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# Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo

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# COLLATERAL DAMAGE: THE AFTERMATH OF THE POLITICAL CULTURE WARS IN *SCHIAVO*

KATHY L. CERMINARA\*

## INTRODUCTION

Theresa Marie Schiavo died a celebrity at the age of forty-two in Pinellas Park, Florida, in early 2005.<sup>1</sup> She never sought the public spotlight; she never even knew she was a celebrity. She became a celebrity, and one of the best-known figures in bioethics, because of politics.

In testament to the power of the politics surrounding Ms. Schiavo's death, numerous authors have written an incredible amount about her case. Many articles have focused on the constitutional implications of the controversy.<sup>2</sup> Others have discussed the intersection of Ms. Schiavo's case and the interests of people with disabilities,<sup>3</sup> or have analyzed the *Schiavo* case within the framework of

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\* Professor, Nova Southeastern University Shepard Broad Law Center. Thanks go to Barbara Noah for the opportunity to write this, to Mary Coombs for assistance in making this better, and to Jennifer Rolnick for research assistance.

1. Kathy L. Cerminara, *Theresa Marie Schiavo's Long Road to Peace*, 30 DEATH STUD. 101, 111 (2006). For a complete interactive timeline linking to key documents in the case, see Kathy L. Cerminara & Kenneth Goodman, *Key Events in the Case of Theresa Marie Schiavo*, University of Miami—Ethics Program, [http://www6.miami.edu/ethics/schiavo/terri\\_schiavo\\_timeline.html](http://www6.miami.edu/ethics/schiavo/terri_schiavo_timeline.html) [hereinafter Cerminara & Goodman, *Timeline*] (last visited Jan. 16, 2007) (listing her death at the Mar. 31, 2005 entry).

2. See, e.g., Michael P. Allen, *Terri's Law and Democracy*, 35 STETSON L. REV. 179 (2005) [hereinafter Allen, *Terri's Law and Democracy*]; Michael P. Allen, *Congress and Terri Schiavo: A Primer on the American Constitutional Order?*, 108 W. VA. L. REV. 309 (2005) [hereinafter Allen, *Congress and Terri Schiavo*]; Terri D. Keville & Jon B. Eisenberg, *Bush v. Schiavo and the Separation of Powers: Why a State Legislature Cannot Empower a Governor to Order Medical Treatment When There is a Final Court Judgment that the Patient Would Not Want It*, 7 J.L. & SOC. CHALLENGES 81 (2005); Thomas C. Marks, Jr., *A Dissenting Opinion*, *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004), 35 STETSON L. REV. 195 (2005); Barbara A. Noah, *Politicizing the End of Life: Lessons From the Schiavo Controversy*, 59 U. MIAMI L. REV. 107 (2004).

3. See, e.g., Adrienne Asch, *Recognizing Death While Affirming Life: Can End-of-Life Reform Uphold a Disabled Person's Interest in Continued Life?*, in IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?, Hastings Ctr. Special Report 35, No. 6 S31 (2005); Samuel R. Bagenstos, *Judging the Schiavo Case*, 22 CONST. COMMENT. 457 (2005) [hereinafter Bagenstos, *Judging the Schiavo Case*]; Kathy L.

end-of-life decision-making law.<sup>4</sup> Most of the attorneys and other living participants in the drama have written books about their experiences in connection with the case.<sup>5</sup> While none of these authors have ignored, or could have ignored, the politics surrounding what happened to Ms. Schiavo, only a few have concentrated on it.<sup>6</sup> This Article, building on what those authors have written, examines the politics surrounding her death and draws some conclusions about the aftermath for those left behind in the America Ms. Schiavo departed.

### I. THE POLITICS OF SCHIAVO

Because of the extensive amount already written about it, this Article will not recount in exhaustive detail the basic facts of *Schiavo*. Instead, it will briefly introduce the reader to Ms. Schiavo and then enumerate the myriad ways in which politics played a role in her death.

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Cerminara, *Musings on the Need to Convince Some People with Disabilities that End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L.J. 343 (2006) [hereinafter Cerminara, *Musings*]; Lois L. Shepherd, *Terri Schiavo and the Disability Rights Community* (Fla. State Univ. Coll. of Law, Pub. Law & Legal Theory, Working Paper No. 188, 2006), available at <http://ssrn.com/abstract=882480>; see also Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J.L. & GENDER 425, 427 (2006) (using *Schiavo* as a springboard to discuss the positions of disability rights activists in the areas of “nontreatment of infants with disabilities, proposals to legalize assisted suicide, and the practice of prenatal testing followed by selective abortion”).

4. William Allen, *Erring Too Far on the Side of Life: Déjà Vu All Over Again in the Schiavo Saga*, 35 STETSON L. REV. 123 (2005) [hereinafter Allen, *Erring Too Far on the Side of Life*]; Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147 (2005) [hereinafter Cerminara, *Tracking the Storm*]; John A. Robertson, *Schiavo and its (In)significance* 35 STETSON L. REV. 101 (2005); Lois L. Shepherd, *Shattering the Neutral Surrogate Myth in End-of-Life Decisionmaking: Terri Schiavo and Her Family*, 35 CUMB. L. REV. 575 (2005) [hereinafter Shepherd, *Shattering the Neutral Surrogate Myth*].

5. JON B. EISENBERG, *USING TERRI: THE RELIGIOUS RIGHT'S CONSPIRACY TO TAKE AWAY OUR RIGHTS* (2005) [hereinafter EISENBERG, *USING TERRI*]; JON B. EISENBERG, *THE RIGHT VS. THE RIGHT TO DIE: LESSONS FROM THE TERRI SCHIAVO CASE AND HOW TO STOP IT FROM HAPPENING AGAIN* (2006); DAVID C. GIBBS WITH BOB DEMOSS, *FIGHTING FOR DEAR LIFE: THE UNTOLD STORY OF TERRI SHIAVO AND WHAT IT MEANS FOR ALL OF US* (2006); MICHAEL SCHIAVO WITH MICHAEL HIRSH, *TERRI: THE TRUTH* (2006); MARY SCHINDLER ET AL., *A LIFE THAT MATTERS: THE LEGACY OF TERRI SCHIAVO—A LESSON FOR ALL OF US* (2006).

6. See, e.g., George J. Annas, *“I Want to Live”: Medicine Betrayed By Ideology in the Political Debate Over Terri Schiavo*, 35 STETSON L. REV. 49 (2005); Cerminara, *Tracking the Storm*, *supra* note 4; Joshua E. Perry, *Biblical Biopolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and Beyond*, 16 HEALTH MATRIX 553 (2006). Keville and Eisenberg identify one issue raised by *Schiavo* as being “whether politics and popular opinion should play any role in individual medical treatment decisions.” Keville & Eisenberg, *supra* note 2, at 83 (emphasis added).

The basic facts of *Schiavo* were simple. In 1990, at the age of thirty-six, Theresa Marie Schiavo suffered a cardiac arrest. Initially, her husband and parents were united in seeking aggressive treatment, including experimental therapy, in an attempt to revive her from what physicians said was a persistent vegetative state (PVS).<sup>7</sup> After three to four years of such efforts, however, Ms. Schiavo's husband began to accept physicians' statements that she would never regain cognitive function.<sup>8</sup> Ms. Schiavo's parents and siblings did not.<sup>9</sup> Thus, they objected when Mr. Schiavo, acting as Ms. Schiavo's guardian, approached the Florida guardianship court to ask the court to determine whether Ms. Schiavo would want to be maintained on medically supplied nutrition and hydration in the condition in which she existed.

### A. *The Litigation*

When Mr. Schiavo filed suit in 1998, the case was a typical end-of-life decision-making case of no great import, presenting well-settled issues under Florida law. Florida law clearly permitted withholding or withdrawing life-sustaining treatment when a patient was in a PVS.<sup>10</sup> Florida lawmakers also clearly considered medically supplied nutrition and hydration to be a form of life-sustaining treatment.<sup>11</sup> Thus, if the court determined by clear and convincing evidence that Ms. Schiavo would not have wanted medically supplied nutrition and hydration to continue when she lay in a PVS, the law was clear that treatment should be withdrawn. After a five-

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7. The law uses the term "persistent vegetative state," although neurologists differentiate between a "persistent" and a "permanent" vegetative state. Roughly speaking, a patient is said to be in a persistent vegetative state when in a "cognitively unresponsive state" for more than a month, and to be in a permanent vegetative state if the condition lasts for twelve months. Nancy L. Childs & Walt N. Mercer, *Brief Report: Late Improvement in Consciousness After Post-Traumatic Vegetative State*, 334 *NEW ENG. J. MED.* 24, 24-25 (1996).

8. SCHIAVO WITH HIRSH, *supra* note 5, at 87-89, 99.

9. See generally SCHINDLER ET AL., *supra* note 5.

10. See FLA. STAT. ANN. § 765.302(1) (West 2005) (specifying that a patient may, in advance, direct the withholding or withdrawal of "life-prolonging procedures" at a time in which he or she is, *inter alia*, in a persistent vegetative state).

11. See FLA. STAT. ANN. § 765.101(10) (West 2005) (defining "life-prolonging procedure" to include "artificially provided sustenance and hydration"); see also *In re Guardianship of Browning*, 568 So. 2d 4, 11-12 (Fla. 1990) (finding a constitutional right to refuse medically supplied nutrition and hydration); David Casarett et al., *Appropriate Use of Artificial Nutrition and Hydration—Fundamental Principles and Recommendations*, 353 *NEW ENG. J. MED.* 2607, 2607 (2005) (describing agreement that medically supplied nutrition and hydration as being treatment as "well established among ethicists, clinicians and the courts").

day evidentiary hearing, during which it considered, and either credited or discounted, the testimony of eighteen witnesses, the court did so determine and authorized Mr. Schiavo to withdraw treatment.<sup>12</sup>

Thereafter began a lesson in the use of end-of-life litigation as an exercise of political power. Numerous amici curiae joined in the case, primarily vitalist and disability-rights activists protesting the court's ruling and Mr. Schiavo's position in the litigation.<sup>13</sup> Multiple motions and appeals caused the case to travel throughout the judicial system several times between 2001 and 2003. It is not too much to say, as George Annas has, that the attorneys filing the multiple appeals were not "doing law" but rather "doing politics."<sup>14</sup> Nevertheless, the courts continued to affirm the trial court's decision. Ms. Schiavo's medically supplied nutrition and hydration would be discontinued.

