care decision . . . must be based on the proxy's informed consent and on the decision the proxy reasonably believes *the patient would have made under the circumstances. If there is no indication of what the patient would have chosen*, the proxy may consider the patient's best interest in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn.[24]

Before exercising the incapacitated patient's rights to select or define healthcare under that provision, the proxy must consult with physicians about the nature of the patient's condition and be satisfied that the patient is in an end-stage, terminal, or persistent vegetative state, that there is no hope of recovery, and that

18. 452 So. 2d 921 (Fla. 1984).
19. *Id.* at 926.
20. 568 So. 2d 4 (Fla. 1990).
21. *Id.* at 17.
22. Fla. Stat. §§ 765.101–765.546 (2004).
23. Fla. Stat. § 765.1105 (2004).
24. Fla. Stat. § 765.401(2) (2004) (emphasis added).

the patient "does not have a reasonable medical probability of recovering capacity so that the right could be exercised by the patient."[25] Even then,

> [A] proxy's decision to withhold or withdraw life-prolonging procedures must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient's best interest.[26]

The Florida statute was one of the more liberal laws in the nation in that it explicitly allowed non-treatment if there was no evidence of a prior directive and the non-treatment would serve the best interest of the patient. That standard left many questions open, but it provided a workable way for families and physicians to resolve these questions in an ethically sound and legally acceptable way. Until *Schiavo*, agreement among families and physicians was likely if a patient was in a persistent vegetative state and in many other end-of-life situations as well.

III. APPLYING THE STANDARD IN SCHIAVO*: A LEGAL ASSESSMENT*

Families and physicians have usually been in agreement about decisions to provide or withhold/withdraw treatment from incompetent patients. The few disputes that have percolated up to the courts have been of two types. One type has involved cases in which doctors or hospitals refused to follow advance directives or proxy requests for or against treatment.[27] The second type, of

25. Fla. Stat. §§ 765.305, 765.205 (2004).

26. Fla. Stat. § 765.401(3).

27. Suits against physicians, hospitals, or officials responsible for prolonging care against the proxy or surrogate's wishes are notoriously hard to prosecute successfully. *See e.g. Blouin ex rel. Est. of Pouliot v. Spitzer*, 356 F.3d 348 (2d Cir. 2004) (affirming a district court's decision granting state officials and hospital personnel qualified immunity from a claim that they unconstitutionally intervened in medical treatment decisions for a terminally ill patient). On the other hand, doctrines of futility have sometimes allowed doctors and hospitals to refuse or withdraw treatment even though the family insists on continuing it. *See e.g.* Leigh Hopper, *No Easy Calls When Baby Is Terminally Ill*, Houston Chron. A1 (Feb. 9, 2005) (reporting that healthcare workers who removed life support from a six-month-old baby over the mother's objections were authorized to do so under the Texas Futile Care Law).

which *Schiavo* is an example, involves disputes between family members over a course of action.

Michael and Terri Schiavo were married in 1984 when in their early twenties.[28] In 1990, Terri suffered a cardiac arrest and brain damage due to lack of oxygen.[29] She was given a percutaneous endoscopic gastrostomy (PEG) to provide nutrition and hydration and Michael was appointed her guardian.[30] Several hospital or rehabilitation facilities provided care for Terri over the next several years.[31] At a certain point, Michael, who had been appointed guardian of Terri in 1990, and Terri's parents, the Schindlers, had a falling out.[32] A dispute arose over the proceeds of the malpractice litigation arising from Terri's treatment after her cardiac arrest.[33] Michael and the Schindlers also disagreed over the course of the therapy being provided to Terri.[34]

In May 1998, Michael petitioned a Florida court to authorize the removal of Terri's PEG tube.[35] The Schindlers opposed the request, claiming that Terri would have wanted to remain alive.[36] Following a trial, Pinellas County Circuit Judge George Greer ruled in February 2000 that Terri was in a persistent vegetative state and would have wanted the PEG tube removed.[37] The Second District Court of Appeal upheld the ruling, and the Florida Supreme Court declined review.[38]

The Schindlers then began a series of legal actions that delayed the execution of the court's decision to have the feeding tube

28. Kathy L. Cerminara & Kenneth Goodman, *Key Events in the Case of Theresa Marie Schiavo*, http://www.miami.edu/ethics2/schiavo/timeline.htm (accessed Mar. 15, 2005). For additional relevant resources, as well as an interactive timeline tracking developments from the date of Terri's birth to the most recent legislative and judicial activity, see Kathy L. Cerminara & Kenneth Goodman, *Schiavo Case Resources*, http://www.miami.edu/ethics2/schiavo_project.htm (accessed Mar. 15, 2005).

