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The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives

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Although tragic, the plight of Terri Schiavo provides a valuable case study. The conflicts and misunderstandings surrounding her situation offer important lessons in medicine, law, and ethics. Despite media saturation and intense public interest, widespread confusion lingers regarding the diagnosis of persistent vegetative state, the judicial processes involved, and the appropriateness of the ethical framework used by those entrusted with Terri Schiavo's care. First, the authors review the current medical understanding of persistent vegetative state, including the requirements for patient examination, the differential diagnosis, and the practice guidelines of the American Academy of Neurology regarding artificial nutrition and hydration for patients with this diagnosis. Second, they examine the legal history, including the 2000 trial, the 2002 evidentiary hearing, and the subsequent appeals. The authors argue that the law did not fail Terri Schiavo, but produced the highest-quality evidence and provided the most judicial review of any end-of-life guardianship case in U.S. history. Third, they review alternative ethical frameworks for understanding the Terri Schiavo case and contend that the principle of respect for autonomy is paramount in this case and in similar cases. Far from being unusual, the manner in which Terri Schiavo's case was reviewed and the basis for the decision reflect a broad medical, legal, and ethical consensus. Greater clarity regarding the persistent vegetative state, less apprehension of the presumed mysteries of legal proceedings, and greater appreciation of the ethical principles at work are the chief benefits obtained from studying this provocative case.

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On 25 February 1990, Terri Schiavo, 26 years of age, collapsed in the hall of her apartment and experienced severe hypoxia for several minutes. She had not executed a living will or a durable power of attorney. Four months after her injury, Mrs. Schiavo was judged incompetent and her husband, Michael Schiavo, was appointed her legal guardian without objection from her parents, Robert and Mary Schindler. Because she was unable to swallow, Mrs. Schiavo underwent placement of a percutaneous endoscopic gastrostomy (PEG) tube. By late 1990, Mrs. Schiavo was determined to be in a persistent vegetative state.

UNDERSTANDING THE PERSISTENT VEGETATIVE STATE

The Schiavo case rests critically on the concept of the persistent vegetative state and the certainty of the prediction that a patient in this state will have no meaningful recovery. The persistent vegetative state is distinguished from several other states of reduced consciousness. Brain death implies the loss of not only all higher brain functions but also all brainstem functions, including pupillary light reflexes, reflex eye movements, respirations, and gag and corneal reflexes. Determination of brain death is straightforward and is generally accepted as a criterion for death. Coma is a complete state of unresponsiveness to stimuli, although the patient may have brainstem reflexes. Stupor and obtundation refer to states of reduced consciousness in which meaningful responses are still possible, if the patient receives enough stimulation. Finally, the "locked-in syndrome" denotes the condition of a patient who is paralyzed and cannot move or speak but is completely awake. Such patients can often communicate by blinking their eyes or looking up and down.

The American Academy of Neurology, along with representatives of the American Neurological Association, the Child Neurology Society, the American Association of Neurological Surgeons, and the American Academy of Pediatrics, set up a Multi-Society Task Force to establish criteria for diagnosing the persistent vegetative state. In 1994, the Task Force published its findings (1–3), which have been adopted as a practice guideline by the American Academy of Neurology. The Task Force estimated that 10 000 to 25 000 adults and 6000 to 10 000 children in the United States are in the persistent vegetative state. The criteria for this diagnosis must be met at least 1 year after traumatic brain injury in young patients and at least 3 months after nontraumatic illnesses.

The Task Force reviewed case series from the literature, which included 434 adults and 106 children with traumatic brain injury and 169 adults and 45 children with nontraumatic injuries, mostly related to hypoxia. Of the patients in the persistent vegetative state for more than 3 months after nontraumatic injuries, the probability of moderate disability or good recovery was 1% (99% CI, 0% to 4%), but for patients still in the persistent vegetative state at 6 months, this probability was 0%. No patient, even those with traumatic brain injury, has been reported to recover after a full year of being in the persistent vegetative state. Delayed recoveries after traumatic brain injury are more common than with nontraumatic brain injuries. Certainly, no patient has recovered after 15 years, the period during which Terri Schiavo survived in this state. The criteria make clear that the patient can have periods of sleep alternating with periods of an awake-like state, in

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Table 1. **Requirements for the Examination of Persistent Vegetative State***

No evidence of awareness of self or environment, no interaction with others
No meaningful response to stimuli
No receptive or expressive language
Return of sleep–wake cycles, arousal, even smiling, frowning, yawning
Preserved brainstem/hypothalamic autonomic functions to permit survival
Bowel and bladder incontinence
Variably preserved cranial nerve and spinal reflexes

* Reference 3.

which his or her eyes are open and may move about, and the patient may breathe, yawn, and open his or her mouth, but not interact meaningfully with others (**Table 1**).

