

**SPECIAL COMMUNICATION**

# Disorders of Consciousness and Disordered Care: Families, Caregivers, and Narratives of Necessity



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**Abstract**

By their nature, care decisions for patients with severe disorders of consciousness must involve surrogates. Patients, so impaired, have lost their decision-making capacity and the ability to direct their own care. Surrogates—family members, friends, or other intimates—must step in and make decisions about ongoing care or its withdrawal. This article shares the narrative experiences of these surrogate decision makers as they encounter the American health care system and accompany patients from injury through rehabilitation. Through their perspectives, the article considers challenges to ongoing care and rehabilitation that are a function of a prevailing medical infrastructure and reimbursement framework better suited to patients with acute care needs. Specific attention is paid to the ethical challenges posed by reimbursement strategies such as “medical necessity” as well as those proposed for the Affordable Care Act. The argument concludes that when it comes to care for a disorder related to consciousness, its provision is not discretionary, and its receipt is not an entitlement but a civil right.

Archives of Physical Medicine and Rehabilitation 2013;94:1934-9

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One of the great ironies, if not tragedies, of the evolving scientific understanding of disorders of consciousness is that most patients are not the beneficiaries of these advances. Indeed, most patients are the victims of a pervasive level of neglect dictated by cultural forces that previously I have linked to the evolution of the right-to-die movement<sup>1,2</sup> and the lingering perception that brain injuries are immutable and beyond hope.<sup>3</sup>

These forces adversely influence the care of patients with disorders of consciousness and undermine proper diagnosis and access to emerging treatment and clinical trials. In this article, I will detail this climate of care as understood by families of patients with these conditions. I will also make some recommendations for reform.

In this task, I will draw on my work as a clinical ethicist at an academic medical center as well as narratives obtained from families touched by severe brain injury. Most of these families accompanied patients to Weill Cornell Medical College for participation in neuroimaging and electrophysiological studies designed to

elucidate mechanisms of injury and recovery. In tandem with these scientific studies, we conducted in-depth interviews of more than 35 patient surrogates using methods in narrative ethics tracking their experiences in seeking and obtaining care from the time of injury into acute care, rehabilitation, and chronic care.<sup>4</sup> The collection of these narratives and their analysis were approved by the Weill Cornell Medical College Institutional Review Board.

The debriefs, which will inform a forthcoming monograph, *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness* (Cambridge University Press), are heartwrenching and instructive. They speak to a pervasive nihilism on the part of the health care system that discounts the possibility of recovery, despite scientific evidence to the contrary that prospects are not uniformly grim if patients receive an accurate diagnosis, are given time to recover, and provided access to pharmacologic or neuroprosthetic trials that might accelerate or prompt improvement.

Paradoxically, despite noteworthy progress in the neuroscience of disorders of consciousness<sup>5</sup> and emerging evidence-based recommendations for practice,<sup>6</sup> patients—at least as evidenced in our sample—encounter a disinterested,<sup>7</sup> if not hostile health care system.<sup>8</sup> Notwithstanding differences in race, ethnicity, class, socioeconomic status, and state of origin, surrogates tell a depressingly stereotypical tale of neglect.<sup>9</sup> Patients often receive an incorrect diagnosis from clinicians,<sup>10</sup> who mistakenly assume a static view of brain states despite the fact that half of patients

Presented at the Brain Injury Summit, sponsored by Craig Hospital, January 11, 2012, Beaver Creek, CO.

Supported by an Investigator Award in Health Policy Research from the Robert Wood Johnson Foundation, and grants from the Buster and Jerold B. Katz Foundations.

No commercial party having a direct financial interest in the results of the research supporting this article has conferred or will confer a benefit on the authors or on any organization with which the authors are associated.

who sustain a traumatic coma and remain unconscious for a month will end up in a minimally conscious state (MCS),<sup>11</sup> emerge from MCS, or more fully recover.<sup>12,13</sup> Of course, patients who are in coma for an hour, a day, or a week have a better prognosis. Nonetheless, many acute care physicians presume that a patient who is in a vegetative state (VS) in the first days, weeks, and months after injury will remain there forever. These diagnostic misconstruals carry with them prognostic implications that lead to recommendations to withhold and/or withdraw life-sustaining therapy, or to convert the patient into an organ donor. These “palliative” recommendations are often made while the patient is still in the emergency department or during the early days of hospitalization while still comatose.

