
Affirming the right to care, preserving the right to die: Disorders of consciousness and neuroethics after Schiavo

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ABSTRACT

In this article, I attempt to untangle some of the cultural, philosophical, and ethical currents that informed the Schiavo case. My objective is to better apprehend what the Schiavo case means for end-of-life care in general and to assert that our discourse about the ethical issues attendant to brain injury will be impoverished if we limit our discussions about disorders of consciousness solely to the vegetative state. If we ignore emerging developments in neuroscience that are helping to elucidate the nature of these disorders and fail to broaden the conversation about brain injury, beyond the unmitigated futility of the permanent vegetative state, we will imperil others who might improve and be helped. Through such efforts we can help mitigate the tragedy of the Schiavo case and overcome the rhetoric that marked the national discourse in March 2005. Once the complexity of disorders of consciousness is appreciated, rhetorical statements about a right to die or a right to life are exposed as being incompatible with the challenge of providing care to such patients. This is especially true as neuroscience brings greater diagnostic refinement to their assessment and management, a topic addressed in this article, which specifically focuses on the clinical and ethical implications of the recently described minimally conscious state. Instead of staking out ideological positions that do not meet the needs of patients or families, we should strive to both *preserve the right to die* for those who are beyond hope *while affirming the right to care* to those who might benefit from coming advances in neuroscience. If we can achieve that delicate balance, we will be able to transcend the partisan debate that shrouded the life and death of Theresa Marie Schiavo and begin to articulate a *palliative neuroethics of care* for those touched by severe brain injury and disorders of consciousness.

KEYWORDS: Neuroethics, Neuro-palliative care, Terri Schiavo, Terry Wallis, Disorders of consciousness, Brain injury, Ethics

LIFE AND DEATH POLITICS

The April 4, 2005, issue of *U.S. News and World Report* captured the nation's mood (Goldsmith, 2005). Terri Schiavo had died days before and the country

was coming to grips with the saga of the life and death of a young woman in the permanent vegetative state (Goodnough, 2005).

The magazine cover was entitled "Life and Death Politics." A strange title to be sure. In past iterations of right-to-die dramas one might have expected to see a cover with the scales of justice and a stethoscope. Instead *U.S. News and World Report* depicted an earnest young woman looking up toward a crucifix she was holding. Behind her there is a sign with

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the famous image of Ms. Schiavo seeming to look toward her mother. From Not-Dead-Yet, the disability rights group most famous for chaining themselves to the front of the Supreme Court during the cases involving physician-assisted suicide, there is a caption that simply states, “She’s disabled.”

The discourse had become more complicated, more nuanced. It was no longer simply about the right to die but about disability rights and about faith. A sidebar title tellingly indicates what is inside the magazine and what is not: “What the Schiavo case means for the future of religion, law, and privacy.” There is nothing about what the Schiavo case means for medicine or neuroscience—an interesting omission that perhaps indicates the ascendancy of theology over science in that debate, at that time.

Then in a final nod to the controversy that surrounded the case, there is an extra headline that entices the prospective reader with, “Plus: The truth about living wills,” injecting a bit of suspicion into the mix, suggesting that the bioethics “establishment” had not been fully forthcoming about decisions near the end of life.

In this article, I will try to untangle some of the cultural and philosophical currents that informed the cover of that contemporaneous newsweekly. My objective is to better apprehend what the Schiavo case means for end-of-life care in general and to assert that our discourse about the ethical issues attendant to brain injury will be impoverished if we limit our discussions about disorders of consciousness solely to the vegetative state. If we fail to broaden the conversation about brain injury beyond the unmitigated futility of the permanent vegetative state, we will imperil others who might improve and be helped.

