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Challenges & Lessons from the Terri Schiavo Case

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Hessel Bouma III



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In 1990, Terri Schiavo suffered severe brain injury yet lived fifteen years in a vegetative state dependent upon artificial hydration and nutrition. For more than seven years, Terri's husband and her family contested her condition, prognosis, and whether to withhold or continue her medical care through the court system, media, communities of faith, and the legislative and executive branches of the state and federal governments. An examination of medical, moral, religious, and legal aspects of withholding or withdrawing artificial hydration and nutrition suggests the judiciary branch acted responsibly in this tragic case. The Schiavo case challenges us to support more research into severe brain injuries, to prepare our Advance Directives appointing surrogate decision-makers and leaving clear and convincing evidence of our wishes should we be incapacitated, to affirm the lives and choices of persons with disabilities, and to address issues of fairness and justice in the allocations of medical technologies.¹

Under what circumstances, if any, might a person forego life-saving medical technologies?

The 1960s and 1970s saw a rapid rise in biomedical technologies including cardiopulmonary resuscitation, cardiac by-pass machines, ventilators, and organ transplantation. Dr. Lewis Thomas perceived these as “half-way technologies,” altogether too often failing to provide for a full recovery, instead leaving persons in diminished conditions, continually dependent upon technology and medicine.² In the midst of this biomedical revolution, many faith-based healthcare organizations—from hospitals to assisted living centers—adopted mission statements dedicated to saving and prolonging human lives without respect to financial costs, or the possibility that continued technological interventions might be perceived as prolonging dying.

These new technologies led to the rise of bioethics from distinctively Christian as well as secular perspectives. From the outset, scientific discoveries have led the way, often

far out in front of carefully considered bio-ethical responses, public policy, and legal decisions. Foremost among the many vexing questions was, “Under what circumstances, if any, might a person forego life-saving medical technologies?” Over ensuing decades, patients, families, healthcare practitioners and institutions have grappled with some very difficult cases about terminating life-sustaining medical treatments, while bio-ethicists, medical practitioners, the courts, and public policy have slowly and incrementally developed guiding principles and practices that are tested by new cases and further refined when deemed inadequate or unjust. The case of Theresa Schiavo provides such a test.

The Case of Theresa Schiavo³

Theresa (“Terri”) Marie Schindler was born in Pennsylvania, on December 3, 1963, to Robert and Mary Schindler; her family came to include a brother and sister. In the early 1980s, Terri moved to Florida, where she worked as an administrator in an insurance office. In November 1984, she married Michael Schiavo, a restaurant manager. According to the Terri Schiavo Foundation, she attended Catholic mass and maintained a close relationship with her immediate family.⁴

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On February 25, 1990, at age 26, Terri collapsed from cardiac arrest in her home and suffered brain damage due to lack of oxygen. The cardiac arrest was attributed to an imbalance of blood potassium, probably linked to an eating disorder (over 7–8 years, her weight had dropped from 250 lbs to 110 lbs). After several weeks, she emerged from a coma into a vegetative state requiring a percutaneous endoscopic gastrostomy (PEG) tube to provide her with nutrition and hydration but no assistance in breathing. She was transferred to a skilled care and rehabilitation facility, and a court appointed Michael Schiavo as Terri's guardian without objection from her parents. Terri received care in several different skilled care facilities. Michael Schiavo and the Schindlers also attempted to care for her at home for several weeks, and she was taken to California for an experimental implantation of a thalamic stimulator in her brain.

In 1992, Terri was awarded \$250,000 in an out-of-court malpractice settlement. A malpractice trial (a simple blood test that might have detected the potassium imbalance had not been performed at an earlier office visit) resulted in further compensation—\$750,000 placed in trust for Terri's medical care and \$300,000 to Michael Schiavo for loss of companionship. With attorneys' fees, the awards approximated \$1.7 million.

In February 1993, Michael and the Schindlers had a falling out on her course of treatment. Michael decided further treatments were unwarranted and authorized "do not resuscitate" orders. When the Schindlers sought medical information on their daughter, Michael denied them access. The Schindlers attempted to remove Michael as Terri's guardian, but the court dismissed the suit. In March 1994, an initial guardian ad litem reported that Michael had acted "appropriately and attentively" to Terri.

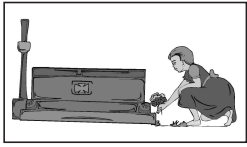
In May 1998, Michael asked the court to authorize removal of Terri's hydration and feeding tube. The Schindlers opposed the request, insisting that their daughter would want to remain alive in this condition. By year's end, a second guardian ad litem concluded Terri was in a persistent vegetative state (PVS) with no chance of improvement, but noted that Michael's decision-making might be influenced by the possibility of inheriting her estate. In the hearings and testimony before the circuit court, Michael Schiavo, his brother, and his brother's wife offered admitted hearsay that Terri had had conversations with them, following the deaths of several close family members, that she would never want to be placed upon artificial life support. While the initial guardian ad litem had expressed doubt about this testimony meeting the legal standard of "clear and convincing evidence" of her wishes, the local district court ultimately deemed that the nature of the testimony, while hearsay, was sufficiently credible and consistent to support its decision to discontinue artificial life support.