29. Cerminara & Goodman, *supra* n. 28.

30. *Id*.

31. *Id*.

32. *Id*.

33. *Id*.

34. *Id*.

35. *Id*. Rather than request withdrawal in his capacity as legal guardian, Michael Schiavo asked the court to assess the matter, as provided by Florida law. *In re Schiavo*, 780 So. 2d at 178–179.

36. Cerminara & Goodman, *supra* n. 28.

37. *Id*.

38. *In re Schiavo*, 780 So. 2d at 176, *rev. denied*, 789 So. 2d 348 (Fla. 2001).

removed until March 18, 2005.[39] These included requests for emergency relief based on claims of new evidence that Michael had lied about Terri's wishes;[40] that she was not in fact in a persistent vegetative state;[41] that she was being denied treatment that would benefit her;[42] that a papal statement about the "naturalness" of artificial nutrition and hydration would have affected her decision;[43] and that she had never had her own lawyer.[44]

The Florida courts have assiduously—perhaps too assiduously—given these claims a full airing. At one point, five neurologists were appointed to advise the courts (two named by the husband, two by the family, and the fifth by the other four).[45] At least three different guardians ad litem served throughout the litigation, the last, a professor of law and public health.[46] Throughout these proceedings, the courts hearing evidence or reviewing it have consistently found that Terri was in a persistent vegetative state, had no hope of improving, and if competent, would have wanted the PEG tube removed.[47]

One extraordinary turn of events in this ongoing saga occurred in October 2003, when Florida politicians succeeded in stopping execution of the judicial order to have her feeding tube removed.[48] This action occurred after all avenues of judicial relief had been exhausted, and the gastrostomy tube was withdrawn pursuant to court order on October 15, 2003.[49] A statewide cam-

39. Cerminara & Goodman, *supra* n. 28.

40. *Id*.

41. Manuel Roig-Franzia, *In* Schiavo *Case, Gov. Bush Seeks Delay to Probe Abuse Allegations*, Wash. Post A3 (Feb. 24, 2005).

42. CNN, *Florida Judge Rejects State Custody Bid in* Schiavo *Case*, http://cnn.com/2005/ALLPOLITICS/03/23/schiavo.jeb.bush/index.html (Mar. 24, 2005) [hereinafter CNN].

43. David Sommer, *Schindlers Use Papal Decree in* Schiavo *Case*, Tampa Trib. A4 (July 21, 2004).

44. *In re Schiavo*, 780 So. 2d at 178.

45. Cerminara & Goodman, *supra* n. 28.

46. Jay Wolfson, *A Report to Governor Jeb Bush In the Matter of Theresa Marie Schiavo* (Dec. 1, 2003) (available at http://www.miami.edu/ethics2/schiavo/wolfson%27s%20report.pdf (accessed June 11, 2005) (one of the more informative accounts of events in the Schiavo controversy).

47. *In re Schiavo*, 780 So. 2d at 180. An autopsy after her death confirmed she had a profound atrophy of the brain consistent with being in a persistent vegetative state and uncovered no evidence that she had been abused. Lisa Greene, *She Never Would Have Recovered*, St. Petersburg Times A1 (June 16, 2005).

48. Cerminara & Goodman, *supra* n. 28.

49. *Id*.

paign led by Randall Terry of Operation Rescue fame, and supported by right-to-life and disability-rights groups, flooded the state legislature with e-mails, faxes, and other communications.[50] The Legislature, which was in special session to consider medical malpractice reform, quickly passed, and Governor Jeb Bush signed, "Terri's Law."[51] This law allowed the Governor "to issue a one-time stay in certain cases," and the PEG was reinserted.[52] Although Michael Schiavo was ultimately successful in having "Terri's Law" found unconstitutional, the litigation delayed final resolution of the case for another eighteen months until Terri's death on March 31, 2005.[53]

As the Schiavo controversy entered its final stages in mid-March 2005, there was a resurgence of judicial and legislative activity. The Florida Department of Children and Family Services tried unsuccessfully to intervene to investigate allegations of abuse.[54] The Florida Legislature sought to pass a statute that would undo the judicial ruling without running afoul of the separation-of-powers issues that undercut "Terri's Law," but the Florida Senate balked at a law requiring an explicit directive to have nutrition and hydration withheld.[55]

Terri's feeding tube was removed on March 18, 2005.[56] Although Congress's Easter recess had already begun, Republicans in the House and Senate reconvened to pass, with bipartisan support, a law granting jurisdiction to the United States District

50. Bill Cotterell, *Judge Orders Schiavo Hearing*, Tallahassee Democrat (Feb. 23, 2005) (available at http://www.tallahassee.com/mld/democrat/news/local/10966645.htm) (describing the efforts of Randall Terry, founder of pro-life vitalist group Operation Rescue, to "urge[ ] Gov. Jeb Bush and Florida legislators . . . to head off any court action removing Terri Schiavo's life supports").

