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## “Culture of Life” Politics at the Bedside — The Case of Terri Schiavo

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For the first time in the history of the United States, Congress met in a special emergency session on Sunday, March 20, to pass legislation aimed at the medical care of one patient — Terri Schiavo. President George W. Bush encouraged the legislation and flew back to Washington, D.C., from his vacation in Crawford, Texas, so that he could be on hand to sign it immediately. In a statement issued three days earlier, he said: “The case of Terri Schiavo raises complex issues. . . . Those who live at the mercy of others deserve our special care and concern. It should be our goal as a nation to build a culture of life, where all Americans are valued, welcomed, and protected — and that culture of life must extend to individuals with disabilities.”<sup>1</sup>

The “culture of life” is a not-terribly-subtle reference to the antiabortion movement in the United States, which received significant encouragement in last year’s presidential election. The movement may now view itself as strong enough to generate new laws to prevent human embryos from being created for research and to require that incompetent patients be kept alive with artificially delivered fluids and nutrition.

How did the U.S. Congress conclude that it was appropriate to attempt to reopen a case that had finally been concluded after more than seven years of litigation involving almost 20 judges? Has the country’s culture changed so dramatically as to require a fundamental change in the law? Or do patients who cannot continue to live without artificially delivered fluids and nutrition pose previously unrecognized or novel questions of law and ethics?

The case of Terri Schiavo, a Florida woman who was in a persistent vegetative state and who died on March 31, was being played out as a public spectacle and a tragedy for her and her husband, Michael Schiavo. Mr. Schiavo’s private feud with his wife’s parents over the continued use of a feeding tube was taken to the media, the courts, the Florida legislature, Florida Governor Jeb Bush, the U.S. Congress, and President Bush. Since Ms. Schiavo was in a medical and legal situation almost identical to those of two of the most well-known patients in medical jurisprudence, Karen Ann Quinlan and Nancy Cruzan, there must be something about cases like theirs that defies simple solutions,

whether medical or legal. In this sense, the case of Terri Schiavo provides an opportunity to examine issues that most lawyers, bioethicists, and physicians believed were well settled — if not since the 1976 New Jersey Supreme Court decision in the case of Karen Quinlan, then at least since the 1990 U.S. Supreme Court decision in the case of Nancy Cruzan. Before reviewing Terri Schiavo's case, it is well worth reviewing the legal background information that was ignored by Congress and the president.

## **THE CASE OF KAREN QUINLAN**

In 1976, the case of Karen Quinlan made international headlines when her parents sought the assistance of a judge to discontinue the use of a ventilator in their daughter, who was in a persistent vegetative state.<sup>2</sup> Ms. Quinlan's physicians had refused her parents' request to remove the ventilator because, they said, they feared that they might be held civilly or even criminally liable for her death. The New Jersey Supreme Court ruled that competent persons have a right to refuse life-sustaining treatment and that this right should not be lost when a person becomes incompetent. Since the court believed that the physicians were unwilling to withdraw the ventilator because of the fear of legal liability, not precepts of medical ethics, it devised a mechanism to grant the physicians prospective legal immunity for taking this action. Specifically, the New Jersey Supreme Court ruled that after a prognosis, confirmed by a hospital ethics committee, that there is “no reasonable possibility of a patient returning to a cognitive, sapient state,” life-sustaining treatment can be removed and no one involved, including the physicians, can be held civilly or criminally responsible for the death.<sup>2</sup>

The publicity surrounding the Quinlan case motivated two independent developments: it encouraged states to enact “living will” legislation that provided legal immunity to physicians who honored patients' written “advance directives” specifying how they would want to be treated if they ever became incompetent; and it encouraged hospitals to establish ethics committees that could attempt to resolve similar treatment disputes without going to court.

## **THE CASE OF NANCY CRUZAN**

Although *Quinlan* was widely followed, the New Jersey Supreme Court could make law only for New Jersey. When the U.S. Supreme Court decided the case of Nancy Cruzan in 1990, it made constitutional law for the entire country. Nancy Cruzan was a young woman in a persistent vegetative state caused by an accident; she was in physical circumstances essentially identical to those of Karen Quinlan, except that she was not dependent on a ventilator but rather, like Terri Schiavo, required only tube feeding to continue to live.<sup>3</sup> The Missouri Supreme Court had ruled that the tube feeding could be discontinued on the basis of Nancy's right of self-determination, but that only Nancy herself should be able to make this decision. Since she could not do so, tube feeding could be stopped only if those

speaking for her, including her parents, could produce “clear and convincing” evidence that she would refuse tube feeding if she could speak for herself.<sup>4</sup>

The U.S. Supreme Court, in a five-to-four decision, agreed, saying that the state of Missouri had the authority to adopt this high standard of evidence (although no state was required to do so) because of the finality of a decision to terminate treatment.<sup>3</sup> In the words of the chief justice, Missouri was entitled to “err on the side of life.” Six of the nine justices explicitly found that no legal distinction could be made between artificially delivered fluids and nutrition and other medical interventions, such as ventilator support; none of the other three justices found a constitutionally relevant distinction. This issue is not controversial as a matter of constitutional law: Americans have (and have always had) the legal right to refuse any medical intervention, including artificially delivered fluids and nutrition.

