## Special Section: Open Forum

# *Lessons from the Injured Brain: A Bioethicist in the Vineyards of Neuroscience*

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I would like to share some reflections on how bioethics fosters dialogue between the sciences and humanities by talking a bit about my work as a physician-ethicist collaborating with neuroscientists studying severe brain injury and mechanisms of recovery. If I am successful in this *Pilgrim's Progress*, I hope I will convince you that *the injured brain can teach us much about ourselves.* It is not something I was prepared to believe as a medical student, when I was more certain of things than I am now.

So let me start at the beginning—or at least the beginning in medical school—when attitudes about illnesses are formed. Unintentionally, medical students learn about diseases you would want to have if you had to be sick and ones that you would seek to avoid like the plague. A sense of what is hopeful and what is hopeless is formed in pathology class and reinforced on the wards, and, right or wrong, these attitudes become entrenched.

No one, then or now, would ever hope to have a brain injury, but what I have learned over the past several years is that my rather entrenched sense of nihilism about brain injury was perhaps more socially constructed than scientifically sound. Let me explain.

When I was a medical student I studied under Fred Plum, one of America's greatest neurologists. Along with Bryan Jennett, a neurosurgeon from Glasgow famous for the Glasgow Coma Scale, Plum first described—and named—the Persistent Vegetative State (PVS).[1] Back in 1972, Plum and Jennett called PVS a syndrome without a name, basically identifying a brain state that was devoid of consciousness but performing the automatic functions of the body, controlling breathing, heart rate, sleep–wake cycles, and reflexes. These patients had intact brain stems, the lower part of the brain, and were in a state, as they explained it, of *wakeful unresponsiveness*. That is, the eyes are open, but open without awareness of self, others, or the environment.

In my mind's eye—I imagined the higher part of the brain as a gelatinous gel floating above the stump of a brain stem. With such injury, I presumed, as we all did back then, that the vegetative state was an immutable one: a state of a permanent loss of consciousness, forever gone and irretrievable.[2]

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That was what was thought, and it was, in a sense, a simplistic and convenient axiom. Convenient, because around the same time, my predecessor bioiethicists were helping to catalyze a movement that would give patients the right to die and to refuse unwanted interventions. Medical technology had burgeoned since the 1950s and America was enthralled with the medical miracles that were now possible thanks to the iron lung, the modern ventilator, and the intensive care unit.[3]

But all was not sanguine. With the advent of ICUs, patients were living longer but not better. States that just a decade or two before would have caused death now meant lingering in a prognostically dire state *with no hope of meaningful recovery.*

And here we return to the vegetative state, the most dire of prognoses, and the 1976 landmark case of Karen Ann Quinlan. Quinlan was a young woman in New Jersey who sustained a cardiac arrest after a drug overdose, leaving her brain starved for oxygen. She was on a ventilator and her parents, who were observant Catholics, asked the courts to let her die when it became clear that she would never recover sentient life.

My teacher, Dr. Plum, was Quinlan's court-appointed neurologist, and he confirmed that she was vegetative. With that, the New Jersey Supreme Court allowed the removal of her ventilator, noting her irretrievable loss of a "cognitive sapient state."[4] But Ms. Quinlan did not die, she continued to breathe.

Dr. Plum once told me, and I paraphrase here: Joe, I knew she would breathe.

A young acolyte, I asked him, How did you know, Dr. Plum?

Without pausing he told me, I took her off the ventilator as part of my neuro exam.

And of course he knew what he was doing. If she were vegetative, her intact brain stem would keep her breathing. I was stunned that he, not the court, first authorized the removal of the ventilator but quickly realized that he had to do this to confirm that she was not brain dead, a situation where the whole brain including the brain stem is dead.[5]

But I digress . . .

This landmark case, to many observers, started the death and dying movement. It also jump-started clinical ethics, because the court suggested that such cases would be better handled closer to the bedside, laying out a role for hospital ethics committees. In short, it was the sort of case that fixed attitudes and beliefs.[6]

So for the next 25 years, the important right to die expanded beyond the vegetative state.[7] The tragedy of the vegetative state prompted bioethicists and clinicians to question the uses of life-sustaining therapies and to begin to draw the line on medical technology for severe brain injury and other "futile" conditions, thus establishing the negative right to be left alone.[8] Through that laudable process, many have died a more comfortable and humane death, outside of the ICU, at home and in hospices, helped by do-not-resuscitate orders, advance directives, and other enfranchising innovations.

By the time I started to do clinical ethics and chair a hospital ethics committee, we had become acculturated to this right to die and the well-worn phrase—that there was "no hope for meaningful recovery"—from neurologists. Thus said, we would dutifully follow patient and family wishes and remove unwanted impediments to an inevitable dying process.

But it wasn't so simple or so neat. Socrates "taught us the unexamined life is not worth living"[9] and that phrase about "meaningful recovery" increasingly seemed an easy platitude that needed to be reexamined so that choices could be intellectually honest. We were learning that brain injury was not as immutable as we had thought. It was time to question both my clinical and bioethical colleagues, precisely as they had trained me to question received truths in the past.