### B. *The Legislation*

After politics through litigation failed, it was time for those opposing the withdrawal of Ms. Schiavo's life-sustaining treatment to turn to politics of the old-fashioned kind. Citizens across the country began to flood both the Florida Legislature and the U.S. Congress with e-mails and telephone calls, although many of them knew nothing about the case other than what they had heard on the radio or television, or had read on Internet blogs or in e-mails. In late 2003, the Florida Legislature authorized Governor John Ellis "Jeb" Bush to order reinsertion of the tube through which Ms. Schiavo received medically supplied nutrition and hydration.<sup>15</sup> After that law was declared unconstitutional,<sup>16</sup> federal legislators acted to authorize review of the case in federal court.<sup>17</sup> They also attempted

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12. *In re Guardianship of Schiavo*, No. 90-2908 GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Feb. 11, 2000).

13. Cerminara, *Tracking the Storm*, *supra* note 4, at 154-55.

14. George J. Annas, Address at the Health Law Teachers' Conference: The Culture of Life and the Politics of American Bioethics (June 2, 2006) (on file with *Western New England Law Review*); see also *University of Maryland Hosts 30th Annual Health Law Teachers Conference*, 14 LAW & HEALTH CARE NEWSLETTER 1, 3 (2006), available at [http://www.law.umaryland.edu/specialty/maryhealth/documents/program\\_newsletter-fall2006.pdf](http://www.law.umaryland.edu/specialty/maryhealth/documents/program_newsletter-fall2006.pdf) (providing a summary of the presentation given by Professor George Annas).

15. 2003 Fla. Laws ch. 3, 418, Pub. L. No. 03-418 (2003), *declared unconstitutional* by *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004).

16. *Schiavo*, 885 So. 2d 321.

17. An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

otherwise to prevent adherence to the state court determination,<sup>18</sup> despite the tremendous amount of review the case had already received in the Florida state court system. At the same time, efforts were under way, not only in the Florida Legislature but also in many state legislatures across the land, to substantially revise end-of-life decision-making law in general, because of the *Schiavo* case.<sup>19</sup>

Terri's Law, the 2003 Florida legislation authorizing the governor to negate the outcome of the state court litigation, transparently put political interests above concern for appropriate government functioning. Michael Allen has called Terri's Law "both an unabashed legislative intrusion on the judicial branch and a simultaneous transfer of legislative authority to the executive branch."<sup>20</sup> He has written eloquently about its "gross deficiencies under even the most basic separation of powers analysis," and has opined that "[q]uite frankly, it is difficult to find any action taken by a legislature or executive in the United States that can be classified as such a fundamental breach of the constitutional separation of powers."<sup>21</sup> By authorizing Governor Bush to order resumption of treatment, the law, written to apply only to the *Schiavo* case, essentially empowered the governor to reverse a judicial decision by acting as a super-surrogate for Ms. Schiavo.<sup>22</sup> Yet the law did not require the governor to investigate, or even to consider, what Ms. Schiavo's wishes would have been with respect to the treatment choice in question, as surrogate decision-makers generally must.<sup>23</sup>

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18. Allen, *Erring Too Far on the Side of Life*, *supra* note 4, at 135 (describing attempts to subpoena Ms. Schiavo to appear before the United States House Committee on Oversight and Government Reform as "motivated not by a search for accurate information, but rather as a ruse for additional delay in the court-ordered removal of Ms. Schiavo's nutrition and hydration tube"); *see also* Thomas W. Mayo, *Living and Dying In a Post Schiavo World*, 38 J. HEALTH L. 587, 591-92 (2005).

19. *See* Cerminara, *Musings*, *supra* note 3, at 381 n.243 (listing bills); *see also* Lois Shepherd, *State Legislative Proposals Following Schiavo: What Are They Thinking?*, 15 TEMP. POL. & CIV. RTS. L. REV. 361 (2006) [hereinafter Shepherd, *State Legislative Proposals Following Schiavo*].

20. Allen, *Terri's Law and Democracy*, *supra* note 2, at 187.

21. *Id.*; *see also id.* at 192 (describing *Bush v. Schiavo*, the Florida Supreme Court decision that invalidated Terri's Law as "a protection of liberty and a rejection of tyranny"); Noah, *supra* note 2, at 116-20.

22. Keville & Eisenberg, *supra* note 2, at 93-95.

23. ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* 3-47 to 3-49 (3d ed., Aspen 2006). It was in fact the lack of decision-making standards that led the Florida Supreme Court to note a delegation problem, not just a separation of powers problem, with the law. *See Bush v. Schiavo*, 885 So. 2d 321, 332-36 (Fla. 2004).

Clearly, Terri's Law had "nothing to do with substituted judgment decision-making and everything to do with politics."<sup>24</sup>

Even before Terri's Law was invalidated, and continuing with renewed frenzy thereafter, the Florida Legislature considered major changes to Florida's end-of-life decision-making law in reaction to *Schiavo*. The Legislature considered multiple bills based on a National Right to Life Committee (NRLC) model statute. Those bills would have limited the rights of Floridians to make end-of-life treatment choices about medically supplied nutrition and hydration. Additionally, the proponents of those bills intended them to require restoration of treatment in Ms. Schiavo's case.<sup>25</sup> The Legislature debated those proposals longer than the incredibly brief three days it took to pass Terri's Law,<sup>26</sup> but nonetheless engaged in that debate in the heat of the moment, while receiving thousands of frantic e-mails and telephone calls pleading for someone to save Ms. Schiavo's life. After Ms. Schiavo had died, and when the immediate political crisis had passed, legislators reflected on what they nearly had done and realized how much the frenzy had affected their judgment. At that time, it became clear that such a bill would not pass.<sup>27</sup>

Previously, legislators in Florida had done a superb job of developing the state's end-of-life decision-making law in a thoughtful, deliberate manner. Legislators had considered all viewpoints the last time they significantly revised the law. At that time, they not

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24. Keville & Eisenberg, *supra* note 2, at 95.

25. Kathy L. Cerminara, *Legislative End-Run Around Supreme Court in Schiavo Case Threatens Separation of Powers*, DAILY BUS. REV., Mar. 18, 2005, at 13; *see also* Annas, *supra* note 6, at 57 (describing attempts in Florida to pass "new legislation aimed at restoring the feeding tube"); Jay Wolfson, *Schiavo's Lessons for Health Attorneys When Good Law is All You Have: Reflections of the Special Guardian ad Litem to Theresa Marie Schiavo*, 38 J. HEALTH L. 535, 537-38 (2005) [hereinafter Wolfson, *Schiavo's Lessons for Health Attorneys*].

26. Noah, *supra* note 2, at 114 n.26.

27. *See* Maya Bell, *Debate About How to Die Rages On, But Chasm Grows*, ORLANDO SENTINEL, Mar. 26, 2006, at A1, available at 2006 WLNR 5017182 (Westlaw) [hereinafter Bell, *Debate About How to Die Rages On*]; Maya Bell, *Governor Abandons Feeding-Tube Efforts*, ORLANDO SENTINEL, Apr. 13, 2006, at B7, available at 2006 WLNR 6227279 (Westlaw). The Florida Senate's Committee on Health Care studied and reported on Florida's existing statutory scheme in late 2005, after Ms. Schiavo's death. Interim Project Report 2006-137, Fla. S. Comm. on Health Care (2005), available at [http://www.flsenate.gov/data/Publications/2006/Senate/reports/interim\\_reports/pdf/2006-137he.pdf](http://www.flsenate.gov/data/Publications/2006/Senate/reports/interim_reports/pdf/2006-137he.pdf). The Committee concluded that, "Florida's laws governing the substantiation and safeguarding of written and oral advance directives work for the majority of Floridians." *Id.* at 9. The Committee did not recommend any "statutory changes." *Id.*



only listened to experts and persons who contacted them about proposed revisions, but they also held public hearings across the state to learn from the experiences of those who might not be able to contact lawmakers themselves.<sup>28</sup> In contrast, the attempts to revise Florida's end-of-life decision-making law in response to *Schiavo* resulted solely from short-sighted, special-interest-motivated attempts to respond to vocal constituents with political weight.

During this same time period, and continuing after Ms. Schiavo had died, myriad state legislatures similarly responded to the *Schiavo* controversy by considering the same sorts of changes to their state end-of-life decision-making laws.<sup>29</sup> Most of their proposed changes also were based on the NRLC Model Act and, thus, primarily addressed the withholding or withdrawal of medically supplied nutrition and hydration as opposed to other life-sustaining treatment.<sup>30</sup> Specifically, the Model Act would have established a presumption that an incapacitated patient wanted medically supplied nutrition and hydration regardless of that patient's medical condition, unless the nutrition and hydration was medically contraindicated or the patient had previously explicitly stated, preferably in writing, that he or she did not desire nutrition and hydration.<sup>31</sup>

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28. See Robert G. Brooks et al., *Advancing End-of-Life Care: Lessons Learned From a Statewide Panel*, 6 J. PALLIATIVE MED. 821 (2003) (describing the operation of the Florida Panel for the Study of End-of-Life Care and the results of its recommendations); see also Allen, *Erring Too Far on the Side of Life*, *supra* note 4, at 134-35 (describing the same panel); Wolfson, *Schiavo's Lessons for Health Attorneys*, *supra* note 25, at 547 (describing Florida law on these issues as having been "carefully crafted" through that process).

29. Mayo, *supra* note 18, at 597-98; see also Shepherd, *State Legislative Proposals Following Schiavo*, *supra* note 19, at 11-14.

30. See Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L. REV. 297, 329 (2006) (stating that legislation in many states was based on the NRLC Model Act); NAT'L RIGHT TO LIFE COMM., MODEL STARVATION AND DEHYDRATION OF PERSONS WITH DISABILITIES PREVENTION ACT (2006) [hereinafter NRLC MODEL ACT], available at <http://www.nrlc.org/euthanasia/modeln&hstatelaw.pdf> (bearing notation "Revised January 2006").