Supreme Court Justice Sandra Day O'Connor, in a concurring opinion (her vote decided the case), recognized that young people (such as Karen Quinlan, Nancy Cruzan, and now Terri Schiavo — all of whom were in their 20s at the time of their catastrophic injuries) do not generally put explicit treatment instructions in writing. She suggested that had Cruzan simply said something like “if I'm not able to make medical treatment decisions myself, I want my mother to make them,” such a statement should be a constitutionally protected delegation of the authority to decide about her treatment.<sup>3</sup> O'Connor's opinion was the reason that the Cruzan case energized a movement — encouraging people to use the appropriate documents, such as health care proxy forms or assignments of durable power of attorney, to designate someone (usually called a health care proxy, or simply an agent) to make decisions for them if they are unable to make them themselves. All states authorize this delegation, and most states explicitly grant decision-making authority to a close relative — almost always to the spouse first — if the patient has not made a designation. Such laws are all to the good.

## **THE SCHIAVO CASE IN THE COURTS**

Terri Schiavo had a cardiac arrest, perhaps because of a potassium imbalance, in 1990 (the year *Cruzan* was decided), when she was 27 years old. Until her death in 2005, she had lived in a persistent vegetative state in nursing homes, with constant care, being nourished and hydrated through tubes. In 1998, Michael Schiavo petitioned the court to decide whether to discontinue the tube feeding. Unlike *Quinlan* and *Cruzan*, however, the Schiavo case involved a family dispute: Ms. Schiavo's parents objected. A judge found that there was clear and convincing evidence that Terri Schiavo was in a permanent or persistent vegetative state and that, if she could make her own decision, she would choose to discontinue life-prolonging procedures. An appeals court affirmed the first judge's decision, and the Florida Supreme Court declined to review it.

Schiavo's parents returned to court, claiming that they had newly discovered evidence. After an additional appeal, the parents were permitted to challenge the original court findings on the basis of

new evidence related to a new treatment that they believed might restore cognitive function. Five physicians were asked to examine Ms. Schiavo — two chosen by the husband, two by the parents, and one by the court. On the basis of their examinations and conclusions, the trial judge was persuaded by the three experts who agreed that Schiavo was in a persistent vegetative state. The appeals court affirmed the original decision of the trial court judge

Despite the irrefutable evidence that [Schiavo's] cerebral cortex has sustained irreparable injuries, we understand why a parent who had raised and nurtured a child from conception would hold out hope that some level of cognitive function remained. If Mrs. Schiavo were our own daughter, we could not hold to such faith.

But in the end this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo's right to make her own decision, independent of her parents and independent of her husband. . . . It may be unfortunate that when families cannot agree, the best forum we can offer for this private, personal decision is a public courtroom and the best decision-maker we can provide is a judge with no prior knowledge of the ward, but the law currently provides no better solution that adequately protects the interests of promoting the value of life.<sup>5</sup>

The Supreme Court of Florida again refused to hear an appeal.

Subsequently, the parents, with the vocal and organized support of conservative religious organizations, went to the state legislature seeking legislation requiring the reinsertion of Ms. Schiavo's feeding tube, which had been removed on the basis of the court decisions.<sup>6,7</sup> The legislature passed a new law (2003-418), often referred to as "Terri's Law," which gave Governor Jeb Bush the authority to order the feeding tube reinserted, and he did so. The law applied only to a patient who met the following criteria on October 15, 2003 — in other words, only to Terri Schiavo:

- (a) That patient has no written advance directive;
- (b) The court has found that patient to be in a persistent vegetative state;
- (c) That patient has had nutrition and hydration withheld; and
- (d) A member of that patient's family has challenged the withholding of nutrition and hydration.