Later, during hospitalization, patients are discharged while still medically unstable, sometimes with near-fatal sequelae, to ill-equipped nursing homes that are unable to manage these neurologically and medically complex patients, often still requiring acute hospitalization. As we will see below, the inability of these chronic care facilities to care for these patients might stem from inadequately trained or equipped staff unable to manage a medical or neurologic emergency. Another factor might be that the staff does not have the clinical skills necessary to identify the transition from VS to MCS using specialized bedside assessments such as the Coma Recovery Scale—Revised. This skill set is more the purview of psychiatry and neuropsychology than “standard” medical or neurologic practice.

For those patients fortunate enough to have demonstrated a requisite degree of early progress to earn a coveted spot in a brain injury rehabilitation center, length of stay is severely limited and governed by “medical necessity.” These regulations require overt behavioral evidence of ongoing improvement to warrant additional benefits. Patients who fail to meet these criteria are dispatched in weeks to nursing homes, venues unsuited to meet their needs or those of expectant families. There, young people with head trauma are commingled with the elderly who have dementia, despite their differing disease trajectories.

In this article, I will elaborate on these findings with representative examples of the lived experiences of surrogates who have accompanied patients from injury on through emergent care, hospitalization, rehabilitation, and chronic care. Their impressions and verbatim narratives are not scholarly in tone but are rich in information. Their content comes from bearing witness to a care system that urgently needs reform of its practices and attitudes toward patients in pursuit of recovered consciousness. That struggle is a heroic one that is wholly dependent on others and the resources that are made available.

## Injury and emergent care

No one is prepared for a sudden brain injury and its consequences on family dynamics. Given the demographics of traumatic brain

injury (TBI) and its impact on young people, the burden of decision making typically falls on parents or a spouse. Surrogates are called on to make critical decisions, often for heretofore, young, healthy patients. Days earlier these patients were vibrant, expecting them to have contemplated their own frailty, much less completed an advance directive or shared their preferences for life-sustaining therapies, is unthinkable. Unguided by the patient’s prior wishes, and confronted by their own fears for the future, surrogates must make decisions about conditions with which they are unfamiliar. As one banker whose wife had sustained a brain injury told us, “Let’s face it, this is a complicated area and I know a lot about the bond market, but I don’t know much about the brain.”

Families are at the mercy of the information that is provided to them. Whereas other areas of medicine may be more familiar to the layperson, most will be naïve to nomenclature shrouding brain states. In their relative ignorance, surrogates can confuse terms such as coma, vegetative state, and minimally conscious state or conflate them, still influenced by post-Schiavo polemics.<sup>13,14</sup> As such, they are vulnerable to being misinformed or misled.

This is especially problematic because early in the course of care, physicians tend to make global statements about prognosis that are not always evidence based. Instead of a more parcellated approach to diagnosis and prognosis, physicians make categorical statements—for example, “there is no hope for meaningful recovery,”<sup>15</sup>—and become prescriptive about family expectations and information disclosure.<sup>16</sup> This occurs in a rather unannounced fashion and even in patients who have sustained a more favorable profile of TBI.

Acculturated to the right to die since the 1976 case of Karen Ann Quinlan,<sup>17</sup> and the loss of consciousness as the inevitable harbinger of the end of life in a medical context, physicians tend to generalize their experience with patients who have lost consciousness in the setting of a terminal medical illness to those who are unconscious because of brain injury.<sup>12,18</sup> They urge surrogates to agree to a do-not-resuscitate order or to a decision to withdraw life-sustaining therapy. Although this counsel can be well intentioned, many physicians fail to appreciate that brain injury is distinct from other maladies that cause loss of consciousness. Too often a false analogy is drawn between acquired head injury and degenerative or terminal disease. The implication is that all is lost and care is futile once consciousness is lost. Moreover, surrogates often take the loss of consciousness, and the inability to interact with others, as a prompt for decisions to withhold life-support when decision-making capacity is lost.<sup>19</sup>

But to state the obvious: not all losses of consciousness are equal. In the setting of a progressive, terminal illness, the loss of consciousness is the end of a process. In brain injury it might well portend the start of a recovery.