In February 2000, the local circuit court judge ruled the tube could be removed as consistent with her wishes. The Schindlers filed a petition asking the judge to permit a "swallowing test" to be performed on Terri to determine if she was capable of receiving nutrients on her own; the judge denied the petition but stayed his order until thirty days after the Schindlers exhausted all appeals. From January to April, the Schindlers and Michael Schiavo fired legal salvos against each other, appealing adverse decisions to higher courts including the Appellate Court, Florida Supreme Court, Federal District Court, and the United States Supreme Court. The trial court judge, upon the mandate of the Appellate Court, ordered Terri's hydration and feeding tube removed (clamped off) on April 24, 2001. Two days later, in response to an emergency motion from the Schindlers, a circuit court judge ordered the tube be reused.

Courts principally decide who should decide, not what the decision should be.

For two and one-half years, the Schindlers and Michael Schiavo continued their suits and countersuits throughout multiple levels of the judicial system before the District Court of Appeals ruled that Terri should be examined by five physicians, two to be chosen by the Schindlers, two by Michael Schiavo, and a fifth physician to be chosen by the court if the two parties could not mutually agree on that individual. On October 15, 2003, Terri's tube was removed on the orders of the circuit judge and the District Court of Appeals. On October 20 and 21, 2003, a special session of the Florida Legislature passed a bill, "Terri's Law," that allowed the governor to issue a "one-time stay in certain cases."⁵ Governor Jeb Bush issued an Executive Order directing reinsertion of the tube and appointing another guardian ad litem, Dr. Jay Wolfson, who also ultimately concluded that Terri was "in a persistent vegetative state with no chance of improvement."⁶

In September 2004, the Supreme Court of Florida issued a 7-0 declaration that the Florida law was unconstitutional, violating the separation of powers. From October into March, an incredible series of lawsuits were filed to continue Terri's PEG tube. These were dismissed at the local level, appealed to higher courts, and invariably rejected.⁷ Ultimately, Judge Greer ruled that on Friday, March 18, 2005, at 1:00 p.m., Michael Schiavo could have the PEG tube removed. As the date approached, the media began a crescendo that fostered prominent protests and matched the ongoing legal dissonance.



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On the weekend of Palm Sunday, March 20, 2005, Congress returned shortly after the start of their week-long Easter break for an emergency session to pass legislation authorizing federal courts to review the case; the President returned from his Texas ranch to sign the legislation. The legislation, written exclusively for Terri Schiavo's case, authorized the federal courts to review whether her rights had been or were being violated. If, upon review, it appeared that any of Terri's rights might have been violated, then the courts could order temporary injunctive relief authorizing reinsertion of the PEG tube to sustain her life while a full court review could take place. Over the next eight days, the federal appellate court in Atlanta and the U.S. Supreme Court refused further reviews, accepting the preceding seven-year judicial process as appropriate. On Thursday, March 31, 2005, Terri Schiavo died, nearly thirteen days after removal of her PEG tube. Even as she died, her parents and husband continued their legal battles over who would be present at her autopsy and where her cremated ashes would be interred.

On June 15, 2005, the medical examiner released his autopsy report. He concluded there was no evidence that Terri had suffered any trauma prior to her 1990 collapse or had had a heart attack or had been given harmful drugs or substances before her death. Rather, her brain had deteriorated to approximately one-half its normal size and, in his opinion, the damage was consistent with a clinical diagnosis of PVS, irreversible, and precluded her eating or drinking orally. Furthermore, the brain damage indicated she was blind.⁸

The case of Terri Schiavo is unique in many respects and carries troubling implications. Usually, courts become involved when the family of an incompetent person cannot achieve consensus on an appropriate course of action. Courts principally decide *who* should decide, not *what* the decision should be. Until this case, medical ethical decisions regarding incompetent patients have been resolved in the courts, not in the executive and legislative branches of government.

The case of Terri Schiavo was particularly confounded by two issues. First, the malpractice settlement, while modest in size and dwindling due to medical and legal costs,

stood to be inherited by Michael Schiavo as her husband, or perhaps by the Schindlers if Michael had divorced Terri. In response to this possibility, Michael offered to donate whatever remained of Terri's medical trust fund to charity. Second, Michael Schiavo began dating other women—with the Schindlers' blessings before any malpractice awards had been attained—and was and is engaged to be married to a woman who has borne two children with him.

Relevant Historical Developments

Until the late 1960s, death had been defined as the irreversible cessation of heart and respiration. The development of heart by-pass machines and artificial respirators coupled with the desire and ability to transplant organs necessitated a new definition of death. In 1968, it was proposed that death be defined as the irreversible loss of whole brain function.⁹ In remarkably short order, states adopted the new medical and legal definition of death.