Again, the injured brain was teaching us lessons that we needed to heed. In the mid-1990s I was mostly working on death and dying and clinical ethics consultation when I joined forces with Nicholas Schiff, a colleague at Cornell and Fred Plum's final neurologist protégé. He shared with me his observations—and those of literally a handful of investigators across the globe[10]—of some strange cases of the vegetative state that did not quite comport with expectations.

Something was not quite right, exciting, mind you, but unnerving, as we had grown up on a kind of scientific and bioethical dogma upon which so much had been predicated clinically. I knew then that bioethics was in for a surprise and that I wanted to help translate these findings into ethical frameworks that would not erode the progress the field had made carving out a right to die.[11]

It was a kind of Pandora's box—if some vegetative patients can get better and respond, does that undermine the entire right to die?[12] After all, that right was initially predicated upon the futility of the condition. It seemed that, for some, the vegetative state was not completely futile. Some might escape its grip, though who and why?

Not understanding what was going on was like being on a passage and not knowing the destination. Dr. Schiff and I both read Stephen Ambrose's *Undaunted Courage* about Lewis and Clark and felt that our journey, while less momentous, was much like trekking out West without the benefit of a AAA guide.[13] We knew we had to work together—science informing the ethics and ethics informing the science—to chart this uncharted territory.

Like the strange fauna and wildlife diligently noted by Lewis, we too saw the unexpected. Lewis and Clark sent samples back to Thomas Jefferson, their scientific patron.[14] We, less elegantly, sent out papers to medical journals. Here are some of the unexpected things we observed. Patients who were vegetative but sometimes spoke isolated words. Schiff and colleagues called it "words without mind."[15] Wildly different scans of vegetative patients depending on how they were injured.[16] Was it head trauma or was it oxygen deprivation? Those with traumatic brain injury looked healthier than those starved of oxygen. We and others knew that those healthier brains also did better.[17]

Even stranger, some patients who were vegetative seemed to progress to a state when they were sometimes conscious, sometimes tracking a person in the room or following a command, only to fall back into oblivion. So much for the immutability of severe brain injury. Rarely, some of the patients might even begin to speak again.

Our colleague Joseph Giacino at JFK Johnson Center in New Jersey would first call these patients minimally conscious in 1997, although there was resistance in professional circles in accepting this designation. Once it was published in the literature in 2002,[18] we all saw more and more of such cases.

For years we encountered skepticism from neurologists and bioethicists. Didn't we know these cases were uniformly hopeless? These folks don't ever get better. Best to end the misery and just let them die.[19]

Again, Schiff and I saw the question of upsetting the consensus over the right to die. We were at the margins, without people being all that interested in our work. I remember talking to one bioethics colleague about my nascent interests and having him stare back at me, not understanding why I was pursuing these questions.

And then two cases came to our attention and the attention of the national media that changed pretty much everything. First, there was Terry Wallis from Arkansas, who sustained a severe head injury in 1984 following an unrestrained motor vehicle accident.[20] He lingered in a nursing home for nearly two decades, diagnosed as being vegetative, before he regained fluent speech in 2003. His first words were "Mom" and "Pepsi." Ronald Reagan was still president. Like Rip Van Winkle he was locked in time.

It turned out he hadn't been vegetative all those years but in that category I mentioned earlier of the minimally conscious state (MCS). His family thought he had been aware of them and sometimes followed their commands, but their observations were discounted as either wishful thinking or denial. The problem, in large part, was that patients like Wallis don't always demonstrate the putative conscious behaviors, and as such those behaviors are not reproducible to skeptical staff. Convinced that such demonstrations couldn't possibly be so, these patients become difficult to identify, having an invisible epidemiology.[21] In Terry Wallis's case, review of the medical record suggests that he became minimally conscious several months after his accident, evolving out of the vegetative state before it became permanent.

The second case is one that is familiar and that is the other Terri—Terri Schiavo, a woman permanently vegetative after a cardiac arrest and oxygen starvation nearly a decade and a half earlier.[22] As is well known, her case escalated to a debate over her diagnosis, with opponents of the right to die trying to suggest the possibility that she was minimally conscious not vegetative, opening that Pandora's box and casting broader doubt on the ethical foundations of the hard-won right to die.

This effort to rewrite her diagnosis was made all the more important because just weeks before the Schiavo case reached the halls of Congress and brought President Bush back from a stay in Crawford to sign her special legislation, our group at Cornell demonstrated that MCS patients have the ability to activate language networks in the brain much like "normals" on functional neuroimaging.[23] Such a finding could be useful to those who sought to assert that Ms. Schiavo was looking and listening to her mother in that famous video clip.[24]

All of this would be academic were it not for the fundamental *biological and hence ethical differences* between these two brain states. Permanently vegetative brains are ones that are literally dis-integrated from themselves.[25] They cannot function as a unit and bring together the broken shards into a mosaic of consciousness.