A balance needs to be struck between preserving the right to die, something that should be sustained, with affirming the right to care for those who need and desire it.<sup>14,20</sup> Currently, at least from this commentator’s perspective, the balance is skewed toward nihilism and an unreflected on, almost reflexive nod toward the right to die for this population. As I have written elsewhere, nothing here should be taken to abridge choice about the use of life-sustaining therapy.<sup>2</sup> But if we truly value informed consent and informed refusal, of which resuscitation is a component, then families need to be better informed about their options. This includes the possibilities for recovery, graded or otherwise, as part of the dialogic process in the acute stages of injury, when so much remains contingent.

### List of abbreviations:

ACA	Patient Protection and Affordable Care Act
ACOs	accountable care organizations
DOC	disorders of consciousness
FPL	federal poverty level
MCS	minimally conscious state
SNFs	skilled nursing facilities
TBI	traumatic brain injury
VS	vegetative state

These forces coalesce in the acute setting in efforts to turn brain-injured patients into organ donors, sometimes by rather zealous efforts of organ procurement organizations charged by statute to ask about donation when death is thought near.<sup>21</sup> The mother of a young man who had been struck by a car as a pedestrian—ironically just before deployment as a Marine to Iraq—told us of the disquieting experience she had in the emergency department. A neurologist, eschewing both diagnostic precision and humanistic tact, told her, “Your son is basically just an organ donor now ... he doesn’t have the reflexes of a frog ... you should really just consider him being an organ donor. That’s the best thing you can do for your son.”

The vulnerability of surrogates to a knowledge deficit, and the susceptibility of patients to intemperate organ “harvest,” calls for less global pronouncements about prognosis in indeterminate cases. In its place, let me propose what I have described as *time-delimited prognostication*, in which prognosis is tied to meeting diagnostic milestones on a timeline after injury. These parameters include time in the comatose state, duration of the VS, and speed at which the patient reaches MCS.<sup>12</sup> This process is much like tracking a hurricane across the South Atlantic en route to the United States. While still a tropical storm midway across the ocean, it is difficult to know whether it will mature into a full-fledged hurricane and where it will make landfall. But that cone of uncertainty decreases with the march of time when prediction can become more accurate. The same can be said about prognostication in brain injury in the acute setting. Although early and definitive prognosis of permanent unconsciousness or death may be justified in a comatose patient when there are clear negative signs such as loss of pupillary function, corneal reflexes, and bilateral somatosensory-evoked responses,<sup>22</sup> transitioning from coma to VS can often reflect a hopeful sign of recovery in the right context.

Because of the prognostic indeterminacy of coma, I would also urge a change in practice patterns about the solicitation of organ donation until the patient’s outcome is clearer. Balancing the need for organ donation against the risk of precluding the recovery of some who might have been prematurely “harvested” for their organs, I would urge a prudential approach and suggest that solicitation not occur until a patient is out of coma, unless the patient’s injury places him/her just above brain death.<sup>23</sup>

## Hospitalization, rehabilitation, and medical necessity

Patients who survive their initial injuries, and families who withstand the aforementioned pressures to withhold or withdraw life-sustaining, are subsequently subjected to placement and discharge pressures once the patients are perceived to be stable. Discharge decisions are, according to our informants, often quite precipitous and without warning, leaving surrogates scrambling to make a choice about where their loved ones will be placed. Families describe sudden notifications that their time in acute care has been expended and that their loved one, who has failed to “properly progress,” will be sent to chronic care. This notification often occurs without warning or the opportunity to evaluate placement options, causing considerable anxiety as families lose the shelter of the hospital, even as patients are still medically unstable for discharge.

In one case, patient diagnosed as vegetative, with central hyperthermia nearly died because of ongoing fever spikes on arrival in a nursing home that had neither the medical nor nursing

staff to provide necessary care. It was a disaster in the making. The patient’s mother told us, “In hindsight, I think it was too early to send him out to a facility where there wasn’t monitoring... there was no way to know he was in any kind of distress unless you actually saw him because he’s not going to yell out or anything like that.” The patient survived his brief foray into chronic care and was readmitted to the hospital for stabilization.