In 1975, 21-year-old Karen Ann Quinlan suffered cardiopulmonary arrest following the ingestion of alcohol and prescription sedatives. Never regaining consciousness, she emerged from the coma to a state of wakefulness (arousal) without cognition and awareness, a condition newly defined as a persistent vegetative state (PVS).¹⁰ Gradually, as her parents came to perceive her ventilator as an extraordinary treatment, and her condition as hopeless, they sought permission from the courts to disconnect the respirator. The New Jersey Supreme Court concurred, and the ventilator was discontinued, though she continued to breathe on her own. She died in 1986 from extensive infections; in an effort to further our understanding of the condition of PVS, her parents authorized an autopsy and publication of the results.¹¹ The Quinlans never viewed their daughter's hydration and nutrition tube as an extraordinary treatment.

In 1977, a 67-year-old, profoundly mentally-impaired (reportedly IQ = 10) man named Joseph Saikewicz was diagnosed with leukemia. A court-appointed guardian advised against chemotherapy; the probate and appellate courts of Massachusetts agreed. They reasoned that incompetent

patients should not be denied a right to refuse treatment and clarified the standard of substituted judgment to include the present and future incompetence of the individual—a “best interests standard” imagining what the incompetent patient would consider in his best interests under these conditions.

Medical practice and the courts have tended to move slowly, deliberately, and incrementally in establishing new, acceptable practices under unusual circumstances.

In 1986, the Supreme Court of Massachusetts, in a 4-3 decision, authorized removal of the hydration and nutrition tube sustaining the life of Paul Brophy. A firefighter and emergency medical technician, Brophy had suffered a brain aneurysm three years earlier at age 46 and lapsed into a PVS. Brophy had once been awarded a medal for rescuing a man from a burning fire, an award he subsequently pitched upon learning that the man had never regained consciousness before dying several months later. He told friends and family that he would never want to be sustained like that. Mrs. Brophy, their five adult children and his seven siblings all concurred in the decision to remove the hydration and nutrition tube. Paul Brophy died eight days later, a dying described as “extremely peaceful.”

In 1983, Nancy Cruzan was seriously injured in a one-automobile accident in Missouri. In PVS, her parents sought to have her hydration and nutrition tube removed over the objections of the healthcare institution and the state. The probate court judge, while agreeing with the Cruzans, requested an appeal directly to the Missouri Supreme Court that overturned the decision. In 1990, the U.S. Supreme Court rendered an ambivalent 5-4 decision that a hydration and nutrition tube could be removed from an incompetent patient if there was “clear and convincing evidence” that this was what the patient would desire. No such evidence had been presented of Nancy’s wishes. That fall, sufficiently clear and convincing evidence of Nancy’s wishes was provided to the probate court, her hydration and nutrition tube was removed, and Nancy died a peaceful death twelve days later.¹² Concurrently, the U.S. Congress passed the Patient Self-Determination Act (PSDA), legislation encouraging people to compose

Advance Directives leaving clear and convincing evidence of their wishes for medical care and surrogate decision-makers in the event they are incapacitated.

More recently, two cases requesting authorization to remove hydration and nutrition tubes of severely neurologically impaired individuals *not* in PVS were refused by state courts. In Michigan, a car-train accident left Michael Martin, age 36, in a “locked-in condition.” Five years later, his wife requested removal of the hydration and nutrition tube as being consistent with his unwritten wishes and how he lived his life. Michael’s sister and mother objected. The local court and Appeals Court agreed with his wife, but the Michigan Supreme Court in a 6-1 decision overturned the lower court decision; the U.S. Supreme Court refused to hear the case. Mr. Martin died several years later when the tube inadvertently came out, and no one insisted upon its reinsertion.

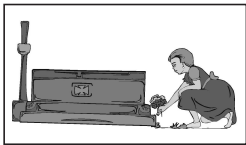
In California, Robert Wendland, age 42, was injured in a truck accident which left him “minimally conscious.” Two years later, his wife, sister, and daughter requested removal of his hydration and feeding tube; his mother disagreed. Six years later, he died of pneumonia, one month before the California Supreme Court unanimously ruled against discontinuation of his hydration and feeding tube.¹³

These key cases reflect that medical practice and the courts have tended to move slowly, deliberately, and incrementally in establishing new, acceptable practices under unusual circumstances. A careful reading of the records would not support the sense that these decisions have been precipitous or a headlong rush down a slippery slope.¹⁴

Three Altered Neurological States: Coma, PVS, and MCS

Severe brain trauma short of death typically produces a coma—complete loss of consciousness lasting for at least one hour. In a coma, the individual’s eyes remain closed and they cannot be aroused.