Ultimately, we can help mitigate the tragedy of the Schiavo case if we overcome the rhetoric that marked the national discourse in March 2005. The simple binary opposition of a right to die versus the right to life is incompatible with the complexity of caring for patients with severe disorders of consciousness. This is especially true as neuroscience brings greater diagnostic refinement to their assessment and management. Instead of staking out ideological positions that do not meet the needs of patients or families, we should strive to both *preserve the right to die* for those who are beyond hope while *affirming the right to care* to those who might benefit from coming advances in neuroscience (Fins, 2005a). If we can achieve that delicate balance, we will be able to transcend the partisan debate that shrouded the life and death of Theresa Marie Schiavo and begin to articulate a *palliative neuroethics of care* for those touched by severe brain injury and disorders of consciousness (Fins, 2005a).

SCHIAVO AND THE FRAGILE CONSENSUS ON END-OF-LIFE CARE

Before we attempt to articulate how a neuro-palliative care ethos might inform the care of patients with severe brain injury, we need to better apprehend how the Schiavo case was able to engage the nation’s leaders and captivate the news media in a vigil of epic proportions (Annas, 2005). At one level, the divisions between the Schindler family, represented by Theresa’s parents and siblings, and Michael Schiavo, her husband, reflected deep divisions in the country as a whole. The red state–blue state phenomenon that has marked recent national elections became embedded in a family tragedy and implicitly gave voice to the nation’s decade-old divisions over abortion rights. Ironically, against the backdrop of Florida politics, the case also exposed lingering tensions about the place of the courts in deciding contentious social questions. Adjudicated decisions by multiple courts to uphold Ms. Schiavo’s right to die led advocates on the right to complain of judicial activism. Their opponents hailed the importance of civil liberties throughout the life cycle. They critiqued the intercession of Congress and President Bush as an unprecedented assault on federalism and the prerogative of states to regulate matters not relegated to the national government (Bumiller, 2005).

From that vantage point, it was also very dramatic that Congress inserted itself in a matter that historically has rested in state courts. When Congress intervened and asked for additional judicial review, it undermined the standing of the courts that routinely rule on issues of health care and family law like wills and estates, domestic matters, and guardianship for health care decisions. The legislative branch has never been the adjudicator of such disputes.

At a clinical level, the case eroded the centrality of autonomy and patient self-determination, which had been guiding principles for clinical ethics and medical practice for decades. The notion of bodily dominion, expressed in the doctrine of informed consent and refusal (Applebaum et al., 1987), was violated when the adjudicated preferences of Ms. Schiavo were trumped by government intervention. This occurred at both the state and federal levels when her feeding tube was reinserted twice over the objection of her legal surrogate, Michael Schiavo.

In a political sense, the case also raised questions about the neutrality of bioethics as an academic field. Conservative critiques maintained that bioethics had become ideological and focused on patient rights at the exclusion of a deontological obligation to preserve and sustain life (Wilson, 2005).

The same issue of *U.S. News and World Report* whose cover page we have just considered had an opinion piece by commentator John Leo (2005, p. 54) who asserted that, "Bioethics has hardened into an activist ideology that pervades the medical world, the schools, and government." His essay was accompanied by a political cartoon depicting a patient in a hospital bed being whisked away by elfin figures, presumably bioethicists, with a disconnected I.V. at his side.

Such divisions made one nostalgic for the consensus in bioethics that led to the passage of the Patient-Self Determination Act (PSDA) in 1990 (Omnibus Reconciliation Act of 1990). As the reader will recall, that was the federal law that required all institutions receiving Medicare funding to ask patients about the presence or absence of advance directives. It also called for each state to have their own law related to advance directives. The PSDA fostered nostalgia because it had bipartisan origins in *Cruzan v. Director, Missouri Department of Health* (1990), another right-to-die case.

Cruzan involved another young woman in the permanent vegetative state and the question of the removal of artificial nutrition and hydration in the setting of decisional incapacity and disagreement about prior wishes (Colby, 2002). The Supreme Court ruled that there was a constitutional right for adult competent patients to refuse life-sustaining therapy including artificial nutrition. It also noted that each state can set evidentiary standards to allow surrogates to withdraw life-sustaining therapy when the patient lacks decision-making capacity.