Where patients head after hospitalization is influenced by their degree of recovery and insurance coverage, which can vary widely and can be seemingly capricious in our sample of respondents. Patients who regain a level of consciousness may be directed to a rehabilitation program. However, those who have not made a requisite amount of overt progress to benefit from structured rehabilitation will be sent to a chronic care facility with uncertain, if any, rehabilitative services. These assessments can be premature as patients are generally only 3 to 4 weeks postevent when disposition is determined. Such determinations can have dire consequences for patients whose pace of recovery is not what utilization reviewers expect. The aforementioned patient with central hyperthermia is a case in point. His recovery several years hence is functionally beyond emergence from MCS, with impaired motor output but the ability to communicate with others via a keyboard and e-mail.

The advent of new interventions that can alter the course or trajectory of brain injury will likely stress present-day structures of care and expectations about how patients will progress. Although therapeutic hypothermia is not applied to patients with TBI, who are the focus of this anthology, its impact on the care trajectory of patients is illustrative of how systems of care might need to respond to equally laudable advances in acute care for TBI. Such interventions will test current structures of care that are accustomed to patients dying or recovering, as in the case with cardiac arrest in concert with the well-established Levy criteria.<sup>24</sup> What will happen when patients who have received therapeutic hypothermia after cardiac arrest have prolonged needs for intensive care because their prognosis has become less certain?<sup>25</sup> Although recent reports of the ability of early electroencephalography to assess the degree of neuronal injury after therapeutic hypothermia is encouraging,<sup>26</sup> hospital systems of care are wholly unprepared for new outcomes that might follow on this innovation.

This is not a fanciful speculation because it might be argued, writ large, that the challenges posed by patients with traumatic disorders of consciousness (DOC) are a direct consequence of intracranial pressure monitoring in the modern era.<sup>27</sup> Death and herniation were tempered by these mitigating interventions, leading to a change in the mix of disorders seen in the acute and rehabilitative contexts. This led to the emergence of minimally conscious patients from a cohort previously destined for death or the permanent VS. Current systems of care still do not know how or where to place these patients.

We are witnessing a similar demographic in patients who have received therapeutic hypothermia for anoxic injury, and that emerging experience is instructive because it reveals that there is no care venue for a patient who does not die, is not in the vegetative state, and does not regain consciousness in the allotted 3 weeks after admission. That some patients might have a prolonged recovery worthy of continued hospitalization because they have unresolved acute care issues or medical problems that are extremely complex is a scenario that will stress conventional structures of care. Similar to displaced persons who have lost their nationality, such patients—regardless of whether they have a traumatic or an anoxic injury—are refugees between acute and

chronic care, awaiting rehabilitation but still not healthy enough for that critical next step.

The advent of acute care interventions and their impact on the care trajectory suggest that the line between acute care and rehabilitation needs to be redrawn, allowing patients to receive the elements of care that they need irrespective of venue. If a patient needs both the vigilance of cardiac telemetry for a recovering heart and intensive neurorehabilitation for an awakening brain, we should redesign systems of care to achieve a proper mix of acute and rehabilitative services.

Such a mosaic of care was articulated in part in the Mohonk Report to the U.S. Congress,<sup>28</sup> which sought to outline a seamless pathway from acute care through rehabilitation and aftercare. Leading experts outlined many of the aforementioned deficiencies and suggested strategies to overcome fragmentation. We envisioned a network approach in order to share specialized expertise and to advance practice and scientific knowledge of these conditions. Networks would be composed of 3 tiers of institutions: skilled nursing facilities (SNFs) where most patients reside; expert acute rehabilitation facilities; and research centers of excellence. These research cores would be the hub around which acute rehabilitation and SNFs would be clustered. This would be organized in a regional fashion in order to have the requisite expertise and innovation available to all patients within a geographic frame. It was envisioned that nationally there might be 3 to 5 research cores, each linked to 10 to 15 acute rehabilitation centers and a myriad of SNFs and patients in the community living at home with support.

It was hoped that such a model could engage in research to better delineate the epidemiology of these conditions, identify markers and predictors of late recovery from DOC, and better apprehend the physiological heterogeneity within VS and MCS and between these conditions.<sup>28</sup> Experts also hoped that the Mohonk recommendations, and this network approach to care, might attract funding to underwrite demonstration projects that would lead to better ongoing medical care (and DOC diagnostic assessment) for a vulnerable population, prone, as we have seen, to medical complications and an astounding rate of misdiagnosis.