In the mid-1990s, a medical task force on PVS reported its findings, and numerous medical organizations soon followed with guidelines for the diagnosis and treatment of individuals in PVS.¹⁵ The PVS is characterized by (1) a complete unawareness of the self and the environment, (2) sleep-wake cycles, (3) either complete or partial preservation of hypothalamic and brain stem function, (4) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli, (5) no evidence of language comprehension or expression, (6) bowel and urinary incontinence, and (7) variably preserved cranial-nerve and spinal reflexes. The original Task Force was willing to declare a patient in PVS if they were still in a vegetative state one month after an acute traumatic or nontraumatic brain injury or lasting



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for at least one month in patients with degenerative, metabolic disorders or developmental malformations. Others have suggested holding off with the designation of PVS until an individual has been vegetative for at least twelve months.¹⁶

The diagnosis of PVS is complex and not strictly objective since the presence or absence of consciousness can only be inferred. Diagnosis is based upon (1) the presence of reflexes characteristic of subcortical functioning rather than learned voluntary responses, and (2) laboratory tests consisting of a combination of EEG with CT-scans and MRI¹⁷ revealing lesions so numerous, severe, and/or diffuse to make awareness highly improbable, and PET-scans¹⁸ determining the extent to which metabolism and/or cerebral blood flow is reduced. From 10,000 to 25,000 individuals are estimated to be in PVS at any given time in the United States.¹⁹ Recovery from PVS is unlikely after one year, with both the likelihood and the degree of recovery diminishing as length of time in PVS increases.²⁰ While there are widespread stories of individuals regaining full or nearly full functioning after extended time in “comas” or “PVS,” members of the Multi-Society Task Force on PVS investigated these cases and found no more than anecdotal evidence.²¹

Individuals in PVS raise a significant existential question. Is someone in PVS still a person, or is the capacity for neurological functioning, at least to the extent of awareness, an essential character necessary for someone to be a person? Quite frequently, loved ones of someone in PVS gradually, over time, come to refer to their loved one in the passive tense: “This was my daughter.” Within the Judeo-Christian faith traditions, one of the primary ways in which we image God is relational—through our four-fold, bi-directional relationships with God, self, others, and creation.²² Robert Wennberg, Christian philosopher and ordained Presbyterian minister concludes:

What is of special value about human life is personal consciousness, which makes it possible for the individual to participate in God’s creative and redemptive purposes for human beings; biological human life is valuable because it sustains and makes possible personal consciousness, but where

there is only biological or somatic human life, that special value no longer attaches to the individual, and biological or somatic death may be allowed to proceed unimpeded.²³

The individual in PVS, if it is irreversible, has irreversibly lost the capacity for these bi-directional relationships. Sustained with artificial hydration and feeding, they can be the recipient of God’s care, our care, and impacted by nature, but they are unable to relate to us or nature, and it is difficult for us to imagine how they can relate to God. Of course, we do not know with absolute certainty when individuals are in irreversible PVS until they die, yet we must face key biomedical decisions with the vague prognosis of “unlikely to recover.” The gospel writers record Jesus’s words of immense hope, “... with God all things are possible” (Matt. 19:26, Mark 10:27, and Luke 18:27). May Christians, who believe in miracles and in an omnipotent and loving God, continue to pray for God’s miraculous intervention even while deciding to withhold or withdraw life-sustaining medical treatments?

More recently, a multi-society task force of neurologists sought to define—based on consensus guidelines rather than evidence—a “minimally conscious state” (MCS) for the 112,000 to 280,000 persons with severe brain injury not quite in PVS.²⁴ In the MCS, patients have partial consciousness; sleep/wake cycles; sufficient motor function to localize noxious stimuli, reach for objects, hold or touch objects in accordance with shape, and automatic movements such as scratching; localized sound location; sustained visual pursuit; inconsistent but intelligible verbalization or gesture; and contingent smiling or crying. Persons emerging from MCS show gradually greater and dependable functionality.

A significant majority of the physician consultants who examined Terri and reviewed her medical records, and judges who reviewed the testimony and records, concluded that she was in PVS.²⁵ The biomedical evidence suggests that someone in PVS is incapable of suffering. Furthermore, the majority of the judges who heard and reviewed the evidence accepted the assertion that she would not want to be sustained in this condition. Despite all this, the Schindlers with the support of many reli-

gious, Right-to-Life and disability groups disputed the diagnosis of PVS and believed she retained some capability for recovery if she was given additional rehabilitation and treatment. They insisted that Terri would want to be sustained as she was and that by removing the PEG tube, they would be killing her, and she would die a gruesome death by dehydration and starvation.

Removing Artificial Hydration and Nutrition

When a person sustains sickness or trauma, the body's natural response is to shut down the digestive processes and diminish or even kill the person's appetite for food. Before the advent of hydration and tube feedings, recovery from major sickness or trauma was impeded by the lack of adequate nutrition, yet such individuals did not sustain additional suffering because they had lost their appetite and were not hungry. Deprivation of water, however, does quickly lead to dehydration, dementia, and suffering in a fully conscious person.

With the development of intravenous, nasogastric, and PEG tubes, it became feasible to provide both nutrition and hydration independent of appetite, allowing persons adequate nutrition and hydration to recover from sickness and accidental or surgical trauma. Some persons—with advanced Alzheimers, amyotrophic lateral sclerosis (ALS) or cancer—who formerly died gradually and naturally yet comfortably with minimal suffering as their ability and desire to eat waned could now be sustained. Until the technology of hydration and nutrition tubes was developed, persons with severe neurological trauma did not survive long enough to enter PVS. Is there an obligation to provide hydration and nutrition through tube feedings under any and all circumstances, or are there instances in which it is permissible to withhold or withdraw them?