Reflecting upon the difficulty of decision making in such circumstances, Justice Sandra Day O'Connor suggested that it would be helpful if there were a mechanism to know preferences in advance of the loss of capacity and suggested a role for advance directives (Annas, 1990). Democratic Senator Daniel Patrick Moynihan from New York and his Republican colleague, John Danforth of Missouri, introduced the bipartisan PSDA and it was signed into law by President George H.W. Bush (McCloskey, 1991).

In recounting this familiar history, I want to emphasize two points. The first is to point out that if Ms. Schiavo had an advance directive at the time of her cardiac arrest in 1990, she would have been ahead of the cultural curve that brought advance directives to clinical practice under the guise of the PSDA (Fins, 2004). Indeed, asking why Ms. Schiavo did not possess an advance directive was often nothing more than rhetorical device to attack self-determination and polemically label advance care planning as nothing more than "procedural liberalism" (Cohen, 2005).

The second, and most obvious, point is to contrast the end-of-life care politics of the two Bush administrations and distinguish the pragmatic approach of the first Bush administration to the end-of-life care and PSDA with the ideological stance of the second administration. The contrast between the harmony surrounding the presidential signing of the PSDA with the acrimony surrounding President George W. Bush's emergent flight back from Crawford to sign a federal "Terri's Law" could not be more pronounced (Hulse & Kirkpatrick, 2005; Kirkpatrick & Stolberg, 2005).

Behind the political theatrics was an attempt to rewrite the script of how we die. Although decades of progress had been made since the Quinlan case (*In re Quinlan*, 1976), where the concept of the vegetative state was first brought to national consciousness (Annas, 1996), and *Cruzan* (1990) where the Supreme Court articulated a fundamental right to refuse life-sustaining therapy including artificial nutrition and hydration, Schiavo reopened old questions that had seemingly been settled in law and practice.

Among them was the legitimacy of the vegetative state as a diagnostic category and whether artificial nutrition and hydration should be construed as a life-sustaining therapy at all. Once such questions were raised, the debate could be engaged at a more fundamental level in order to establish a "culture of life" (Office of the Press Secretary, 2005). The effect was startling. In 8 brief years, Terri Schiavo was on the cover of the newsweeklies instead of Jack Keivorkian. The effort to expand the right to die into to a right to physician-assisted suicide had been reversed, with a new struggle to stave off further erosion of patient self-determination at life's end (Fins, 2006).

A DIAGNOSTIC DEBACLE

Schiavo was at the center of the debate, in part, because the vegetative state was at the center of how America came to articulate a right to die (Fins, 2003). The reader will recall that in *Quinlan* (1976), the justification of the removal of her ventilator was predicated on her "loss of a cognitive sapient state." If that ultimate benchmark of futility could be brought into question, if Schiavo could be demonstrated—on her national stage—to actually be cognitive or sapient, the legitimacy of the diagnostic construct could be cast in doubt. Then the right to die could be eroded.

Echoing the scholarship of the American sociologist C. Wright Mills, author of *The Power Elite* (2000), an ascendant Republican majority in the House and Senate, with concurrence of the Presi-

dent, sought to redraft norms that had pervaded society for decades. As Mills noted:

Far from being dependent upon the structure of institutions, modern elites may smash one structure and set up another in which they then enact different roles. In fact, such destruction and creation of institutional structures, with all their means of power, when events seem to turn out well, is just what is involved in “great leadership,” or when they seem to turn out badly, great tyranny. (Mills, 2000)

And that is precisely what happened when Congress sought to create new regulatory structures to govern decisions at the end of life by seeking to *redefine* the vegetative state.

Legislators with no medical training and several physicians, who seemingly ignored that training that they had received, made statements asserting that Schiavo was not vegetative. The Senate Majority Leader, a cardio-thoracic transplant surgeon by training, maintained that, “There seems to be insufficient information to conclude that Terri Schiavo is in a persistent vegetative state. . . . I don’t see any justification in removing artificial nutrition and hydration” (Samuel, 2005, pp. 16–17).