The constitutionality of this law was immediately challenged. In the fall of 2004, the Florida Supreme Court ruled that the law was unconstitutional because it violates the separation of powers — the division of the government into three branches (executive, legislative, and judicial), each with its own powers and responsibilities.<sup>8</sup> The doctrine states simply that no branch may encroach on the powers of another, and no branch may delegate to another branch its constitutionally assigned power. Specifically, the court held that for the legislature to pass a law that permits the executive to "interfere with the final judicial determination in a case" is "without question an invasion of the authority of the

judicial branch.”<sup>8</sup> In addition, the court found the law unconstitutional for an independent reason, because it “delegates legislative power to the governor” by giving the governor “unbridled discretion” to make a decision about a citizen's constitutional rights. In the court's words:

If the Legislature with the assent of the Governor can do what was attempted here, the judicial branch would be subordinated to the final directive of the other branches. Also subordinated would be the rights of individuals, including the well established privacy right to self determination. . . . Vested rights could be stripped away based on popular clamor.<sup>8</sup>

In January 2005, the U.S. Supreme Court refused to hear an appeal brought by Governor Bush. Thereafter, the trial court judge ordered that the feeding tube be removed in 30 days (at 1 p.m., Friday, March 18) unless a higher court again intervened. The presiding judge, George W. Greer of the Pinellas County Circuit Court, was thereafter picketed and threatened with death; he has had to be accompanied by armed guards at all times.

Ms. Schiavo's parents, again with the aid of a variety of religious fundamentalist and “right to life” organizations, sought review in the appeals courts, a new statute in the state legislature, and finally, congressional intervention. Both the trial judge and the appeals courts refused to reopen the case on the basis of claims of new evidence (including the 2004 statement from Pope John Paul II regarding fluids and nutrition<sup>9</sup>) or the failure to appoint an independent lawyer for her at the original hearing. In Florida, the state legislature considered, and the House passed, new legislation aimed at restoring the feeding tube, but the Florida Senate — recognizing, I think, that this new legislation would be unconstitutional for the same reason as the previous legislation was — ultimately refused to approve the bill. Thereupon, an event unique in American politics occurred: after more than a week of discussion, and after formally declaring their Easter recess without action, Congress reconvened two days after the feeding tube was removed to consider emergency legislation designed to apply only to Terri Schiavo.

## **CONGRESS AT THE BEDSIDE**

Under rules that permitted a few senators to act if no senator objected, the U.S. Senate adopted a bill entitled “For the relief of the parents of Theresa Marie Schiavo” on March 20, 2005. The House, a majority of whose members had to be present to vote, debated the same measure from 9 p.m. to midnight on the same day and passed it by a four-to-one margin shortly after midnight on March 21. The President then signed it into law. In substance, the new law (S. 686) provides that “the U.S. District Court for the Middle District of Florida shall have jurisdiction” to hear a suit “for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.” The parents “have standing” to bring the lawsuit (the federal court had previously refused to hear

the case on the basis that the parents had no standing to bring it), and the court is instructed to “determine de novo any claim of a violation of any right of Theresa Marie Schiavo . . . notwithstanding any prior State court determination . . .” — that is, to pretend that no court has made any prior ruling in the case. The act is to provide no “precedent with respect to future legislation.”

The brief debate on this bill in the House of Representatives (there were no hearings in either chamber and no debate at all in the U.S. Senate) was notable primarily for its uninformed and frenzied rhetoric. It was covered live on television by C-SPAN. The primary sponsor of the measure, Congressman Thomas DeLay (R-Tex.), for example, asserted that “She’s not a vegetable, just handicapped like many millions of people walking around today. This has nothing to do with politics, and it’s disgusting for people to say that it does.” Others echoed the sentiments of Senate majority leader and physician Bill Frist (R-Tenn.), who said that immediate action was imperative because “Terri Schiavo is being denied lifesaving fluids and nutrition as we speak.”

Other physician-members of the House chimed in. Congressman Dave Weldon (R-Fla.) remarked that, on the basis of his 16 years of medical practice, he was able to conclude that Terri Schiavo is “not in a persistent vegetative state.” Congressman Phil Gingrey (R-Ga.) agreed, saying “she’s very much alive.” Another physician, Congressman Joe Schwarz (R-Mich.), who was a head and neck surgeon for 27 years, opined that “she does have some cognitive ability” and asked, “How many other patients are there with feeding tubes? Should they be removed too?” Another physician-congressman, Tom Price (R-Ga.), thought the law was reasonable because there was “no living will in place” and the family and experts disagreed. The only physician who was troubled by Congress’s public diagnosis and treatment of Terri Schiavo was James McDermott (D-Wash.), who chided his physician-colleagues for the poor medical practice of making a diagnosis without examining the patient.

Although he deferred to the medical expertise of his congressional colleagues with M.D. degrees, Congressman Barney Frank (D-Mass.) pointed out that the chamber was not filled with physicians. Frank said of the March 20 proceedings: “We’re not doctors, we just play them on C-SPAN.” The mantras of the debate were that in a life-or-death decision, we should err on the “side of life,” that action should be taken to “prevent death by starvation” and ensure the “right to life,” and that Congress should “protect the rights of disabled people.”

