Ever since Karen Quinlan unexpectedly survived the removal of her respirator,[1] law and bioethics have struggled to address the conundrum of the patients who live unresponsively in a sleep/wake cycle, their lives sustained by standard (if laborious) nursing care and the minimally invasive technology of tube feeding.[2] Thousands of patients live in this ?persistent vegetative state? (PVS).[3] Since the decision of the New Jersey Supreme Court in Quinlan, controversies over whether to continue tube feeding of persons in PVS have had an outsized influence in the development of judicial, legislative, and even clinical standards regarding the use of life-sustaining treatment.[4]

This year marks the respective 25th and 10th anniversaries of two such milestone developments: the decision of the Supreme Court in Cruzan v. Director, Missouri Department of Health,[5] and the death of Terri Schiavo.[6] In assessing the continued impact of these cases, it is appropriate to ask whether the legal standards reflected in these cases remain up to the task for which they were developed. Or, are they based on legal fictions that, while of temporary utility in bringing resolution to a limited number of cases, fail to encompass the full range of clinical and ethical issues presented by the care of such patients? Particularly as neuroscience counters the settled notions about the PVS that underlay the decisions in Cruzan, Schiavo, and related cases, should the disciplines of clinical ethics and legal ethics forge an independent understanding of the duties owed to patients in PVS and related disorders such as the minimally conscious state?[7]

Cruzan: The Limits of Discerning Patient Intent

The case of Nancy Cruzan reached the U.S. Supreme Court at the end of a decade of ferment over the legal and ethical propriety of ceasing to tube feed patients in PVS.[8] On one side were
those courts, and a seeming majority of medical ethicists, who concluded that that removal of a feeding tube was indistinguishable from, and thus equally licit to, the removal of a ventilator, the entry of a do not resuscitate order (DNR), or the foregoing of surgery. Since it was well established that family members or other surrogates could make these latter decisions on behalf of an incapacitated patient (not limited to those in PVS), there was little difficulty in permitting the cessation of tube feeding on the same legal and ethical grounds.

Pitted against this view were those courts, and a smaller coterie of ethicists, who contended halting nutrition and hydration was different because of the basic and symbolic nature of feeding, and the inevitability of death from dehydration or starvation. The clinical fact that withdrawal of nutrition and hydration was accomplished simply by capping the feeding tube supported the view that this was somehow different from withdrawing or foregoing an invasive measure such as a ventilator or CPR. The state appellate courts that addressed these cases were often closely divided; however, by the end of the 1980s, the trend was toward the ?licit? view of allowing tube feeding to be halted.

The Missouri Supreme Court?s decision in Cruzan decisively bucked this trend. In reversing a trial judge?s ruling that Joseph Cruzan could authorize cessation of tube feeding for his daughter, who suffered traumatic brain injury in an automobile accident leading to PVS, the court rejected key pillars of the consensus view, first formulated in Quinlan, that surrogate decision-makers could readily stand in the shoes of an incapacitated patient, with an equivalent right to reject life-sustaining medical treatment. First, the court limited the right to refuse life-sustaining treatment to patients who could actually give an informed consent to such a decision, and applied traditional standards of informed consent such as reasoned judgment, voluntariness, and clear understanding of risks and benefits. Not surprisingly, the court found that casual statements made by Ms. Cruzan to a housemate about not wanting to be kept alive in a debilitated state did not meet this rigorous standard.

Second, the court rejected the Quinlan doctrine of substituted judgment, which had permitted parents or other family to assert the ?autonomy? or ?privacy? rights of PVS patients to reject medical treatment, even in the absence of clear prior statements of intent. Third, the Missouri court rejected a broad reading of Quinlan?s holding that the state?s interest in life diminishes as the condition of the patient worsens; that doctrine, it held, can apply only in cases of impending death. In other cases, including those of PVS and other severe handicaps, the state?s interest in life remains undiminished, even to the point of being ?unqualified.? Finally, the court held that the state could assert this undiminished interest in preserving life to override a family?s request to remove treatment as non-burdensome as a feeding tube.