As the Terri Schiavo case demonstrates, the withholding or withdrawing of hydration and feeding tubes can be a most vexing and divisive ethical decision. On the one hand, food and water are so basic to life. We may not deprive people of access to food and water; to do so constitutes abuse and, if they die as a consequence, does it not constitute murder? Scripture lends support for this position. As Christians, we are called to defend the weak, the sick, and the powerless. In the Christian tradition, it is Jesus Christ who reminds us that when we see someone who is hungry, we are to give them food, and someone who is thirsty, we are to give them drink (Matt. 26: 31-46). We can and may rejoice when hydration and feeding tubes lead to healing or sustaining human life.

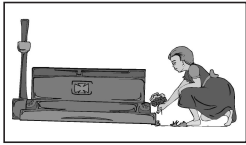
On the other hand, food and water through intravenous lines, nasogastric tubes, or PEG tubes are artificial or unnatural, mechanical, medical treatments. They can be invasive to our bodily integrity, as alien as ventilators that

force breathing. Artificial hydration and nutrition tubes sometimes may be perceived more as prolonging dying than sustaining living. When artificial hydration and nutrition tubes do not lead to healing but sustain suffering in a conscious person's life or simply sustain life in an unconscious person, does it not leave these persons enslaved to invasive medical technology? May the conscious person not choose to forego the treatment? May family and friends not choose also for their unconscious loved one to be freed from the invasive treatment?

Unlike physician-assisted suicide and voluntary or involuntary euthanasia, the act of removing artificial hydration and feeding tubes does not intend death nor is it the primary cause of death.

In societies in which it is feasible to provide artificially hydration and nutrition (and many of the societies of our world cannot), it is most important to offer hydration and nutrition tubes, but respect for each patient's bodily integrity must allow him or her the freedom to choose to forego this treatment. Allowing persons and their surrogate decision-makers to withhold or withdraw artificial hydration and nutrition also can be seen as consistent with Christian values. Life is a good, but not an absolute good that must be sustained under any and all circumstances; to insist upon that is to make human life a god.²⁶ In the Christian tradition, "God's cause includes life, human flourishing, and embodied integrity ..." God's cause is "life, not death; health, not sickness; freedom, not bondage; care, not condemnation."²⁷

With patients in PVS, removing artificial hydration and feeding tubes does not result in the patient's suffering as they lack the neurological capacity to perceive and process pain and suffering. Unlike physician-assisted suicide and voluntary or involuntary euthanasia, the act of removing artificial hydration and feeding tubes does not intend death nor is it the primary cause of death. Rather, it accepts that death is the likely outcome and allows death to occur without further invasion of bodily integrity, a death that surely would have occurred after the initial neurological trauma leading to PVS had artificial hydration and nutrition not been instituted in the first place. In the one to two weeks it typically takes for the individual's organs to decline due to dehydration and chemical imbal-



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ances, there remains the opportunity for divine intervention, compassionate care, and loving, supportive family and friends to bid their sad final farewells while thanking God for the life of their loved one. Good, compassionate care, even as a patient in PVS is dying (basic hospice or palliative care) provides ice chips for the patient's mouth, eye drops for the eyes, and moist cloths for exposed skin. Healthcare practitioners, family members and friends of someone in PVS dying after the removal of artificial hydration and nutrition almost invariably report that their dying, while sad, was very peaceful.

Lessons

First, given the many confounding factors present in the Schiavo case, it is unlikely to set much if any new legal precedent. Particularly troubling, however, is the unprecedented involvement of the more political legislative and executive branches of state and federal governments in an individual case. There are adequate checks and balances in the levels of the judicial system, and courts have not acted precipitously or hastily. That the healthcare system and Michael Schiavo sustained care for Terri in PVS for more than fifteen years, the last seven of them as her case slowly progressed through the appropriate courts reflects considerable caution and patience. The Florida Supreme Court decision declaring "Terri's Law" unconstitutional and the refusal of the federal appellate court and U.S. Supreme Court to further review the case appear to uphold this practice.²⁸

The legislative and executive branches of state and federal governments do have important roles to fulfill in setting policies affecting end-of-life care. Society would be well served if Congress and the executive branch would address the many inequities in the U.S. healthcare system including assuring a basic minimum of healthcare for persons who are uninsured or underinsured, funding Medicaid and Medicare at levels that adequately cover actual expenses, and setting standards for Advance Directives that would assure their legal recognition throughout the entire country. As Stephen Lammers noted: "One cannot demand that Schiavo and others in her condition be treated while cutting funding for health care." He also noted the irony that Terri's

long-term care was achieved through a combination of a sizeable malpractice settlement and government healthcare programs, and legislators who were arguing to sustain her life were also seeking to limit the size of malpractice settlements or cutting funding for aspects of Medicare and Medicaid.²⁹

Second, there remains a profound need for more neurological research in brain trauma, PVS, and MCS. Can we develop better diagnostic techniques to distinguish those patients who are comatose or vegetative but showing a likelihood of recovery from those who are unlikely to recover? Such research may enable our diagnoses and prognoses to be more objective.³⁰ Here, too, Congress and the executive branch can promote additional biomedical research into PVS and MCS.

