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## ***Cruzan* and the Other Evidentiary Standard: A Reconsideration of a Landmark Case Given Advances in the Classification of Disorders of Consciousness and the Evolution of Disability Law**

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CRUZAN AND THE OTHER EVIDENTIARY  
STANDARD: A RECONSIDERATION OF A  
LANDMARK CASE GIVEN ADVANCES IN  
THE CLASSIFICATION OF DISORDERS OF  
CONSCIOUSNESS AND THE EVOLUTION  
OF DISABILITY LAW

*Joseph J. Fins\**

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I. EVIDENCE AND ACCURACY

IT is more than a bit ironic that the decision in *Cruzan v. Director, Missouri Department of Health*<sup>1</sup> hinged on the relationship of evidentiary standards and the Due Process Clause of the Fourteenth Amendment. The question before the U.S. Supreme Court was whether Missouri's Supreme Court had correctly ruled that they could assert a clear and convincing evidence standard for consequential decisions made by surrogates on behalf of an incompetent patient.<sup>2</sup> The U.S. Supreme

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1. 497 U.S. 261 (1990).

2. *See id.* at 267-69.

Court affirmed the Missouri court's decision and asserted that there had been no violation of the Due Process Clause.<sup>3</sup> For the majority, the question of evidence related to the quality of knowledge that might allow a surrogate to make a decision to withdraw life-sustaining therapy.<sup>4</sup> In the absence of clear and convincing evidence to the contrary, treatment would continue and thus life would be preserved.<sup>5</sup>

In his dissent, Justice Brennan, joined by Justices Marshall and Blackmun, also focused on the quality of the evidence. But he took a different approach. He did not dispute the State's legitimate interest in protecting the rights of the incompetent.<sup>6</sup> Rather, he argued that care could only be provided legitimately when it was known to cohere with Nancy Cruzan's wishes.<sup>7</sup> The goal was not to prolong Ms. Cruzan's life but to preserve her liberty.<sup>8</sup> To do so, it would be necessary to provide "Nancy Cruzan, now incompetent, with as accurate as possible a determination of how she would exercise her rights under these circumstances."<sup>9</sup> If it were determined that continued treatment was consistent with her prior preferences, the State could "legitimately assert an interest in providing that treatment."<sup>10</sup> Short of that knowledge, the goal was to be as accurate as possible in discerning what her wishes might be.

Justice Brennan continued by asserting that "accuracy, therefore, must be our touchstone," maintaining that "*until* Nancy's wishes have been determined, the only state interest that may be asserted is an interest in safeguarding the accuracy of that determination."<sup>11</sup> He argued that by establishing a clear and convincing evidence standard, Missouri had paradoxically "fashioned a rule that lessens the likelihood of accurate determinations."<sup>12</sup> Instead of speaking to the specificity of Ms. Cruzan's wishes, Missouri's presumption towards treatment in the absence of known preferences "skew[ed] the result away from a determination that as accurately as possible reflect[ed] the individual's own preferences and beliefs."<sup>13</sup> Worse than preserving life, that standard was "a rule that transform[ed] human beings into passive subjects of medical technology."<sup>14</sup> Justice Brennan argued that Missouri could neither safeguard patient choice by misappropriating it nor by depriving surrogates of their rightful prerogative of making choices on behalf of those closest to them.

Both the majority opinion and the dissents in *Cruzan* centered on the importance of evidence related to patient choice. Nonetheless, each side

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3. *Id.* at 286–87.

4. *Id.*

5. *Id.*

6. *Id.* at 303 (Brennan, J., dissenting).

7. *Id.* at 304.

8. *Id.* at 315.

9. *Id.*

10. *Id.*

11. *Id.* at 315–16.

12. *Id.* at 326.

13. *Id.* at 325.

14. *Id.*

saw it differently. For the majority, the absence of evidence led to a default proposition to treat. For the minority, the moral warrant to treatment was lacking absent prior knowledge of patient wishes.

Justice Stevens summed up the consensus on the importance of the evidence and captured the differing way those facts could inform the law. In his dissent, Justice Stevens wrote:

My disagreement with the Court is thus unrelated to its endorsement of the clear and convincing standard of proof for cases of this kind. Indeed, I agree that the controlling facts must be established with unmistakable clarity. The critical question, however, is not how to prove the controlling facts but rather what proven facts should be controlling.<sup>15</sup>

But there was another sort of evidence—controlling facts—upon which the majority and minority agreed. While each side viewed the clear and convincing standard differently, neither questioned whether Ms. Cruzan was in the persistent vegetative state.<sup>16</sup> While the role of patient preferences was disputed, Ms. Cruzan’s diagnosis was taken as a certain predicate. Herein lies the irony: in the thirty years since the *Cruzan* decision, the diagnostic classification of the vegetative state and other disorders of consciousness has evolved. Since *Cruzan*, our nosology has expanded to include the permanent vegetative state (1994),<sup>17</sup> the minimally conscious state (2002),<sup>18</sup> and the *chronic* vegetative state, which supplanted the permanent vegetative state in 2018.<sup>19</sup> These refinements in our diagnostic thinking have brought greater specificity to the assessment of these conditions and with it the reexamination of the clinical presumptions that went unquestioned in *Cruzan*.

In this article, I will review how our understanding of the vegetative state and other disorders of consciousness have developed since *Cruzan* and what this new nosology means for patients with severe brain injury and their families.<sup>20</sup> I will trace this refinement of diagnostic classification

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15. *Id.* at 350 (Stevens, J., dissenting).

16. *See, e.g., id.* at 266 (majority opinion); *id.* at 302 (Brennan, J., dissenting).

17. Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (First of Two Parts)*, 330 *NEW ENG. J. MED.* 1499, 1500 (1994) [hereinafter Multi-Society Task Force on PVS, *Part I*]; Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (Second of Two Parts)*, 330 *NEW ENG. J. MED.* 1499, 1572–79 (1994) [hereinafter Multi-Society Task Force on PVS, *Part II*].

18. Joseph T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 *NEUROLOGY* 349, 349 (2002) [hereinafter Giacino et al., *The Minimally Conscious State*].

19. Joseph T. Giacino et al., *Practice Guideline Update Recommendations Summary: Disorders of Consciousness*, 91 *NEUROLOGY* 450, 456 (2018) [hereinafter Giacino et al., *Practice Guideline Update Recommendations Summary*].

20. Much of the historical and clinical background for this evolution is drawn from Joseph J. Fins, *Disorders of Consciousness, Past, Present, and Future*, 28 *CAMBRIDGE Q. HEALTHCARE* 603, 604 (2019) [hereinafter Fins, *Disorders of Consciousness, Past, Present, and Future*]. *See also* Joseph J. Fins, *Disorders of Consciousness in Clinical Practice: Ethical, Legal and Policy Considerations*, in *JEROME B. POSNER ET AL., PLUM AND POSNER’S DIAGNOSIS OF STUPOR AND COMA* 449–77 (5th ed. 2019) [hereinafter Fins, *Disorders of Consciousness in Clinical Practice*]. *See generally* Joseph T. Giacino et al., *Disorders of*

and address the broader normative and legal challenges posed by covert consciousness in patients with cognitive motor dissociation. I will conclude by considering our obligations to patients with disorders of consciousness in the applicability of American disability rights law.

