

Disorders of Consciousness, Past, Present, and Future

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Abstract: This paper, presented as the 2019 Cambridge Quarterly Neuroethics Network *Charcot Lecture*, traces the nosology of disorders of consciousness in light of 2018 practice guidelines promulgated by the American Academy of Neurology, the American College of Rehabilitation Medicine and the National Institute on Disability, Independent Living and Rehabilitation Research. By exploring the ancient origins of Jennett and Plum's persistent vegetative state and subsequent refinements in the classification of disorders of consciousness—epitomized by the minimally conscious state, cognitive motor dissociation, and the recently described chronic vegetative state—the author argues that there is a counter-narrative to the one linking these conditions to the right to die. Instead, there is a more nuanced schema distinguishing futility from utility, informed by technical advances now able to identify covert consciousness contemplated by Jennett and Plum. Their prescience foreshadows recent developments in the disorders of consciousness literature yielding a layered legacy with implications for society's normative and legal obligations to these patients.

Keywords: persistent vegetative state; permanent vegetative state; chronic vegetative state; disorders of consciousness; practice guideline; disorders of consciousness; neuroethics; disability rights; Karen Ann Quinlan; Fred Plum; Bryan Jennett

*Una vida salvada merece ser vivida**

Introduction

In September 2018, the American Academy of Neurology (AAN), the American College of Rehabilitation Medicine (ACRM), and the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) published a systematic evidence-based review¹ and a new practice guideline² on the care of patients with disorders of consciousness. The guideline calls for improved standards of assessment and care, the use of emerging diagnostic and treatment modalities, as well as the prevention of medical complications that can confound diagnosis or adversely affect morbidity and mortality. The evidence-based review and practice guideline are landmark documents which supplant the 1994 Multi-Society Taskforce Report on the Vegetative State³ and the 2002 Aspen Criteria delineating the minimally conscious state (MCS).⁴ Their import is flagged by their simultaneous publication in *Neurology* and the *Archives of Physical Medicine and Rehabilitation*.

For the neuroethics community, the most salient feature of the guideline is the redesignation of the permanent vegetative state as the *chronic* vegetative state.⁵

* "A life that is saved, deserves to be lived." Federación Española de Daño Cerebra. Spanish Federation of Brain Injury. Accessed 15 April 2015 at: 4-12-45-29.admin.2014-manifesto-dia-dano-cerebral-adquirido-fedace.pdf

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Based on an expert review of the epidemiology and biology of the permanent vegetative state, the authors believe that 20 percent of patients thought to be permanently vegetative could regain consciousness, necessitating the change.

This is a notable change in nomenclature which transcends the science of brain recovery and takes on broader cultural significance. From *Quinlan* and *Cruzan* on to the debate over Terri Schiavo, the vegetative state has become something of a catechism in North American bioethics.⁶ Its irreversibility became the moral predicate upon which the legal right to die was established and sustained.⁷

Treatment of the vegetative state was futile because of the perceived fixity of this brain state. Once the vegetative state became permanent, stasis had overcome the brain making further recovery unlikely, if not impossible. This made additional interventions disproportionate, up to and including life-sustaining therapies. Such was the prevailing theory which informed the *Quinlan* decision and subsequent societal expectations about the vegetative state.

This has been a powerful legacy which has helped to expand patient and family dominion over choices at life's end. While the *Quinlan* decision has generally been for the good, enfranchising patients and families with choices at life's end, it has also had the unintended consequence of generalizing a presumption of futility beyond the vegetative state to other conditions, with which it has been confused and conflated.⁸ This has led to the marginalization of a highly vulnerable population and the perception that the treatment of brain injury is futile.

We now appreciate that this perception is scientifically inaccurate. While many patients with severe brain injury will not recover, others will, in part because of dynamic processes within the injured brain. This may come as a surprise to those whose views were molded by the strong linkage of brain injury to the establishment of a right to die. But it would be less of a surprise to those who originally described these conditions. They were less nihilistic. Their categories were less value-laden and more carefully drawn than history remembers them. Instead of the expected stasis that informed the *Quinlan* decision, the primary neurology literature was more nuanced and cautious with its predictions about outcomes. The purpose of developing a new nosology to describe these brain states was not to establish a right to die, but rather to distinguish those who might be helped from those who couldn't. It was not just a question of futility but also one of utility.