51. 2003 Fla. Laws ch. 418.

52. *Id*.; Cerminara & Goodman, *supra* n. 28.

53. *Bush v. Schiavo*, 885 So. 2d 321, 337 (2004); Cerminara & Goodman, *supra* n. 28. One of the few articles written in favor of the law was that of O. Carter Snead, who also happens to be the general counsel to President George W. Bush's Bioethics Council. O. Carter Snead, *Dynamic Complementarity: Terri's Law and Separation of Powers Principles in the End-of-Life Context*, 57 Fla. L. Rev. 53 (2005).

54. Roig-Franzia, *supra* n. 41. The trial judge, Circuit Court Judge George Greer, rejected the motion, and the motion was upheld on appeal. CNN, *supra* n. 42.

55. Samantha Gross, *Florida, Congressional Efforts to Keep Terri Schiavo Alive Hit Roadblocks*, http://journals.aol.com/justice1949/JUSTICEFORTERRISCHIAVO/entries/675 (Mar. 17, 2005). For a discussion of the merits of such a bill, see *infra* nn. 95–96 and accompanying text.

56. Cerminara & Goodman, *supra* n. 28.

Court for the Middle District of Florida for a de novo review of whether the Florida courts had respected Terri's constitutional rights.[57] The federal judge hearing the case refused to order that the feeding tube be reinserted.[58] He found that Congress had not changed the requirements for a preliminary injunction, and that her parents were unlikely to succeed on the merits.[59] When the United States Court of Appeals for the Eleventh Circuit upheld this decision[60] and the United States Supreme Court denied review,[61] the legal battle to "save" Terri Schiavo's life was over.

A. The Schindlers' Claim

The Schiavo controversy that perturbed the Florida courts and national media for several years was not about the legal standard for decisions regarding incompetent persons, but rather about how that standard should be applied in the case of Terri Schiavo. Under the *Quinlan* substituted judgment paradigm incorporated into Florida law, surrogates or proxy decision-makers, or courts ruling in their stead, have the legal authority to request that care be withheld or withdrawn based on a judgment that such a decision is what the patient, if competent, would have chosen. Although Terri had not signed a living will, her husband and others testified to statements she had made commenting on news stories and television programs that she would not want to be kept alive in a comatose state with no hope of recovery.[62] Given the evidence presented to the court of her medical condition, her statements, and her values, it was reasonable for the courts to

57. Steve Turnham, *Inside the Politics of the Schiavo Bill*, http://www.cnn.com/2005/ALLPOLITICS/03/23/schiavo.bill.wrangling/index.html (Mar. 23, 2005). When the bill was not agreed on before recess, committees in the United States House of Representatives and Senate issued subpoenas to Terri Schiavo and others in the case to appear before Congress on March 25 for a hearing. *Id.* Use of the subpoena power to overturn or interfere with an ongoing state case is highly unusual and of unknown legality. *Id.* It did not stop removal of Terri's feeding tube on March 18. *Id.* Passage of a law granting federal jurisdiction over the case mooted legal questions concerning the validity of the subpoena. *Id.*

58. *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378, 1382 (M.D. Fla. 2005).

59. *Id.* at 1383.

60. *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1296 (11th Cir. 2005).

61. *Schiavo ex rel. Schindler v. Schiavo*, 125 S. Ct. 1692 (2005).