While it is impossible to relitigate Cruzan's diagnosis thirty years later, these developments, both scientific and normative, should prompt a reflective pause when considering care decisions for patients with disorders of consciousness. What appeared to be clinically categorical has become, with time, new clinical insights, and emerging therapeutic interventions, a more nuanced problem space. The presumptions of futility so associated with the vegetative state, and more generally severe brain injury, and so central to the right to die have to some extent been upended by our emerging knowledge of these brain states. Medicine and the law have to balance a right to die with a correlative right to care for those who might yet be helped and whose prior wishes, or those of their surrogates, desire continued treatment.<sup>21</sup> While these developments do not fundamentally abridge the right to self-determination, they do impose a heightened clinical, ethical, and juridical responsibility to ascertain the evidentiary base upon which care decisions will be predicated. To that end, ideology must give way to emerging evidence about brain injury when considering the clinical predicate upon which value choices are made.<sup>22</sup> Nothing less will suffice. As Justice Brennan presciently noted, "Accuracy, therefore, must be our touchstone."<sup>23</sup>

## II. THE ORIGINS OF THE VEGETATIVE STATE AND THE SUBSEQUENT CLASSIFICATION OF DISORDERS OF CONSCIOUSNESS

*Cruzan* forms part of a troika of cases involving women in the vegetative state that deeply informed how Americans think about death, dying, and the right to die.<sup>24</sup> The 1990 case of *Cruzan* is bookended both by *In re Quinlan*, which was decided by the U.S. Supreme Court in 1976<sup>25</sup> and by the national debate over Terri Schiavo in 2005 that mobilized the in-

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*Consciousness After Acquired Brain Injury: The State of the Science*, 10 NATURE REVIEWS NEUROLOGY 99 (2014).

21. Joseph J. Fins, *Affirming the Right to Care, Preserving the Right to Die: Disorders of Consciousness and Neuroethics After Schiavo*, 4 SUPPORTIVE & PALLIATIVE CARE 169, 170 (2006) [hereinafter Fins, *Affirming the Right to Care, Preserving the Right to Die*].

22. Joseph J. Fins & Fred Plum, *Neurological Diagnosis Is More than a State of Mind: Diagnostic Clarity and Impaired Consciousness*, 61 ARCHIVES NEUROLOGY 1354, 1355 (2004).

23. *Cruzan v. Dir., Mo. Dep't. of Health*, 497 U.S. 261, 316 (1990) (Brennan, J., dissenting).

24. This section is drawn in part from the author's previous work, including JOSEPH J. FINS, *A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END* (2005); JOSEPH J. FINS, *RIGHTS COME TO MIND: BRAIN INJURY, ETHICS AND THE STRUGGLE FOR CONSCIOUSNESS* (2015) [hereinafter FINS, *RIGHTS COME TO MIND*]; Fins, *Disorders of Consciousness, Past, Present, and Future*, *supra* note 20; Fins, *Disorders of Consciousness in Clinical Practice*, *supra* note 20.

25. *In re Quinlan*, 355 A.2d 647, 647 (N.J. 1976).

tercessions of Congress and President George W. Bush.<sup>26</sup> In the aggregate, these three cases helped to advance a right to die in American jurisprudence.

Collectively these cases helped to enfranchise surrogates to make decisions on behalf of incapacitated patients. Indeed, it has been argued that the origins of the Patient Self-Determination Act (PSDA), which stipulated that all states have a mechanism for advance care planning, and the need for individuals to express their end-of-life preferences in advance of decisional incapacity originated from Justice O'Connor's opinion in *Cruzan*.<sup>27</sup> Her *Cruzan* opinion inspired Senators Danforth and Moynihan to write the Patient Self-Determination Act,<sup>28</sup> which has since been enshrined in clinical practice as a means for patients to engage in advance care planning. These developments in law and practice point to the centrality of *Cruzan*, and her sister cases, in the evolution of end-of-life care in the United States and the centrality of the vegetative state to this process.<sup>29</sup>

At the core of this evolution were perceptions about the futility of the vegetative state.<sup>30</sup> This view had its origins in *Quinlan*, a case also involving a young woman, Karen Ann Quinlan, in the vegetative state.<sup>31</sup> Chief Judge Hughes of the New Jersey Supreme Court asked Fred Plum, the co-originator of the persistent vegetative state, to provide expert testimony and confirm Ms. Quinlan's diagnosis. Plum examined Ms. Quinlan and his testimony formed a key component of Chief Judge Hughes's decision to allow for the removal of Ms. Quinlan's ventilator.<sup>32</sup> He wrote,

[I]t 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 could 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.<sup>33</sup>

The justification for the withdrawal of life-sustaining therapy hinges on this loss of higher cognitive function with the implication that personhood had also been irretrievably lost. This was the ultimate in medical futility and shaped perceptions for decades. And it still does for patients with severe brain injury. A recent study from Canada reported that 70.2% of

26. Fins, *Affirming the Right to Care, Preserving the Right to Die*, *supra* note 21, at 170.

27. *Cruzan*, 497 U.S. at 287–92 (O'Connor, J., concurring).

28. See Elizabeth L. McCloskey, *The Patient Self-Determination Act*, 1 KENNEDY INST. ETHICS J. 163, 166 (1991).

29. See generally A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END, *supra* note 24.

30. Joseph J. Fins, *Constructing an Ethical Stereotaxy for Severe Brain Injury: Balancing Risks, Benefits and Access*, 4 NATURE REVIEWS NEUROSCIENCE 323, 323 (2003).

31. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

32. *Id.* at 654–55.

33. *Id.* at 654, 653.

deaths during an acute hospitalization for severe brain injury were attributable to a decision to withdraw life-sustaining therapy.<sup>34</sup>

The vegetative state was not a brain state amenable to repair or restoration, and these perceptions shaped physician attitudes and grounded a right to die in the futility of the vegetative state. While the right to die has expanded beyond those in the vegetative state, it had its start there.<sup>35</sup> Brain injuries of such gravity were immutable and attempts to sustain—much less treat—patients in the vegetative state were ethically disproportionate because nothing could be done to help. Ms. Quinlan’s autopsy published in the *New England Journal of Medicine* in 1994 only sustained this perception.<sup>36</sup> The findings indicated her brain weighed 835 grams, which is just over half the weight of a normal brain; had a thinning cortex; and had hydrocephalus ex vacuo, meaning massively enlarged ventricles.<sup>37</sup> This was not a brain that would seemingly sustain higher integrative function or have prospects for recovery.