The U. S. Supreme Court, by a narrow 5-4 majority, affirmed the Missouri decision on equally narrow grounds: that it was permissible, under the federal Constitution, for Missouri to require ?clear and convincing? evidence of Ms. Cruzan?s intent before authorizing the cessation of her feeding. The court explained that this standard is appropriate because the interests at stake are more substantial, both on an individual and societal level, than those involved in a run-of-the-mine civil dispute, such as those involving disputes over money, in which the lower ?preponderance of the evidence? standard is sufficient to meet a party?s burden of proof. The Court assumed that Missouri allowed for some measure of surrogate decision-making, but agreed that Missouri could limit a surrogate?s right to act by requiring statements of prior intent.
(even in writing) more formal than those ascribed to Ms. Cruzan. Furthermore, while clearly signaling that a state may allow family members to make the decision in the absence of such a clear statement of intent, the Court held that there was no constitutional requirement for Missouri to do so. The State could so act, the Court concluded, because of its legitimate interests in preserving life, preventing suicide and homicide, and rejecting decisions based on ‘quality of life.’

The four dissenting Justices, echoed by critics of the Cruzan majority, castigated its endorsement of the ‘clear and convincing’ standard. The real issue, they contended, was not Missouri’s right to require high standards of due process to protect Nancy Cruzan’s life; rather, the issue was whether Missouri had any interest at all in the preservation of her life. Due to Ms. Cruzan’s debilitated condition, Missouri could not assert an ‘unqualified’ interest in preserving life, or any such interest at all, until it determined that she would want to continue the treatment. According to Justice Brennan, ‘the State has no legitimate general interest in someone’s life, completely abstracted from the interest of the person living that life, that could outweigh the person’s choice to avoid medical treatment.’ Justice Stevens was more explicit:

Nancy Cruzan is obviously alive in a physiological sense. But for patients like [her] . . . there is a serious question as to whether the mere persistence of their bodies is ‘life’ as that word is commonly understood, or as it is used in the Constitution and the Declaration of Independence. The State’s unflagging determination to perpetuate Nancy Cruzan’s physical existence is comprehensible only as an attempt to define life’s meaning, not as an attempt to preserve its sanctity.

One could logically conclude from these statements that the dissenting Justices endorsed a ‘right to die’ and perhaps even a presumption that patients in this condition would choose to exercise that right, and thus have a right (in the absence of contrary evidence of their intent) to have others exercise it for them. While the Cruzan majority rejected this position, its reframing of the Missouri Supreme Court’s decision as one providing ‘procedural safeguards’ in contrast to the heftier, substantive protections actually articulated by the Missouri court would have downstream effects not anticipated at the time of the decision. Those effects were quickly evident.
When the case of Nancy Cruzan went back to the trial court, new evidence was adduced that Nancy once served as a teacher?apos;s aide in a school of deaf-blind children (all of whom required laborious assistance in feeding or tube feeding). Two colleagues testified that they and Ms. Cruzan agreed in a lunchroom conversation that they would not want to be kept alive in the condition of some of the students they were serving, especially one 3-year-old who had the mental capacity of a newborn. The witnesses could not remember any specific, direct statements by Nancy, only her general agreement with the sentiments of the group. The trial judge found these statements sufficient to satisfy the ?clear and convincing? evidence standard, a questionable ruling in light of the rigorous standards imposed by the Missouri Supreme Court. However, the state did not appeal, and the opportunity was thus lost for further clarification of what type of prior statements would or would not meet those standards. Thus, Nancy Cruzan died, within months of a Supreme Court decision that, many assumed, would result in her life being sustained indefinitely.

The consequences of the Supreme Court?apos;s decision were immediate. First, in order to promote the use of ?living wills? and other forms of advance directives, Congress passed the Patient Self-Determination Act, requiring hospitals and other health care institutions to inquire, upon admission, whether a patient had executed such a document?and to provide information on how to do so.[28] Second, commentators also noted that five members of the Supreme Court?the dissenters, plus Justice O?Connor?had rejected any distinction between tube feeding and other forms of life-sustaining medical treatment, thus ?settling? any dispute on that issue.[29] Third, and perhaps most important, the ?clear and convincing? evidence standard evolved into a form of legal fiction. Far from requiring evidence commensurate with the standards of informed consent, the functional standard in PVS cases would be closer to that endorsed by the Cruzan dissenters. ?Some? evidence of patient intent, coupled with a presumption that most patients would choose not to live in this condition and a negation of any countervailing state interest in the preservation of life, would be sufficient to permit the cessation of feeding in such cases.[30]

