

# Rethinking Disorders of Consciousness: *New Research and Its Implications*

BY JOSEPH J. FINS

Over the past several years, deciding whether to withdraw life-sustaining therapy from patients who have sustained severe brain injuries has become much more difficult. The problem is not the religious fundamentalism that infused the debate over the care of Terry Schiavo, the Florida woman in a permanent vegetative state whose case has drawn national attention. Rather, the difficulty stems from emerging knowledge about the diagnosis and physiology of brain injury and recovery. The advent of more sophisticated neuroimaging techniques like MRI and PET scans, in tandem with electrophysiologic and observational studies of brain-injured patients, have led to an effort to differentiate disorders of consciousness more precisely. The crude categories that have informed clinical practice for a quarter century are becoming obsolete.

It used to be enough for a neurologist or neurosurgeon to write a note in the chart grimly recording the patient's neurological exam and then concluding with the global statement, "no hope for meaningful recovery." It can no longer be so simple. With a better understanding of brain injury and mechanisms of recovery, we should be suspicious of blanket statements that might, we now believe, obscure important differences among different patients' prospects for recovery, although even those patients we now think may recover may still be left with profound and perhaps intolerable burdens of disability.

Recovery from coma depends on a patient's age, the site of injury, and whether the damage was done by trauma, anoxia (oxygen deprivation), or other processes. The

most severe brain injuries may lead to brain death. If patients survive and begin to recover from coma, they often first enter into the vegetative state, first described by Bryan Jennett and my teacher, Fred Plum, in 1972. The vegetative state is a paradoxical state of "wakeful unresponsiveness" in which the eyes are open but there is no awareness of self or environment. When a vegetative state continues beyond thirty days, it is described as "persistent." A vegetative state is generally considered permanent three months after anoxic injury and twelve months after trauma.

All of this is news since I went to medical school. I was taught that the vegetative state was immutable and fixed. Vegetative brains were, if I recall the phrase correctly, "gelatinous gels." The futility of this brain state was the basis for the establishment of the right to die in cases like *Quinlan* and *Cruzan*. Recent studies have shown, however, that patients can regain some evidence of consciousness before the vegetative state becomes permanent. In the window between the persistent and permanent vegetative state, patients can progress to what has been described as the "minimally conscious state" (MCS). Unlike vegetative patients, the minimally conscious demonstrate unequivocal, but fluctuating, evidence of awareness of self and the environment. The natural history of MCS patients is not yet known. Near the upper boundary of this category, patients may say words or phrases and gesture. They also may show evidence of memory, attention, and intention. Patients are considered to have "emerged" from MCS only when they can reliably and consistently communicate.



Unfortunately, all of this is easier to explain in theory than to observe in practice. First and foremost is the challenge of diagnosis. To the untrained eye, MCS patients may appear very similar to those who are vegetative. These diagnoses can be confused and conflated and in the earlier phases of illness need to be considered very carefully in the context of the mechanism of injury. In a patient with non-anoxic injury, even small gains beyond the vegetative level may herald the potential for significant further recovery. Some recent studies suggest that the diagnostic distinction between MCS and PVS is missed by neurologists at rates that would be intolerable in other clinical domains. To be fair, however, a neurologist acting in good faith might examine an MCS patient when his level of arousal was low and elicit an exam that is indistinguishable from a vegetative patient.

But there is another sort of diagnostic error that occurs when the objectivity of diagnosis is infiltrated by value judgments. Instead of dealing with the moral ambiguity associated with balancing the burdens and possible benefits of continuing care, there is a tendency

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among some practitioners to act paternalistically and label some who might be minimally conscious as vegetative. By being categorical, the more difficult choices are side-stepped and the morass of the minimally conscious state is avoided. With “no hope for meaningful recovery,” care can be withdrawn. But even if this is true—and it may be, since a patient in a minimally conscious state may indeed have no hope for meaningful recovery—our greater level of knowledge about these conditions calls for more diagnostic clarity.

Diagnostic distortion has also been used to undermine the right to die. In *Schiavo*, right to life advocates asserted that she was not vegetative. By suggesting consciousness where there was none, these opponents of choice at the end of life cast doubt on the ethical propriety of removing life-sustaining therapy. They persisted even though court-appointed physicians found that she was vegetative, and even when the Florida Supreme Court determined that there was clear and convincing evidence for this diagnosis.

A third sort of diagnostic distortion is journalistic. Differing brain states can be conflated either through ignorance of the facts or deliberately—to hype a case or new scientific development. The latter occurred in a *New York Times Magazine* article that discussed our work with minimally conscious patients and its implications for the centrality of diagnostic discernment and the use of neuroimaging techniques. Although the text was for the most part accurate, the headlines and pull-quotes mistakenly labeled the patients as vegetative. One notable header: “New research suggests that many vegetative patients are more conscious than previously supposed—and might eventually be curable. A whole new way of thinking about pulling the plug.”