While a low chance of recovery was certainly true in Ms. Quinlan’s case, we have come to understand in the decades since *Quinlan* that patients who appear clinically identical to Ms. Quinlan may in fact have been a heterogeneous group with different neurocircuitry and a greater capacity for recovery. These are biological distinctions with clinical, normative, and legal implications that are worthy of additional parsing.

To fully understand these critical distinctions, we need to trace our evolving knowledge of disorders of consciousness and begin with a consideration of the vegetative state—what it is and how it came to be. Eighteen years before *Cruzan* was decided, Bryan Jennett and Fred Plum described the persistent vegetative state. In a landmark article in the *Lancet* in 1972, they described a state of wakeful unresponsiveness in which the eyes were open but there was no awareness of self, others, or the environment.<sup>38</sup> They sought to designate what they described as a “syndrome without a name.”<sup>39</sup> Their efforts had an outsized reach because of their respective standing in medicine. Jennett was a distinguished Scottish neurosurgeon who had previously described the Glasgow Coma and Outcome Scales.<sup>40</sup> Plum, who was my teacher and later colleague at Cornell, was a preeminent American neurologist who had described the Locked-

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34. Alexis F. Turgeon et al., *Mortality Associated with Withdrawal of Life-Sustaining Therapy for Patients with Severe Traumatic Brain Injury: A Canadian Multicentre Cohort Study*, 183 CAN. MED. ASS’N J. 1581, 1581 (2011).

35. See Fins & Plum, *supra* note 22, at 1354–55.

36. See Hannah C. Kinney et al., *Neuropathological Findings in the Brain of Karen Ann Quinlan: The Role of the Thalamus in the Persistent Vegetative State*, 330 NEW ENG. J. MED. 1469, 1472–74 (1994).

37. *Id.* at 1470.

38. Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 LANCET 646, 734–35 (1972).

39. *Id.* at 735–37.

40. Geoff Watts, *Obituary: Bryan Jennett*, 371 LANCET 646, 646 (2008).

in-State in 1966 (with his colleague Jerome B. Posner)<sup>41</sup> and had begun to characterize disorders of consciousness in his scientific and clinical work.<sup>42</sup>

From the start, the vegetative state has been paradoxical. First, the physiology and appearance of these patients at the bedside has prompted confusion and, in some quarters, contention. Paradoxically, they appear to be awake and seem to have recovered from coma, which is an eyes closed state of unresponsiveness. On closer examination, however, their eyes are open but unknowing, which is disappointing to expectant loved ones. The eyes, which are thought to be the windows to the soul, are open *but* unresponsive and unaware. Families are devastated when they realize that a sign they took to be emblematic of the return of consciousness was in fact simply the recovery of the brain stem leading to what Jennett and Plum so elegantly described as a state of wakeful unresponsiveness.<sup>43</sup> Only reflexive functions which derive from the recovery of the brain stem are intact.<sup>44</sup> Higher integrative functions involving the cortex are not present.<sup>45</sup> Only the *vegetative* functions exist, hence the framework offered by Chief Judge Hughes in *Quinlan*.

The term “vegetative,” which seems pejorative to the unschooled, actually derives from Aristotle’s *De Anima* and the hierarchical brain function cited in that decision.<sup>46</sup> Aristotle, the botanist and taxonomist, distinguished the nutritive or vegetative faculties from the higher (animalic) ones that produce sensation and cognition.<sup>47</sup> Plum was aware of the conception of a vegetative nervous system and appropriated it to hierarchically distinguish the autonomic functions subsumed by the brain stem from the cognitive and sapient functions of the cerebral cortex.<sup>48</sup>

The vegetative state when first described by Jennett and Plum also had a temporal component, hence the modifier “persistent.” In their *Lancet* article, they explained why they chose the term “persistent” against other alternatives.<sup>49</sup> They wanted to convey a high likelihood of long duration but, at that juncture, felt uncomfortable asserting that the state was permanent.<sup>50</sup> The data was not there for them to sustain that argument so

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41. See FRED PLUM & JEROME B. POSNER, *DIAGNOSIS OF STUPOR AND COMA* 93 (1st ed. 1966).

42. See Joseph J. Fins, *A Once and Future Clinical Neuroethics: A History of What Was and What Might Be*, 30 *J. CLINICAL ETHICS* 27, 27–34 (2019); see also Lawrence K. Altman, *Fred Plum, Neurologist Who Helped Coin ‘Persistent Vegetative State,’ Dies at 86*, *N.Y. TIMES* (June 12, 2008), <https://www.nytimes.com/2010/06/13/health/13plum.html> [https://perma.cc/WH49-CU5V].

43. Jennett & Plum, *supra* note 38, at 734–35.

44. *Id.*

45. *Id.*

46. ARISTOTLE, *DE ANIMA* (R.D. Hicks trans., 1907); see also Zoe M. Adams & Joseph J. Fins, *The Historical Origins of the Vegetative State: Received Wisdom and the Utility of the Text*, 265 *J. HIST. NEUROSCIENCES* 140, 144–49 (2017).

47. ARISTOTLE, *supra* note 46, at 412a22–415b5.

48. Fred Plum et al., *Coordinated Expression in Chronically Unconscious Persons*, 353 *PHIL. TRANSACTIONS ROYAL SOC’Y* 1929, 1929–30, 1932–33 (1998).

49. Jennett & Plum, *supra* note 38, at 736–37.

50. *Id.*



they settled on “persistent” to convey the likely duration of this brain state and to leave open the possibility that there might be additional recovery over time.<sup>51</sup> Their explanation is worth noting for its nosological humility and unwillingness to go beyond the available data. They observed: “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.”<sup>52</sup>

As the foregoing indicates, Jennett and Plum were exceedingly cautious about the claims they could make. This was also the case for what was observed at the bedside during the clinical examination. In an aside that seems remarkably prescient to me, they comment on the persistent vegetative state, noting that “it seems that there is wakefulness without awareness.”<sup>53</sup> They carefully hedged their bets because, without the ability to peer inside the injured brain, they could not know for sure. So, they carefully suggested that their state of wakeful unresponsive was based on what was observed, and it seemed that this reality cohered with the patient’s inner state. Their recognition of the limits of bedside evaluation would prove prescient given the subsequent identification of covert consciousness utilizing functional neuroimaging.

Before that technology developed, the vegetative state underwent subsequent refinement. Four years after *Cruzan* was decided, the Multi-Society Task Force (MSTF) further classified the vegetative state as persistent and permanent. In a two-part report published in the *New England Journal of Medicine* in 1994, the vegetative state was reclassified as *persistent* if it lasted for one month and as *permanent* either three months after *anoxic* brain injury or twelve months after *traumatic* brain injury.<sup>54</sup>

The 1994 MSTF framework soon began to prove problematic as it was becoming clear that some patients were violating these temporal markers and recovering consciousness after entering into the permanent vegetative state. These patients, who appeared vegetative but were in a liminal state of consciousness, were subsequently described as being in the minimally conscious state (MCS), a category codified in 2002.<sup>55</sup> MCS patients had the capacity for intention, attention, or memory and interacted with their environment unlike the wakeful, unresponsive vegetative patient.<sup>56</sup> They may look up when someone came into the room, respond to their name, or reach for a cup but did so unreliably and inconsistently. When

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51. *See id.* at 735.