The basis for their claims was a multihour videotape, made years before, which seemed to suggest that Ms. Schiavo was looking toward her mother when called. The video was compelling and heart wrenching. A young woman and a hopeful mother trying to make eye contact and then appearing to do so in the briefest of video snippets. It made for good television, but bad medicine, especially when physician-members like Representative David Weldon (R-FL) (2005) asserted, “By my medical definition, she was not in a vegetative state based on my review of the videos, my talking to the family and my discussing the case with one of the neurologists who examined her.”

Notwithstanding the effort to make the diagnostic act idiosyncratic, value-driven, or uninformed by actually examining the patient, it is critical to note that there *are* definitive medical criteria for what constitutes a vegetative state. It’s not simply a values choice. It’s not what an individual doctor thinks or hopes or wants. It’s not what public opinion polls suggest it should be.

As first articulated in their landmark 1972 *Lancet* paper, Jennett and Plum define the vegetative state as “syndrome without a name” and one of “wakeful unresponsiveness” (Jennett & Plum, 1972). In the vegetative state the patient’s eyes are open but there is no cognitive activity. Patients have apparent sleep–wake cycles, random eye move-

ments, and even a startle reflex, all autonomic activity reflective of an intact brain stem in the absence of higher cortical function. Criteria exist for the diagnosis based upon expert consensus panels and scholarly monographs (Jennett, 2002; Multi-Society Task Force on PVS, 1994a, 1994b).

Dr. Plum and I made a similar point in the wake of earlier deliberations in the Florida legislature in 2003 leading to a reinsertion of Ms. Schiavo’s feeding tube. We noted that the neurological assessment of patients in the vegetative state is “more than a state of mind” (Fins & Plum, 2004). Clinical assessment must hinge on diagnostic rigor and established criteria. It must not be arbitrary or idiosyncratic. Although each of us can ascribe a differing moral valuation to life in the vegetative state, we felt it important not to transform the diagnostic act into a values choice. That valuation should follow upon diagnostic discernment able to distinguish states of permanent unconsciousness from ones in which patients retained the prospect of recovery of a “cognitive sapient state.” To conflate brain states, for political purposes, only serves to undermine clinical and scientific integrity. Moreover it has adverse consequences for other patients who are not permanently vegetative but might be labeled as such.

The efforts like those we witnessed in Congress, however, transcended medicine and had the capability of destabilizing society by changing the social norms that have governed civil life and upon which we depend. The great jurist and Supreme Court Justice Benjamin Cardozo (1929, pp. 581–582) once praised the two learned professions, medicine and the law, as those which were “united in common quest, the quest for the rule of order, the rule of health and disease, to which for individuals as a society we give the name of law.” By attempting to change the balance between state and federal government and by delegitimizing medical practice and clinical diagnosis, proponents of congressional intercession laid a blow to the rule of law of which Cardozo spoke. In doing so they undermined the two learned professions upon which a functioning open and civil society must depend (Fins, 2005d).

THE CENTRALITY OF THE MINIMALLY CONSCIOUS STATE

In his remarkable essay “The Leaven of Science,” Sir William Osler (1904, p. 90) observed that, “The determination of structure with a view to the discovery of function has been the foundation of progress.” And so it has been in the history of medicine. Yet in the political cauldron of Schiavo, the opposite was true. The effort to undermine the diagnostic legitimacy of the vegetative state was

aided, ironically, by new knowledge concerning disorders of consciousness, most notably the recent description of the *minimally conscious state* (MCS) (Giacino et al., 2002).

Those opposed to the removal of Ms. Schiavo's feeding tube sought to engender doubt about her diagnosis by raising the specter of her being misdiagnosed and actually in the minimally conscious state. This effort to conflate diagnostic categories was a disservice to those in the minimally conscious state who should be considered clinically and ethically distinct from those who are permanently vegetative.

