

# Schiavo: A Hard Case Makes Questionable Law

by Rebecca Dresser

Since the 1970s *Quinlan* case, decisions about life-sustaining interventions have been a major focus of bioethics inquiry. By the end of the 1990s, however, professionals and the general public were paying less attention to this topic. After the U.S. Supreme Court rulings on physician-assisted suicide, it seemed that most of the major issues about end-of-life choices had been settled.

But appearances can be deceiving. In the final months of 2003, another end-of-life controversy captured the nation's attention. This new dispute over life-sustaining treatment demonstrated that sharp disagreements persist regarding the acceptable conditions for forgoing treatment. The dispute over Terri Schiavo's care triggered heavy media coverage and actions by officials in all three branches of Florida's state government.

Thanks to the extensive publicity, most readers are familiar with the facts of the case. In 1990, Terri Schiavo's heart stopped. Paramedics revived her, but oxygen deprivation had already produced severe brain damage. Later that year, her husband, Michael Schiavo, was appointed her guardian. For several years, he and his wife's parents, the Schindlers, remained friendly. But their cooperative relationship ended after malpractice litigation produced an award of about one million dollars, which went into a trust fund to cover the patient's care.

By the mid-1990s, Michael Schiavo concluded that his wife would not recover. In 1998, he asked a court to per-

mit removal of the patient's feeding tube. The Schindlers opposed this request. By 2003, various challenges and counter-challenges had been considered in numerous court proceedings. The courts, applying Florida statutes and case law, determined that Michael Schiavo's request to withdraw treatment should be honored.<sup>1</sup>

The Schindlers continued to oppose treatment withdrawal, however, and certain organizations and state officials expressed support for their position. In October 2003, at the behest of Governor Jeb Bush, the Florida legislature passed a law authorizing the governor to block the court order to remove the tube, pending additional testing to ascertain whether the patient could ingest food orally. This law's constitutionality then became an issue for the courts.

In the meantime, Governor Bush issued a stay keeping the tube in place and a guardian *ad litem* was appointed to prepare a case summary and recommendations on whether the stay should be continued. Last December, the guardian *ad litem*, Jay Wolfson, submitted his report.<sup>2</sup> It is a detailed and thoughtful account that concludes by recommending further testing to evaluate the patient's swallowing ability. It also urges the parties to agree in advance about the effect test results should have on the treatment decision. As the report notes, "Given the history of this case, [the testing] would not, in and of itself, assure a resolution, and is not, therefore, deemed either feasible or of value to Theresa Schiavo without prior agreement."

## Sources of Disagreement

At least five points underlie the family dispute that is responsible for keeping this case in the legal spotlight. One is whether Terri Schiavo is in a persistent vegetative state. An evidentiary hearing in 2002 focused on this question. Three neurologists, including one appointed by the court and two chosen by Michael Schiavo, said that she met the criteria for PVS. A neurologist and a radiologist selected by the Schindlers said that her condition was less severe than that. Though the court found clear and convincing evidence that Terri Schiavo met the criteria for PVS, the parents believe that more tests are needed to evaluate her current capacities.

Terri Schiavo's prognosis is another point of contention. At the earlier evidentiary hearing, the physicians testifying for the parents said that they thought she could be helped by certain interventions (hyperbaric therapy or "vasodilatation" therapy). But neither of these witnesses could cite research or other published reports to support their claims. Moreover, as the report of the guardian *ad litem* noted, "Theresa has far outlived any documented periods from which persons in persistent vegetative states have emerged in any functional capacity."

The relatives are divided as well on the question of what treatment choice this patient would make if she could evaluate her situation. Michael Schiavo insists that his wife would prefer to have the feeding tube withdrawn; the Schindlers say she would want her current care to continue, especially if there is, as they believe, a possibility of improvement. The judges acknowledged that they had received limited information about Terri Schiavo's prior wishes, but found the evidence sufficient to meet the clear and convincing standard required by law.

Terri Schiavo's relatives also have conflicting views on two ethical issues relevant to the case. First, her husband thinks that life in her current situation has no value to her, that it would be more respectful to forgo treatment and allow her to die. In contrast, her parents see continued life as a benefit to her.

Second, Michael Schiavo considers the feeding tube a medical intervention similar to resuscitation and antibiotics. But to the Schindlers, tube feeding is not significantly different from ordinary nourishment. From this vantage point, a decision to remove the feeding tube would subject their daughter to death by starvation.

The fate of the challenge to what is informally known as “Terri’s Law” will turn in part on interpretations of the Florida and U.S. Constitutions’ separation-of-powers provisions. Critics contend that in enacting this law, the Florida legislature and governor impermissibly intruded on the judicial power to decide specific cases.