The redesignation of the permanent vegetative state as *chronic* is but the most recent acknowledgement of this capability for recovery. So too was the differentiation of the persistent versus the permanent vegetative state in 1994⁹ and the 2002 consensus statement on the minimally conscious state which distinguished MCS from the vegetative state.¹⁰ MCS was subsequently subcategorized as MCS+ and MCS-, with each designation having functional and prognostic significance.¹¹

In this paper, I will discuss how the current nosology describing disorders of consciousness has evolved over the past four decades. I will consider its origins in antiquity, application in clinical practice, and reshaping in modernity by technological advance. I will suggest how this diagnostic schema was misappropriated, misunderstood, and co-opted by ideology with lingering effects. Grappling with this layered legacy and the emerging neuroscience of brain resilience and covert consciousness, I will suggest that we need to affirm our normative obligations to patients with disorders of consciousness.

The Origins of the Vegetative State

Our story begins with the publication of the landmark *Lancet* paper describing the persistent vegetative state by Bryan Jennett and Fred Plum.¹² These were two giant figures in clinical neuroscience. Jennett was the Scottish neurosurgeon who promulgated the Glasgow Coma and Outcome Scales. Plum was the American neurologist who first identified the Locked-in-State and was the long-time chairman of neurology at Cornell, where he was my teacher. They came together in 1972 to describe a “syndrome in search of a name,” writing of a state of wakeful unresponsiveness in which the eyes are open, but there is no awareness of self, others or the environment, a function of isolated brain stem activity without higher cortical function.

It is interesting to note that the unresponsive wakefulness syndrome (UWS) which has come into vogue amongst European neurologists,¹³ derives almost literally from the original description of the vegetative state by Jennett and Plum, but with a critical difference. In their paper, Jennett and Plum observe of the persistent vegetative state that, “it *seems* wakefulness without awareness.” (Italics added.) While this statement gives authorial provenance to Jennett and Plum for UWS, it also provides a nuanced view on their confidence in definitively asserting that the wakefulness of the vegetative is invariably without underlying awareness. Or put another way, what is observed at the bedside may not correlate with what might actually be going on inside the brain.

Plum was an exceedingly skilled editor and wordsmith. The insertion of “seems” was certainly not accidental but rather an intentional hedge against the possibility of observational error at the bedside producing a discordance with an internal brain state. This degree of semantic precision was exceedingly prescient in 1972, given that functional neuroimaging did not yet exist to query the injured brain and demonstrate such variance.

Jennett and Plum’s caution has been borne out by a history neither lived to see. We now appreciate that a staggering number of patients in chronic care who appear to be in the vegetative state following traumatic brain injury are actually in the minimally conscious state. We also have come to appreciate that patients who appear vegetative at the bedside can harbor covert consciousness and demonstrate volitional responsiveness when given neuroimaging tasks. Both of these groups of patients appear vegetative but are wakeful *and* responsive. But until they are identified, their covert consciousness is further obscured by labelling them as UWS.

Jennett and Plum understood the limits of the neurological phenotype to fully capture a patient’s actual brain state. Absent some deeper knowledge of brain circuitry or neurological genotype—to borrow a Mendelian analogy^{14,15}—one could only assert that patients who appeared vegetative *seemed* awake without awareness. Of course the use of the allegedly more “progressive” UWS designation for this brain state simply asserts unresponsive wakefulness without the critical admission that it might be misleading. While Jennett and Plum’s caution was brilliantly foresighted four decades ago, the invocation of UWS constitutes erroneous usage today when we know that there can be a discordance between one’s behavioral exam and inner state. Renaming the vegetative state as UWS makes the name less precise diagnostically.