31. See Nat'l Right to Life Comm., Spurred by Schindler-Schiavo Case, Model State Law to Prevent Starvation & Dehydration Proposed [hereinafter *Spurred by Schindler-Schiavo Case*], <http://www.nrlc.org/euthanasia/ModelBillAnnouncement.html> (last visited Jan. 16, 2007). Compare NRLC MODEL ACT, *supra* note 30, with H.B. 701, 2005 Leg. Reg. Sess. (Fla. 2005) (version introduced in Florida during the *Schiavo* debates). The existence of such a presumption in favor of the administration of medically supplied nutrition and hydration echoes a presumption appearing in the Roman Catholic Ethical and Religious Directives for Catholic Hospitals (ERD) promulgated by the National Conference of Catholic Bishops. Leonard J. Nelson, III, *Catholic Bioethics and the Case of Terri Schiavo*, 35 CUMB. L. REV. 543, 556-57 (2005) (citing Directive 58 of the 1994 ERD, reiterated in the 2001 ERD). The similarity between the NRLC Model Act and the ERD raises at least two concerns. First, one wonders at the propri-

Public opinion polls and surveys indicated that most constituents did not in fact want end-of-life decision-making choices to be limited in this manner,<sup>32</sup> but politicians introduced the bills because they listened to vocal e-mailers and callers, as well as to the powerful special interest groups behind those e-mailers and callers. While this simply may be one of the consequences of having a representative rather than a parliamentary government,<sup>33</sup> the phenomenon certainly illustrates the power of political forces in *Schiavo*.

Finally, it is impossible to forget the most nationally visible political activity relating to Ms. Schiavo. In early March 2005, slightly more than three weeks before Ms. Schiavo's death, federal legislators began introducing bills about the case in the U.S. House of Representatives.<sup>34</sup> Later in March, in an "event unique in American politics,"<sup>35</sup> the U.S. Congress reconvened from Easter recess to pass emergency legislation that would give Ms. Schiavo's parents the right to file suit in federal court to have the case reviewed again.<sup>36</sup> Just as in the Florida Legislature, debate was "frenzied"<sup>37</sup>

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ety of an attempt to virtually pluck a concept from a Roman Catholic document and insert it into state law in multicultural America. Second, even if such incorporation of a particular religion's directives into law is appropriate, the ERD, as Nelson notes, is not as clear with respect to withholding or withdrawal of medically supplied nutrition as focus on this single provision would indicate. *See id.*

32. *See* Robert J. Blendon et al., *The American Public and the Terri Schiavo Case*, 165 ARCHIVES INTERNAL MED. 2580, 2584 (2005) (concluding, based on meta-analysis of the results of twelve opinion surveys, that "[e]fforts to place more restrictions on choices in cases similar to Terri Schiavo's are likely to prompt vocal opposition from those who favor maintaining the choices currently available or expanding them"). Medical professionals would not like to see such laws either. *See* AM. MED. ASSOC'N, AMA-YPS DELEGATE'S REPORT 4 (2005), available at <http://www.ama-assn.org/ama1/pub/upload/mm/17/a2005delegatesreport.pdf> (see "Resolution 209," resolving that the AMA opposes such legislation); Gina Shaw, *Schiavo's Legislative Legacy: New Look at Consent, Living Wills, and Advance Directives*, NEUROLOGY TODAY, June 2005, at 1 (describing neurologists' concerns about such legislation).

33. *Cf.* R. Alta Charo, *Realbioethik*, HASTINGS CTR. REP., July-Aug. 2005, at 13 [hereinafter Charo, *Realbioethik*] (identifying "fear [of] the ten-second spot" as one of the reasons that a politician would not vote against the federal legislation regarding *Schiavo*).

34. *See* Cerminara & Goodman, *Timeline*, *supra* note 1, at Mar. 8, 2005 entry.

35. Annas, *supra* note 6, at 58.

36. *See* Allen, *Congress and Terri Schiavo*, *supra* note 2, at 318-20 (describing the legislation, which granted federal courts jurisdiction to hear claims arising "under the Constitution or laws of the United States related to the withholding or withdrawal of food, fluids, or medical treatment").

37. Annas describes the debate in the U.S. House of Representatives as being "notable primarily for its incredibly uninformed and frenzied rhetoric" and notes that C-SPAN covered it live. Annas, *supra* note 6, at 61; *see also* Bagenstos, *Judging the Schiavo Case*, *supra* note 3, at 458 (describing the "[l]ack of meaningful congressional

and was prompted by myriad calls and e-mails to members of Congress from constituents who were themselves motivated by emotion whipped up for political purposes.<sup>38</sup> The law itself, limited to authorization of a suit by Ms. Schiavo's parents,<sup>39</sup> did not go so far as Congress might have tried to go,<sup>40</sup> but it nevertheless was notable in terms of both policy-making and its manner of passage.<sup>41</sup> Michael

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deliberation" in a "highly charged atmosphere" and "the attempts by many politicians to use the courts (as weapons or targets) in a political battle").

38. See Ronald Cranford, *Facts, Lies and Videotapes: The Permanent Vegetative State and the Sad Case of Terri Schiavo*, 33 J.L. MED. & ETHICS 363, 369 (2005) (describing a "strategy of misinformation" involving the use of videotapes originally created to assist the courts in understanding Ms. Schiavo's condition "to mislead much of the media and public into believing that Terri could meaningfully and cognitively interact with her parents and thus was not in a vegetative state").

39. In that sense, the law seemed like a private law. The U.S. Senate website discusses a private bill in the following manner:

A private bill provides benefits to specified individuals (including corporate bodies). Individuals sometimes request relief through private legislation when administrative or legal remedies are exhausted. Many private bills deal with immigration—granting citizenship or permanent residency. Private bills may also be introduced for individuals who have claims against the government, veterans [sic] benefits claims, claims for military decorations, or taxation problems. The title of a private bill usually begins with the phrase, "For the relief of . . ." If a private bill is passed in identical form by both houses of Congress and is signed by the President, it becomes a private law.

U.S. Senate, Legislation, Laws, and Acts, [http://www.senate.gov/legislative/common/briefing/leg\\_laws\\_acts.htm](http://www.senate.gov/legislative/common/briefing/leg_laws_acts.htm) (last visited Jan. 16, 2007). The federal law was indeed titled, "An Act For the relief of the parents of Theresa Marie Schiavo." An Act for the Relief of the Parents of Theresa Marie Schiavo, S.686, 109th Cong. (2005), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/032005-USSenate\\_Compromise\\_in\\_Schiavo.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/032005-USSenate_Compromise_in_Schiavo.pdf). Yet, as is apparent from its citation, the Act has been accorded a Public Law number. See Pub. L. No. 109-3, 119 Stat. 15 (2005).

40. As Michael Allen notes, the proposed Protection of Incapacitated Persons Act, H.R. 1332, 109th Cong. (2005), would have gone further in authorizing federal court review of whether the Constitution or federal laws had been violated in any case in which the State court authorize[d] or direct[ed] the withholding or withdrawal of food or fluids or medical treatment necessary to sustain the incapacitated person's life, but . . . not . . . a claim or cause of action in which no party disputes, and the court finds, that the incapacitated person, while having capacity, had executed a written advance directive valid under applicable law that clearly authorized the withholding or withdrawal of food or fluids or medical treatment in the applicable circumstances.

Allen, *Congress and Terri Schiavo*, *supra* note 2, at 318 n.36; Protection of Incapacitated Persons Act, H.R. 1332, 109th Cong. § 2 (2005), available at [http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109\\_cong\\_bills&docid=f:h1332eh.txt.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_bills&docid=f:h1332eh.txt.pdf).

41. Allen identifies two levels of objections to it based on policy, as opposed to constitutional objections. First, "[t]he ultimate result was federal interference in a basic, personal decision, something that seems quite difficult to justify." Allen, *Congress and Terri Schiavo*, *supra* note 2, at 315 & n.29. Second, the way in which Congress passed it and the President signed it was "not the way in which many citizens would hope or expect their government to form policy." *Id.*

Allen has aptly described this federal law as “appear[ing] to be focused largely on a combination of political opportunism and political cowardice instead of rational policy determinations.”<sup>42</sup>

These are only the major political activities, not even the most bizarre ones, that surrounded Ms. Schiavo’s death. The U.S. House Committee on Oversight and Government Reform incredibly attempted to use its subpoena power, as Ms. Schiavo lay dying, to require that she be maintained in order to appear before it, with equipment intact, for a hearing and an inspection of her medical equipment.<sup>43</sup> It is impossible to forget the day Floridians realized that Ms. Schiavo’s case was being considered simultaneously within the federal courts, the state courts, the federal legislature, the state legislature, and Florida’s Department of Children and Families.<sup>44</sup> That was also the day on which Governor Bush intended to order the Florida Department of Law Enforcement to storm Ms. Schiavo’s hospice to remove her and resume her treatment.<sup>45</sup> Even after Ms. Schiavo’s death, Governor Bush ordered a prosecutor to investigate whether Michael Schiavo had delayed calling 911 on the night of Ms. Schiavo’s cardiac arrest fifteen years previously.<sup>46</sup>

In sum, it is safe to say that politics abounded in *Schiavo* and its aftermath nearly from start to finish, from the courtroom to the legislature, to the governor’s mansion, to the Oval Office. The task remains to learn from the political firestorm.

## II. THE AFTERMATH

*Schiavo* unquestionably will impact end-of-life decision-making in America for years to come. Both individuals and individual

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42. See *id.* at 314.

43. Exhibit 2, Emergency All-Writs Petition In the Matter of Schiavo v. Robert Schindler & Mary Schindler, 932 So. 2d 264 (Fla. Mar. 18, 2005) (No. 90-2908-GD-003), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/031805-USHousePetition\\_Sct.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/031805-USHousePetition_Sct.pdf).

44. See Cerminara & Goodman, *Timeline*, *supra* note 1, at Mar. 23, 2005 entry; see also *In re Schiavo*, 932 So. 2d 264 (Fla. Dist. Ct. App. 2005) (describing state court activity with respect to the Department of Children and Families’ position).

45. SCHIAVO WITH HIRSH, *supra* note 5, at 239, 307 (stating that these events all happened on the same day); see also Dara Kam, *Agents Readied in Case “Legal Window” Opened*, PALM BEACH POST, Mar. 26, 2005, at 8 (describing plans to “seize” Ms. Schiavo if an opportunity arose). Governor Bush also had ordered the Florida Department of Law Enforcement to rush into the hospice to take Ms. Schiavo to a hospital immediately upon the passage of Terri’s Law in 2003. See SCHIAVO WITH HIRSH, *supra* note 5, at 239.

46. Cerminara & Goodman, *Timeline*, *supra* note 1, at June 17 & June 27, 2005 entries.

cases will be affected, while the general tone and pattern of end-of-life decision-making law likely will change. Even beyond the realm of end-of-life decision-making law, the politics of *Schiavo*, for better or worse, serves as an example of a more general politicization of bioethics. Finally, *Schiavo* teaches some major lessons about the functioning of our American constitutional republican form of government.