The following day, U.S. District Court Judge James D. Whittemore issued a careful opinion denying the request of the parents for a temporary restraining order that would require the reinsertion of the feeding tube.<sup>10</sup> The judge concluded that the parents had failed to demonstrate “a substantial likelihood of success on the merits” of the case — a prerequisite for a temporary restraining order. Specifically, Judge Whittemore found that, as to the various due-process claims made, the case had been “exhaustively litigated”; that, throughout, all parties had been “represented by able counsel”; and that it was not clear how having an additional lawyer “appointed by the court [for Ms. Schiavo] would

have reduced the risk of erroneous rulings.” As to the allegation that the patient's First Amendment rights to practice her religion had been violated by the state, the court held that there were no state actions involved at all, “because neither Defendant Schiavo nor Defendant Hospice are state actors.”

Whittemore's decision was reasonable and consistent with settled law, and was, not suprisingly, upheld on appeal. The case of Terri Schiavo resulted in no changes in the law, nor were any good arguments made that legal changes were necessary. The religious right and congressional Republicans may nonetheless attempt to use this decision to their advantage. Despite the fact that Congress itself sent the case to federal court for determination, some Republicans have already begun to cite the ruling as yet another example of “legislating” by the courts. For they liken the action permitted — the withdrawal of a feeding tube — to disfavored activities, such as abortion and same-sex marriage, that courts have allowed to occur. All three activities, they argue, represent attacks on the “culture of life” and necessitate that the President appoint federal court judges who value life over liberty.

## **PROXY DECISION MAKERS, PERSISTENT VEGETATIVE STATES, AND DEATH**

A vast majority of Americans would not want to be maintained in a persistent vegetative state by means of a feeding tube, like Terri Schiavo and Nancy Cruzan.<sup>11</sup> The intense publicity generated by this case will cause many to discuss this issue with their families and, I hope, to sign an advance directive. Such a directive, in the form of a living will or the designation of a health care proxy, would prevent court involvement in virtually all cases — although it might not have solved the problem in the Schiavo case, because the family members disagreed about Terri Schiavo's medical condition and the acceptability of removing the tube in any circumstances.

Despite the impression that may have been created by these three cases, and especially by the grandstanding in Congress, conflicts involving medical decision making for incompetent patients near the end of life are no longer primarily legal in nature, if they ever were. The law has been remarkably stable since *Quinlan* (which itself restated existing law): competent adults have the right to refuse any medical treatment, including life-sustaining treatment (which includes artificially delivered fluids and nutrition). Incompetent adults retain an interest in self-determination. Competent adults can execute an advance directive stating their wishes and designate a person to act on their behalf, and physicians can honor these wishes. Physicians and health care agents should make treatment decisions consistent with what they believe the patient would want (the subjective standard). If the patient's desires cannot be ascertained, then treatment decisions should be based on the patient's best interests (what a reasonable person would most likely want in the same circumstances). This has, I believe, always been the law in the United States.<sup>12</sup>

Of course, legal forms or formalities cannot solve nonlegal problems. Decision making near the end of life is difficult and can exacerbate unresolved family feuds that then are played out at the patient's bedside and even in the media. Nonetheless, it is reasonable and responsible for all persons to designate health care agents to make treatment decisions for them when they are unable to make their own. After this recent congressional intervention, it also makes sense to specifically state one's wishes with respect to artificial fluids and hydration — and that one wants no politicians, even physician-politicians, involved in the process.

Most Americans will agree with a resolution that was overwhelmingly adopted by the California Medical Association on the same day that Congress passed the Schiavo law: “Resolved: That the California Medical Association expresses its outrage at Congress' interference with these medical decisions.”

If there is disagreement between the physician and the family, or among family members, the involvement of outside experts, including consultants, ethics committees, risk managers, lawyers, and even courts, may become inevitable — at least if the patient survives long enough to permit such involvement. It is the long-lasting nature of the persistent vegetative state that results in its persistence in the courtrooms of the United States. There is (and should be) no special law regarding the refusal of treatment that is tailored to specific diseases or prognoses, and the persistent vegetative state is no exception.<sup>13,14</sup> Nor do feeding tubes have rights: people do. “Erring on the side of life” in this context often results in violating a person's body and human dignity in a way few would want for themselves. In such situations, erring on the side of liberty — specifically, the patient's right to decide on treatment — is more consistent with American values and our constitutional traditions. As the Massachusetts Supreme Judicial Court said in a 1977 case that raised the same legal question: “The constitutional right to privacy, as we conceive it, is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice.”<sup>15</sup>