The Task Force discussed several causes of the persistent vegetative state. After acute traumatic and nontraumatic brain injury, this state usually evolves out of an initial coma. In degenerative and metabolic disorders of the nervous system, the patient gradually sinks into this state. Severe developmental malformations of the central nervous system can produce the persistent vegetative state, but only in patients with anencephaly can this diagnosis be made before 3 months of observation. In all cases, the persistent vegetative state is a diagnosis based on observation over time. Diagnostic tests, such as computed tomography (CT) scanning or magnetic resonance imaging (MRI), can document the loss of much of the cerebral cortex (4, 5). Functional brain imaging methods, such as functional MRI, single-photon emission CT, and positron emission tomography scanning (6, 7), may show the cortex's lack of arousal to stimuli, but these tests are still investigational and have been validated only in small case series. In general, the position of the Task Force was that diagnostic tests "may support the dx of PVS [persistent vegetative state], but none adds to the diagnostic specificity with certainty" (3). This recommendation has not changed in the years since the publication of the Task Force guidelines. A related issue is the distinction between persistent and permanent vegetative states. In general, although a vegetative state can be diagnosed at 1 month after an acute brain injury or hypoxia, the permanent vegetative state can be diagnosed after 3 months in patients with nontraumatic brain injuries and after 12 months in patients with traumatic brain injuries. This renders the definition of permanent vegetative state identical to the definition given above for persistent vegetative state. The guidelines also state: "A PVS [persistent vegetative state] patient becomes permanently vegetative when the diagnosis of irreversibility can be established with a high degree of clinical certainty, i.e., when the chance of regaining consciousness is exceedingly rare" (3). A final provision of the American Academy of Neurology practice guidelines discusses the decision to withhold fluids and nutrition through a feeding tube (**Table 2**) (8).

THE LEGAL HISTORY AND COMMENTARY

Throughout the early 1990s, Michael Schiavo and the Schindlers worked together coordinating extensive rehabilitation efforts for Mrs. Schiavo, including regular and aggressive physical, occupational, and speech therapies. Despite their best efforts and explorations of all potentially viable treatments, her condition failed to improve.

By the mid-1990s, Mr. Schiavo's relationship with the Schindlers had chilled. Increasingly, Mr. Schiavo understood that his wife's condition was irreversible. In addition, he insisted that he knew his wife would not want to live in a persistent vegetative state. The Schindlers, however, insisted that Mrs. Schiavo be kept alive through artificial nutrition and hydration. Unable to reach a consensus with his wife's parents, Mr. Schiavo decided not to request withdrawal of the PEG tube. Instead, he petitioned the guardianship court "to function as the proxy" and asked the court "to make an independent determination of Mrs. Schiavo's terminal condition and to make the decision to continue or discontinue life-prolonging procedures" (9).

In January 2000, Judge George Greer held a trial to resolve the dispute over the extent of Terri Schiavo's neurologic devastation and to determine how she would exercise her right of privacy, or liberty interest, to forgo life-supporting medical treatment, if she were able to communicate. The proceeding was adversarial in nature, with both Mr. Schiavo and the Schindlers presenting witnesses and making arguments pursuant to the rules of evidence and civil procedure.

It is important to note that end-of-life guardianship controversies, such as those that emerged in this case, are resolved on the basis of state law, which varies throughout the United States. In Florida, both statutes and case law recognize the fundamental right of every individual to control his or her person, regardless of the capacity to communicate (10). In Terri Schiavo's case, where the inability to communicate directly was established and no written medical directive existed, Florida law considers previously made oral declarations, as long as they satisfy the standard of "clear and convincing evidence" (11).

At the 2000 trial, the opposing parties presented Judge Greer with Mrs. Schiavo's entire medical history, numerous exhibits, and the testimony of 18 witnesses, including the parties, 2 physicians, and various family members. On

Table 2. **American Academy of Neurology Practice Guidelines***

"The decision to discontinue fluid and nutrition should be made in the same manner as other medical treatment decisions"
"Artificial provision of nutrition and hydration is analogous to other forms of life-sustaining treatment, such as . . . a respirator"
"Administration of fluids and nutrition by medical means, such as a gastrostomy tube, is a medical procedure"
"Treatments which provide no benefit to the patient or the family may be discontinued. . . . Medical treatment provides no benefit to patients in a persistent vegetative state, once the diagnosis is established"

* Reference 8.

the first issue of her medical condition and whether Mrs. Schiavo had the ability or potential to communicate her wishes directly, the court found that she met the statutory definition of the persistent vegetative state and that there was no hope of her regaining consciousness or the ability to communicate (12). The court's analysis then shifted to the issue of exercising Mrs. Schiavo's autonomy rights, independently of state, family, or public opinion. After hearing from all of the witnesses and observing their cross examinations, Judge Greer determined that testimony from the 3 witnesses recalling Mrs. Schiavo's prior oral declarations that "she would not want to live like that" satisfied the clear-and-convincing evidence standard (12). Accordingly, the court ordered that the PEG tube be removed.