The usage of UWS however was not motivated by diagnostic considerations. Instead, it was driven by a desire to counter the perception that the vegetative

appellation was demeaning, given its apparent equation of those in that state with a vegetable. Regrettably, this new language has failed to take account of some old history.

In a 1998 essay Plum himself counters this pejorative linkage, explaining the origins of the vegetative state. He asks, "How did the vegetative state gets its name? Not as the reader might think. Patients' families sometimes challenge us, implying that we have regarded the patient as a vegetable. Not so! The conception of a vegetative nervous system goes a long way back."¹⁶

Recently, Zoe Adams and I have recounted the etymology of the vegetative appellation drawing on Plum's scholarship.¹⁷ Plum traces the origins of the vegetative state to the French physician Xavier Bichat (1771–1802), and the American neurologist and endocrinologist Walter Timme (1874–1956), who draws a line to Aristotle's *De Anima* [On the Soul].^{18,19} To characterize the awake but unresponsive state, Plum invoked a bifurcated nervous system as articulated by Bichat who wrote of a *vie de relation* (animalic) versus *vie de nutrition* (vegetative) nervous system. Plum felt that invoking vegetative as a classification was preferable to other names in use at the time such as apallic syndrome or *coma vigilie*.

Aristotle, himself a classifier and a botanist, introduces the vegetative faculty in Book II of *De Anima*. In his taxonomy the first faculty is nutritive or vegetative. It is foundational and modeled on the plant. In Aristotle's formulation, the vegetative can neither sense nor perceive. Beyond the vegetative, there is sensation, movement and thought, the purview of animals and humans. These are ascending and dependent hierarchical faculties, much like Jennett and Plum conceived the relationship between the autonomic brain stem and the cerebral cortex. But unlike the synergism of the autonomic and higher integrative functions in Jennett and Plum's formulation, Aristotle held that the vegetative and higher levels of function are binary and distinct. They do not interact as they do in the human brain. An entity, or being, is either one or the other in this dichotomous and static taxonomy. Human consciousness, in contrast, depends on both the brain stem and cortex. The former for arousal the later for integrative functions. If only arousal is present, the patient is wakeful but unresponsive, e.g., vegetative.

In formulating their definition, Jennett and Plum were also concerned about the duration of the vegetative state and how to characterize temporal issues. They chose *persistent* as the modifier and not *permanent* to convey the contingency of its duration. This left open the possibility of further recovery over time. They wrote:

Certainly we are concerned to identify an irrevocable state, although the criteria needed to establish that prediction reliably have still to be confirmed. Until then "*persistent*" is safer than "*permanent*" or "*irreversible*"; but "*prolonged*" is not strong enough, and unless it is quantified it is meaningless...²⁰

Jennett and Plum's hesitancy to conclude that the vegetative state was permanent, coupled with their insertion that the individual in that state *seems* to be unaware reflects their caution with respect to categorization and temporality. The redesignation of the permanent vegetative state as chronic speaks to the rigor of Jennett and Plum's original formulation and the precision of their analysis.

Legacy of Quinlan

Despite these clinical caveats, in jurisprudence the Quinlan decision became all about irrevocability and the futility of the vegetative state. Drawing upon Dr. Plum's testimony, who served as a court appointed expert, Chief Judge Hughes of the New Jersey Supreme Court delimited a right to die that was closely linked to the futility and irreversibility of the vegetative state. He wrote, ... "It was indicated by Dr. Plum that the brain works in essentially two ways, the vegetative and the sapient... We have no hesitancy in deciding... that no external compelling interest of the State should compel Karen to endure the unendurable, only to vegetate a few more measurable months with no realistic possibility of returning to any semblance of *cognitive or sapient life*."²¹

Here the moral warrant to withdraw life-sustaining care is the loss of higher cognitive function with no realistic possibility of its return. And yet, it is a curious decision. If the vegetative state was what it purported to be, then how could Ms. Quinlan "endure the unendurable"? It is unlikely that this aside was a misstatement about Ms. Quinlan's inner state. Judge Hughes had just adjudicated that she had no realistic possibility of recovery based on Plum's testimony. It is more likely that Judge Hughes' opinion reflected the discomfort of those around Ms. Quinlan who found life without the return of cognition and sapience a life without meaning and untenable. Those losses, central to the return of personhood, were unendurable for her family and friends. Faced with this tragedy, the withdrawal of life-sustaining therapy became proportionate and indeed, preferable.