52. *Id.*

53. *Id.* at 734.

54. *See* Multi-Society Task Force on PVS, *Part II, supra* note 17, at 1575.

55. *See, e.g.,* Joseph T. Giacino & Kathleen Kalmar, *The Vegetative and Minimally Conscious States: A Comparison of Clinical Features and Functional Outcome*, 12 J. HEAD TRAUMA & REHABILITATION 36, 37 (1997).

56. Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35, 37 (2009).

they were not responding, they were often mistaken for being in the vegetative state. Caroline Schnakers and her colleagues found that 41% of traumatic brain injury patients in chronic care that were thought to be vegetative were in fact in the MCS with the Coma Recovery Scale-Revised, a behavioral assessment tool.<sup>57</sup>

Functional neuroimaging revealed that MCS patients, who were often mistaken for being vegetative, were in fact biologically distinct. Unlike vegetative patients who did not have intact neural networks,<sup>58</sup> those in MCS had widely distributed neural networks capable of the integrative function necessary to sustain consciousness or to perceive pain.<sup>59</sup> Functional imaging also revealed the possibility of awareness in patients who appear to be in the vegetative state. In a seminal paper published in 2006, Adrian Owen and his colleagues reported “awareness” in a patient who was behaviorally in the vegetative state based on clinical examination.<sup>60</sup> This patient was able to demonstrate volitional responses on neuroimaging and activate anatomic regions of interest when asked to perform motor, spatial, and linguistic tasks, such as imagining playing tennis or walking around a house, and distinguishing similarly sounding words with differing meanings.<sup>61</sup>

This was a highly significant finding because it showed the potential for *covert consciousness*, namely a discordance between what was observed at the bedside and what might actually be going on inside a patient’s head.<sup>62</sup> This possibility, realized thirty-four years after Jennett and Plum wrote their *Lancet* article, prompted Jennett and Plum to note that the vegetative state *seems* to be one of wakeful unresponsiveness.<sup>63</sup> In 1972, they did not have the technological means to definitively know that what was observed at the bedside was always an accurate representation of the brain’s inner state.

Jennett and Plum’s editorial caution was more prescient than they might have even appreciated at the time. The possibility of covert consciousness—or cognitive motor dissociation (CMD), as my colleague Nicholas Schiff has described it<sup>64</sup>—represents a class of patients who are capable of volitional responses on fMRI but unable to respond motorically. The utilization of functional imaging<sup>65</sup> and electrophysiologic mea-

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57. *Id.* at 36.

58. Steven Laureys et al., *Cortical Processing of Noxious Somatosensory Stimuli in the Persistent Vegetative State*, 17 *NEUROIMAGE* 732, 734–35 (2002).

59. Nicholas D. Schiff et al., *fMRI Reveals Large-Scale Network Activation in Minimally Conscious Patients*, 64 *NEUROLOGY* 514, 522 (2005).

60. Adrian M. Owen et al., *Detecting Awareness in the Vegetative State*, 313 *SCIENCE* 1402, 1402 (2006).

61. *Id.*

62. See Joseph J. Fins & Nicholas D. Schiff, *Shades of Gray: New Insights into the Vegetative State*, 36 *HASTINGS CTR. REP.* 8, 8 (2006).

63. See Jennett & Plum, *supra* note 38.

64. See Nicholas D. Schiff, *Cognitive Motor Dissociation Following Severe Brain Injuries*, 72 *JAMA NEUROLOGY* 1413, 1415 (2015).

65. Brian L. Edlow et al., *Early Detection of Consciousness in Patients with Acute Severe Traumatic Brain Injury*, 140 *BRAIN* 2399, 2400 (2017).

tures<sup>66</sup> can help these patients who may be in chronic care or, as has been more recently shown, still hospitalized in intensive care. Notably, patients who are found to have covert consciousness have a more favorable one-year outcome than those who do not have covert consciousness.<sup>67</sup> In the aggregate, this data has significant, clinical, normative, and legal implications for patient care.<sup>68</sup>

Although we should expect the continued evolution of medicine's classification of disorders of consciousness, an important milestone was reached in 2018 when 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 both a systematic, evidence-based review<sup>69</sup> and a new practice guideline<sup>70</sup> pertaining to these patients. These papers, along with a commentary on ethical palliative and legal considerations which I was privileged to write with my co-author James L. Bernat,<sup>71</sup> were simultaneously published in *Neurology* and the *Archives of Physical Medicine and Rehabilitation*. These papers called for better assessment and care for patients with disorders of consciousness and a reversal of the presumption of futility that has undermined the care of this population.<sup>72</sup> From a nosological point of view, this body of work supplants the 1994 MSTF report on the vegetative state<sup>73</sup> and affirmed the prior MCS Aspen Neurobehavioral Conference Workgroup criteria.<sup>74</sup> Importantly, it called

66. See, e.g., Jan Claassen et al., *Detection of Brain Activation in Unresponsive Patients with Acute Brain Injury*, 380 *NEW ENG. J. MED.* 2497, 2498–99 (2019).

67. *Id.* at 2501–02.

68. See Brian L. Edlow & Joseph J. Fins, *Assessment of Covert Consciousness in the Intensive Care Unit: Clinical and Ethical Considerations*, 33 *J. HEAD TRAUMA & REHABILITATION* 424 (2018). An additional word on nomenclature is noted with respect to the vegetative state. Recently in Europe, neurologists have been referring to the vegetative state as Unresponsive Wakefulness Syndrome (UWS), in part because of the view that the vegetative state is pejorative. See Steven Laureys et al., *Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome*, 8 *BMC MED.* 68, 68–69 (2010). The renaming of the vegetative state is problematic on several counts. First, and most significantly, is the adoption of a behavioral description in light of covert consciousness as discerned by neuroimaging described previously. Second is the incomplete and inaccurate appropriation of the term itself. Jennett and Plum, when describing the vegetative state, observed that “it seems that there is wakefulness without awareness” and, thus, should lay claim to authorial provenance. See Jennett & Plum, *supra* note 38, at 734. And beyond that is their careful insertion of “seems,” which spoke to the limits of bedside assessment, a concern vindicated by the detection of covert consciousness and cognitive motor dissociation. *Id.* Third, is the failure to appreciate the etymologic origins of the vegetative state dating back to Aristotle as described above. See Adams & Fins, *supra* note 46, at 140–53.

69. Joseph T. Giacino et al., *Comprehensive Systematic Review Update Summary: Disorders of Consciousness*, 91 *NEUROLOGY* 461 (2018) [hereinafter Giacino et al., *Comprehensive Systematic Review Update Summary*].