**Schiavo: A Misuse of ?Autonomy??**

Nowhere was this functional standard more prominently on display than in the battle which ended with the death of Theresa Marie Schindler Schiavo on March 31, 2005. The atmospherics of that battle between Ms. Schiavo?apos;s husband and her parents may have led to the impression that the case established new legal principles and that the seven years of litigation (with more than 50 separate court decisions) was necessary to shape those principles. Neither impression is true. Cruzan was settled law by the time the Schiavo controversy arose; several months after Cruzan, the Florida Supreme Court ruled that a surrogate, armed with clear and convincing evidence of a patient?apos;s intent, could authorize the removal of life support (including tube feeding) from a permanently incompetent patient.[31] Schiavo was ultimately about the capacity of the legal system to fairly apply those principles where one party, in this case Ms. Schiavo?apos;s parents, claimed (among other points) that the evidence was not sufficient to meet the ?clear and convincing? standard.

The flawed decision of Pinellas County Circuit Court Judge George Greer set the stage for the ultimate result.[32] On February 11, 2000, Judge Greer found: (1) that Ms. Schiavo was in a
persistent vegetative state, and thus unable to state her preferences regarding continued medical treatment; (2) that her husband and court-appointed guardian, Michael Schiavo, was the appropriate person to act as her surrogate; and (3) that prior statements made by Ms. Schiavo to her husband and to members of her husband’s family constituted “clear and convincing” evidence that she would not want her life sustained in this condition.[33]

The decision was a mirror image of the second Missouri trial court decisions in *Cruzan*. The evidence adduced regarding Ms. Schiavo’s intent was, if anything, murkier than that presented in either phase of *Cruzan*: in reaction to the terminal illness of her mother and to watching an unidentified television program regarding the care of a severely brain-injured patient, she allegedly said that she would not want to be “kept alive on a machine,” or, if comatose, sustained by “tubes.”[34]

While plenty has been written about the competing, and ultimately irreconcilable “narratives” of the Schiavo case, it seems more fruitful to consider the legacy of both cases; in particular, whether the deaths of Nancy Cruzan and Terri Schiavo tell us as much about our attitudes toward those in a permanently incapacitated state as they do about the law’s purported protection of “patient autonomy.”

Prior commentators have noted the evidence suggesting that such “patient autonomy” may not be the overriding value influencing these decisions.[35] In *Schiavo*, the legal fiction of “patient autonomy” extended further: due to the dispute between family members, the court took it upon itself to determine the proper course of treatment for Ms. Schiavo, based on its own assessment of the facts and law.[36] This may explain why, in a little-noticed aspect of his February 2000 decision, Judge Greer cited testimony that the expressions of intent attributed to Ms. Schiavo were the type of expressions “made in those types of situations as would be expected by people in this country in that age group at that time. . . . "Hooked to a machine? means they do not want life artificially extended when there is no hope of improvement.”[37]

Did Judge Greer consider this as evidence that made it more likely that Ms. Schiavo made these statements? Or evidence that it was the type of a statement a “normal” person would make? The first court to review Judge Greer’s decision discounted this evidence, concluding that Judge Greer had made a proper “surrogate decision.”[38] Yet that court also seemed to load the dice when summarizing the central issue in the case:

In the final analysis, the difficult question . . . was whether Theresa Marie Schindler Schiavo, not after a few weeks in a coma, but after ten years in a persistent vegetative state that has robbed her of most of her cerebrum and all but the most instinctive of neurological functions, with no hope of a medical cure but with sufficient money and strength of body to live indefinitely, would choose to continue the constant nursing care and the supporting tubes in hopes that a miracle would somehow recreate her missing brain tissue, or whether she would wish to permit a natural death process to take its course and for her family members and loved ones to be free to continue their lives.[39]

The question, reminiscent of how the *Cruzan* dissenters framed the issue, virtually answers itself. If it needs to be posed in this fashion, why set the bar for evidence of the patient’s intent at the highest level in civil law? (This also was the point of the *Cruzan* dissents, but for reasons different
Moreover, if this indeed is the question, then the search for any prior statements that can be cobbled together to form impregnable evidence of the patient’s prior intent seems designed to satisfy a useful legal fiction: that it is the patient’s intent that is determinative and not the judgments of family members or others. The interests of patient and surrogate may well converge, particularly in regard to the care of a PVS patient. But they are distinct, and the presumption that they have been kept distinct by the device of requiring clear evidence of patient intent seems a dubious fiction. It is not honored in practice (as seen both in Cruzan and Schiavo) and is perhaps not even intended to be honored.