62. *Schiavo*, 885 So. 2d at 325.

find that this was the decision that "[she] would have made under the circumstances" if competent.[63]

The Schindlers, however, disputed that Terri would have chosen withdrawal of the PEG tube if competent. In the early stages of the case, the Schindlers argued that there was no clear and convincing evidence, as Terri's husband asserted, that she would want feeding stopped.[64] Her parents denied that she had ever made such statements and claimed that they were fabricated by the husband out of his desire to be rid of Terri so that he could marry the woman with whom he had subsequently fathered two children.[65] In the final stages of the litigation, they also tried to use a 2005 statement by the Pope about the unacceptability of withholding food and water as grounds for a rehearing to show that Terri, as an observant Catholic, would not have chosen a course of action contrary to papal teaching.[66]

B. Reframing the Claim

Although the Schindlers' main strategy was to attack the sufficiency of the evidence about what Terri would have chosen if competent, after April 2001 they also asserted that Terri was not in a persistent vegetative state and could be helped by new treatments that Michael was denying her.[67] They pointed to events recorded on videotape and run on television[68] and websites[69] that showed her "responding" to stimuli, such as following with her eyes the movement of a balloon, and her parents' oral communication with her. The weight of expert neurological opinion indicates that a person in a persistent vegetative state may

63. Fla. Stat. § 765.401(2).

64. Sommer, *supra* n. 43.

65. *Id*.

66. *Id*. That statement was not an official statement of church teaching, and thus it was not obligatory upon all Catholics. *See* Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the* Schiavo *Cases*, 35 Stetson L. Rev. 147, 169 (2005) (explaining that "[t]he United States Conference of Catholic Bishops must offer further guidance before Roman Catholic institutional policies in the United States must change").

67. I am indebted to Kathy Cerminara for making clear when this reframing of the Schindlers' claim first occurred. *Id*.

68. See *infra* n. 69.

69. The Terri Schindler-Schiavo Foundation, *Tracking a Balloon for Dr. Cranford*, http://www.terrisfight.org (accessed June 6, 2005).

appear to be following a moving object, but in fact is still unconscious. During the end stages of the *Schiavo* case, a news report of PET scans of the language-processing areas of the brain showing that some people in comas still have awareness even if they lack the ability to respond could only confirm the suspicions of skeptics.[70] According to tests of five patients, the same areas of the brain lit up when patients in comas and those not in comas were subjected to language stimuli.[71]

After a full airing of this claim, the trial court again found that Terri was in a persistent vegetative state and ordered that the feeding tube be removed.[72] Yet, spurred by misleading media and website presentations, the impression persisted that there was serious doubt about whether Terri was in fact in a persistent vegetative state, thus opening the door to the claim that she should be kept alive so that she might have a chance to improve.[73]

The reframing of the case as one involving a person who was not in a persistent vegetative state but was conscious and communicative became a key strategic move that helped mobilize

70. Benedict Carey, *New Signs of Awareness Seen in Some Brain-Injured Patients*, N.Y. Times A1 (Feb. 8, 2005). But there is no good reason to take this study as undercutting the medical findings. First, Terri Schiavo has been repeatedly found to be in a persistent vegetative state, not merely a coma. Second, no one has replicated the study, and no one would claim that this finding alone, which has not been published in a scientific journal, has settled the point. Nobel Prize author Nadine Gordimer describes a person in a vegetative state as follows: "[W]hat did visits help a man . . . who did not know there was anyone present, did not know that he himself was present. . . . What is a presence? Must consciousness be receptive, cognitive, responsive, for there to be a presence? Didn't the flesh have a consciousness of its own, the body signaling [sic] its presence through the lungs struggling to breathe with the help of some machine, the kidneys producing urine trickling into a bag. . . ." Nadine Gordimer, *None to Accompany Me* 210 (Farrar, Straus & Giroux 1994).

71. Carey, *supra* n. 70, at A1.

72. Cerminara & Goodman, *supra* n. 28. To assess this claim, the trial court appointed five neurologists as experts. Although the two experts named by the Schindlers claimed that they had success with treating patients in comas and/or Terri was not in a coma, the other three said the evidence was clear that she had lost almost all cortical function, she was in a persistent vegetative state, and there were no known published treatments that could help her.

73. *E.g. Hannity and Colmes* (Fox News Network Mar. 10, 2005) (TV broadcast). A typical example of this media attention, this segment featured a business man, Robert Herring, who recounted his offer to Michael Schiavo of one million dollars if he would cede his decisionmaking rights over Terri to the parents. Herring based his offer on his perception that "there [was] hope for Terri" and that he wanted to "give the lady a chance." Shown on a split screen were videotape images of Terri in a hospital gown following the movement of a balloon with her eyes, suggesting to viewers that she was conscious and not comatose.

widespread support from the disability-rights and right-to-life communities and eventually Governor Bush, the Florida Legislature and members of Congress. By arguing that Terri was conscious and could be treated, the Schindlers were able to transform the case from one about the inferred wishes or best interests of a permanently comatose person to a story about the unjustified killing of a disabled person whose condition could be improved if not for an uncaring husband interested in inheriting her malpractice settlement and marrying the woman with whom he had fathered two children.