70. Giacino et al., *Practice Guideline Update Recommendations Summary*, *supra* note 19.

71. Joseph J. Fins & James L. Bernat, *Ethical, Palliative, and Policy Considerations in Disorders of Consciousness*, 91 *NEUROLOGY* 471 (2018).

72. See, e.g., FINS, *RIGHTS COME TO MIND*, *supra* note 24, at 309–11.

73. Multi-Society Task Force on PVS, *Part I*, *supra* note 17; Multi-Society Task Force on PVS, *Part II*, *supra* note 17.

74. Giacino et al., *The Minimally Conscious State*, *supra* note 18.

for the re-designation of the permanent vegetative state as *chronic*, as a review of the available data suggested that 20% of patients thought to be in the permanent vegetative state could recover to a higher level of function.<sup>75</sup>

This is a striking number—and open to ideological hyperbole—given the place that the perceived permanence of the vegetative state has played in law and medicine. With Bernat, I sought to temper this number and explain *who* these patients were.<sup>76</sup> First, it is critical to note that for 80% of patients the vegetative state remains permanent after the prior milestones were reached following anoxic or traumatic injury.<sup>77</sup> Second, for the 20% of patients with the possibility of additional recovery, it is equally necessary to stratify the sample.<sup>78</sup> Bernat and I noted that nearly half of these patients were likely to have been in the MCS all along but were misdiagnosed, given the 41% error rate noted by Schnakers.<sup>79</sup> These patients would have been found to have been in MCS by behavioral assessment using the Coma Recovery Scale-Revised. Some patients might have had intact neural networks that were dormant until activated by neuromodulation using pharmacologic agents such as Amantadine, which has been shown to accelerate the recovery of consciousness in a randomized clinical trial,<sup>80</sup> or Zolpidem, which has been shown in case reports to cause changes in brain state, activating dormant neural networks resulting in the return of consciousness.<sup>81</sup>

Alternately, a state change could have been prompted by electrical, magnetic, or sonic neuromodulation, such as investigational approaches utilizing deep brain stimulation,<sup>82</sup> transcranial magnetic stimulation,<sup>83</sup> and directed ultrasound.<sup>84</sup> Stimulated, these patients might have been able to manifest a behavioral response at the bedside or on neuroimaging, placing them in the CMD category. A smaller fraction might have had late structural changes<sup>85</sup> and been unassessed, again having the potential to manifest responses behaviorally if tasked or on neuroimaging.

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75. See Fins & Bernat, *supra* note 71, at 472.

76. See *id.* at 472–73.

77. *Id.* at 472.

78. See *id.*

79. See Schnakers et al., *supra* note 56, at 37.

80. Joseph T. Giacino et al., *Placebo-Controlled Trial of Amantadine for Severe Traumatic Brain Injury*, 366 *NEW ENG. J. MED.* 819, 823–24 (2012).

81. Christine Brefel-Courbon et al., *Clinical and Imaging Evidence of Zolpidem Effect in Hypoxic Encephalopathy*, 62 *ANNALS NEUROLOGY* 102, 103 (2007).

82. Nicholas D. Schiff et al., *Behavioral Improvements with Thalamic Stimulation After Severe Traumatic Brain Injury*, 448 *NATURE* 600, 600–02 (2007).

83. Aldo Ragazzoni et al., *Clinical Neurophysiology of Prolonged Disorders of Consciousness: From Diagnostic Stimulation to Therapeutic Neuromodulation*, 128 *CLINICAL NEUROPHYSIOLOGY* 1629, 1634–35 (2017).

84. Martin M. Monti et al., Letter to the Editor, *Non-Invasive Ultrasonic Thalamic Stimulation in Disorders of Consciousness After Severe Brain Injury: A First-in-Man Report*, 9 *BRAIN STIMULATION* 940, 940–41 (2016).

85. Daniel J. Thengone et al., *Local Changes in Network Structure Contribute to Late Communication After Severe Brain Injury*, *SCI. TRANSLATIONAL MED.*, Dec. 7, 2016, at 1, 8.

The point of elaborating on the 20% is to note that most patients were either already in MCS (and unidentified), under-stimulated, or in CMD. Only a small fraction would have had the structural changes that most lay readers would associate with late recovery. This clarification is necessary to temper expectations of miracle cures and also stress the permanence of unconsciousness for the 80% of patients in the newly designated chronic vegetative state.

### III. THE NEW NOSOLOGY: REREADING *CRUZAN* IN THE TWENTY-FIRST CENTURY

With these developments in mind, let us turn to Ms. Cruzan and her diagnosis. We now know that under prevailing nosologic schema she would no longer be categorized as being in the persistent vegetative state. Her accident was in 1983, the case went to the Supreme Court of Missouri in 1988, and then her case went to the U.S. Supreme Court in 1990.<sup>86</sup> By 1994, she would have been characterized as in the permanent vegetative state given the framework offered by the MSTF; that is, until 2018 when she would have been redesignated as in the chronic vegetative state according to the new criteria promulgated by AAN, ACRM, and NIDILRR. Such is the evolving nosology of classification.

But of course, these re-designations presume the evidentiary predicate agreed to by both the Supreme Court of Missouri and the U.S. Supreme Court, namely that Ms. Cruzan was in the vegetative state.<sup>87</sup> Given the evolution of these diagnostic categories and new scientific understanding of disorders of consciousness, it is only natural—indeed tempting—to ask the provocative question of whether her diagnosis was correct. That is, Was she in the vegetative state or perhaps the MCS?

There is a precedent for asking this sort of question about whether a patient could be in a borderline brain state. Plum once recounted to me that in order to assess the lower limit Ms. Quinlan's diagnosis he had taken her off the ventilator as part of his examination, as the court-appointed neurologist tasked to confirm her diagnosis in the persistent vegetative state.<sup>88</sup> I was shocked that he took this upon himself, as the case *itself was about the removal of Ms. Quinlan's ventilator*. But, of course, Plum, in his sanctioned diagnostic role, had to disconnect the patient from the ventilator to see if she had an intact brain stem that could drive respiratory effort. If she did not breathe on her own as he performed this apnea test, her diagnosis would have been brain death. But she did breathe; thus, she had an intact brain stem consistent with the diagnosis

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86. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc), *aff'd sub nom.*, 497 U.S. 261 (1990).

87. *See Cruzan*, 497 U.S. at 266; *Cruzan*, 760 S.W.2d at 411.

88. *See generally In re Quinlan*, 355 A.2d 647, 654–55 (N.J. 1976).

of the vegetative state. As is well appreciated, she lived for many years, breathing on her own.<sup>89</sup>

With this precedent in mind, let us engage in the post hoc thought experiment and consider the upper limits of Ms. Cruzan's diagnosis. Let us begin with the clinical history. In *Cruzan v. Harmon*,<sup>90</sup> we read the initial details of Ms. Cruzan's injury. We learn that Ms. Cruzan was in a car accident.<sup>91</sup> A state trooper arrived six minutes later to find Ms. Cruzan face down in a ditch not breathing.<sup>92</sup> Paramedics arrived nine minutes later and restored cardiac and respiratory function in another three minutes.<sup>93</sup> An initial head CT scan did not show any brain abnormalities.<sup>94</sup> It was estimated that Ms. Cruzan had been anoxic for twelve to fourteen minutes, more than enough time to cause "permanent brain damage."<sup>95</sup> This suggests that she had a mix of traumatic and anoxic brain injury, with the latter likely being more determinative given its potential to inflict global harm on the brain.