A Way Forward: Wrestling Neurological Fact from Legal Fiction?

The dilemma between potentially competing interests is the Gordian knot of surrogate decision-making. This dilemma is manifested daily in clinical settings and (fortunately) far more rarely in the courts. It is as likely to arise in cases where families demand treatment that may be considered futile or medically inappropriate as in cases where families ask for withdrawal of treatment. While an incapacitated patient’s prior statements may be relevant in such circumstances, they often do not speak to the specific circumstances at hand, and thus may be of limited guidance to the clinician. In most cases, such statements are most useful in ratifying, as opposed to dictating, the shared decision reached by physicians and family members that a particular treatment or means of life support should be employed or withheld.

The types of statements made by Nancy Cruzan and Terri Schiavo might best be seen in this light: they seemed to ratify, rather than determine, decisions reached by their surrogate decision-makers, years after the respective patients were diagnosed in PVS, that further efforts at sustaining life were futile, inappropriate, or contrary to letting the natural process of death take its course. Other surrogates, in thousands of cases, have made different decisions regarding their family members in PVS; are they in fact (or should they be) put to the burden of establishing, by clear and convincing evidence, that this is what their loved ones would want done? The commitment to preserving life in these myriad cases is no different from that expressed by the Schindlers for their daughter; it seems gratuitous (or worse) that the Schindlers and their supporters were and continue to be vilified for seeking to continue a course of treatment that is standard of care for comparable patients in medical facilities throughout the country.

The courts play an essential role when consensus cannot be reached, as in the tragic case of Ms. Schiavo. The Florida courts failed to see, however, that their adherence to the Cruzan paradigm opened them to legitimate charges of failing to secure due process for a patient whose family members (on both sides of the dispute) had potential conflicts of interest. The evidence of Ms. Schiavo’s prior statements would not have satisfied the standard of clear and convincing evidence in any other context; for this reason, and due to the intra-family dispute, the appointment of a guardian ad litem (GAL) to represent the patient’s exclusive interests would have been a judicious step. Two GALs were appointed early in the litigation, but their roles were limited and their appointments allowed to lapse once they reported to the court. The purpose of the much-maligned “Terri’s Law” passed by the Florida legislature (and later found unconstitutional by the Florida courts) was to have such a GAL appointed. The guardian appointed under this law urged in his report that the position continue to be filled until the end of
the case. The courts rejected the pleas of the Schindler family to have this done, just as they, in the end, forbade the family from even attempting to feed or hydrate Ms. Schiavo by mouth. It is far from certain that the presence of a permanent GAL would have led to a more prompt and less rancorous resolution of this dispute. However, an advocate for her exclusive interests would have had an authority to litigate and speak on her behalf that may have risen above the din of controversy the case engendered.

Looking forward, the legal paradigm expressed in *Cruzan* and *Guardianship of Schiavo* is not the only aspect worth revisiting. After the autopsy on Ms. Schiavo, pictures of her cranial scan were widely circulated (an oddity in this era of HIPAA compliance) and trumpeted as evidence that she was in a hopeless PVS. Cranial scans prove nothing of the sort; they may confirm the extent of traumatic brain injury, but the diagnosis of PVS itself remains a clinical one. No one doubted that Ms. Schiavo had suffered traumatic brain injury, and the scans circulated could not prove that she was incapable of any understanding or interaction with her environment.

Such issues take on greater urgency now that the phenomenon of neuroplasticity has supplanted the prior belief that various regions of the brain are ?hardwired? to perform functions exclusive to those of any other region. The recognition of neuroplasticity?specifically, the capacity of the brain and central nervous system to adapt to injury and even regenerate neurons?has opened up avenues of research and potential therapy unheard of in 1976, or even in 2005. Neuroscience now recognizes that traditional diagnostic tools (EEG) cannot rule out some level of cognitive awareness in patients diagnosed in a vegetative state. Furthermore, responsive brain activity (though not speech or movement) is possible in some patients with well-diagnosed PVS. (The misdiagnosis of PVS remains a separate problem).