Third, we need to encourage everyone to develop an Advance Directive³¹ which designates one's preferred surrogate decision-maker (or Durable Power of Attorney for Healthcare Decisions) and what kinds of treatments one would want or not want in the event one is incapacitated. For Christians, this is an opportunity to express our Christian values about our own living and dying, recognizing that death, while still an enemy, is a conquered enemy and acknowledging that God is sovereign over life and death. Ideally, the surrogate decision-maker knows the person and the person's values well, and is willing and able to make healthcare decisions in a manner consistent not with the surrogate decision-maker's values but the values of the person who is now incapacitated and incompetent. In the absence of an Advance Directive specifying a designated surrogate decision-maker, most states turn, in descending order of priority, to (a) the spouse, (b) an adult son or daughter, (c) either parent, or (d) an adult brother or sister, or they may appoint an unrelated surrogate-decisionmaker.

If there was a single point in time when the Schindlers lost their case for sustaining their daughter's life, it was when her husband of five years, Michael Schiavo, was appointed her guardian at his request, consistent with the laws of the state of Florida, and with the support of the Schindlers. As more and more families are dysfunctional or spread out geographically, and couples of

the opposite or same sex live in a close but non-marital relationship together, it is increasingly difficult to ascertain who might be the best surrogate decision-maker for a patient. When couples enter into the covenant of marriage, just when does a spouse become a better surrogate decision-maker than the parents and family?

The 1990 Patient Self Determination Act requires all healthcare professionals and institutions in the United States to provide assistance in making an Advance Directive. Despite these provisions for more than a decade, the majority of Americans still do not have an Advance Directive. Advance Directives, while potentially very helpful, are not cure-alls. To be effective, they need to be shared with closest family and friends, and reviewed regularly, particularly as life changes. And while an Advance Directive in Terri's situation could have made her wishes as clear and convincing as possible, its legitimacy could still have been tested in the courts. Christians should prepare Advance Directives to make clear their wishes consistent with their Christian values regarding life and death.³² To do so is a profound act of love, easing some of the burden of these decisions from loved ones when tragedy strikes. With good communication about our Advance Directives, our dying is much more likely to be private, peaceful, with dignity, and not public court battles.

Fourth, we need to constantly reassure persons with disabilities through words and actions that they are valued and their wishes for medical treatment to be administered or withheld or withdrawn will be honored. Honoring Terri Schiavo's wishes under these circumstances need not be and ought not be a cause for fear that we are descending a precipitous slippery slope leading to involuntary euthanasia for persons with disabilities. At the same time, it is likely that one of the next morally vexing end-of-life issues will be whether we may remove artificial hydration and nutrition from individuals in MCS in the absence of clear and convincing written evidence, such as has been rejected by state Supreme Courts in Michigan with Michael Martin and California with Robert Wendland. But what these cases seem to foretell is that it is likely to be a very slow — appropriately so — process.

Fifth, the Christian community as well as society as a whole need to engage in the difficult conversations about fairness and justice in the allocations of resources including medical technologies. Most of the leading causes of human morbidity and mortality in the world today are preventable or treatable, many at only modest expense by U.S. standards, if only we had the appropriate resolve. A Christian "culture of life" will not rest until it has pursued fairness and justice for all our neighbors. ♦

Notes

¹An abbreviated version of this paper was presented as "Medical Ethics & Neurosciences at the End of Life: Lessons from the Terri Schindler-Schiavo Case" in the Medical Bioethics Symposium at the 59th Annual Meeting of the American Scientific Affiliation, Trinity Western University, Langley, British Columbia, July 24, 2004. The paper includes additional developments through June 16, 2005.

²Lewis Thomas, "The Technology of Medicine," *New England Journal of Medicine* 285, no. 24 (1971): 1366-8. Also reprinted in Lewis Thomas, *The Lives of a Cell: Notes of a Biology Watcher* (New York: The Viking Press, 1974), 31-7.

³The case story through 2003 is assembled from Thomas Fields-Meyer, "Who Decides?" *People* 60, no. 19 (2003): 80-2; Cathy Lynn Grossman, "'Tricky Business' in a Life-and-Death Debate," *USA Today* (October 23, 2003), p. 6D; Richard Jerome, "What to Do About Terri," *People* 53, no. 6 (2000): 77-8; Claudia Wallis, "The Twilight Zone of Consciousness," *Time* 162, no. 17 (2003): 43-4; and Richard Willing, Anita Manning, and Deborah Sharp, "Florida Case Raises Hard End-of-Life Questions: Unique Legal, Medical Issues Surround Schiavo," *USA Today* (October 23, 2003), 1A-2A. For an extensive timeline of the events and links to key legal documents, see www.miami.edu/ethics2/schiavo/timeline.htm; last accessed: June 15, 2005.

⁴Terri Schindler-Schiavo Foundation, www.terrisfight.org; last accessed: May 17, 2005; as of June 16, 2005, the site is under reconstruction to undertake a new mission in the memory of Terri Schiavo. The Foundation stated it is operated by "a group of volunteers dedicated to protecting the life and liberty of a disabled woman." As an advocacy group, its portrayal of events in Terri's case were not without bias, appearing to be most consistent with the views of Robert and Mary Schindler.