This set a precedent for our attitudes toward end-of-life care. Over the ensuing decades, physicians became acculturated to a right to die grounded in the ultimate futility of the vegetative state. It was a condition in which nothing can or should be done. These injuries were immutable, and thus interventions were disproportionate. And the data supported that view. Take the Quinlan autopsy results published in the *New England Journal of Medicine* in 1994.²² Her brain was a gelatinous gel with a thin cortex and hydrocephalus *ex vacuo*. It weighed just 835 grams, just over half of a normal weight, after a decade of degeneration. This was not a biological substrate that could undergird consciousness.

The futility and permanence of the vegetative state became more deeply associated with the right to die. In an editorial accompanying the publication of the autopsy results, Marcia Angell of the *New England Journal of Medicine* explicitly made the link, thanking the Quinlans "for turning their personal calamity into a public benefit by launching the right-to-die movement."²³ This association was continued in other cases involving young women in the vegetative state, notably the case of Nancy Beth Cruzan²⁴ and the national debate over Terri Schiavo.²⁵ The former was litigated in the US Supreme Court and the latter drew the attention of President George W. Bush and the US Congress.

The presumption was that these people were not going to get better, fostering therapeutic nihilism and a static view of brain injury. In clinical practice, this led to premature decisions to withhold or withdraw life-sustaining therapy, to donate organs, institute palliative care referrals, or discharge to nursing homes ill-equipped to care for patients still acutely recovering from their injuries.

To be clear, I am neither against palliative care nor questioning the right of patients or their surrogates to make choices at life's end. I wrote a book on the topic and have been an advocate for improved palliative care for dying patients.²⁶

My point is that these questions need to be informed choices that reflect the possibilities for recovery and which are not engineered to a specific outcome, one way or another. That is, we need to both preserve the right to die and affirm the right to care for those who seek it.²⁷ Unfortunately, practice patterns have stressed the former at the expense of the later.

A paper from *Neurology* by Wijicks and Rubinstein entitled, "The family conference: End-of-life guidelines at work for comatose patients" is reflective of these attitudes. The authors provide their readers with the following guidance:

The attending physician of a patient with a devastating neurologic illness will have to come to terms with the futility of care ... Those families who are unconvinced should be explicitly told they should have markedly diminished expectations for what intensive care can accomplish and that withdrawal of life support or abstaining from performing complex interventions is more commensurate with the neurologic status.²⁸

This is problematic on multiple scores. First, is time course. The title of the piece speaks to advice related to comatose patients. We know that coma is a self-limited state, generally lasting two weeks unless it is medically prolonged. These recommendations indicate that the prognosis will become clear this early during the course of care. Second, there is a presumption of futility, when it may not exist, and the paternalistic directive to convince families to lower their expectations and withhold or withdraw aggressive care that is proportionate to the patient's condition. Of course, in many cases, the patient's prognosis remains unknown while still in coma.²⁹

A narrative from *Rights Come to Mind* provides a graphic illustration of the counsel offered by Wijicks and Rubinstein. The patient was a young Marine who was struck by a car as a pedestrian just before his deployment. In an IRB-approved study of family narratives of patients with disorders of consciousness done to research my book, she recounted the following exchange with her son's neurologist:

Mother: And actually I had a neurologist tell me "your son is basically just an organ donor now."

JJF: And when did that happen?

Mother: Within the first 72 hours. She said, "well he doesn't have the reflexes of a frog."

JJF: He doesn't have the reflexes of a frog?