The minimally conscious state is a state of severely altered consciousness in which there is minimal but definite behavioral evidence of self or environmental awareness (Schiff, 2005). An MCS patient may say words or phrases and gesture or show evidence of memory, attention, and intention. Unlike vegetative patients who have reflexive eye movements, so famously captured on the edited videotape where Ms. Schiavo seemed to look at her mother, MCS patients may purposefully and intentionally track objects in their visual field. Assessment of MCS patients, however, is complicated by the fact that these MCS behaviors are episodic and inconsistent, so when patients are not exhibiting them, they may be mistaken as being in the vegetative state.

Clinical assessment is further complicated by the fact that disorders of consciousness are not static but evolve over time. A loss of consciousness may evolve to death by cardio-pulmonary criteria, brain death (cessation of whole brain function including brain stem), coma (an eyes-closed state of unresponsiveness), or spontaneous recovery. From coma a patient can spontaneously recover consciousness or move into the *vegetative state*, an eyes-open state of unresponsiveness reflective of recovery of brain stem function.

Patients may recover consciousness from the vegetative state, but when that state persists for more than 30 days, it is described as *persistent*. That descriptor of the vegetative state is further refined as *permanent* if its duration is more than 3 months after anoxic brain injury and 12 months after traumatic brain injury (Jennett, 2002). These variable time frames reflect the differing etiologies of injury and the variable pathophysiologic changes that they evoke (Schiff et al., 2002).

It is important to appreciate these time frames and outer limits of the persistent vegetative state before that state becomes permanent. This liminal period provides a window during which movement into MCS remains possible. This is a critical juncture of brain state transformation because MCS is

the platform for additional recovery to consistent evidence of consciousness. Having said this, it is important to note that this is a complicated and variable process. One recent report indicates that the trajectory to recovery of consistent consciousness—if it occurs—may rarely take decades (Lammi et al., 2005). Patients are considered to have *emerged* from the minimally conscious state when evidence of consciousness become consistent and they can reliably communicate (Giacino et al., 2002).

CONTEXTUAL CHALLENGES TO DIAGNOSTIC ACCURACY

As we just noted, it is critical to appreciate the time course of potential recovery of consciousness and to be able to differentiate whether a patient has entered the minimally conscious state. Movement into MCS indicates that they are now conscious and have the potential for additional recovery. Unfortunately, given the current configuration of our health care system, this evolution of brain states is a daunting process to track diagnostically (Fins, 2005a).

At the risk of being misconstrued about the Schiavo case (Didion, 2005), this diagnostic challenge was *not* an issue in her case. She was sufficiently evaluated by neurologists for the Florida Supreme Court (Supreme Court of Florida, No. SC04-925, 2004) to conclude that there was "clear and convincing evidence that she was in a persistent or permanent vegetative state." The notation that there was clear and convincing evidence to support this ruling is important to note because it means that the standard of evidence was very high. This judicial ruling was substantiated by the assessment of the independent *Guardian Ad Litem*, Jay Wolfson, appointed by Governor Jeb Bush (Wolfson, 2005, 2006).

Most patients with a disorder of consciousness receive far less medical scrutiny than Ms. Schiavo did and the accuracy of their diagnosis is by no means assured (Fins, 2005c). The risk of misdiagnosis is unacceptably high and would be unacceptable in other domains of medicine (Childs et al., 1993; Andrews et al., 1996; Wilson et al., 2002).

The reasons for this begin with the acute care setting, which is capable of providing superb emergent care but is ill equipped to meet their longitudinal needs. If we hope to meet our ethical obligations to patients with disorders of consciousness and provide their surrogates with accurate and longitudinally updated diagnoses, we need to appreciate some of the barriers to on-going assessment.

The reasons for this are multifactorial but first among them is that patients with disorders of consciousness may need a longer period of time to

declare themselves than other critically ill patients in the acute care setting. In a setting where decisional constructs operate in days and weeks, and not months, it becomes too easy to mistake the failure to improve quickly as an indication that no improvement will be possible at all. In this setting, it becomes convenient to make global—and often unsubstantiated—comments about a diverse sets of patients with disorders of consciousness having “no hope for meaningful recovery” even though emerging data indicate that prospects for recovery are variable depending on the nature of the injury, its etiology, and its anatomic locale in the brain (Laureys et al., 2004; Fins, 2005e).