⁵For the text of the law, see http://election.dos.state.fl.us/laws/03laws/ch_2003-418.pdf. Note that the law appoints a guardian ad litem to report not only to the court, but also the governor, and for the law to apply, the court must have found the patient to be in PVS.

⁶Dr. Wolfson's remarkable report is accessible at www.miami.edu/ethics2/schiavo/wolfson%27s%20report.pdf; last accessed: June 16, 2005.

⁷An appeal by the Governor and the Schindlers of the Supreme Court of Florida ruling was subsequently rejected as well. At one point, the Schindlers sought another trial predicated upon a new argument that Terri would want to be kept alive in this condition since she was Catholic and last March, Pope John Paul II said that people in vegetative states have a right to health care and nutrition. Attorneys for Michael Schiavo contended that Terri was not a practicing Catholic and that her religious beliefs had been taken into account in earlier decisions.

⁸Abby Goodnough, "Schiavo Autopsy Says Brain Was Untreatable," *New York Times* (June 16, 2005), A1 & A5; in an unprecedented move, but to refute numerous allegations, Michael Schiavo authorized the public release of Terri Schiavo's autopsy report at <http://news.findlaw.com/nytimes/docs/schiavo/61305autopsyrpt.pdf>; last accessed: June 16, 2005.

⁹"A Definition of Irreversible Coma. Report of the Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death," *Journal of the American Medical Association* 205, no. 6 (1968): 337-40.

¹⁰B. Jennett and F. Plum, "Persistent Vegetative State After Brain Damage. A Syndrome in Search of a Name," *Lancet* 1 (1972): 734-7.

¹¹Hannah C. Kinney, Julius Korein, Ashok Panigrahy, Pieter Dikkes, and Robert Goode, "Neuropathological Findings in the Brain of Karen Ann Quinlan—The Role of the Thalamus in the Persistent Vegetative State," *New England Journal of Medicine* 330, no. 21 (1994): 1469-75.

¹²Much has been made and written of the Nancy Cruzan case. For an extraordinary, in-depth look at the personal, familial, legal, and political dimensions of the case, see the *Frontline* episode, "The Death of Nancy Cruzan," which aired on 24 March 1992, or the book written by the Cruzan's attorney throughout their ordeal, William H. Colby, *Long Goodbye: The Deaths of Nancy Cruzan* (Carlsbad, CA: Hay House, Inc., 2002).

¹³Bernard Lo, Laurie Dornbrand, Leslie E. Wolf, and Michelle Groman, "The Wendland Case—Withdrawing Life Support from Incompetent Patients Who Are Not Terminally Ill," *New England Journal of Medicine* 346, no. 19 (2002): 1489–93.

¹⁴The situation described pertains to adults. The situation for children is somewhat different, partially decided by the courts with levels of interventions having been mandated by Presidential order under the Department of Health and Human Services, subsequently tested in the courts, and ultimately legislated by Congress in the Child Abuse Amendments of 1984. For an excellent review of these developments and their present standing, see John A. Robertson, "Extreme Prematurity and Parental Rights After *Baby Doe*," *Hastings Center Report* 34, no. 4 (2004): 32–9.

¹⁵Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State," *New England Journal of Medicine* 330, no. 21 (1994): 1499–1508, and 330, no. 22 (1994): 1572–79.

¹⁶J. Hume Adams, D. I. Graham, and Bryan Jennett, "The Neuropathology of the Vegetative State After an Acute Brain Insult," *Brain* 123 (2000): 1327–38.

¹⁷Andreas Kampfl, Gerhard Franz, Franz Aichner, et al., "The Persistent Vegetative State After Closed Head Injury: Clinical and Magnetic Resonance Imaging Findings in 42 Patients," *Journal of Neurosurgery* 88 (1998): 809–16.

¹⁸Nicholas D. Schiff, Urs Ribary, Diana Rodriguez Moreno, et al., "Residual Cerebral Activity and Behavioural Fragments Can Remain in the Persistently Vegetative Brain," *Brain* 125 (2002): 1210–34.

¹⁹Hannah C. Kinney and Martin A. Samuels, "Neuropathology of the Persistent Vegetative State: A Review," *Journal of Neuro-pathology and Experimental Neurology* 53, no. 6 (1994): 548–58.

²⁰See A. Kampfl, E. Schmutzhard, G. Franz, et al., "Prediction of Recovery from Post-traumatic Vegetative State with Cerebral Magnetic-imaging," *Lancet* 351 (1998): 1763–7. The study followed 80 adult patients with closed-head injury. After twelve months, 42 were in PVS and 38 were showing some signs of recovery. Of those showing signs of recovery, clinical evaluations had detected the signs of recovery for 62% of the patients at three months, and 96% of patients at six months.