This initial description is confounding as it presumes that Ms. Cruzan had only been apneic (not breathing) since the arrival of the initial emergency responder. More than likely, she had been partially or completely deprived of oxygen to some degree longer than that, as she was found both apneic and asystolic. The other incongruity is the normal CT scan done upon admission. There was neither evidence of diffuse axonal injury seen with anoxic injury nor any evidence of traumatic brain injury although she had been in a car accident and was said by the attending physician to have sustained a contusion. While there was no evidence of either anoxia or contusion on the scan, it is important to appreciate that these findings can manifest themselves on subsequent CT scan studies. Later CT scans—as reported in *Cruzan*—showed large ventricles and thinning of the cortex, consistent with grave injury, and "massive enlargement of the ventricles filling with cerebrospinal fluid in the area where the brain has degenerated," as well as "cortical atrophy [which was] irreversible, permanent, progressive and ongoing."<sup>96</sup>

Ms. Cruzan remained in a coma for three weeks,<sup>97</sup> which may be slightly longer than the norm, but she may have been sedated or have had confounding reasons to remain in that unresponsive, eyes-closed state. But then there is a striking and troubling comment in the record from *Cruzan*: "Thereafter, she seemed to improve somewhat and was able to

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89. See FINS, RIGHTS COME TO MIND, *supra* note 24, at 40; see also Joseph J. Fins, *Lessons from the Injured Brain: A Bioethicist in the Vineyards of Neuroscience*, 18 CAMBRIDGE Q. HEALTH CARE ETHICS 7, 8 (2009).

90. *Cruzan*, 760 S.W.2d 408.

91. *Id.* at 410–11.

92. *Id.* at 411.

93. *Id.*

94. *Id.*

95. *Id.*

96. *Id.* at 410–11.

97. *Id.* at 411.

take nutrition orally.”<sup>98</sup> A feeding tube was placed subsequently “to assist her recovery.”<sup>99</sup> Nonetheless, “valiant efforts” were made to rehabilitate her “without success.”<sup>100</sup>

What to make of this report of her ability to take nutrition orally? If it were a purposeful action, it would belie the diagnosis of the vegetative state. Should that make us wonder if she were minimally conscious? Jennett, in his monograph on the vegetative state, notes that the MSTF “concluded that most patients preserve the swallowing reflex but that coordination is impaired.”<sup>101</sup> While there is some dispute about whether the ability to take oral feeding precludes the vegetative diagnosis, Jennett believed that whether or not these patients needed artificial nutrition and hydration was not diagnostically dispositive but “a matter of practicality rather than of pathophysiology.”<sup>102</sup>

William H. Colby, the attorney for the Cruzans, recounts in his memoir, *Long Goodbye: The Deaths of Nancy Cruzan*, the testimony of Ronald C. Cranford, a neurologist and witness for the plaintiffs.<sup>103</sup> Cranford, a distinguished neurologist from the University of Minnesota and expert in the vegetative state, had spent considerable time examining Ms. Cruzan.<sup>104</sup> In his testimony to the trial court, Cranford explained that the mere ability to swallow is not purposeful but rather reflexive.<sup>105</sup> Colby summarized Cranford’s testimony on this point: “Placing food carefully in the back of the mouth to activate a brain stem mediated swallowing reflex is not eating.”<sup>106</sup>

And what of her apparent response to pain and sound? Does that make the case for the MCS and not the persistent vegetative state? As reported in *Cruzan*, “[H]er highest cognitive brain function is exhibited by her grimacing perhaps in recognition of ordinarily painful stimuli, indicating the experience of pain and apparent response to sound.”<sup>107</sup>

Pain is described in contradictory ways by the Justices in *Cruzan* and seems to be a topic of confusion and an object of psychological projection. Justice Scalia, in his concurring opinion, making a distinction between withdrawing life support and suicide, asserted, “Petitioners rely on [the following] distinction[ ] to separate Nancy Cruzan’s case from ordinary suicide: . . . that she is permanently incapacitated and in pain,”<sup>108</sup> a

98. *Id.*

99. *Id.*

100. *Id.*

101. BRYAN JENNETT, *THE VEGETATIVE STATE: MEDICAL FACTS, ETHICAL AND LEGAL DILEMMAS* 18 (2002) (referencing Multi-Society Task Force on PVS, *Part I, supra* note 17, at 1499–508).

102. *Id.*

103. *See* WILLIAM H. COLBY, *LONG GOODBYE: THE DEATHS OF NANCY CRUZAN* 129–55 (2002).

104. *See id.* at 130–32.

105. *See id.* at 131–32.

106. *Id.* at 133.

107. *Cruzan v. Harmon*, 760 S.W.2d 408, 411 (Mo. 1988) (en banc).

108. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 296 (1990) (Scalia, J., concurring).

contention about the petitioners which, in my view, is not supported by the record. Justice Stevens, in his dissenting opinion, cited Judge Blackmar from Missouri and stated that “[t]here is evidence that Nancy may react to pain stimuli.”<sup>109</sup> Judge Blackmar also added the prospect of psychic suffering: “If she has any awareness of her surroundings, her life must be a living hell.”<sup>110</sup> When we read of such inferences—or Justice Brennan’s dissent, in which he observed that being in “[s]uch conditions are, for many, humiliating to contemplate, as is visiting a prolonged and anguished vigil on one’s parents, spouse and children”<sup>111</sup>—one must ask whose pain and suffering is the object of concern? Is it the patient or those who are pressed into that vigil?

This tendency to conflate the patient’s potential for pain and suffering with those of their intimates was a feature of Chief Judge Hughes’s decision in *Quinlan*. Note the wording of his decision allowing the removal of Ms. Quinlan’s ventilator:

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 could 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.<sup>112</sup>

Citing the testimony of Plum and correctly distinguishing the autonomic or vegetative functions of the brain from the cognitive and sapient ones, Chief Judge Hughes nonetheless wrote that the State was compelling “Karen to endure the unendurable.”<sup>113</sup> There is illogic in this passage. If a patient is vegetative, they are not enduring anything. They are unaware of self, others, and the environment. Chief Judge Hughes clearly appreciates this but, nonetheless, writes of compelling Ms. Cruzan “to endure the unendurable.”<sup>114</sup> More likely than not, as suggested by Justice Brennan’s comments about “anguished vigil,”<sup>115</sup> Chief Judge Hughes is referring to the distress inflicted upon the Quinlans who would be forced to watch their daughter in the vegetative state. The pain and suffering is neither Ms. Quinlan’s nor Ms. Cruzan’s; rather, it is the pain and suffering of their families.