Such statements, in turn, may erroneously support decisions to prematurely withhold and/or withdraw life-sustaining therapy before the patient has had time to declare him or herself prognostically. This difficulty is most notable in decisions to withdraw life-sustaining therapy like artificial nutrition and hydration (ANH). Although ANH has been deemed by the Courts, most notably in *Cruzan* (1990), to be a form of life-sustaining therapy, some religious traditions view the provision of food and water as normative and ordinary, not extraordinary care (Beauchamp & Childress, 1994). These views offer a paradox for the care of patients with disorders of consciousness. It may be more “palatable” to remove “extraordinary” measures like ventilatory support from a comatose patient, early in the course of care when their ultimate prognosis is still in doubt than to withdraw ANH, perceived by some as “ordinary” care, from a permanently vegetative patient when the prospect of regaining consciousness has been irretrievably lost (Fins, 2005e).

Other factors may lead clinicians to prematurely foreclose the prospect of recovery and view care for patients with a disorder of consciousness as being futile. This becomes apparent if we consider the case of organ donation. The diagnosis of brain death was articulated to allow for the utilitarian process of retrieving organs to meet broader societal needs (Beecher, 1968; Stevens, 1995). Despite this laudable objective, it is not uncommon for organ procurement personnel to urge evaluation of patients with Glasgow Coma scales of three to five as potential candidates for organ “harvest” even though some of these patients may rarely retain the prospects of good recovery (Meli, 2003).

Economic pressures also present barriers to the proper assessment and care of patients with disorders of consciousness (Banja, 1999). This may lead to early discharge for patients who fail to demonstrate “medical necessity,” an ill-defined term used by “Medicare and Medicaid and insurance contracts to refer to medical services that are generally rec-

ognized as appropriate for the diagnosis, prevention, or treatment of disease and injury” (Committee on Child Health Financing, 2005). Unfortunately, the nature of recovery of consciousness does not easily fit into notions of medical necessity borrowed from more conventional maladies. Recovery of ambulation following joint replacement is far more predictable than how patients regain consciousness following severe brain injury. Although the need for further rehabilitation following orthopedic surgery may lessen once a patient reaches certain clinical milestones, prolonged plateaus in cognitive function may not signify that recovery has ceased. These concerns about medical necessity are compounded by recent changes in the Medicare prospective payment system that appear to have negative implications for the quality and accessibility of in-patient rehabilitation after acute hospitalization (Hoffman et al., 2003).

Beyond this, because of the geographic separation of acute care and rehabilitation settings, many acute care clinicians have little idea about the course of their patients after hospital discharge. This can lead to distortions among acute care practitioners about what might be achieved over time. This may breed a sense of nihilism about the value of ongoing care because patient prognosis is based upon their limited perspective and contextual experiences (Christakis, 1999; Fins, 2002).

The challenge to proper diagnostic assessment is further compounded over time, especially when the patient is discharged from the hospital that initially provided care. Time of hospital discharge is an especially vulnerable time unless the patient is transferred to a specialty center for brain injury. Upon discharge, the patient may carry the diagnosis of being in the vegetative state but may evolve into being in the minimally conscious state only to have this go unnoticed and undiagnosed.

The reasons for this error of omission are multifactorial, not the least of which is the novelty of MCS as a diagnostic category, as it entered the literature as recently as 2002 (Giacino et al., 2002). In addition, many clinicians cling to the false belief that being persistently vegetative is a fixed and immutable state when in fact it is possible to move into MCS before the persistent state becomes permanent. This misconstrual of fact, coupled with an unwillingness to challenge an “authoritative” discharge diagnosis from the referring hospital (Fins, 2005a) may lead staff to disregard evidence of consciousness and discount family reports of suggestive behaviors as denial (Fins, 2005e). This problem is compounded by the episodic and inconsistent nature of the behaviors displayed by MCS patients. If behaviors reported by family are not reproducible

for clinicians, protestations of loved ones will be dismissed as wishful thinking and not perceived as useful clinical evidence.