A central concern was the need to integrate DOC expertise into the care environments (most often SNFs) where these patients reside after acute care. Finally, it was also hoped that network research would better inform how we communicate with families over the course of injury and recovery.<sup>28</sup>

That was the aspirational model articulated in Mohonk. It was visionary in 2006 and remains a pressing necessity today. Sadly, little progress has been made to achieve such systemic reform, again despite the astounding scientific advancements that we have witnessed since 2006. In fact, such an expansive view of reform is challenged at the most basic level by the malignant reimbursement constraints of regulations like medical necessity, which undermine care and constrain the ability to underwrite patients enrolled in research.

By statute, Medicare will pay for what is “reasonable and necessary for the diagnosis and treatment of illness or injury to improve functioning of a malformed body member.”<sup>29</sup> Reasonable and necessary is thought to refer to questions of amount, frequency, duration, and efficacy of the proposed treatments, determinations that if “misjudged” by rehabilitation facilities can result in penalties and paybacks that can imperil a facility’s fiscal well-being. These incentives/disincentives can adversely impact patient access to rehabilitation when its potential benefit is uncertain, as it often is.<sup>30</sup>

The pleas of families are instructive, not just for their appeal to human solidarity, but because they remind us of the artifice of medical necessity, which after all is a human construct that addresses fiscal and not biological realities about mechanisms of recovery. The wife of a patient in an essentially locked-in state made the following trenchant observation of the contradictions in our discourse: “You know, they keep telling me brain trauma, the brain is so complex. And I’m thinking then why stop the therapy? He may not do it right now, but in a month he might do it...” True, we just do not know in many cases.

To further complicate matters, medical necessity has us looking to incomplete forms of evidence when assessing brain injury. Despite the primacy of the behavioral examination,<sup>31</sup> it is not the only mode of assessment to demonstrate that improvement is indeed occurring. But it is what matters. Centers for Medicaid and Medicare Service regulations require that patients demonstrate overt behavioral medical progress in order to continue to receive treatments or rehabilitation. This is a problem that is compounded by our growing awareness that improvements in the brain, as indicated by neuroimaging findings, are not always consonant with behavioral manifestations of progress.<sup>32-35</sup> This discordance could leave the utilization reviewer with the mistaken notion that the absence of overt behavioral advance invariably means that recovery has stalled.

Another equally challenging problem is that of time frames of recovery.<sup>36</sup> If medical necessity coheres to known frames of recovery for better understood and trackable conditions (such as hip fracture), then brain injury is in another dimension.<sup>36</sup> One reaches a certain number of paces in rehabilitation after hip surgery on a predictable timeline, whereas the pattern is often unknown in brain injury, with recoveries being less predictable and slower than in somatic recoveries. The mother of a young woman with a brainstem stroke and thalamic bleed pointed to the inconsistency of rules of only receiving “physical therapy if you progress from one level to another in a certain number of days. So obviously someone who is minimally conscious is less likely to succeed in those categories even though they might need physical therapy, those benchmarks don’t work for people who are not conscious. But they’re still used.”

These rules coupled with premature discharge from the hospital further limit time in rehabilitation. Take the example of a woman in her mid-50s who sustained fat emboli to her brain after orthopedic surgery. She was discharged to a 30-day trial period in a coma emergence program while still receiving mechanical ventilation. Her speech-therapist daughter felt it was “unfair” because precious rehabilitation time was consumed with pulmonary issues that rightly should have been addressed during her hospitalization. As she put it, “These things should have happened in the acute care situation. She should have been weaned off there, she should have been sort of ready to go into a rehab center... (?) We lost a week’s worth of therapy there that maybe she could have gotten.”

## Brain injury and the Affordable Care Act

Given all the accumulated biases against patients with DOC and the counterfactual perception that nothing can or should be done for this population, I worry that patients with DOC will be especially vulnerable to some provisions of the Patient Protection and Affordable Care Act (ACA), legislation signed into law by President Obama in 2010<sup>37</sup> and the subject of a recent

constitutional challenge before the Supreme Court.<sup>38</sup> A full review of the law is beyond the scope of this article. My comments should not be taken as criticism of this generally laudable legislation but rather a commentary on its potential impact on patients with DOC.