Returning to Judge Blackmar’s conclusion, quoted by Justice Brennan, we see echoes of this very language. Judge Blackmar in his dissent wrote, “The principal opinion attempts to establish absolutes, but does so at the expense of human factors. In so doing it unnecessarily subjects Nancy and

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109. *Id.* at 332 (Stevens, J., dissenting) (quoting *Cruzan*, 760 S.W.2d at 429 (Blackmar, J., dissenting)).

110. *Id.* at 337 (quoting *Cruzan*, 760 S.W.2d at 429 (Blackmar, J., dissenting)).

111. *Id.* at 311 (Brennan, J., dissenting).

112. *In re Quinlan*, 355 A.2d 647, 654, 663 (N.J. 1976).

113. *Id.* at 663.

114. *Id.* at 661.

115. *Cruzan*, 497 U.S. at 311 (Brennan, J., dissenting).



those close to her to continuous torture which no family should be forced to endure.”<sup>116</sup> Here, it seems clear that Judge Blackmar believed that the Cruzan family was being tortured by having to bear witness to—that is, “endure”—continued life-sustaining measures they felt were unjustly inflicted upon their daughter. But the text of Judge Blackmar’s dissent remains ambiguous because he maintained that the continued treatment mandated by the majority “subjects Nancy,” as well as her family members, to “continuous torture.”<sup>117</sup> Like Chief Judge Hughes’s opinion, the inference in Judge Blackmar’s dissent is clear about who is actually being tortured. Nonetheless, the language of the text is challenging if one wants to assert some degree of higher cognitive function to vegetative patients.

I point to these ambiguities regarding pain because they cloud the picture about the vegetative patient’s ability to perceive pain and experience suffering. For our purposes of confirming the diagnosis, it is essential to determine whether Ms. Cruzan’s seeming expressions of pain or distress are in any way dispositive of awareness. Specifically, the question is, Was her grimacing purposeful or reflexive? Was it autonomic or intentional? Simply examining the language, we note the insertion of “perhaps” before the description of the perception.<sup>118</sup> The possibility of a perception versus a reflex is suggested by the “experience of pain,”<sup>119</sup> which could imply cognizance or understanding. The language is highly ambiguous, descriptive without regard, and more confounding than it would first appear.

To return to Jennett’s treatise on the vegetative state, he writes, “Most patients show some response to painful stimuli. A stimulated limb may withdraw or there may be a generalized movement of all four limbs . . . .”<sup>120</sup> He continues, with special relevance to our question regarding Ms. Cruzan, noting that the aforementioned movements are “sometimes accompanied by facial grimacing and perhaps a groan.”<sup>121</sup> He concludes by explaining that “[i]t is generally held that these responses are all at reflex level and do not indicate that pain is being experienced at a conscious level.”<sup>122</sup> Cranford testified to the same. According to Colby’s account of Cranford’s testimony:

Dr. Cranford dispassionately explained the exam of the day before to Judge Teel. To Cranford, the medical reality was clear: A grimace is a reflex, which in healthy people we automatically associate with

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116. *Cruzan v. Harmon*, 760 S.W.2d 408, 429–30 (Mo. 1988) (en banc) (Blackmar, J., dissenting).

117. *Id.*

118. *See, e.g., id.* at 411 (majority opinion) (noting that the trial court found that Ms. Cruzan was “oblivious to her environment except for reflexive responses to sound and perhaps painful stimuli; . . . [and] her highest cognitive brain function is exhibited by her grimacing perhaps in recognition of ordinarily painful stimuli, indicating the experience of pain and apparent response to sound”).

119. *See id.*

120. JENNETT, *supra* note 101, at 15.

121. *Id.*

122. *Id.*

pain. Nancy's grimaces could never have connection to pain as we understand it, because the part of her brain that could perceive, understand, and feel pain was simply gone.<sup>123</sup>

Similarly, Ms. Cruzan's "apparent response to sound"<sup>124</sup> is consistent with the vegetative state and not necessarily indicative of awareness of her environment. Jennett explains, "It seems clear that cortical integrity is not required for sudden light or sound to stimulate a brief orienting reflex with the eyes blinking and the head and eyes turning briefly towards a strong auditory or visual stimulus."<sup>125</sup> Colby reports that Cranford's "conclusion was that Nancy was in a classic persistent vegetative state."<sup>126</sup>

From our vantage point, thirty years hence, one must agree with Cranford's conclusion. He was a skilled neurologist who carefully examined the patient. He was well versed in the literature surrounding the vegetative state and highly respected as a clinician and as an academic neurologist. As an author of the MSTF, he had vast experience assessing such patients. In Cranford's obituary in the *Lancet*, Eelco Wijdicks of the Mayo Clinic asserted that Cranford "had seen more patients in persistent vegetative state than anyone else."<sup>127</sup> Wijdicks noted Cranford's "clinical acumen," stating that Cranford "was without any question one of the world's experts in persistent vegetative state."<sup>128</sup>

#### IV. BEYOND CRUZAN: CURRENT DIAGNOSTIC AND THERAPEUTIC CHALLENGES

Having acknowledged Cranford's expertise and a fact pattern consistent with the vegetative diagnosis for Ms. Cruzan, it is equally important to appreciate subsequent developments that might inform the assessment of future patients thought to be in the vegetative state. Ms. Cruzan was evaluated without a behavioral metric tool called the Coma Recovery Scale-Revised, which was designed to assess disorders of consciousness and has been found to be superior to the Glasgow Coma and Outcome Scales.<sup>129</sup> This assessment tool has been revalidated by the AAN, ACRM, and NIDILRR's evidence-based review<sup>130</sup> and endorsed by its practice guideline.<sup>131</sup> Less validated and still investigative methods of assessment include neuroimaging and electrophysiologic testing. The value of these methods is their ability to assess covert consciousness.<sup>132</sup>

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123. COLBY, *supra* note 103, at 132.

124. *Cruzan*, 760 S.W.2d at 411.