#### A. *Lessons for Individuals and Relating to Individual Cases*

The political furor surrounding *Schiavo* will impact the individual patient care setting in at least two ways. First, as has been widely discussed, people reacted to *Schiavo* by flocking to hospitals, clinics, physicians' offices, and other health care provider locations, not to mention attorneys' offices, to obtain and execute advance directive forms.<sup>47</sup> While that development would seem to indicate that health care providers in the future will see more patients who have advance directives, such a conclusion does not necessarily follow. This reaction to a highly publicized end-of-life decision-making case is not a new phenomenon and is not likely to have a long-lasting effect. A similar rush to execute advance directive forms happened after the landmark U.S. Supreme Court case *Cruzan v. Director*,<sup>48</sup> but the percentage of persons with advance directives still was not very high at the time of *Schiavo*, fifteen years later.<sup>49</sup> In fact, one wonders if Americans simply must, every fifteen years or so, endure debate over the propriety of withdrawing life-sus-

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47. Shaw, *supra* note 32, at 2-3 (quoting the Death with Dignity spokesperson, who stated: "All the web sites that help prepare advance directives have had a huge increase in traffic"); Diane C. Lade, *Free Seminars Focus on End-of-Life Papers*, S. FLA. SUN-SENTINEL, May 10, 2005, at 4B, available at 2005 WLNR 23632439 (Westlaw) (quoting Secretary of Florida Department of Elder Affairs as saying that the effort to provide more information about advance directives "was in response to the Terri Schiavo case"); Diane C. Lade, *Schiavo Debate Hits Home for the Young: More People Are Thinking About Living Will Forms*, S. FLA. SUN-SENTINEL, Aug. 1, 2005, at 1A, available at 2005 WLNR 23670975 (Westlaw) ("How do you get young people to make out a living will when they have no concept of their own mortality? Two words: Terri Schiavo."); *Schiavo Case Revives Interest in Wills*, TAMPA TRIB., Mar. 24, 2005, at 14, available at 2005 WLNR 13854639 ("As the struggle between [Terri Schiavo's] parents and husband over the removal of a feeding tube continues, Americans are signing living wills as never before.").

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

49. PEW RESEARCH CTR. FOR THE PEOPLE & THE PRESS, STRONG PUBLIC SUPPORT FOR THE RIGHT TO DIE: MORE AMERICANS DISCUSSING—AND PLANNING—END-OF-LIFE TREATMENT 2 (2006) [hereinafter PEW REPORT], available at <http://people-press.org/reports/display.php3?ReportID=266> (showing that in 1990, 12 percent of those surveyed had living wills; in 2005, the number had risen to 29 percent).

taining treatment from a young woman<sup>50</sup> to raise their consciousness about advance directives and to re-energize them into discussing end-of-life treatment choices with each other.

The political furor sparked by *Schiavo* will also likely affect individual surrogate decision-makers in the future. Michael Schiavo endured a great deal of criticism, including death threats aimed at both him and his family.<sup>51</sup> State officials investigated his actions and his motives several times.<sup>52</sup> During the heat of the battle, and even after the autopsy on Ms. Schiavo's body, several commentators opined that his recollection of her wishes must have been false because he waited so long to voice and act upon those wishes.<sup>53</sup> Even if he truly believed that he was representing Ms. Schiavo's wishes (and the court found that he was), he easily could have been frightened into abandoning the pursuit of those wishes.<sup>54</sup> While some would have praised such an outcome, and in fact may have intended their actions to result in such abandonment, a precise and critical examination of the criticism Michael Schiavo endured leads

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50. The seminal case in end-of-life decision-making law is *In re Quinlan*, 355 A.2d 647 (N.J. 1976), which involved a young woman. In 1990, fifteen years after *Quinlan*, the U.S. Supreme Court decided *Cruzan*, again involving a young woman. Then *Schiavo* involved a young woman in the early twenty-first century. Ms. Schiavo died fifteen years after *Cruzan* was decided and thirty years to the day after *Quinlan* was decided. See generally WILLIAM H. COLBY, UNPLUGGED: RECLAIMING OUR RIGHT TO DIE IN AMERICA (2006); Annette E. Clark, *The Right to Die: The Broken Road From Quinlan to Schiavo*, 37 LOY. U. CHI. L.J. 385 (2006).

51. SCHIAVO WITH HIRSH, *supra* note 5, at 287 (describing letters "that talked about how kids disappear from their homes every day"); *id.* at 290 (quoting threat on blog: "'If we kill Michael Schiavo, the parents will be her closest relatives. FL gun owners, it's in your hands'"); see also *Man Arrested in Alleged Schiavo Case Murder Plot*, CNN.COM, Mar. 26, 2005, <http://edition.cnn.com/2005/US/03/25/arrest.schiavo>.

52. The Department of Children and Families received, investigated, and ruled unfounded, eighty-nine complaints of abuse in the four years after the trial court's decision. Maya Bell, *Schiavo Records Show No Abuse*, S. FLA. SUN-SENTINEL, Apr. 17, 2005, at 6B. Even after Ms. Schiavo's death in 2005, Governor Bush ordered a state investigation into whether criminal charges should be filed against Mr. Schiavo based on questions about how quickly he had called 911 in 1990, some fifteen years earlier. Abby Goodnough, *Governor Bush Seeks Another Inquiry in Schiavo Case*, N.Y. TIMES, June 18, 2005, at A1, available at 2005 WLNR 9670154 (Westlaw). After investigation, the prosecutor recommended that no charges be filed. David Royse, *Inquiry Finds No Sign of Crime in Schiavo's Death*, S. FLA. SUN-SENTINEL, July 8, 2005, at 6B.

53. SCHIAVO WITH HIRSH, *supra* note 5, at 176.

54. At one point in early 2005, he was ready to abandon the case, but, at the urging of his attorney, he decided he could not do so because "it wasn't just about Terri anymore. It was about all the rest of the people who didn't want the government telling us how we could die . . . . And whether we were going to let a vocal minority change the rules for everybody." *Id.* at 288.

to a surprising conclusion—one that the activists who protested his position certainly would not support.

Michael Schiavo endured criticism on both a substantive and a procedural level. Procedurally, the objection was that he must have been misrepresenting Ms. Schiavo's wishes to refuse treatment because he waited too long to voice those wishes. Focusing on that criticism could cause a surrogate who is sure that his or her loved one wishes to reject treatment to rush to carry out those wishes. Michael Schiavo's delay, his willingness to try measures that could obviate the need for life-sustaining treatment, resulted in suspicion and accusations, so the lesson others take away may be to do the opposite: authorize withholding or withdrawing treatment as soon as possible. In other words, sadly, the political furor engendered in *Schiavo* could encourage exactly the opposite sort of surrogate decision-making from that which society wants. Rather than giving treatment a chance to work, and authorizing withdrawal only after it becomes clear that the patient thereafter will exist in a condition in which he or she did not want to exist, surrogate decision-makers may react to the criticism leveled at Michael Schiavo by acting quickly to assert their loved one's wishes. This is not wise as a policy or a medical matter.

On the other hand, some of the criticism of Michael Schiavo was a reaction to the substance of Ms. Schiavo's wishes, rather than the timing of his assertion of those wishes. On that level, future surrogate decision-makers, with *Schiavo* in mind, could hesitate to carry out patients' desires to refuse nutrition and hydration because they fear inviting such criticism themselves. Such a fear is likely unfounded, given that most end-of-life decision-making takes place privately rather than in a public setting. Nevertheless, after the spectacle this country endured in early 2005, both surrogate decision-makers and health care providers hereafter may unduly hesitate to honor patients' wishes to withhold or withdraw life-sustaining treatment. With good cause or not, they may fear sparking publicity and a major political debate.

Clinical bioethics expert Kenneth Goodman calls this phenomenon "being *Schiavo*'ed," which he defines as "the fear of a case becoming public and drawing a well-funded campaign to require treatment."<sup>55</sup> Although unlikely to materialize, the fear has foundation. For example, less than a month after Ms. Schiavo died, the

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55. Bell, *Debate About How We Die Rages On*, *supra* note 27 (quoting Kenneth Goodman, director of Florida's bioethics network).

attorney who represented her parents asked a Georgia court “to protect innocent life in the case of Mae Magouirk.”<sup>56</sup> The *Magouirk* case, like the *Schiavo* case, involved a family dispute over whether a patient (in *Magouirk*, an 81-year-old widow) should receive medically supplied nutrition and hydration.<sup>57</sup> Portrayed as being inspired by the *Schiavo* case, the *Magouirk* case actually began even before this attorney became involved in it.<sup>58</sup> Like the *Schiavo* case, the *Magouirk* case spawned blog entries and e-mails from pro-life activists to the presiding judge.<sup>59</sup> It even prompted the hospice in which Ms. Magouirk was a patient to issue a press release clarifying that it did not deny patients food and water.<sup>60</sup> For unknown reasons, it never sparked nationwide furor as *Schiavo* did, but it still serves as a stark illustration that the *Schiavo*-type, bitter, highly publicized dispute is not unique.<sup>61</sup> Caregivers might not wish to risk becoming involved in such a dispute, so they may continue treatment beyond the time at which they and the patient would have wanted to cease care.

Such threats of publicity or well-funded lawsuits<sup>62</sup> arise only rarely, but are certain to be present when “repeat players,” such as vitalist and disability activists, enter the realm of end-of-life decision-making law. “Repeat players” are those who are familiar with the court system and who previously have engaged in litigation and

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56. Press Release, Christian Commc'n Network, Terri Schiavo Attorney Calls on Georgia Court to Feed Elderly Woman (Apr. 14, 2005) [hereinafter “Terri Schiavo Attorney Calls on Georgia Court to Feed Elderly Woman”] (on file with the author).

57. *Id.*

58. Compare Denis O'Hayer, *Georgia Case Mirrors Schiavo Battle*, 11ALIVE NEWS, Apr. 8, 2005, [http://www.11alive.com/news/news\\_article.aspx?storyid=61478](http://www.11alive.com/news/news_article.aspx?storyid=61478) (describing the circumstances of the dispute as of April 8, 2005), with Terri Schiavo Attorney Calls on Georgia Court to Feed Elderly Woman, *supra* note 56 (dating the involvement of the Schindlers' attorney to April 14, 2005).