This reframing of the situation brought the case within the discourse of the disability-rights community, thereby attracting the energies of the many groups fighting against devaluation of life or denial of medical care solely because of disability. One wing of that movement took a vitalist position: if any life remains at all, it must be protected, no matter how unconscious, compromised, or debilitated that person is.[74] This slant on the case also brought in right-to-life advocates, most notably Randall Terry,[75] and groups committed to protecting innocent human life.[76] Because gastrostomy feeding was also at issue, the case could also be presented as one of "killing by starvation," which further mobilized right-to-life support.[77] After the invalidation of Terri's Law opened the door to the removal of the PEG tube, the Schindlers then argued that Terri was being sentenced to death without the due process that even killers on death row received.[78]

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74. *See generally Euthanasia.com*, http://www.euthanasia.com/index.html (last updated 2005) (providing links to websites of numerous organizations opposed to euthanasia).

75. The Society for Truth and Justice, *Saving Terri Schiavo*, http://www.societyfortruthandjustice.com/prod01.htm (Oct. 26, 2003).

76. A strong pro-life position on *Schiavo* would shore up any Florida politician's standing with that state's right-to-life voters. Unsurprisingly, pro-life Governor Jeb Bush aggressively supported efforts to save Terri's life. Governor Bush's actions also bolstered the 2004 reelection campaign of his brother, President George W. Bush, by helping to keep the issue of protecting life in the public eye and thus helping to motivate voters.

77. The Society for Truth and Justice, *supra* n. 75.

78. Daniel Webster, *"Death Sentence" Is Unjust*, USA Today 10A (Jan. 27, 2005). As Florida State Senator Daniel Webster put it, "Capital felons on trial for their lives in Florida are entitled to independent counsel, competent representation, trial by jury and automatic review of their death-penalty case by the Florida Supreme Court. Yet Terri, utterly innocent of any wrongdoing, received none of these protections." *Id.*

The *Schiavo* case grew and proliferated because of a confluence of two factors. One was the Schindlers' animosity toward Michael and their apparent inability to recognize an unpleasant medical reality. The second was the presentation of Terri's condition as one that right-to-life and disability-rights groups could argue involved killing an innocent human life.[79] While only the most vitalist of those groups would argue that all people in persistent vegetative states should be maintained as long as possible, the ambiguity introduced in April 2001 of whether she was in fact in such a condition enabled the case to be reframed in a way that raised broader issues about the right to life and treatment accorded to disabled persons, eventually dragging both the Republican-controlled Florida Legislature and the United States Congress into the fray.

These developments raised two issues that deserve more attention: (1) whether there is a need for reform in the law concerning the withdrawal of treatment from comatose and other incompetent persons, and (2) the role that the right-to-life movement is likely to play in future end-of-life and related controversies.

IV. DECISIONMAKING FOR INCOMPETENT PERSONS: IS LEGAL REFORM NEEDED?

Although the *Schiavo* case paraded itself as a dispute about the facts used in applying a settled legal standard, the case has drawn attention to the inherent ambiguities in the decisional paradigm of substituted judgment—determining what the patient would have chosen if competent. The biggest hole revealed was the indeterminacy of the substituted judgment test and the way that it could be manipulated in its application. Although the malleability of the test was well known to bioethicists, what was unique was how a well-financed litigant was able to appeal to the uncertainty of the test to keep the case going for so long. Having lost in the courts, the Schindlers' legislative allies might seek changes in the substituted judgment paradigm that will make decisionmaking at the end of life even more difficult than it is now.

79. Jon B. Eisenberg, *The Terri Schiavo Case: Following the Money*, The Recorder (S.F.) 4 (Mar. 4, 2005).

A. Weaknesses and Strengths of Substituted Judgment

The substituted-judgment paradigm has two main weaknesses and one strength. One weakness is the lack of clarity about what exactly is meant by "what the person would have chosen if competent." As previously shown, there are at least three ways to read that standard.[80] These include what the person now if competent with competent values and interests would choose (the "Time 1 Self"); what a competent person with the values and interests of someone who is incompetent would choose (the "Time 2 Self"); or what best serves the interests of the incompetent person as he or she is now. All of these interpretations involve subtle analyses of facts that are not easily specified or operationalized. It is a separate question, however, whether we should try to make more specific what the test means.