From a general policy perspective, there are definite problems with the Florida officials’ spur-of-the-moment decision to override the courts’ application of the state’s preexisting law on end-of-life treatment. If legislators and the governor think that this law is flawed, there is an established process for proposing changes, one that would permit hearings and a more informed debate over the merits of such a proposal.

At the same time, the events surrounding *Schiavo* point to shortcomings in the accepted approach to end-of-life decisionmaking for incompetent patients. The case is commonly cited to demonstrate the importance of making an advance directive. The claim is that if Terri Schiavo had more clearly expressed her preferences about life-sustaining treatment, or had formally designated a relative to act as her proxy decisionmaker, the ugly and protracted family conflict would have been avoided. This outcome might not have occurred, however. After all, Michael Schiavo has been the patient’s legal guardian since 1990. He has the same legal authority to decide as would his wife’s designated proxy. The question is whether an advance directive would have led Terri Schiavo’s family to accept a treatment decision that at least some of them personally opposed. Suppose that this patient had expressed a clear wish not to receive nutritional support if she became permanently unconscious. Her parents might nevertheless have raised questions

about her diagnosis and prognosis. Suppose she had explicitly chosen her husband as a proxy decisionmaker. Her parents might still have sought to overturn that appointment.

*Schiavo* demonstrates the need for mediation and other dispute resolution procedures to address family disagreements over life-sustaining treatment. Hospital ethics consultants and committees informally engage in such efforts, but alternative dispute resolution has not been adopted to address family medical disagreements to the extent that it has to address child custody and other family law problems.<sup>3</sup> Terri Schiavo’s guardian *ad litem* worked to broker an agreement between the parties on how to resolve the conflict, but he was unsuccessful. The attempt to reach a compromise might have produced better results if it had occurred years ago, when Michael Schiavo initially proposed withdrawing the feeding tube.

*Schiavo* also highlights a pressing demand for substantive ethical and policy guidance in end-of-life decisionmaking. Further work is needed to clarify the scope of permissible decisionmaking when the patient’s former treatment preferences are imprecise or contested. The trial court deemed the testimony on Terri Schiavo’s prior preferences adequate, but admitted that there was not very much evidence to consider.

This case is one of many in which an incapacitated patient failed to express formal and definite choices about specific conditions and treatment interventions. Since *Quinlan*, advance directives have been promoted and legally recognized, but they are made by a minority of individuals. The directives that exist are often imprecise and raise other practical and ethical questions.<sup>4</sup> To respond to these cases, ethicists and policymakers must develop an enriched approach to evaluating the patient’s interests, one that improves on the relatively unsophisticated best interest standard that exists today. What is needed is guidance on when decisions by relatives are within the range of choices that are morally acceptable and when those choices are sufficiently detrimental to the patient that they should not be honored.

*Schiavo* is the third high-profile court case involving a family disagreement over life-sustaining treatment for an incapacitated patient without a clear advance directive.<sup>5</sup> Such cases are likely to become more common in the future, with the expected increase in the population of individuals with dementia. The events in Terri Schiavo’s case show that end-of-life decisions must remain a high priority for the bioethics field.

1. A summary of the proceedings is in *Schindler v. Schiavo*, 851 So.2d 182 (Fla. Dist. Ct. App. 2003).

2. J. Wolfson, *A Report to Governor Jeb Bush in the Matter of Theresa Marie Schiavo*, 1 December 2003. Available at [http://www.myflorida.com/myflorida/governorsoffice/review\\_year/litem\\_report.htm](http://www.myflorida.com/myflorida/governorsoffice/review_year/litem_report.htm)

3. N. Dubler and C. Lieberman, *Bioethics Mediation: A Guide to Shaping Shared Solutions* (New York: United Hospital Fund, 2004); A. Frank, *From Story to Law: Euthanasia and Authenticity*, in *Law at the End of Life: The Supreme Court and Assisted Suicide*, ed. C. Schneider (Ann Arbor: University of Michigan Press, 2000): 275-290.

4. See A. Fagerlin and C. Schneider, “Enough: The Failure of the Living Will,” *Hastings Center Report* 34, no. 2 (2004): ; R. Dresser, “Precommitment: A Misguided Strategy for Securing Death With Dignity,” *Texas Law Review* 81 (2003): 1823-47; P. Ditto et al., “Advance Directives as Acts of Communication: A Randomized Clinical Trial,” *Archives of Internal Medicine* 161 (2001): 421-30.

5. The other two cases are *In re Martin*, 538 N.W.2d 399 (Mich. 1995) and *Conservatorship of Wendland v. Wendland*, 28 P.3d 151 (Cal. 2001).