59. See O'Hayer, *supra* note 58 (quoting the judge handling the case, Probate Judge Donald Boyd, as saying that he had “been accused several times of murder” and had received “close to a hundred e-mails”); James Joyner, Terri Schiavo Activists Move On to Mae Magouirk (Apr. 9, 2005), [http://www.outsidethebeltway.com/category/us\\_politics/terri\\_schiavo\\_case](http://www.outsidethebeltway.com/category/us_politics/terri_schiavo_case) (follow the “Terri Schiavo Activists Move On to Mae Magouirk” hyperlink) (blog entry discussing the Mae Magouirk case).

60. See O'Hayer, *supra* note 58.

61. *Cruzan* also sparked protests. See WILLIAM H. COLBY, LONG GOODBYE, THE DEATHS OF NANCY CRUZAN 360-78 (2002).

62. Jon Eisenberg has traced the funding for Ms. Schiavo's parents' side of the litigation to major, wealthy foundations and has detailed the amounts that attorneys on both sides of the controversy were paid. EISENBERG, USING TERRI, *supra* note 5, at 94-109.



anticipate doing so in the future.<sup>63</sup> Repeat players have a number of advantages over “one shotters” in any individual case.<sup>64</sup> For example,

Repeat players have low stakes in the outcome of any particular case and have the resources to pursue their long term interests. They can anticipate legal problems and can often structure transactions and compile a record to justify their actions. They develop expertise and have access to specialists who are skilled in dealing with particular types of cases or issues. They enjoy economies of scale and encounter low start-up costs for any particular case.<sup>65</sup>

When individual cases like *Schiavo* are swept up in political storms because of the involvement of repeat players,<sup>66</sup> the power of those players can be astonishing.

Use of litigation to achieve political ends is a time-honored tradition in some areas of the law,<sup>67</sup> and this Article does not argue that it is inappropriate in all cases. More than 30 years ago, Abram Chayes recognized that much of the litigation in this country no longer represented the traditional bipolar model of a lawsuit with compensation for an injured plaintiff as its primary goal and a party-initiated and party-controlled process.<sup>68</sup> Chayes identified a form of lawsuit he labeled “public law litigation,” in which “lawsuits do not arise out of disputes between private parties about private rights” but “the object of litigation is the vindication of constitutional or statutory policies.”<sup>69</sup> School desegregation cases, prisoners’ rights cases, and certain corporate and environmental law cases, to name a sampling, illustrate the public law litigation Chayes

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63. Marc Galanter, *Why the “Haves” Come Out Ahead: Speculations on the Limits of Legal Change*, 9 *LAW & SOC’Y REV.* 95, 97-99 (1974).

64. “One shotters” are persons, businesses, or organizations that deal infrequently with the legal system. *Id.* at 97.

65. Joel B. Grossman et al., *Do the “Haves” Still Come Out Ahead?*, 33 *LAW & SOC’Y REV.* 803, 803 (1999).

66. See Cerminara, *Tracking the Storm*, *supra* note 4 (detailing the involvement of vitalist disability activists as *Schiavo* transformed from an individual case to a cause célèbre).

67. See, e.g., RICHARD KLUGER, *SIMPLE JUSTICE: THE HISTORY OF BROWN V. BOARD OF EDUCATION AND BLACK AMERICA’S STRUGGLE FOR EQUALITY* (1977) (describing the path, through a series of court cases, toward the landmark U.S. Supreme Court decision of *Brown v. Board of Education*, 349 U.S. 294 (1954), ruling segregation of the races in public schools unconstitutional).

68. Abram Chayes, *The Role of the Judge in Public Law Litigation*, 89 *HARV. L. REV.* 1281, 1282-84 (1976). Chayes spoke particularly of federal litigation but noted that litigation in state courts followed a similar trend. *Id.* at 1284 n.12.

69. *Id.* at 1284.

analyzed.<sup>70</sup> Using litigation to achieve what might be termed political ends, as Chayes described, can be appropriate in health care settings, such as those in which patients with little consumer or political power seek to call attention to the illegality of certain widespread, uniform practices on the part of insurers,<sup>71</sup> or in which advocacy groups seek to enjoin enforcement of regulatory policies impacting health care access.<sup>72</sup>

Such use of litigation for political purposes is not appropriate, however, in cases like *Schiavo*.<sup>73</sup> In *Schiavo*, there was at issue no widespread activity—no law, regulation, policy, or practice—affecting a large group of people.<sup>74</sup> Vitalist disability activists (who do not constitute all disability activists)<sup>75</sup> would argue that the decision Mr. Schiavo made, to ask a court to authorize the withdrawal of medically supplied nutrition and hydration from Ms. Schiavo, is in fact indicative of common and widespread disability discrimination. In the litigation itself, they argued that Mr. Schiavo, and others advocating cessation of treatment, devalued Ms. Schiavo's existence because of a disability from which she suffered,<sup>76</sup> just as many other persons with disabilities are inappropriately and illegally devalued every day. In making that argument in court about Ms. Schiavo's treatment, however, the activists who participated as amici curiae<sup>77</sup>

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70. *Id.*; see also Beth Van Schaack, *With All Deliberate Speed: Civil Human Rights Litigation as a Tool for Social Change*, 57 VAND. L. REV. 2305, 2308 (2004) (describing “public impact” litigation in the context of human rights).

71. Kathy L. Cerminara, *The Class Action Suit as a Method of Patient Empowerment in the Managed Care Setting*, 24 AM. J.L. & MED. 7, 8-11 (1998).

72. See, e.g., *Abigail Alliance for Better Access to Developmental Drugs v. Von Eschenbach*, 445 F.3d 470 (D.C. Cir. 2006) (remanding action seeking to enjoin enforcement of a Food & Drug Administration policy limiting access to certain experimental drugs), *petition for reh'g denied*, 469 F.3d 129 (D.C. Cir. 2006); *Grijalva v. Shalala*, 946 F. Supp. 747 (D. Ariz. 1996) (alleging a breakdown in the federal government's system of health maintenance organization oversight and review), *aff'd*, 152 F.3d 1115 (9th Cir. 1998), *vacated*, 526 U.S. 1096 (1999).

73. See generally Alan Meisel, *The Role of Litigation in End of Life Care: A Reappraisal*, HASTINGS CTR. REP., Nov.-Dec. 2005, at S247.

74. See Chayes, *supra* note 68, at 1308 (describing one advantage of the public law model as being that it permits “ad hoc applications of broad national policy in situations of limited scope”).

75. See Cerminara, *Musings*, *supra* note 3.

76. See, e.g., *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223 (11th Cir. 2005), *aff'g*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005), *reh'g en banc denied*, 403 F.3d 1261 (11th Cir. 2005), *stay denied*, 125 S. Ct. 1692 (2005); *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289 (11th Cir. 2005), *aff'g* 358 F. Supp. 2d 1161 (M.D. Fla. 2005), *reh'g en banc denied*, 404 F.3d 1282 (11th Cir. 2005), *stay denied*, 125 S. Ct. 1722 (2005). See generally Bagenstos, *Judging the Schiavo Case*, *supra* note 3, at 457.

77. See *supra* text accompanying note 13.

or who funded Ms. Schiavo's parents' efforts<sup>78</sup> were misusing the litigation process.

Rather than address the court in a case about the quintessentially individual features of Ms. Schiavo's situation, such activists should have limited their involvement to legislative lobbying. End-of-life decision-making cases, including Ms. Schiavo's, are quintessentially individual, involving private matters such as life-and-death choices, which most people agree should not even be in court, much less litigated by interest groups.<sup>79</sup> It is only when some dissatisfied individual or group of individuals with a personal stake in a case seeks judicial review that such cases even go to court. They are private. They are personal. They are individual. They stand in sharp contrast to the sorts of cases involving allegations of widespread wrongdoing, such as those in which students and parents challenge school segregation laws or patients seek review of uniform insurance practices applied in determining payment or denial of claims for health care coverage. There is no room in this personal sort of litigation for forces other than those who know and care for the patient. In *Schiavo* in particular, use of litigation for broader political ends resulted in misdirection: "[T]he person of Theresa Schiavo became lost in the media and political process, particularly during the last two years of her life, when third party interests attached themselves to her case."<sup>80</sup> According to Ms. Schiavo's guardian ad litem, who attempted to mediate a resolution during late 2003, "Once third parties and the press became involved, the mold was set and there was no desire or capacity among the parties to seek compromise."<sup>81</sup>

In sum, *Schiavo* did not present the sort of situation in which persons without political voice are trying to challenge a coherent policy or law.<sup>82</sup> Contrary to the wishes of activists who attempted to portray it as such, it was not the sort of case through which struc-

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78. See *supra* note 5.

79. See MEISEL & CERMINARA, *supra* note 23, at 3-7 (stating that generally decisions about foregoing treatment should be made in the clinical setting rather than through the courts).

80. Wolfson, *Schiavo's Lessons for Health Attorneys*, *supra* note 25, at 547.

81. Jay Wolfson, *Erring on the Side of Theresa Schiavo: Reflections of the Special Guardian ad Litem*, HASTINGS CTR. REP., May-June 2005, at 19.

82. See Abigail Alliance for Better Access to Developmental Drugs v. von Eschenbach, 445 F.3d 470 (D.C. Cir. 2006), *petition for reh'g denied*, 469 F.3d 129 (D.C. Cir. 2006); KLUGER, *supra* note 67 (describing challenges to uniform statutory implementations of "separate but equal" policies in schoolhouses across the land). Regarding the limits of litigation in the development of end-of-life decision-making law, see Meisel, *supra* note 73.

tural reform can be achieved to remedy broad-based legislative, administrative, or policy failures.<sup>83</sup> Rather, the case was a traditional bipolar case, with private interests at issue, arising in an area of law that calls for determinations based on the wishes of each individual patient. The shame of Ms. Schiavo's case being hijacked in the judicial system by special interests, and the shame of the thought that other family members, surrogate decision-makers, or health care providers might feel "*Schiavo*'ed," is that the involvement of outside political interests is uncommon, unnecessary, and improper in this type of case.