Mother: Of a frog ... he said "you should really just consider him being an organ donor. That's the best thing you can do for your son." And I said, "I completely disagree with you. I'm not making him an organ donor. Go back in there and do the best you can."³⁰

Needless to say, this is a troubling account. The language is horrific. The allusion to a pithed frog from high school biology is a rather callous way to describe his brain state. And the time course is premature, so soon after the injury.

Beyond the anecdotal, there is epidemiological evidence that these attitudes have had an impact on outcomes. A study from Canada indicated the impact of decisions to withdraw life-sustaining therapy on hospital mortality in patients with traumatic brain injury. Overall in-hospital mortality was 31.7 percent with decisions to withdraw life-sustaining therapy, accounting for 70.2 percent of these deaths.³¹

How do we account for these practice patterns? I believe they are shaped by broader cultural perceptions dating to Quinlan, and flawed analogic reasoning. I do not think it stems from the mal-intent of physicians. Instead, I believe these practices originate in concluding that the loss of consciousness which characterizes severe brain injury is analogous to its loss in end-stage disease.³² In most areas of clinical practice, the loss of consciousness represents the sequela of a terminal illness, end-stage dementia, advanced cancer, or renal disease. Surrogates take the patient's loss of consciousness, and inability to interact, as a prompt to make decisions to withhold or withdraw life-sustaining therapy.

In contrast, TBI patients *present* with a loss of consciousness. That is where the process begins, not necessarily where it ends. While an initial loss of consciousness can be a terminal event, it can also be the pathway to recovery. To presume that the loss of consciousness in TBI is analogous to that in other areas of practice is to misconstrue its prognostic significance. This error, coupled with the presumption that the treatment of severe brain injury is invariably futile, leads to the high rates of withdrawals of life-sustaining therapies early in the course of care and the placement of many patients in what is euphemistically described as "custodial care," where they are deprived of adequate rehabilitation.³³

A Counter-Narrative

Although it was out of our gaze, there was a counter narrative to the presumptive futility of brain injury. In an undated manuscript from his archives housed at New York Weill Cornell Medicine from the 1970s, Plum sought to risk-stratify patients with severe brain injury who might be helped. He wrote that:

We have studied over a 100 patients... can identify within 24 hrs by their neurological signs alone who will can not recover above a vegetative level...who will do well...This leaves a middle group for whom more information is needed but where presenting every effort at treatment must be made to know their maximal potential and how to judge their early signs...³⁴

For Plum, the identification of the vegetative state was more than helping to advance a right to die, which he endorsed, but also the prompt to classify and distinguish brain states and prognosis. It was not just about the futility of care but its possible utility.

In 1977, just two years after Ms. Quinlan's overdose, which placed her into the vegetative state, Plum was profiled in *The New York Times*, conducting a study, with Jennett in Glasgow, on outcomes from severe brain injury.³⁵ They tracked over 1,000 comatose patients treated in New York and Glasgow for at least two years to assess treatments, improve prognostication, and develop practice guidelines to help inform family choices. As Plum described it, the task was to articulate

“the scientific basis of tomorrow’s medical ethics.”³⁶ Through these efforts, he was tightly linking ethics to empiricism, implicitly acknowledging that the right to die was not the only plausible option.³⁷

By 1994, the state of knowledge had progressed to further refine the vegetative state into persistent and permanent subcategories. The Multi-Society Task Force (MSTF) determined that the vegetative state became *persistent* once it has persisted for one month and that it became *permanent* three months following *anoxic* injury and 12 months after *traumatic brain injury*.³⁸ But even here, there is more nuance than first appears. While the notion of permanence is often taken as self-fulfilling, the distinction is contingent and probabilistic. James L. Bernat, a distinguished neurologist and participant in the efforts that scripted the MSTF, spoke about the debate on the new nomenclature and its limits. He told me that:

The adjective “persistent” refers only to a condition of the past and continuing disability with an uncertain future, whereas “permanent” implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis.³⁹

In this frame, permanence becomes probabilistic. It is not a diagnosis but rather a prognosis about a future state. This language was prompted, in part, by the rare outlier cases who seemed to recover outside the aforementioned temporal markers for permanence.