MCS patients can. Their brains can sometimes integrate, episodically becoming conscious and interactive, a truly marvelous accomplishment, even if it happens briefly. In such brief shining moments, they are again one of us, able to communicate, able to interact, able to be with the other. That's not to say Terri Schiavo ceased to be part of the human community. It's just that MCS patients can reciprocate and participate in the exchange, which I believe is an ethically salient diagnostic difference.[26] MCS patients are also different because the machinery is there and potentially in place to achieve this integration if only . . . if only something were physiologically different.[27]

Imaging studies of Terry Wallis done at Cornell showed what was described as new axonal sprouting—new connections between existing neurons in his brain.[28]

Were these changes responsible for his regained ability to speak? As yet we do not know. But it is suggestive and a hypothesis that needs to be pursued systematically and prospectively with lots of patients, melding scientific investigation of the neurobiology of recovery with longitudinal epidemiologic tracking of patients over time.[29]

Or consider the equally notable case of Don Herbert, the Buffalo firefighter who had "awakened" nearly a decade after sustaining primarily traumatic brain injury with an uncertain degree of hypoxia after being injured in a house fire in late December 1995.[30] For nearly a decade, Herbert—like Wallis—received custodial care, lingering in a nursing home. He was too damaged to be helped at the best of places across the country. Then in May 2005, after getting a drug cocktail prescribed by an earnest physiatrist, he began speaking fluently. The story was quite dramatic and the nursing home contacted Herbert's family. Linda, his wife, was en route and told her teenage son Nicholas to call the nursing home to keep his father talking until she got there.

The exchange between father and son was poignant, as reported in Rich Blake's just-published *The Day Donny Herbert Woke Up*.[31] Nicholas was but a toddler when Herbert was hurt and Donny could not believe that the teenager's voice was Nicky's, his little buddy. "This isn't Nicholas—he's a baby, he can't talk!" The teen responded to his Dad, "I can talk. . . . Do you know how old I am?" He told him, "I'm thirteen." Don responded, "Holy _."

Linda Herbert later asked Nicholas how he thought his father sounded. Nicholas didn't know. He couldn't recall hearing his father's voice before. But for nearly a full day, the Herbert family and circle of friends did hear Donny's voice and a whole life was packed into those few hours. I was reminded of Joyce's *Ulysses* when a lifetime's worth of stories can be told—by a "cast of characters"—in a narrative that spans but a single day.[32]

For Don, family, and friends it was an exuberant and hopeful time, though Herbert, the dutiful father, felt guilty, thinking he had somehow abandoned his family. "I've been gone a long time. . . ."

There was also the wonderment about how this had occurred and worry about how long it might last. Although his "awakening" was striking, it wasn't a total surprise. Like Terry Wallis, Herbert gave early glimmers of consciousness. He was not vegetative all those years but minimally conscious. But during that whole time, save for his family, there was little curiosity about his story. The medical establishment was too imprinted with their diagnostic categories to question themselves and their nosology.

Fortunately, the tide may be turning. Drug trials have begun to see if such awakenings can be reproduced.[33] We have a trial at Cornell with collaborators at JFK Johnson in New Jersey and the Cleveland Clinic attempting to use bilateral thalamic deep brain stimulation in the minimally conscious state. To date we have reported on one patient in a paper in *Nature* who has regained capabilities with the intervention.[34] For 6 years he had been in MCS, occasionally communicating with a finger or his eyes. He did not speak and could not eat by mouth. He had a feeding tube.

At this writing, he is able to speak 6 or 7 words at a time, recite the first 16 words of the Pledge of Allegiance, and take his meals by mouth. More amazingly to me, he seems to have regained personal agency lost in his injury. He now responds to a nickname and is voicing preferences when asked. To be sure, he is still incredibly impaired and we are a long way from calling this a treatment, but it is a hopeful first step for those who have been neglected and marginalized for so long.

But even this scientific progress brings with it questions of whether these "halfway technologies," as Lewis Thomas put it, are real progress.[35] Is it better to be unaware of one's predicament, as was Terri Schiavo, or increasingly aware, like Terry Wallis? Which would you prefer? For you and for your loved ones, your kids?

Recently, I have begun to ask questions like this of families who come to see us in New York for imaging studies and other kinds of evaluation. Through in-depth interviews we are trying to learn of their experiences and formulate goals of care for this terra incognita of brain injury. The results, as you might expect, are mixed, but Terry Wallis's mother—with whom I am in frequent contact—told me recently of a family gathering, a party, they had in Arkansas. (I share her recollection with her kind permission.)

In the midst of the festivities Terry turned to his mother and said, "Mama, life is good." And so it might be for him and many others whose brain injury teaches all of us:

To be *prudent* in our judgments, reminding us to use practical reason and try to reach right judgments from a sound empirical footing,
To be *just and fair* to those who live on society's margins, giving access to care to those so long neglected,
To have *fortitude* or firmness in overcoming obstacles that get in the way of affirming the right of these patients to care, even as we preserve their hard-won right to die,
And finally, to have *temperance* in being moderate and careful in our formulation of goals of care, never overstepping through scientific zealotry.

There you have it: *Prudence*, *Justice*, *Fortitude*, and *Temperance*, the Four Cardinal Virtues.[36] These are virtues upon which progress in both the art and science of medicine have always hinged; as we move forward we should remain mindful of their lessons.

## Notes

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