### B. *Lessons About the Tone and Pattern of End-of-Life Decision-Making*

More broadly, the tenor of the *Schiavo* debate may have altered the tone and pattern of end-of-life decision-making law in general. Addressing the broad questions at hand through litigation is inappropriate, as just noted, but it is perfectly appropriate to address those broad questions in the legislative arena. In that arena, some changes would still develop, although the lack of legislative success in significantly revising state end-of-life decision-making statutes thus far reinforces the impression that politicians erred in introducing bills to do so.<sup>84</sup> Surveys and public-opinion polls certainly indicate as much.<sup>85</sup> The law thus far has emerged intact, a victory for those who celebrate the ability to refuse life-sustaining treatment, including medically supplied nutrition and hydration. The very fact that more than a dozen state legislatures considered such bills, however, demonstrates the strength of the political forces behind them. Those forces undoubtedly will continue to influence this area of the law, in at least the following ways.

The National Right to Life Committee (NRLC), founded to oppose *Roe v. Wade*,<sup>86</sup> will continue, and may even strengthen, its efforts to revise end-of-life decision-making law in accordance with its mission of "restor[ing] legal protection to innocent human

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83. See generally Owen M. Fiss, *Foreword: The Forms of Justice*, 93 HARV. L. REV. 1 (1979) (identifying such cases as the type in which judicial involvement on such a broad scale is appropriate).

84. See Ellen Goodman, *Deserting A Culture War*, S. FLA. SUN-SENTINEL, Apr. 1, 2006, at 17A (asking, "What if they gave a culture war and nobody came?" with respect to the failure of such legislation).

85. See generally Blendon et al., *supra* note 32; PEW REPORT, *supra* note 49.

86. *Roe v. Wade*, 410 U.S. 113 (1973) (finding a constitutional right to choose to terminate a pregnancy).

life.”<sup>87</sup> The NRLC is the organization that drafted the model legislation that many legislators in Florida and other states unsuccessfully introduced during and after *Schiavo*. The model legislation is still available on the NRLC’s website, and it is still playing with emotions through its inflammatory title, the “Model State Starvation and Dehydration of Persons with Disabilities Prevention Act.”<sup>88</sup> It has been amended since its initial promulgation,<sup>89</sup> but it remains available and ready for submission to legislators for reintroduction in state legislatures. The NRLC’s *Terri’s Legacy Plan*, currently dedicated to “build[ing] a network . . . to help protect the lives of people like” Ms. Schiavo, may lead to advocacy in favor of the model legislation once initial network-building has gotten underway.<sup>90</sup> Certainly the network, created through the Terri Schindler Schiavo Foundation, has advocacy as one of its goals.<sup>91</sup>

The NRLC also has promulgated and displays prominently on its website a “pro-life living will” titled *The Will to Live*.<sup>92</sup> Strong proponents of patient autonomy would have difficulty arguing that it is inappropriate for a patient to make clear in a living will that he or she wishes to receive certain treatments, but this document seems to do more than offer that option. Lois Shepherd describes this document and the NRLC website’s descriptions of and justifi-

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87. H.B. 701, 2005 Leg. Reg. Sess. (Fla. 2005); Nat’l Right to Life Comm., Mission Statement, <http://www.nrlc.org/Missionstatement.htm> (last visited Jan. 16, 2007).

88. NRLC MODEL ACT, *supra* note 30; *see also Spurred by Schindler-Schiavo Case, supra* note 31.

89. *Compare* NRLC MODEL ACT, *supra* note 30 (bearing notation “revised January 2006”), *with* H.B. 701, 2005 Leg. Reg. Sess. (Fla. 2005) (version introduced in Florida during the *Schiavo* debates).

90. *See* Terri’s Legacy Project, <http://www.nrlc.org/Projects/Legacy/index.html> (last visited Jan. 16, 2007) (identifying Terri’s Legacy Plan as helping to build the network created by “the Terri Schindler Schiavo Foundation (established by Terri’s parents, brother and sister)”).

91. Terri Schindler Schiavo Found., About the Foundation, [http://www.terrisfight.org/mainlinks.php?table=main\\_about\\_the\\_foundation\\_2&id=143](http://www.terrisfight.org/mainlinks.php?table=main_about_the_foundation_2&id=143) (last visited Jan. 16, 2007).

92. *See* ROBERT POWELL CTR. FOR MED. ETHICS, NAT’L RIGHT TO LIFE, STATE OF FLORIDA, HEALTHCARE SURROGATE, WILL TO LIVE FORM 7 (2005) [hereinafter WILL TO LIVE FORM], *available at* <http://www.nrlc.org/euthanasia/willtolive/docs/florida.rev1105.pdf>. Through the “Will to Live Project,” individuals can get online access to “Will to Live” forms appropriate for the state that they live in. Nat’l Right to Life Comm., “Will to Live” Project, <http://www.nrlc.org/euthanasia/willtolive/StatesList.html> (last visited Jan. 16, 2007); *see also* Nat’l Right to Life Comm., The Will to Live Project, <http://www.nrlc.org/euthanasia/willtolive/index.html> (last visited Jan. 16, 2007) (for a discussion of the various reasons to fill out one of the offered forms); Terri Schindler Schiavo Found., Will to Live, <http://www.terrisfight.org/quicklinks.php?id=41> (last visited Jan. 16, 2007) (replication of the “Will to Live” form).

cations for it, as having two aims: (1) to make people feel less secure about whether their end-of-life choices will be honored once they are incapacitated, and (2) to make people choose rather than refuse treatment.<sup>93</sup> Indeed, the document has a section titled “General Presumption for Life” and specifies that “[f]ood and water are not medical treatment, but basic necessities,” so that nutrition and fluids are to be administered by any means possible “to the full extent necessary both to preserve [the signer’s] life and to assure [the signer] the optimal health possible.”<sup>94</sup> There is no need here to address the legal inaccuracy of the statement discussing “food and water” as if they were the same as medically supplied nutrition and hydration.<sup>95</sup> Nor is this an appropriate point at which to discuss the inadvisability of administering nutrition and hydration “to the full extent possible.”<sup>96</sup> Rather, the importance of such statements in this setting is to demonstrate how the NRLC seeks to continue to influence people’s attitudes and thought processes with respect to end-of-life decision-making.

The NRLC Model Act also includes a provision that could foreshadow an increase in investigative and regulatory oversight of end-of-life decision-making. It specifically authorizes a “state protection and advocacy agency” or a “public official with appropriate jurisdiction to prosecute or enforce the laws” to file a lawsuit to protest any proposed withholding or withdrawal of medically supplied nutrition and hydration.<sup>97</sup> Such authorization reaches beyond the already-existing powers of such an official to take action to prevent abuse or violations of the law. To understand this, it is essential to remember that the law currently contemplates private medical decision-making, out of the spotlight, without the intrusion of others except when one of those involved—someone acquainted with the patient—protests a treatment decision. Court review does not occur in the vast majority of cases, if all involved agree that a

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93. Shepherd, *State Legislative Proposals Following Schiavo*, *supra* note 19.

94. WILL TO LIVE FORM, *supra* note 92, at 7.

95. See Cerminara, *Musings*, *supra* note 3, at 352-53.

96. For a graphic depiction of a situation in which it is possible to administer medically supplied nutrition and hydration, yet one in which almost no one would think it was a good idea, see Alicia J. Ouellette, *When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1, 13-18 (2004). The article describes the case of Sheila Pouliout.

97. NRLC MODEL ACT, *supra* note 30, § 5; see Shepherd, *State Legislative Proposals Following Schiavo*, *supra* note 19, at 15, 17 (describing proposals in Ohio to essentially give priority to potential surrogate decision-makers who agree to provide medically supplied nutrition and hydration).

treatment decision is what the patient would have wanted.<sup>98</sup> In contrast, this provision of the NRLC Model Act would authorize an action for injunctive relief not only by persons who know the patient but also by state officials

to secure a court determination, *notwithstanding the position of a guardian or surrogate*, [as to] whether there is clear and convincing evidence that the person legally incapable of making health care decisions, when legally capable of making such decisions, gave express and informed consent to withdrawing or withholding hydration or nutrition in the applicable circumstances.<sup>99</sup>

In other words, the Model Act would authorize governmental officials to file a lawsuit against surrogate decision-makers and health care providers to question withholding or withdrawal of medically supplied nutrition and hydration even when all those actually involved agree that withholding or withdrawal is appropriate. The opinions of those who know best would not count in the sense of shielding them from being dragged into court. Instead, members of the NRLC and others sharing similar views alert state officials about instances of the withholding or withdrawal of medically supplied nutrition and hydration because of a general policy-based belief that withholding or withdrawing it is always improper.<sup>100</sup> They want the power of the government to extend beyond attempts to intervene in cases in which individual wishes are determined,<sup>101</sup> and instead affirmatively question the decisions of those who know the patient best. State officials who are politically beholden to groups such as the NRLC may begin to look for ways to do just that, regardless of whether the NRLC Model Act is passed within their respective jurisdictions.

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98. MEISEL & CERMINARA, *supra* note 23, § 3.18[E] (“On balance, the courts have been unreceptive to the idea of routine judicial review.”); *id.* § 3.19 (describing presumption against judicial review). *But see id.* § 3.22 (describing limited categories of cases in which judicial review is required in some jurisdictions).

99. NRLC MODEL ACT, *supra* note 30, § 5A (emphasis added).

100. As noted previously, in *Schiavo*, Florida’s Department of Children and Families (DCF) received more than 100 reports about Ms. Schiavo. Many were duplicative. *In re* Records of the Dep’t of Children & Family Servs., Nos. 05-1879-CI-003 & 05-2347-CI-003 (Fla. Cir. Ct. Apr. 14, 2005), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/DCF\\_Abuse\\_Investigations\\_part\\_1.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/DCF_Abuse_Investigations_part_1.pdf); see Cerminara & Goodman, *Timeline*, *supra* note 1, at April 15, 2005 entry. Duplication would occur if, for example, many people were calling DCF with separate reports based on the same e-mail or blog entry.

101. *Cf. In re* Guardianship of Schiavo, 932 So. 2d 264 (Fla. Dist. Ct. App. 2005) (rejecting an attempt by Florida’s Department of Children and Families to intervene in the *Schiavo* case).