The second weakness is what counts as evidence of that choice. A written advance directive would seem to be most reliable, but even then, one can raise questions about whether the maker of the advance directive fully understood that her Time 1 Self directive would apply at the stage when the maker would no longer have the interests and values that she had by virtue of her competency at the Time 1 Self stage when she made the directive. But if there was no written or specific oral directive, should statements made casually while watching a television program or news report about similar cases be given credence? In addition to issues of the credibility of the evidence, there is the deeper problem of why Time 1 Self preferences should control decisions at the Time 2 Self stage when the person's interests were likely to be very different from what they were as perceived through the lens of competency at Time 1.

Ironically, the very weaknesses of the test are also the key to its appeal. Despite the conceptual confusion and vagueness of the test, the idea of doing "what the patient would want if competent" is nevertheless alluring because it displaces attention from and

80. Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. Med. & Health Care 234 (Fall 1989); John A. Robertson, *Second Thoughts on Living Wills*, 21 Hastings Ctr. Rpt. 6 (Nov.–Dec. 1991); John A. Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 76 Colum. L. Rev. 48 (1976) [hereinafter Robertson, *Organ Donations*].

thus obfuscates the deeper value choice made about the moral worth of persons with such severely compromised cognitive abilities. I would submit that it is this displacement from the underlying normative judgment that explains the widespread acceptance of the *Quinlan* paradigm and its likely persistence once the klieg lights of the Schiavo controversy have dimmed.

By asking what the person would have wanted if competent, we may pretend that we are respecting the person as a choosing, competent individual and deciding the question on a patient-centered, not an other-directed, basis. A more realistic appraisal is that we are making judgments about the value of the life of permanently comatose or incompetent patients, but do not want to do so explicitly. When persons have permanently lost their rational faculties, the ability to experience benefits and harms, and the capacity for symbolic interaction that make life meaningful, there is a widespread though implicit recognition that physicians and families need not be as diligent or exigent in preserving their lives as they would with patients who are fully competent. While this obfuscating function would not sanction murder, it does lead to the acceptance of treatment withdrawal when proxy or surrogate decision-makers and physicians agree that the time to stop treatment has arrived.[81]

Making such judgments explicitly and directly is difficult, and perhaps even dangerous because of the ease of extending such evaluations to less marginal cases. As a result, it is better to make those judgments surreptitiously in the guise of inferred autonomy and the appearance of the patient's choice, as the substituted judgment test enables us to do. Our feelings and practices are caught between the need for sunlight and transparency and the reluctance to make difficult decisions openly (between Louis Brandeis' dictum that "the best disinfectant is sunlight"[82]

81. This idea is evident in sociological findings and in such ideas as Norman Cantor's constructed preference approach. Norman L. Cantor, *Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients without Advance Instructions*, 48 Rutgers L. Rev. 1193, 1241–1267 (1996) [hereinafter Cantor, *Constructive Preference Standard*]; Norman L. Cantor, *Twenty-five Years after* Quinlan*: A Review of the Jurisprudence of Death and Dying*, 29 J. L. Med. & Ethics 182, 192–93 (2001).

82. Louis D. Brandeis, *Other People's Money and How the Bankers Use It* 92 (Frederick A. Stokes Co. 1914).

and T.S. Eliot's reminder that "humankind cannot bear too much reality"[83]).

B. The Likelihood of Legislative Changes

Having cast the spotlight of public scrutiny on the legal standards for end-of-life decisionmaking for incompetent patients, an important question is whether the passions stimulated by the *Schiavo* case will lead to legislative changes that make decisionmaking at the end of life more difficult than it now is for families and physicians. The short-run danger is greatest in Florida, but right-to-life and disability-rights groups may seek legislation in other states as well.

Professor Kathy Cerminara has identified the most immediate procedural and substantive changes that are likely to occur in Florida.[84] On the procedural side, the most likely change would be to prevent anyone who, like Michael Schiavo, stands to inherit from the incompetent patient to act as guardian or proxy for end-of-life decisions. But since spouses and family members may often inherit under state intestacy statutes or wills, they would be barred from serving in this capacity. Yet they are the ones that know the patient best and the ones most often there to serve as a surrogate or proxy decision-maker. A law barring them from serving in a proxy or guardian capacity would be a major impediment in many end-of-life settings.

On the substantive side, Professor Cerminara is also on strong ground in decrying any legislative move to require that there be an explicit advance directive to have gastrostomy tubes and other means of medical nutrition and hydration stopped.[85] Such proposals drape the highly medical nature of these interventions with the symbolic associations of taking food and water. In this case, the question of whether a surgical intervention should occur and then chemical nutrients be delivered to the body is intertwined with the symbolically charged act of denying a person food and water.