The Schindlers appealed Judge Greer's decision. The appellate court reviewed both the substantive evidence and procedural formalities at the 2000 trial and concluded that after 10 years in a persistent vegetative state with no hope of recovery, the ultimate issue was whether Mrs. Schiavo "would choose to continue the constant nursing care and the supporting tubes . . . or whether she would wish to permit a natural death process to take its course" (13). The appellate court affirmed Judge Greer's conclusion that the clear and convincing evidence required removal of the PEG tube.

Judge Greer ordered cessation of Terri Schiavo's artificial nutrition and hydration on 24 April 2001. Two days later, however, the treatment resumed when the Schindlers presented a different trial court judge with 7 affidavits from licensed physicians. Although none of the physicians had physically examined Mrs. Schiavo, each contended that she was neither in a persistent vegetative state nor beyond the aid of medical treatment. In 2002, after numerous legal proceedings, the Schindlers successfully convinced the appellate court "to permit discovery and conduct an evidentiary hearing only for the purpose of assessing Mrs. Schiavo's current medical condition, the nature of the new medical treatments described in the affidavits and their acceptance in the relevant scientific community . . ." (14).

At the 2002 hearing, again in the context of an adversary proceeding, Judge Greer heard testimony from 5 board-certified experts whose examinations of Mrs. Schiavo were videotaped. Mr. Schiavo's 2 experts, as well as the independent, court-appointed expert, were all neurologists who unanimously concluded that Mrs. Schiavo had irreversible neurologic damage and was undoubtedly in a persistent vegetative state. The Schindlers' experts, 1 radiologist and 1 neurologist, questioned whether Mrs. Schiavo was in such a state and advocated for the use of hyperbaric oxygen and vasodilation therapies.

Judge Greer found the Schindlers' experts unconvincing and their rehabilitation theories unsupported by the mainstream neurologic community. "Viewing all of the evidence as a whole, and acknowledging that medicine is not a precise science," the court found "the credible evidence overwhelmingly support[ed] the view that Terri Schiavo remain[ed] in a persistent vegetative state" (15). Accordingly, the court once again ordered the withdrawal of the feeding tube (15).

On appeal, Judge Greer's decision was again scrutinized for both procedural and substantive error. The appellate court affirmed Judge Greer's decision, emphasizing that the proceedings in 2000 and again in 2002 had been undertaken with care, objectivity, and according to "a cautious legal standard designed to promote the value of life" (16). In conclusion, the appellate court stated that the "value of life" could be adequately promoted "if all people are . . . entitled to a personalized decision about life-prolonging procedures" (16).

With Terri Schiavo's "personalized decision" determined at the 2000 trial and her medical condition conclusively confirmed at the 2002 hearing, artificial hydration and nutrition were stopped for the second time, on 15 October 2003, pursuant to court order. This order was superseded 6 days later when the Florida legislature passed and Governor Jeb Bush signed Terri's Law, which provided the governor unfettered discretion to order resumption of Mrs. Schiavo's medical treatment.

Eleven months later, the Florida Supreme Court held Terri's Law unconstitutional as a violation of separation of powers (17), and a third date was set for removal of the PEG tube. On 18 March 2005, the tube was removed for the final time, and despite the intervention of Congress and President George W. Bush, Terri Schiavo's saga ended with her death on 31 March 2005.

On 1 April 2005, an autopsy was performed, revealing that Mrs. Schiavo's brain was "grossly abnormal and weighed only 615 grams"—less than half of the expected weight for an adult her age—and showing neuronal loss in her occipital lobes consistent with cortical blindness (18). There was also extensive loss of neurons in the basal ganglia and in the hippocampus, and loss of Purkinje cells in the cerebellum. In short, the findings from the autopsy were fully consistent with the expectation of widespread, hypoxic–ischemic brain damage. In addition, the presence of an implanted thalamic stimulator explained why an MRI scan was never done.

In our opinion, the law did not fail Terri Schiavo. In fact, no end-of-life guardianship case in U.S. history has generated as much high-quality evidence, judicial attention, or legal scrutiny as the Terri Schiavo case. Throughout a lengthy trial and evidentiary hearing, countless motions, oral arguments, and numerous appeals to every available state and federal court, this case shows that the judicial process works at the end of life.

The Florida guardianship law was clear, and the law was followed. The judiciary was charged with 2 questions: 1) What was Terri Schiavo's medical condition? 2) In such a condition, what would she choose to do? In the midst of an intense and intractable family dispute, amid dizzying media attention and unprecedented political intervention,

the judicial process produced 2 answers. The process and the resulting answers were reviewed repeatedly by cautious, nonpartisan judges who demonstrated restraint and care in adjudicating Mrs. Schiavo's case pursuant to her individual liberty and privacy interests.