Persons working in this area of the law also must prepare for continued debate over standards of proof. Most states require that clear and convincing evidence support a request for withholding or withdrawing life-sustaining treatment from a patient who has no decision-making capacity.<sup>102</sup> Florida law incorporates such a standard of proof, and the courts found it satisfied, although, as commentators have noted, the evidence supporting the conclusion that Ms. Schiavo would not have wanted treatment was not overwhelming.<sup>103</sup> Since *Schiavo*, calls have gone out for increased emphasis on ensuring that evidence is truly clear and convincing before a court may authorize withdrawal of treatment.<sup>104</sup> At least one commentator has even argued for a “beyond a reasonable doubt” standard of proof,<sup>105</sup> reflecting the frustration felt by those who disagreed with the courts’ decisions in *Schiavo*. Battles over the standard of proof will continue, which is unfortunate since the reality is that no one talks about these issues with any level of specificity. To require too much proof would be to sentence people to endure invasive treatment they do not want. Some people will lose their right to prevent others from poking, prodding, and invading their bodies at a time when they did not want such intervention, all because they did not use specific enough language in discussing the matter in advance, when they could not have known specifics.<sup>106</sup>

Finally, *Schiavo* will reverberate in discussions about resource allocation. Money and other resources such as labor, drugs, and time are limited, and end-of-life treatment consumes its fair share of each. In the opinion of Jay Wolfson, the guardian ad litem appointed for Ms. Schiavo under Terri’s Law, *Schiavo* will force peo-

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102. See MEISEL & CERMINARA, *supra* note 23, § 3-10. This requirement properly represents a judgment about how much evidence a court will require, not a determination of the applicable substantive decision-making standard. See Meisel, *supra* note 73, at S50 (noting the conflation of the burden of proof and the substantive decision-making standard as a source of confusion).

103. Shepherd, *State Legislative Proposals Following Schiavo*, *supra* note 19, at 13-14; see also Shepherd, *Shattering the Neutral Surrogate Myth*, *supra* note 4, at 584.

104. Shepherd, *State Legislative Proposals Following Schiavo*, *supra* note 19, at 29; Elizabeth Price Foley, *Legislature Can Get It Right This Time*, MIAMI HERALD, Mar. 4, 2005, available at 2005 WLNR 23025509 (Westlaw) (proposing that the legislature amend Florida law to specify factors to be considered in determining whether clear and convincing evidence exists).

105. Steven G. Calabresi, *The Terri Schiavo Case: In Defense of the Special Law Enacted by Congress and President Bush*, 100 Nw. U. L. REV. 151, 164-65 (2006).

106. See, e.g., Shaw, *supra* note 32 (quoting a neurologist as saying “[i]t’s extremely difficult for people to anticipate every treatment about which decisions need to be made in the future,” and “it’s simply unreasonable to expect young adults” to execute advance directives).



ple to think differently about end-of-life resource allocation as a matter of state and federal policy, institutional practice with respect to technical treatments, and risk management.<sup>107</sup> Wolfson urges that such consideration become explicit, saying, “If five years from now, we should face another *Schiavo* case, it would be a tragedy of public policy.”<sup>108</sup> It is unlikely, however, that policymakers, the public, or even health care providers will address these issues explicitly, despite the shadow of *Schiavo*. Once again, as with individuals who resist specifying their wishes clearly, it is difficult to anticipate and talk about painful subjects.

### C. *Lessons About Bioethics*

It also is possible to go beyond end-of-life decision-making law and see *Schiavo* as a symbol of generally increasing politicization in bioethics. George Annas says that politicization has occurred generally in bioethics over recent years,<sup>109</sup> and *Schiavo* seems like an illustration in stark relief.

One may identify politicization in bioethics through at least two different techniques. The first is to examine the methods through which persons speaking as bioethicists engage in analysis. Annas notes that recent events involve individuals calling themselves bioethicists who opine based upon their religious backgrounds and senses of morality rather than engaging in analysis based upon principles, case-based reasoning, or other traditional modes of philosophical discourse.<sup>110</sup> For Annas, *Schiavo* illustrates this phenomenon through the involvement in its latter stages of a neurologist named William Cheshire.<sup>111</sup> Eight days prior to Ms. Schiavo’s death, Dr. Cheshire signed an affidavit in support of treatment discussing morality and ethics along with neurological opinions.<sup>112</sup> Based on this and other recent events in bioethics, Annas asks whether “bioethics [must] accept rigid fundamentalist be-

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107. Wolfson, *Schiavo’s Lessons for Health Attorneys*, *supra* note 25, at 551.

108. *Id.*

109. Annas, *supra* note 6, at 74-75 (referring to the appointment of Leon Kass, a neoconservative in favor of banning stem cell research, as chair of the President’s Council on Bioethics).

110. *Id.*

111. *Id.* at 73-74.

112. See Aff. of William Polk Cheshire, Jr. (Mar. 23, 2005), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/032305\\_Cheshire\\_affidavit.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/032305_Cheshire_affidavit.pdf); see also Cerminara & Goodman, *Timeline*, *supra* note 1, at “Dr. Cheshire’s Affidavit” in March 23, 2005 entry.

lievers as bioethicists just because they call themselves bioethicists.”<sup>113</sup>

Alternatively, one may identify politicization in bioethics by examining the way that bioethics has influenced the outcome of overarching public policy debates. Autonomy and self-determination have been the buzz words of power within bioethics over the past forty or so years. Recently, however, those buzz words have come under fire. Carol Levine sees a “sustained critique of individual autonomy as a guiding principle” in a recent report issued by the President’s Council on Bioethics.<sup>114</sup> Similarly, pointing in part to debates over stem-cell and fetal tissue research, former member of the National Bioethics Advisory Committee R. Alta Charo says that “conservatives seem to feel that liberal bioethics has been an obstacle to regulating medicine and scientific research” through its emphasis on the principles of autonomy and self-determination.<sup>115</sup> Bioethicists and the courts in *Schiavo* emphasized Ms. Schiavo’s autonomy and self-determination as a basis for withdrawing her treatment; those opposing withdrawal of treatment argued that her autonomy was not at issue because the only way she appropriately could have exercised her autonomy was through an advance directive, and she had no advance directive. Echoing Charo, it seems that *Schiavo* protesters believed that by permitting an incapacitated person’s wishes to be determined through evidence other than a written advance directive, “liberal bioethics has been an obstacle to” regulation of medical decision-making. At both the beginning and end of life, “bioethicists” with the qualifications Annas notes are more frequently advancing political positions contrary to the positions of those advocating autonomy and self-determination.

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113. Annas, *supra* note 6, at 74.

114. Carol Levine, *The President’s Council on Autonomy: Never Mind!*, HASTINGS CTR. REP., May-June 2006, at 46, 46-47. The report, titled *Taking Care: Ethical Caregiving in Our Aging Society*, and available at [http://www.bioethics.gov/reports/taking\\_care/taking\\_care.pdf](http://www.bioethics.gov/reports/taking_care/taking_care.pdf), criticizes instruction advance directives and questions involvement of family when a patient is unable to make his or her own health care decisions. Some of the criticism of advance directives is well-placed. See generally Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CTR. REP., Mar.-Apr. 2004, at 30. But Levine notes, “If many Americans have signed advance directives and appointed proxies in the aftermath of the Schiavo case, it was at least partly to avoid family conflicts and to preserve family unity, not as an expression of unbridled individual autonomy.” Levine, *supra*, at 47. She sees the report as diminishing those attempts.

115. R. Alta Charo, *Passing on the Right: Conservative Bioethics is Closer Than It Appears*, 32 J.L. MED. & ETHICS 307, 310 (2004) [hereinafter Charo, *Passing on the Right*].

This statement does not imply that consideration of religious viewpoints necessarily leads to inappropriate politicization. Religious viewpoints have always played a part in bioethics, including authorizing refusals of life-sustaining treatment.<sup>116</sup> The Roman Catholic theological doctrine of double effect, for example, has become well-recognized in both bioethics and law.<sup>117</sup> Yet there are differences between religious and secular bioethics; most notably, “[u]nlike secular bioethics, individual autonomy is not the ultimate value in Catholic bioethics.”<sup>118</sup> Such differences should be recognized. Persons espousing Catholic theology or a Jewish mode of moral analysis (to name but two different categories of religiously based thought) generally have acknowledged the differences between the two types of bioethics.<sup>119</sup> Notably, William Cheshire did not identify himself as a moral theologian or even as being of a particular moral background. He filed his affidavit as a bioethicist and a neurologist.<sup>120</sup> It was only upon noticing certain facts in his background and investigating him that the importance of his religious beliefs in his decision-making process became clear.

*Schiavo*, in fact, turns out to be a prime example of a situation in which “it is the politics we are debating more often than the bioethics, and it may well be that sweeping political forces will determine the policy outcomes more than the merits of the individual arguments.”<sup>121</sup> It is easy in this debate to forget that ethical analy-

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116. See, e.g., Daniel P. Sulmasy, *Terri Schiavo and the Roman Catholic Tradition of Forgoing Extraordinary Means of Care*, 33 J.L. MED. & ETHICS 359 (2005). See generally Peter Clark, *Contemporary Catholic Health Care Ethics* by David F. Kelly, 21 J.L. & RELIGION 201, 201 (2005) (book review) (“The influence of religion on health care ethics is often lost to many secular bioethicists today.”).

117. See Edward C. Lyons, *In Incognito: The Principle of Double Effect in American Constitutional Law*, 57 FLA. L. REV. 469, 471-73 (2005).

118. Leonard J. Nelson, III, *Catholic Bioethics and the Case of Terri Schiavo*, 35 CUMB. L. REV. 543, 544 (2005). “Double effect, traced historically to Thomas Aquinas, proposes that under certain circumstances, it is permissible unintentionally to cause unforeseen ‘evil’ effects that would not be permissible to cause intentionally.” Lyons, *supra* note 117, at 471; see also MEISEL & CERMINARA, *supra* note 23, § 5.02[D] (describing the “philosophical principle of double effect, originating in Roman Catholic moral theology, which states that there are situations in which it is morally justifiable to cause evil in the pursuit of good”).

119. See, e.g., David M. Smolin, *Does Bioethics Provide Answers?: Secular and Religious Bioethics and Our Procreative Future*, 35 CUMB. L. REV. 473 (2005); see also Shelly Cohen, Note, *De-Moralizing Death: A Humanistic Approach to the Sanctity of Life*, 14 ELDER L.J. 91 (2006).

120. See Cerminara & Goodman, *Timeline*, *supra* note 1, at “Dr. Cheshire’s Affidavit” in March 23, 2005 entry.

121. Charo, *Realbioethik*, *supra* note 33, at 14.

sis and public policy are two different things.<sup>122</sup> In *Schiavo*, as with so many other current issues, conversations revolved around questions of human dignity rather than political philosophy.<sup>123</sup>

Unfortunately, however, the differences between those two areas of concern are huge; debate over the role each of them does or should play in American society in the twenty-first century will be an ongoing theme of bioethics over the next few years.