When we learned about such errors prior to publication, Fred Plum and my colleague Nicholas Schiff and I contacted the magazine’s editor to request a change. She told us the distinction was unimportant. It was, in her view, merely a matter of semantics. The article ran without the changes we had requested. The magazine published a correction weeks later along with our letter to the editor, but by then it was too late. Few people read corrections. Just recently a family we were counseling discovered the article in an Internet search and brought it up during an ethics consultation. If there was hope for vegetative patients, could there not be hope for their loved one? We sought to explain how the *Times* got it wrong and provide as much diagnostic and prognostic information as we could.



Each of these distortions is troubling. If a distortion is a physician’s it undermines the integrity of the clinical transaction. If it is inspired by ideology it politicizes a process that is better left to scientific judgment. And if it occurs through journalistic hubris, it perpetuates misunderstanding in the popular culture.

Families will have more than enough difficulty contending with disorders of consciousness even when they are properly diagnosed. Assuming that families can ascertain a credible diagnosis and prognosis, how should they make decisions about care? How should a slim prospect of recovering consciousness be balanced against the burdens associated with enduring disability? The protracted time frame during which recovery *might* occur could require a vigil that lasts for months and still might lead only to disappointment.

A long vigil may also preclude options to withdraw life-sustaining therapy. Consider the implications of the recent Papal statement on the ethical mandate to provide artificial nutrition and hydration to vegetative patients. If an observant Catholic family were to follow Church teachings, they might be able to discontinue “extraordinary” measures early in the patient’s course when the prognosis was still unknown, but they might not be able to discontinue artificial nutrition and hydration later on, once it was clear that the patient would not

make any progress from the vegetative state. This might cause some families to be more risk-averse and withdraw extraordinary measures earlier in the course of illness while treatments like ventilators were still in place. The paradox is striking: A Papal statement intended to promote life might have the unintended consequence of limiting the chance of recovery for some.

To make matters even more complicated, these decisions will likely take place beyond the reach of the hospital and the expertise that is available in clinical ethics and neurology. Transfers out of the acute care setting can lead to errors of diagnostic omission and a failure to follow patients longitudinally as their condition evolves.

Such was the fate of Terry Wallis, an Arkansan who suffered traumatic brain injury in 1984 after a car accident. After he was diagnosed as being in a vegetative state, he was discharged to a nursing home, where he lingered for nineteen years. Although his family saw evidence of awareness, he did

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not receive an examination by a neurologist and never underwent an imaging study. His family was told that a work-up would be too expensive. The implication was that it was also pointless.

His case gained national press coverage in July 2003 when he began to speak. Headlines suggested that he had miraculously emerged from a coma. A closer examination of the record reveals that he had probably moved from the vegetative state to the minimally conscious state within the first months after his injury and then remained improperly diagnosed for years.

Stories like these send a chill up my spine. Some patients diagnosed as vegetative are probably in fact intermittently sentient but unable to communicate. The isolation, abandonment, and neglect they experience is unimaginable. Though their numbers may be small—there is no reliable data on how common this phenomenon is—they still make a claim of justice on all of us who know that some conscious but non-communicative individuals may have been relegated to the margins of the human community. And they are but a small segment of a larger group of institutionalized patients with severe brain injuries who are receiving what has been described as merely “custodial care.”

All of these patients deserve better. The small community of neuroscientists who have taken an interest in mechanisms of brain injury and recovery needs to be expanded, and bioethicists need to grapple with the imponderables, both theoretical and practical, that attend to disorders of consciousness. There is no shortage of questions about the nature of the self, personal identity, and autonomy to occupy us. Colloquially put, how much of yourself do you have to lose to cease to be you? The implications for an ethic grounded in self-determination are obvious and ripe for engagement by both theoretical and practical ethicists.

The lesson from narratives of individuals who have suffered from brain injury is that the physiologic is only part of

the story. Although injury to the same brain substrate might produce memory loss or language difficulties, these impairments are superimposed on each patient’s personal psychology and past, producing highly individual losses rather than generic deficits. Likewise the recovery will be highly individual. Consider the physician who sustains an injury to her frontal lobe, spends the next ten years learning how to sequence daily tasks that previously were second nature, and along the way becomes an accomplished abstract artist, her creative impulses disinhibited perhaps by her injury. Or the athlete who worked in the financial sector and struggles to relearn the arithmetic skills that she once possessed, accommodating her expectations to her altered abilities. Each of these stories is about rediscovering a new self while recalling a lost identity.

If we hope to help patients and families make the tough choices following brain injury, we will need to embrace the ambiguity that goes along with long courses of recovery and questions about altered selves. These decisions will be more challenging than decisions to remove life support in the face of overwhelming sepsis or pursue treatment in the face of widely metastatic cancer. We will also need to demand diagnostic honesty and precision. In discussing diagnoses with families we will need to strike a balance between realism and hope. The objective must be to bring greater attention to the minimally conscious patient without engendering expectations for the permanently unconscious. If we are successful, we will protect both the right to die and the right to care, as paradoxical as that may seem in today’s clinical and political climate.

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### Further Reading

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