COMPETING ETHICAL FRAMEWORKS

Expressed as an ethical principle, the central focus in this case is respect for autonomy (19). Many have argued, however, that the proper moral framework is not autonomy at all, but rather sanctity of life, discrimination toward the disabled community, or the moral character of those empowered to decide. Examining these alternative frameworks is important, both to discern why respect for autonomy is the key ethical feature of this case and to display the weaknesses of the alternatives.

Several commentators argued that the central question of the Terri Schiavo case is a struggle between sanctity of life versus quality of life. For example, columnist David Brooks advanced this thesis, neatly dividing the contending parties into "social conservatives," who believe in the "intrinsic value" of all life and "social liberals," who emphasize "quality" (20). However, this rendering of the ethical issues is too neat, and it compounds descriptive vagueness with stereotypes, thus ensuring that the debate remains at the superficial level of moral slogans. Unless one adopts the position that sheer biological existence is what is sacred about human life, considerations of sanctity inevitably involve judgments of quality. More important, this dichotomous rendering of the issues begs the essential question of whose notion of "sanctity" and "quality" counts. By taking the autonomy and liberty interests of patients as the central question, the courts preserved the prerogative of individuals to decide according to their own values, even after they have lost the ability to speak for themselves.

Others felt passionately that discontinuing Terri Schiavo's artificial nutrition and hydration would initiate a cascading disregard for disabled persons or others who are judged to have poor quality of life (21). The fundamental flaw with this approach is overgeneralization. It is descriptively inaccurate to refer to a person in the persistent vegetative state as being disabled. For example, there are far more differences than similarities between Terri Schiavo and persons who have paralysis, such as the late Christopher Reeve. A related kind of overgeneralization is the idea that the action taken in the Terri Schiavo case has wide-ranging public policy implications. The wisdom of deciding this case within the moral framework of individual autonomy and liberty interests is that it portends nothing as a general policy for what should be done to and for other persons in the persistent vegetative state. In fact, stressing liberty as the fundamental issue means precisely that individuals will be able to choose for themselves and that a variety of differing living wills and legitimate proxy decisions can be honored.

Finally, some argued that Michael Schiavo should not be allowed a voice in decisions concerning his wife's treatment because over the 15-year period of caring for her, he developed a relationship with another woman. Those who espoused this perspective seemed ignorant of Mr. Schiavo's aggressive attempts to rehabilitate his wife during the 1990s. However, the more general flaw in reasoning here is an elementary one in ethics—seeking to discredit the person making the decision instead of considering the merits of the decision itself. The courts correctly avoided this ad hominem fallacy, although many media commentators did not.

Securing individual liberties and honoring self-determination for oneself and others were the impetus for the founding of the United States and have been a prominent part of the American sensibility ever since. However, protecting the liberty interests of those who have lost competence was not always the favored framework for either law or medical ethics (22). It has become so for both fields through a series of momentous court decisions and through changes in medical ethics that both prefigured the court decisions and became codified in the wake of them. For instance, the cases of Karen Ann Quinlan in 1976 (23), Paul Brophy in 1986 (24), and Nancy Cruzan in 1990 (25) all involved patients in the persistent vegetative state who did not have written advance directives. In each of these cases, the courts deemed the liberty and privacy interests of the patient as paramount.

Likewise, medical codes of ethics echo this legal consensus when they frame end-of-life issues in terms of autonomy and affirm the right of patients to informed consent and respect for their wishes, even beyond their loss of competence, when it can be reasonably determined what they would have wanted (26). Of course, to assert that respect for self-determination is paramount does not mean that it is the only principle at work in this and similar cases—it also does not mean that discerning someone's preferences for medical care from the accounts of others is simple or without problems. Rather, our claim is that using self-determination as the primary framework is simply the best we can do and is far less problematic than relying on medical or parental beneficence, quality of life, or sanctity-of-life judgments. Relying fundamentally on these other norms would jeopardize the rights of Terri Schiavo and patients like her to receive or not to receive continuing interventions and would threaten this basic principle of U.S. law and American medical ethics.

CONCLUSION

The Terri Schiavo case will probably remain controversial, with some people feeling strongly that the wrong decision was made. We have argued that, to the contrary, this case is an example of good standards and processes in medicine, law, and ethics. It exemplifies the use of medical consensus to create standards to diagnose persistent vege-

tative state, it is characterized by careful proceedings and review in keeping with a long tradition of legal procedure, and it embodies respect for self-determination as a fundamental U.S. principle that honors both individual preferences and a wide moral pluralism.

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