²¹The case of Gary Dockery illustrates the problem. A Tennessee policeman, he was shot in the head in 1988 and was seriously neurologically impaired. Seven and one-half years later, as pneumonia set in, he suddenly began talking for eighteen hours, recalling names and events from before his injury. He was sedated for surgery but never regained consciousness after surgery, and died fourteen months later. Neurologists emphatically insisted he had not been in PVS but probably had been "minimally conscious." Seriously misleading headlines fueled the public's misconceptions and myths: Melina Beck and Vern E. Smith, "To Him It Was Still 1988: The 'Coma Cop' Wakens," *Newsweek* (26 February 1996): 56; and "Officer Who Emerged from Long Coma Dies," *New York Times* (15 April 1997), Section A, p. 21. A recent news article states: "Dr. Bernat [a member of the Multi-Society Task Force on PVS] said his 1994 panel looked into more than 70 'alleged late recoverers' and found that 'there wasn't a single one that was verified, so I'm very skeptical.'" Donald G. McNeil, Jr., "In Feeding-Tube Case, Many Neurologists Back Courts," *New York Times* (26 October 2003), Section 1, p. 18. More recently, the case of Donald Herbert, a Buffalo, New York, firefighter seriously brain injured in 1995, raised similar concerns. He emerged from a coma to progress to what is probably the minimally conscious state, and then dramatically began speaking coherently for fourteen hours. Several media reports erroneously reported he had emerged from a coma, but

most made a special effort to point out that he had been in MCS rather than PVS, and that his situation differed from that of Terri Schiavo.

²²Hessel Bouma III, Douglas Diekema, Edward Langerak, Theodore Rottman, and Allen Verhey, *Christian Faith, Health, & Medical Practice* (Grand Rapids, MI: Eerdmans, 1989), 33.

²³Robert N. Wennberg, *Terminal Choices: Euthanasia, Suicide, and the Right to Die* (Grand Rapids, MI: Eerdmans, 1989), 176.

²⁴J. T. Giacino, S. Ashwal, N. Childs, et al., "The Minimally Conscious State: Definition and Diagnostic Criteria," *Neurology* 58 (2002): 349–53; James L. Barnett, "Questions Remaining About the Minimally Conscious State," *Neurology* 58 (2002): 337–8. For an intriguing account of someone who seems to be emerging from his minimally conscious state, see Carl Zimmer, "What If There Is Something Going On in There?" *New York Times* (28 September 2003), Section 6: 52–6.

²⁵For a thorough accounting, see the report of Jay Wolfson, Guardian ad Litem at www.miami.edu/ethics2/schiavo/timeline.htm as an entry under 1 December 2003; last accessed: May 17, 2005. Note, too, that for "Terri's Law" to apply to her, it had to be acknowledged that she was in PVS; Governor Bush's Executive Order acknowledged the PVS diagnosis.

²⁶Allen Verhey, "Taking Sides for Schiavo: Necessary Decisions," *Christian Century* 122, no. 8 (2005): 9–10.

²⁷Bouma III, et al., *Christian Faith, Health, & Medical Practice*, 21.

²⁸For a thoughtful secular analysis from the perspective of a prominent healthcare law professor, see George J. Annas, "'Culture of Life' Politics at the Bedside—The Case of Terri Schiavo," *New England Journal of Medicine* 352, no. 16 (2005): 1710–5.

²⁹Stephen E. Lammers, "Schiavo and the Health Care System: What Wasn't Discussed," *Christian Century* 122, no. 8 (2005): 11.

³⁰First, the call for additional research includes the NIH Consensus Development Panel on Rehabilitation of Persons With Traumatic Brain Injury, "Rehabilitation of Persons With Traumatic Brain Injury," *Journal of the American Medical Association*, 282, no. 10 (1999): 974–83. Second, much of the sorely needed research would have minimal risk (and probably marginal benefits to most patients undergoing the research but considerable potential benefit to future patients, their families and society) and could be done with the abundance of patients in PVS and MCS if their surrogate decision-makers approved. Third, some significant preliminary work has and is being done.

³¹A model Advance Directive called "Five Wishes" is available at www.agingwithdignity.com. This Advance Directive, legally recognized in 35 states and the District of Columbia, encourages the individual to identify (1) the person he or she wants to make medical care decisions when the individual cannot, (2) the kind of medical treatment the individuals wants or does not want, (3) how comfortable the individual wants to be, (4) how the individual want people to treat him or her, and (5) what the individual wants his or her loved ones to know.

³²To consider some thoughtful positions by Christians on the issues of withholding and withdrawing medical treatments, see, for example, Chapter 10 on "Death and Covenantal Caring" in Bouma III, et al., *Christian Faith, Health, & Medical Practice*, 268–307; The authors carefully develop four end-of-life principles for Christians: (1) A Christian need not regard the mere prolongation of biological life as intrinsically beneficial; (2) A Christian need not strive to endure irremediable and intense suffering when it eclipses the good of relationships with God, self, and others; (3) Christians should not be devastated by the state of dependency that sometimes characterizes sickness and dying; and (4) End-care decisions Christians make for themselves must not be grounded exclusively in how these decisions affect them personally. See also, chapter 5 on "Passive Euthanasia" and chapter 6 on "The Permanently Unconscious Patient" in Robert N. Wennberg, *Terminal Choices: Euthanasia, Suicide, and the Right to Die* (Grand Rapids, MI: Eerdmans, 1989), 108–77.