#### D. *Lessons About American Constitutional Republican Government*

A broader political issue is the appropriate role of various branches of government. While students of constitutional law are (or at least should be) well-aware of the limits put on the various branches of government in the American constitutional system, it became painfully obvious during the legislative debates on *Schiavo* that much of the general public was not. The courts especially were attacked, through political statements, such as “[t]he actions on the part of the Florida court are unconscionable,”<sup>124</sup> and denunciations of judges as activists for approving withdrawal of Ms. Schiavo’s medically supplied nutrition and hydration.<sup>125</sup> It was obvious that some members of the public, and perhaps some legislators, failed to understand that trial courts engage in fact-finding and that appellate courts are not and should not be empowered to revisit that fact-finding.<sup>126</sup> Similarly, it was obvious that citizens did not understand

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122. Charo, *Passing on the Right*, *supra* note 115, at 311 (noting “the enduring question of the relationship between ethical analysis and public policy. Moral angst is one thing; federal criminalization of research or medical practice is another”).

123. In describing the focus of the President’s Commission on Bioethics, Charo cautions against underestimating the “significant difference between arguing that something is unethical and arguing that it is (or ought to be) prohibited by federal law.” *Id.*

124. *Santorum Fights to Save Life of Terri Schiavo* (Mar. 17, 2005), reprinted in *THE CASE OF TERRI SCHIAVO: ETHICS AT THE END OF LIFE* 130 (Arthur L. Caplan et al., eds., Prometheus Books 2006) (statement of U.S. Sen. Rick Santorum (R-Pa.)); see also Kurt Darr, *Terri Schindler Schiavo: End-Game*, 83 NEXUS 29, 30 (2005) (stating that “many observers forgot their basic high school civics when they asserted that the three branches of government . . . are co-equal”).

125. James J. Peters, *Labels Create Chaos in Courts*, ORLANDO SENTINEL, Mar. 23, 2005, at A15, available at 2005 WLNR 23739433 (Westlaw).

126. In response to a request from Ms. Schiavo’s parents that the Florida District Court of Appeal review the trial court’s ruling *de novo*, the court reminded them, “It is simply not proper for this court to review such a fact-intensive determination.” *In re Schiavo*, 851 So. 2d 182, 186 (Fla. Dist. Ct. App. 2003). Bowing to their concerns, however, the court went a step further and assured them that it had dug into the evidence and that “[i]f we were called upon to review the guardianship court’s decision *de novo*, we would still affirm it.” *Id.*

the way the judiciary serves as a “check” on the legislative and executive branches in our system of government.<sup>127</sup> Regardless of one’s agreement or disagreement with the outcome of a particular court case, there is value to upholding the court system and the way it works.<sup>128</sup> Such a lesson is often a foundational point in basic civics education. Yet it was lost in this case.

Perhaps it was lost because basic civics education seems to have fallen by the wayside. In a survey administered to Florida adults in December 2005, only 59 percent of those surveyed were able to identify the three branches of government as being the judicial, executive, and legislative branches.<sup>129</sup> The American Bar Association conducted a nationwide poll showing the same results in July 2005.<sup>130</sup> In Florida, 16 percent of those surveyed identified the government’s branches as “Republican, Democrat and Independent,” in a stunning demonstration of just how much power political parties have.<sup>131</sup>

Such findings prompted the Florida Bar to lobby for and to engage in more civics education, and its lobbying efforts resulted in the passage of a law requiring students in public middle schools to successfully complete “[t]hree middle school or higher courses in social studies, one semester of which must include the study of state

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127. For example, ignoring the fact that Ms. Schiavo’s medically supplied nutrition and hydration had been withdrawn in accordance with a duly entered, final court order, activists pressured Governor Bush to “protect” Ms. Schiavo from “abuse” by removing her from her hospice and reinserting the tube through which she could receive that nutrition and hydration. See David Sommer & Blaine Silversmith, *Legal Defeats Mount for Schiavo Parents*, TAMPA TRIB., Mar. 25, 2005, available at <http://www.tampatrib.com/MGBH2M0ZP6E.html> (quoting activist as saying, “Gov. Bush and the Department of Children and Families do not have to ask permission of a judge to enforce the statutes that are on the books . . . . It’s an appalling lack of will”); see also Keville & Eisenberg, *supra* note 2, at 12. But see Bagenstos, *Judging the Schiavo Case*, *supra* note 3, at 471-72 (arguing that the courts at the federal level failed to respect Congress).

128. Kathy L. Cerminara, *With Schiavo, Congress Thumbs Nose at Courts*, ORLANDO SENTINEL, Mar. 23, 2005, at A15, available at 2005 WLNR 23739416 (Westlaw).

129. *Bar Pushes for More Civics Education*, FLA. BAR NEWS, Feb. 1, 2006, at 1 [hereinafter *Bar Pushes for More Civics Education*]; see also Press Release, The Florida Bar, Poll Shows Need for More Civics Education for Florida Adults (Jan. 11, 2006) (with other supporting information about the poll and the Bar’s efforts) (on file with *Western New England Law Review*), available at <http://www.floridabar.org/TFB/TFBPublic.nsf/WNewsReleases/07303EEA70164467852570F20079DACE?OpenDocument>.

130. See AM. BAR ASSOC., CIVICS EDUCATION (2005), available at [http://www.abanews.org/docs/divisionofpowers\\_705.pdf](http://www.abanews.org/docs/divisionofpowers_705.pdf).

131. *Bar Pushes for More Civics Education*, *supra* note 129.

and federal government and civics education.”<sup>132</sup> One hopes that such a step will help remedy this breathtaking lack of knowledge, reminiscent of the misunderstanding of governmental structure displayed during *Schiavo*. Such misunderstanding clearly is more widespread than one might hope or expect, and it has its roots in a lack of sufficient knowledge of governmental basics.

In the *Schiavo* controversy, many spoke about how the elected representatives of the people were coming to the rescue of a woman lying in bed, while activist judges did not care about her. Such arguments ignore the fact that, in Florida, judges, including the trial court judge who decided *Schiavo*, are elected.<sup>133</sup> They also ignore the fact that legislators, the peoples’ elected representatives, later realized that they had not been acting in accordance with the majority’s wishes, but only in accordance with the wishes of the most vocal, when they acted.<sup>134</sup> Rather, as Annas has quoted Jeffrey Rosen:

[T]he conservative interest groups have it exactly backward. Their standard charge is that unelected judges are thwarting the will of the people by overturning laws passed by elected representatives. But in our new topsy-turvy world, it’s the elected representatives who are thwarting the will of the people, which is being channeled instead by unelected judges.<sup>135</sup>

In *Schiavo*’s aftermath ultimately lies an opportunity to improve citizens’ involvement in and awareness of end-of-life decision-making. Whether that happens, however, may depend at least in part on how well basic civics educational efforts work.

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132. FLA. STAT. ANN. § 1003.4156(1)(a)(3) (West 2006); see Gary Blankenship, *More Emphasis To Be Placed On Civics Education*, FLA. BAR NEWS, June 1, 2006, at 1. Others have noted a similar need for education about end-of-life treatment and decision-making. Mayo, *supra* note 18, at 590; James L. Bernat, *What Relevance to Neurologists Is the Tragic Case of Terri Schiavo?*, 5 NEUROLOGY TODAY 4, 5 (May 2005) (advocating “professional and public education about the medical facts of patients with states of impaired consciousness”).

133. Judge Greer, in fact, faced a re-election challenge. He won by a healthy margin. Cerminara & Goodman, *Timeline*, *supra* note 1, at Aug. 31, 2004 entry.

134. See Annas, *supra* note 6, at 78 n.109 (citing polls conducted immediately before and after Ms. Schiavo’s death indicating that “seventy-six percent of Americans disapproved of congressional involvement in the *Schiavo* case . . . eighty-two percent of Americans sa[id] Congress and the President should stay out of deciding what happens to Terri Schiavo,” and “seventy-five percent of Americans say it was ‘not right’ for Congress to intervene in the *Schiavo* case”).

135. *Id.* at 78 (quoting Jeffrey Rosen, Center Court, N.Y. TIMES WKLY. 6-17 (June 12, 2005)).

## CONCLUSION

More than a year after Theresa Schiavo's death, little has changed. The judicial rulings in her case and the ultimate impact of the statutes passed to address her situation have, for the most part, left intact previously existing end-of-life decision-making law. Yet it is possible to recognize both existing and potential effects of the political culture wars surrounding Ms. Schiavo's death.

Regardless of their positions with respect to Ms. Schiavo's case in particular, most observers would believe that its effect was positive in the sense that it heightened citizens' awareness of certain areas of the law. More people than before began discussing end-of-life treatment choices with their families and friends as a result of *Schiavo*. More people than before obtained and executed forms for written advance directives in attempts to ensure that their families and friends did not have to debate what they would want done if they ended up lying in a PVS, dependent on medically supplied nutrition and hydration. *Schiavo* also increased recognition of the limited amount most Americans know and understand about the way their government works. *Schiavo* did some good to the extent that it may result in better end-of-life decision-making processes and in more educational efforts to assist citizens in playing their roles in society.

Collateral damage also exists, however. The political culture wars surrounding the final months of Ms. Schiavo's life confirmed the existence of deep schisms between certain factions of society. Those who joined in the protests against withdrawal of Ms. Schiavo's medically supplied nutrition and hydration raised questions about extremely well-settled areas of law and bioethics. They did so in an emotionally charged atmosphere, using rhetoric and imagery that is not likely to quickly fade. They continue to advocate legislative changes that were proposed and failed to pass during the final period of Ms. Schiavo's life.

In this manner, the *Schiavo* experience could cast a pall over future end-of-life decision-making in at least three ways. First, the media spectacle it turned into is likely to lurk as a threat in the minds of surrogate decision-makers and health-care providers, whose primary goal instead should be to worry about doing what the patient would have wanted. Second, and more broadly, activists will continue to attempt to change the law in a manner that would diminish the focus on individual patients and substitute broad-based restrictions on individual patient choice. Finally, *Schiavo*

symbolizes the sort of politicization of bioethics that many in the business of providing health care likely wish they could avoid. Medical care and end-of-life decision-making are supposed to be about what individual patients need and the way they want their lives to end, not about the symbolism that politically motivated groups can attach to each case.