TERRY WALLIS

This combination of factors conspired in the now oft-reported case of Terry Wallis, a 39-year-old nursing home patient who had carried the “vegetative” diagnosis for 19 years following traumatic brain injury in 1984. He began to speak in the summer of 2003 (Schiff & Fins, 2003). Since then he has continued to improve, laying down new memories, regaining cognitive function and motor skills (author’s observations, 2003–2005).

But until his emergence from MCS in 2003, the observations of the Wallis family were dismissed as wishful thinking (interviews conducted by the author with the Wallis Family, 2003–2006). His family believed that he was episodically aware but their concerns were dismissed and unverified. Clinicians did not accede to requests for neurological assessment or imaging studies, citing the expense or futility of further evaluation. In retrospect, from available records and public information, it seems clear that Wallis had migrated into MCS before the persistent vegetative state became permanent and that he had been in MCS for nearly two decades before he emerged to demonstrate unequivocal and consistent evidence of consciousness and functional communication. Since Wallis’s story was reported, more accounts of emergence are being reported by patients who have labored under inaccurate diagnostic assessment. Other examples include patients like Donald Herbert, the Buffalo, New York, firefighter, although details are scant and longitudinal follow-up is not known (O’Connor, 2005).

To learn from these examples of diagnostic omission is to accept the professional mandate to be rigorous in the evaluation of patients with disorders of consciousness. This will require the use of all available information, including new diagnostic strategies (Kobylarz & Schiff, 2004, 2005) and family perceptions and reports. It is important to appreciate that families will spend the most time at the bedside. Clinicians should try to scientifically confirm their observations when they are accurate and to humanely refute them when they are not reliable. Either way, it is critical to be respectful of what the family believes they have seen and to acknowledge the potential value of their observations. If they are correct, the diagnostic process will be advanced. If denial and hope have captured their hearts, a willingness to entertain the validity of their observations will help manage expectations

and avoid conflicts over the “facts” so emblematic of the Schiavo case.

NEURO-PALLIATIVE CARE: AN OLD METAPHOR FOR A NEW PROBLEM

These structural barriers to diagnostic assessment can only be overcome with a change in *mindset* about the needs of patients and families whose lives have been altered by severe brain injury. Instead of uniformly seeing all patients as if vegetative and viewing severe disorders of consciousness through the historic prism of *Quinlan* and *Cruzan* (Fins, 2003), our views need to evolve. We need to appreciate that although the right to die originated in the vegetative state, it does not end there (Fins & Plum, 2004). Enhanced diagnostic engagement of patients with severe disorders of consciousness represents neither an erosion of the hard won right to die nor an endorsement of life in such brain states. Ensuring a proper diagnosis is simply being intellectually honest and faithful to the notion of informed consent and informed refusal.

So how do we affirm the right to care and still preserve the right to die? I would assert that the construction of this apparent oxymoron can be accommodated by thinking of the needs of patients with severe disorders of consciousness by articulating palliative goals of care (Fins, 2006). That is, the achievement of goals that minimize the physical and bio-psycho-social burdens experienced by patients and their families.

In the context of severe brain injury, palliative care is first focused on assuring diagnostic discernment to determine whether the patient is conscious or not. The presence of consciousness will determine the potential for suffering and distress and inform judgments about the proportionality of ongoing care.

Central to this assessment is whether the patient will regain the ability for functional and reliable communication. This question is closely linked to the key issue of consciousness, because recent functional imaging studies done by my colleague Nicholas D. Schiff and others have indicated that patients who are minimally conscious, but not yet emerged have the ability to respond to passive language paradigms (Schiff et al., 2005). These investigators observed the activation of widely distributed and integrated cortical language systems in MCS patients when narratives read by family members were played to them. However, when the tapes were reversed, producing a gibberish with the same frequency spectrum, activation did not occur beyond the primary sensory area.