We cannot know whether Nancy Cruzan or Terri Schiavo would be among the presently small class of PVS patients who can be ?reached? through advances in neuroscience. Nor is it clear, at the relatively early stage of these developments, whether the law ought to reach different conclusion regarding the right of surrogate decision-makers to authorize the withdrawal of life support. While the law may be settled, and the views of most biomedical ethicists clear (i.e., that there is no distinction between removing the various forms of life support) many in society view the cessation of feeding of an otherwise stable PVS patient as abandonment with the intent to cause death. Similar questions will arise regarding the treatment of patients dependent on a pacemaker; such devices can be rendered inoperable by the remote action of a technician. Will decisions to do so for incapacitated patients be justified by prior statements that they ?did not want to be kept alive by a machine?? Will the consensus that all forms of life support are ethnically fungible need to be revisited as medical technology continues to advance?

The future legacy of *Cruzan* and *Schiavo* thus remains unclear. The legal fictions they represent, even if useful to resolve courtroom controversies, do not inspire trust or belief as paradigms to guide good clinical decision-making. The dilemmas that professionals and society face in caring for the permanently incapacitated are unlikely to be resolved by the search for talismanic statements of prior intent that have occupied the courts. Surrogate decision-makers, whether appointed by the patient prior to incapacity, designated by operation of law, or acknowledged de facto, are increasingly recognized as a better instrument for taking decisions on behalf of the patient?superior even to a ?living will? executed by the patient. Ethical surrogates obviously would not ignore what they know of the patient?s values and preferences, nor would they regard
as having no value the continued life of the patient. They will, instead, struggle with the unavoidable question: ?Have we ?done enough? to care for and sustain this life?? This is a question to which *Cruzan* and *Schiavo* offer little resolution but to which a disciplined and compassionate approach to clinical ethics and an acceptance of our human ambivalence about death (and, hence, about decisions that may result in death) will likely hold the key.[48]

[1] *In re Quinlan*, 70 N.J. 10, 51 (1976) (stating assumption that Ms. Quinlan would die if her respirator were removed, and that her condition was deteriorating).


[3] Joy Hirsch (?Raising Consciousness,) *Journal of Clinical Investigation* 115, no. 5 (2005): 1102) estimated 15,000 U.S. patients in PVS, and 100,000 patients in ?minimally conscious state? [at the time of publication]. Joshua E. Perry, Larry R. Churchill, and Howard S. Kirshner, ?The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives,? *Annals of Internal Medicine* 143, no. 10 (2005): 744) estimated that there were 10,000 to 25,000 adults and 6,000 to 10,000 children in U.S. in PVS [at the time of publication].


[14] Id. at 417.

[15] Id.

[16] Id. at 418, 424-25.

[17] Id. at 419.

[18] Id. at 424.


[20] Id. at 283.


[23] Id. at 285-86.


[26] Id. at 345 (Stevens, J., dissenting).

[27] Id. at 323-26 (Brennan, J., dissenting); Id. at 348-350 (Stevens, J., dissenting).


[31] In re Guardianship of Browning, 568 So.2d 4 (Fla. 1990).

[32] For a fuller account, see, Destro, ?Learning Neuroscience the Hard Way,? 879-883, and O. Carter Snead, ?The (Surprising) Truth about Schiavo: A Defeat for the Cause of Autonomy,? Constitutional Commentary 22 (2005): 397-402. Among the unquestionable errors were not correctly spelling ?Quinlan,? and misstating the date of Karen Quinlan?s death by nine years?which was critical to his evaluation of and dismissal of certain testimony provided by the Schindlers regarding their daughter?s prior statements of intent.

[33] In re The Guardianship of Theresa Marie Schiavo, Pinellas County Cir. Ct., No. 90-2908GD-003 (Order dated February 11, 2000).

[34] Guardianship of Theresa Marie Schiavo, at 9.


[37] Guardianship of Theresa Marie Schiavo, 6.

[38] Schindler v. Schiavo, 780 So.2d 176, 179 (Fla.App. 2d Dist. 2001).


[44] Ibid., 853-858.


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