By the late 1990s, it was becoming clear that nested within the vegetative cohort were minimally conscious (MCS) patients who did not behave like classic vegetative state patients.⁴⁰ They seemed to defy the definition of permanence, and demonstrated rare behaviors that betrayed the vegetative diagnosis. Unlike the wakeful unresponsiveness of the vegetative patient, MCS patients were responsive to the environment, albeit episodically and inconsistently. They might reach for a cup, say their names, or look up at someone who entered the room.

First described in 1997,⁴¹ with the classification codified in 2002,⁴² MCS patients were biologically distinct from vegetative ones. On functional neuroimaging MCS patients had widely distributed neural networks,⁴³ in contrast to vegetative patients who did not exhibit these network responses.⁴⁴ This was a key distinction with functional implications with respect to the processing of language and perception of sensory input, including pain.^{45,46}

Beyond demonstrating the differing neurophysiologic substrates of the vegetative and minimally conscious states, neuroimaging also revealed the limitations of behavioral assessment at the bedside. In 2006 Owen and colleagues demonstrated “awareness” in a patient who was clinically vegetative on examination. When asked to imagine herself playing tennis, walking about her house and disaggregating linguistically similar words, she lit up motor, spatial and language regions of interest on volitional imaging.⁴⁷

This was a highly significant finding because it revealed *covert consciousness*. This was exactly what Jennett and Plum had so presciently anticipated back in 1972.⁴⁸ With the advent of modern neuroimaging, a patient who *seems* wakeful and unresponsive can be revealed as harboring covert consciousness. With my colleague, Nicholas D. Schiff, I described such patients as being in a *nonbehavioral minimally conscious state*, noting the discordance between what was observed and the underlying brain state of the patient.⁴⁹

Schiff has since expanded this concept to a broader range of patients with cognitive motor dissociation (CMD).⁵⁰ CMD patients are unresponsive at the bedside but demonstrate volitional responses on fMRI. They can range from those in MCS up to those in the Locked-in-State. More recently, Edlow and colleagues have demonstrated covert consciousness in TBI patients while still in the intensive care unit.⁵¹ Both of these findings have clinical and normative implications for patient assessment and care. They suggest the need for a new nosology that accounts for the possibility of covert consciousness in patients with both acute and chronic injury.⁵²

Nosologic Humility and Neuroscience

As I reflect upon the normative importance of covert consciousness, I can not help but recall the story of Terry Wallace, an Arkansan man who sustained a severe head injury following a motor vehicle accident in 1984. For nearly two decades he was thought to have been in the vegetative state. That is, until 2003 when he began to speak spontaneously, demonstrating that he was minimally conscious. A subsequent review of his medical records suggested that he had been in the minimally conscious state for most of the time following his injury. His covert consciousness only became apparent when he began to speak.

But there is chilling evidence from 1993 that he was aware and yet unresponsive.⁵³ As told to me by his mother, Angilee, and recounted in *Rights Come to Mind*, Terry was residing in a nursing home. A roommate with advanced dementia got tangled up in his bedsheets and asphyxiated himself. Although it was clinically impossible for a vegetative patient to be upset by the tragedy, a nurse's aide intuited that Terry was distressed and called his mother to come by. When Mrs. Wallis arrived, "Terry was lying there with his eyes open wide, he would not go to sleep, I mean he was making no noise at the time." Only later, after he began to talk and was told that he had likely been minimally conscious at that time did Mrs. Wallis appreciate that Terry had been able to appreciate the night's events. In retrospect, she realized, "So I don't know what he saw, I know he saw something. And I know it had, *now*, I knew then it had to be something bad."

Nosologically, there was not a name for Terry's condition. He was diagnosed as being in the vegetative state but had covert consciousness. The minimally conscious state would not be codified for another decade. This should give us pause and harkens back to the original nosological humility of Jennett and Plum, when they cautioned that patients *seem* wakeful and unresponsive. Our descriptive nosology is still but a poor proxy for the circuit-based mechanisms that inform the patient's functional status.