83. T.S. Eliot, *Burnt Norton*, in *Four Quartets* 118 (Harcourt Inc., 1943).
84. Cerminara, *supra* n. 66, at 159–176.
85. *Id*. at 170–174.

Just as it has long been accepted that discontinuing oxygen to a person on a respirator is appropriately described as withholding medical care, so too is the discontinuation of artificial nutrition and hydration through a surgically inserted tube in the stomach a form of withholding medical care.[86] Medically provided nutrition and hydration deserve no special status or need for protection once the decision to withhold or withdraw medical treatment from an incompetent patient has been made. The bills before the Florida Legislature to require an advance directive to have gastrostomy tubes removed would treat PEG differently from dialysis, respirators, and other medical interventions.[87] Because so few people make advance directives, the bills would prolong unnecessarily the dying of incompetent persons and the suffering of their families.[88] The bills should be defeated.

I am less troubled by Professor Cerminara's concern about legislative change that would limit the ability to use constructed preferences to satisfy the substituted-judgment test.[89] That issue arose at the first evidentiary hearing before Judge Greer.[90] Michael Schiavo's lawyer had introduced sociological evidence about the preferences of people at the end of life, showing an overwhelming preference not to be kept alive on machines.[91] The Schindlers claimed that introduction of this evidence tainted the hearing because evidence of what other people would want is not relevant to what Terri herself would have chosen.[92] Although the Second District Court of Appeal did not find reversible error,[93] the question of whether such evidence is relevant could lead to legislative action to bar it.

The problem according to Professor Cerminara is that such evidence is often used to help construct the preferences of persons who have not left direct evidence of what they would want when incompetent.[94] If no direct evidence of that preference is available,

86. *Cruzan*, 497 U.S. at 265; *In re Conroy*, 486 A.2d 1209, 1216 (N.J. 1985).

87. Fla. Sen. 2128, 107th Leg., Reg. Sess. (Mar. 16, 2005); Fla. H. 701, 107th Leg., Reg. Sess. (Mar. 9, 2005).

88. *Id.*

89. Cerminara, *supra* n. 66, at 164–167.

90. *Id.* at 150.

91. *Id.*

92. *Id.* at 150–151.

93. *Id.* at 151.

94. Cantor, *Constructive Preference Standard*, *supra* n. 81, at 1241.

one could reasonably argue that the person would want what most people in that situation have said that they want—not to be kept alive. Any legislative effort to bar such evidence would mean that treatment could not be withheld in most instances of substituted judgment. At that point, the decision would have to be made on the basis of the incompetent person's best interests.[95]

The difficulty then posed is that judgments based on incompetent patients' best interests are highly fraught with normative significance, even in cases of persistent vegetative states. The logic of persistent vegetation, for example, assumes that a person is totally unconscious and experiences no pain or sensation, even though reflex and involuntary movements occur. If so, persons in persistent vegetative states have no interests. Whether they continue to live or die should then be of no moment to them. On that logic, one could refuse or continue treatment, take organs from them to transplant to others, or use them in intrusive medical experiments simply because without interests, they are no longer capable of being harmed. Yet it is doubtful that any legislature would pass legislation that explicitly recognizes that persons in persistent vegetative states have suffered the equivalent of death or that they may be actively killed.[96]

I predict that the *Schiavo* case will not lead to much remedial legislation to correct flaws in the substituted-judgment approach to decisionmaking for incompetent patients. Our current system, though flawed, has done a serviceable job of blending notions of autonomy, protection of the weak and vulnerable, and respect for life. The *Schiavo* case has shown how misperceptions, denial, and displacement of other conflicts can prolong a case and make it difficult to resolve, but the case has not uncovered any fatal gaps

95. The problem identified here is one of the ambiguities inherent in the substituted-judgment test. In its strictest formulation, what an incompetent person would want if competent in light of his situation as a permanently incompetent person would be whatever best serves his interests in that situation. Properly understood, substituted judgment merges into the best-interests test. *See* Robertson, *Organ Donations*, *supra* n. 80 (describing the ambiguity of interpreting an incompetent person's best interests based on the person's interests when competent versus the person's interests when incompetent).