These patients remained unable to follow simple commands or communicate reliably. Although this response to language does not indicate consciousness, much less understanding or cognition, it does suggest the possibility. It indicates that patients, who are often perceived as being apart from a human community marked by communication, are potentially capable of processing language, albeit at some unknown level.

This makes MCS patients saliently different from those who are vegetative. Vegetative patients exposed to similar auditory stimuli *failed* to demonstrate an integrated neuronal systems response (Laureys et al., 2000). MCS patients seem capable of integrating the modular functions of the brain whereas the vegetative brain is dis-integrated. At the risk of being anthropomorphic, it could be asserted that the vegetative brain is not talking to itself. The minimally conscious brain, in contrast, is more organized, suggesting a potentiality for even higher integrative function.

The images of these minimally conscious brains were compelling, prompting all manner of speculation. For example, there was a statistically significant increase in the activation of the occipital cortex in response to auditory stimuli, though this part of the brain is usually responsible for processing of visual information. Does this suggest plasticity or recovery of function? Does it suggest that these patients were visualizing the semantic content of language? And, if they do, could it be said that they are processing language?

If MCS patients are processing language, there are a number of ethical implications, given the centrality of language to notions of human community and solidarity (Winslade, 1998; Searle, 2002). This potential is a grave one, because it raises the possibility of a life of the mind, even though that possibility had seldom been acknowledged. It suggests the potential for interaction and engagement that is *not* possible with those who are vegetative.

Moreover, it suggests that MCS patients may harbor enough residual cognitive capacity to have some degree of insight into their plight, disability, and the isolation imposed upon them by others, unaware of their potential ability to comprehend (Fins, 2000; Carey, 2005). This sort of sequestration, should it be present, might be experienced as among the most horrific sort of suffering: fears about an unknown plight compounded by unintentional and unknowing disregard by others who are unaware of the patient's potential for grief.

Although the reality of such experiences are to be determined in MCS patients, the possibility that they may be present leads to an affirmative ethical obligation to discern distress and to meet whatever

suffering is present with compassion to help the recovering patient with the healing of a fractured self.

The palliative care community is especially well suited to the formidable challenge addressing this potential for suffering, which Eric Cassell has described as a threat to the integrity of the self (Cassell, 1982, 1991). Palliative care from its roots in the religious pilgrimage has, over its history, sought to instill meaning when the self is challenged by the specter of death (Porter, 1997). With the intervention of supportive palliative care and psychotherapy, this threat to the self can be therapeutically transformed and recast into a way of finding meaning in one's remaining days (Breitbart, 2002).

A similar palliative care intervention is envisioned for patients whose severe brain injury imperils or irrevocably alters the self. Some of these patients might have at one time been minimally conscious. Others will have less severe degrees of injury. But each will have to rediscover a new self and reflect on what constitutes an acceptable and bearable existence in matters of work and family life.

Claudia Osborn (1998), a doctor who had brain injury, describes this notion of reconstructing herself. She had sustained an injury that led to the loss of her executive function. This made it impossible for her to remain a practicing physician. Her poignant volume tells of the existential challenge of an altered self. She suggests the inner life of others with more severe injury as yet unable to communicate:

I desperately needed a vision of an achievable future—one I wanted, not just one I could attain. Now that the *me* I knew no longer existed, I had to build another identity and move on, or wither or die. (Osborn, 1998, p. 180)

A palliative neuroethic of care can help give voice to the experience of patients and families whose lives have been inalterably changed by severe brain injury. The palliative care community, well situated by temperament and experience, is encouraged to broaden its purview and begin to meet the clinical and existential needs of this population. With such clinical engagement, we might move beyond the polemics of Schiavo and embark on a true "culture of care" (Fins, 2005*b*) for this marginalized population (Fins, 2003).

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