We are just beginning to appreciate the neurophysiologic dimensions of classification. At a structural level, functional neuroimaging has suggested dynamic white matter changes in his brain that might account for his recovery into the minimally conscious state.⁵⁴ Using diffusion tensor imaging, Voss et al. demonstrated axonal sprouting and pruning in Wallis's brain, 19 years after his injury. These new white matter connections between remaining neurons may have been the biological basis for his recovery and ability to interact, decades after his injury. More recently, Thengone et al. reported similar longitudinal white matter changes in another subject, Maggie Worthen, who is profiled in *Rights Come to Mind*. Over a 54 month period, her brain demonstrated white matter changes across the

hemispheres and in Broca's area that correlated with an improved ability to communicate.⁵⁵

These findings suggest that brain injuries are potentially dynamic and not static.⁵⁶ Remarkably, in the process of recovery, the brain is recapitulating a normal *developmental* process of sprouting and pruning in the service of brain repair. This suggests that the current time frame allocated to rehabilitation is inconsistent with the time course of biological recovery. It suggests that we should recast rehabilitation as education.^{57,58}

Moving from the biology of these brain states to their epidemiology, Terry's experience also prompts a question: How many people are in nursing homes, like Wallis, unidentified with covert consciousness?⁵⁹ Schnakers et al. provide a sober response. She and her colleagues found that 41 percent of TBI patients in chronic care, thought to be vegetative, were in fact in the minimally conscious state when assessed behaviorally with the Coma Recovery Scale-Revised.⁶⁰ Often invisible, these patients have the potential to perceive and engage, even if they are ignored and assumed not to be there. One can only imagine the sense of isolation and loneliness that these patients experience.

Recovery, Resilience, and Rights

The great American pragmatist, John Dewey observed the power of science to transform categories and recast normative responsibilities. He wrote, "Inventions of new agencies and instruments create new ends. They created new consequence that stir men and woman to form new purposes."⁶¹ Neuroimaging and our deepening understanding of the circuitry of consciousness, notably the description of the meso-circuit,⁶² have led to pharmacologic and device dependent interventions to harness the potentiality of the injured brain. Early progress has been made with: the advent of deep brain stimulation⁶³ and derivative approaches such as transcranial magnetic stimulation⁶⁴ and directed ultrasound,⁶⁵ as well as pharmaceutical interventions (Amantadine) that have accelerated⁶⁶ or (Zolpidem) that have prompted state changes⁶⁷ resulting in the recovery of consciousness. While much of this progress is in the proof-of-principle stage, the dawn of a therapeutic era for disorders of consciousness is fast approaching.

Now that we can appreciate that there is covert consciousness and have a means to identify it and intervene, we can not turn away. Writing the majority opinion in the *Obergefell* decision which decriminalized gay marriage, Justice Anthony Kennedy wrote that, "New insights and societal understanding can reveal unjustified inequality within fundamental institutional that once passed and unnoticed and unchallenged."⁶⁸

These patients suffer from a degree of inequality unseen elsewhere in society. They remain segregated in chronic care, far from the advances in neuroscience where their conditions could be better identified and ameliorated. It was to this health disparity that the AAN/ACRM/NIDDLR practice guideline spoke.⁶⁹ But the challenge is not just one of access to care.⁷⁰ Instead it is a question of rights, of fundamental equality, necessitated by new scientific insights, to borrow Justice Kennedy's formulation.

As I have written elsewhere,^{71,72,73,74} the neglect and marginalization of patients with disorders of consciousness is a violation of the Americans with Disabilities Act,^{75,76} and the UN Convention on the Treatment of Persons with Disabilities.⁷⁷ To ignore their consciousness is a fundamental violation of their personhood.

History has been kind to the careful contingency of Jennett and Plum's original formulation.⁷⁸ They were categorical neither about their certainty about the apparent wakefulness and unresponsiveness of the vegetative state nor its permanence. History will judge our generation too and ask how we perpetuated the fundamental injustice of treating conscious individuals as if they were not.

Notes

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Disorders of Consciousness, Past, Present, and Future

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