96. Those judgments are even more difficult when the patient is incompetent but conscious, and lacks a living will. Because such patients have sensations and may interact to some limited extent with others, it will be much more difficult to convince people that they have no interest in living further. Unless the medical interventions are highly burdensome, this means that standard interventions such as respiratory assistance and gastrostomy feeding would be continued.

or flaws in the fairness of the substituted-judgment standard. In the end, the *Schiavo* case teaches us very little about how decisionmaking for incompetent persons should be handled.

V. FUTURE RIGHT-TO-LIFE CONTROVERSIES

Even though the *Schiavo* case is unlikely to change the rules for end-of-life care, it is nevertheless important as an indicator of the deep ethical and cultural fault lines that now exist in American public life. While those divides are notably present in areas as diverse as same-sex marriage and United States membership in an international criminal court, ethical clashes are particularly pronounced around issues of life, death, and biotechnology. No matter how beneficial in other regards, any change seen as loosening the commitment to respect for human life in these areas is staunchly resisted. Given the growing power of the right-to-life movement, that divide is likely to continue for some time.

With assisted suicide, for example, we may reliably expect few other states to adopt an Oregon-type law that allows a small number of terminally ill patients to hasten their own death with drugs prescribed after repeated requests to their physicians.[97] Indeed, the Department of Justice's efforts to remove the federal controlled-substances license from Oregon doctors who participate in assisted suicide may effectively confine that practice to the underground, thus losing the benefits of transparency and sunlight to monitor its use as presently exists.[98] Any system of active euthanasia, such as that now practiced in the Netherlands,[99] is even more distant.

It also means that we will need to be punctilious about other issues that arise at the border of life and death. These include

97. Or. Rev. Stat. Ann. § 127.800–127.897 (2005).

98. *See Or. v. Ashcroft*, 368 F.3d 1118, 1131 (9th Cir. 2004), *pet. for cert. filed, Gonzales v. Or.*, 125 S. Ct. 1299 (2005) (holding that the Department of Justice's directive that physicians who assist terminally ill patients in committing suicide, in accordance with Oregon's Death with Dignity Act, violate the federal Controlled Substances Act was invalid because the directive exceeded the scope of the Attorney General's authority under federal law); Marya Lucas, *Justices Asked to End Oregon Death Act*, 28 Leg. Times 7 (Feb. 14, 2005) (discussing the Department of Justice's appeal of the decision in *Oregon v. Ashcroft* to the United States Supreme Court). The latest report shows that thirty-seven patients ended their lives in this way in 2004, a reduction from forty-two patients in 2003. Don Colbrun, *Fewer Turn to Assisted Suicide*, The Oregonian B01 (Mar. 11, 2005).

99. *Euthanasia.com*, *supra* n. 74.

issues of medical futility, the use of the incompetent in research or as a source of organs, and proposals to respecify the precise moment of death to facilitate the retrieval of organs under dead cadaveric donor protocols.[100] Although such patients may have few or no interests, as is the case when they are in persistent vegetative states, the symbolic aura that surrounds comatose, heart-beating persons will make it very difficult to accept such changes, no matter what their benefits or how small and marginal the compromise with vitalist values. Even surrounding them with procedural safeguards, such as the requirement of an advance directive specifying the precise activity at issue and review by independent physicians or ethics committees, will not be a guarantee that change will be acceptable.

The "culture of life" drama being reenacted in the Schiavo controversy has a parallel in the embryonic stem cell (ESC) debate. Although that debate occurs at the beginning rather than the end of life, it too involves a clash between strongly held vitalist views and a more pragmatic approach to questions of human dignity. Those persons who insist that preimplantation human embryos are living members of the human species oppose their use in research or therapy.[101] Research proponents, on the other hand, stress the embryo's lack of neurological development and potential for actually being placed in a uterus. Stricter standards at the end of life will prevent some patients in severely compromised conditions from dying sooner than they otherwise would, thus adding to the burdens on caregivers and the healthcare system. Not permitting or funding embryonic stem cell research and therapy, on the other hand, could delay or prevent the development of therapies for millions of people. The Schiavo and ESC debates have thus energized both sides in the culture-of-life wars that will continue to divide the country for some time to come.

100. For a discussion of issues relating to the time of death and cadaveric organ donation, see John A. Robertson, *The Dead Donor Rule*, 29 Hastings Ctr. Rpt. 6 (Nov.–Dec. 1999).

101. For an overview of the different sides in the debate, see Pres.'s Council on Bioethics, *Monitoring Stem Cell Research*, http://www.bioethics.gov/reports/stemcell/index.html (accessed Oct. 11, 2005).