Briefly stated, the ACA seeks to enhance efficiencies, improve access to primary and preventive care, lower overall expenditures, and fight fraud and abuse. It will also work to improve quality and strengthen consumer protections and insurance reforms, relying in large part on upgrades to information technology. The centerpiece of these efforts is accountable care organizations (ACOs), groups of physicians and hospitals joined together to provide better care. The financial well-being of ACOs is linked to efficiency and performance measures, coupled with an incentive-based reimbursement process, that will alter historic revenue streams.<sup>39</sup> While assumption of financial risk can lead to enhanced reimbursement, it can also lead to greater losses. Expert opinion indicates that there will be less revenue in academic medicine, even if ACOs are efficient.<sup>40,41</sup>

The Brain Injury Association of America's analysis of the ACA is mixed.<sup>42</sup> On the positive side there will be enhanced Medicaid eligibility to 133% of the federal poverty level (FPL); tax credits to enable insurance purchase for those whose incomes are between 134% and 400% of the FPL; access to more affordable health benefits exchanges; dependent coverage to 26 years; affordable coverage for preexisting conditions; and coverage for high-risk patients for 6 months.<sup>42</sup> There will also be enhanced consumer protections with federal nondiscriminatory rules, with the eventual elimination of annual and lifetime caps.

But rehabilitation was an afterthought in the drafting of ACA.<sup>42</sup> Advocates worked with the Obama administration to get rehabilitation services included in the purview of coverage as one of the key categories of essential (read, covered) health services. Remarkably, even after U.S. Representative Gabrielle Giffords' brain injury, rehabilitation was not in the original bill. Its insertion into the law required appeals by many advocates including the Brain Injury Association of America<sup>42</sup>; Representative Bill Pascrell,<sup>43</sup> chair of the Congressional Brain Injury Caucus; and Pia Carusone,<sup>44</sup> the former chief of staff to Congresswoman Giffords, among others.

The challenge for the community of caregivers who attend patients with severe brain injury is the emphasis on efficiencies in the ACA. Efficiencies assume a knowledge of what would constitute timely and appropriate care, and presuppose that the natural history of a disease or condition is understood and predictable.<sup>45</sup> This is a knowledge threshold we have yet to cross with patients who are minimally conscious.

As is well known to the readership of this anthology, the timing and mechanism of emergence from MCS is neither understood nor easily placed on a timeline.<sup>36</sup> Lammi et al<sup>46</sup> have elegantly made this point. They note that "the low correlation coefficients between duration of MCS and the outcome measures suggest that prognostic statements based on length of time a person is in the MCS cannot be made with confidence."<sup>46(p746)</sup> Despite the expectations of regulators, the brain will recover by biological standards, not reimbursement criteria.<sup>47</sup>

The ACA will inevitably lead to ethical and procedural tensions: incentive-based performance metrics for diseases whose trajectories we understand versus the uncharted path of recovery from brain injury. While enhanced consumer protections might mitigate such concerns, from what families of patients with brain injury have taught me, I would posit that it is better to have, than have to appeal for, services. Furthermore, benefits should go

beyond minimal standards of care. What about sufficient funding for neuroprosthetic interventions, be they device,<sup>48,49</sup> pharmacologic,<sup>50-52</sup> or neuroimaging based<sup>32-35?</sup>

## Struggle for consciousness

One might legitimately question basing scholarly observations and policy recommendations on narratives of laypeople whose only qualification for comment is their proximity to a patient with a DOC. Because these laypeople are relative newcomers to the shadow world of brain injury, it would be easy to discount their contributions to understanding the needs of the patients whom they love and who remain dependent on them. But as the bioethics scholar Howard Brody<sup>53</sup> reminds us, there is an ethical saliency to illness narratives. In this collection, the voices of families, sometimes schooled, sometimes not, deserve a hearing so as to demonstrate that there are human consequences to a level of neglect that we still accept as a standard of care. Their plaintive voices are instructive, reminding us that consciousness is not an entitlement that can be given and taken away but a fundamental human right that must be upheld.<sup>54</sup> The wisdom of these families gives urgency to that imperative and our collective obligation to advocate for these patients and their families.

## Keywords

Affordable Care Act; Brain injury; Disability and civil rights; Disorders of consciousness; Family narratives; Neuroethics; Rehabilitation; Vegetative State

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## Acknowledgments

I thank the many families who generously shared their stories with me, Nicholas D. Schiff, MD, and John Whyte, MD, PhD, for their critical reading of the text, Jennifer Hersh, MD, for her research assistance, and Dr. Alan Weintraub for his invitation to Colorado.

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