125. JENNETT, *supra* note 101, at 11.

126. COLBY, *supra* note 103, at 132.

127. Ivan Oransky, *Obituary: Ronald E. Cranford*, 368 LANCET 112, 112 (2006).

128. *Id.*

129. See Schnakers et al., *supra* note 56, at 37.

130. See Giacino et al., *Comprehensive Systematic Review Update Summary*, *supra* note 69.

131. See Giacino et al., *Practice Guideline Update Recommendations Summary*, *supra* note 19.

132. See generally Claassen et al., *supra* note 66; Edlow et al., *supra* note 65.

While not routinely used in clinical practice, neuroimaging and electrophysiologic testing can help in ambiguous clinical circumstances and avoid a type-II error; that is, missing consciousness when it is indeed present.<sup>133</sup> The challenge that remains is that these methods are not ready for routine clinical practice because the test characteristics of these assessment tools have not been adequately described. Indeed, some of the data thus far is paradoxical. For example, some patients who are able to follow behavioral commands are unable to do the same tasks in the scanner. Moreover, while positive activations may be dispositive of covert consciousness, conclusions cannot be drawn from a negative test.<sup>134</sup> A failure to respond may mean the patient is unconscious. However, the determination may depend on the scientific methodology; the nature of the question or task; the patient's ability, level of arousal, attention span, and ability to attend to the question; or the latency of the patient's response. In one circumstance, a subject's response on the scanner was so delayed that it was buried in the data of the following question, confounding the analysis.<sup>135</sup> Another reason that a patient may fail to respond is because the patient has a sensory disorder and is unable to hear the question. And there is always the possibility that a patient may not *want* to respond. For all these reasons, a nonresponse has to be considered as indeterminate.<sup>136</sup>

Nonetheless, a positive response to a volitional task is highly meaningful. In neuroimaging circles, this is taken as demonstrating the presence of consciousness and not mere passive activation of a region of interest in the brain because, in a volitional task, the patient has to hear the command.<sup>137</sup> For example, the patient is told to imagine swimming but then must do that task in her head to activate the motor strip. This is exceedingly valuable information as it indicates the presence of covert consciousness. As noted previously in my book, *Rights Come to Mind*, in my view, there is "[n]othing more important than knowing that a patient may be conscious, especially when there is a paucity of motor output and the possibility that neuroimaging data, obtained through research or not, might suggest that an individual thought to be vegetative might actually be aware."<sup>138</sup>

There are other neurophysiologic findings that track with the presence of covert consciousness. The ability to follow a volitional command indi-

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133. See generally Claassen et al., *supra* note 66; Edlow et al., *supra* note 65.

134. Joseph J. Fins & Nicholas D. Schiff, *In the Blink of the Mind's Eye*, 40 HASTINGS CTR. REP. 21, 21 (2010).

135. See Joseph J. Fins, *Wait, Wait . . . Don't Tell Me: Tuning in the Injured Brain*, 64 ARCHIVES NEUROLOGY 158, 158 (2012); see also Jonathan C. Bardin et al., *Dissociations Between Behavioral and Functional Magnetic Resonance Imaging-Based Evaluations of Cognitive Function After Brain Injury*, 134 BRAIN 769, 774 (2011).

136. See Fins & Schiff, *supra* note 134, at 23.

137. See Edlow et al., *supra* note 65, at 2411.

138. FINS, RIGHTS COME TO MIND, *supra* note 24, at 201.

cates that the patient has intact *integrative* neural networks.<sup>139</sup> This physiologically distinguishes MCS patients and others with CMD from vegetative patients who lack this integrative functionality.<sup>140</sup> This becomes especially important when we consider how pain is processed and the neuro-palliative care needs of this exceedingly vulnerable patient population.<sup>141</sup> Steven Laureys and his colleagues demonstrated that patients in the vegetative state subjected to a noxious stimulus only activated the primary sensory area and did not activate the more widely distributed pain network involving the cortex and associated areas.<sup>142</sup> This contrasts with patients with intact integrative functions. But if patients in MCS with CMD are misdiagnosed as vegetative and thereby thought to be insensate, then pain medication can be thought to be unnecessary.<sup>143</sup> This omission becomes all the more horrific because these patients cannot reliably express their distress, communicate their pain, or ask for help.<sup>144</sup> This compounds this medical error.<sup>145</sup>

The failure to recognize covert consciousness remains a clinical challenge with ethical and legal implications. A major barrier to diagnosis is the perception amongst clinicians that brain injuries are static and that once a patient has had a devastating injury there is no hope for meaningful recovery. While this perception has its roots in the futility presumptions embedded in cases like *Quinlan* and *Cruzan*, this precept is as old as the writings of Hippocrates himself, who scribed an ancient aphorism that all brain injuries are invariably fatal.<sup>146</sup> While this was contested by Galen, the second century Pergamum physician and undisputed master of the Hippocratic corpus, who observed that he had seen the injured brain

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139. See Joseph J. Fins & Maria G. Master, *Disorders of Consciousness and Neuro-Palliative Care: Toward an Expanded Scope of Practice for the Field*, in OXFORD HANDBOOK OF ETHICS AT THE END OF LIFE 154, 158 (Stuart J. Younger & Robert M. Arnold eds., 2016)

140. See *id.*

141. See *id.* at 163; see also Joseph J. Fins & Barbara Pohl, *Neuro-Palliative Care and Disorders of Consciousness*, in OXFORD TEXTBOOK OF PALLIATIVE MEDICINE 285–291 (Nathan Cherny et al. eds., 5th ed. 2015); Joseph J. Fins, *Neuroethics and Disorders of Consciousness: A Pragmatic Approach to Neuropalliative Care*, in THE NEUROLOGY OF CONSCIOUSNESS, COGNITIVE NEUROSCIENCE AND NEUROPATHOLOGY 234, 240–41 (Steven Laureys & Giulio Tononi eds., 2008).

142. See Steven Laureys et al., *Central Processing of Noxious Somatosensory Stimuli in the Persistent Vegetative State*, 17 NEUROIMAGE 732, 734 (2002).

143. Camille Chatelle et al., *Pain Issues in Disorders of Consciousness*, 28 BRAIN INJURY 1202, 1205 (2014).

144. Joseph J. Fins, *When No One Notices: Disorders of Consciousness and the Chronic Vegetative State*, 44 HASTINGS CTR. REP. 14, 15 (2019).

145. See Chatelle et al., *supra* note 143, at 1205–06; Fins & Bernat, *supra* note 71, at 473; Joseph J. Fins, *Brain Injury and the Civil Right We Don't Think About*, N.Y. TIMES (Aug. 24, 2017), [https://www.nytimes.com/2017/08/24/opinion/minimally-conscious-brain-civil-rights.html?\\_r=0](https://www.nytimes.com/2017/08/24/opinion/minimally-conscious-brain-civil-rights.html?_r=0) [<https://perma.cc/GZU6-E3EL>] [hereinafter Fins, *Brain Injury and the Civil Right We Don't Think About*].

146. See HIPPOCRATES, APHORISMS § VI, para. 18 (Francis Adams trans., 1849) (400 B.C.E.), <http://classics.mit.edu/Hippocrates/aphorisms.1.i.html> [<https://perma.cc/Y9X6-JPHP>].

healed,<sup>147</sup> the sentiments expressed by Hippocrates remain the norm and not the exception, notwithstanding scientific progress to the contrary.

Patients who receive heroic acute care, saving lives that decades past would have been lost, are routinely transferred to chronic care facilities where they receive what is euphemistically described as custodial care. Brain injuries are taken as fixed and immutable and not more properly viewed as *syndromic* and subject to evolution.<sup>148</sup> As delineated in the Mohonk Report to the Congressional Brain Injury Caucus<sup>149</sup> and described in my book, *Rights Come to Mind*,<sup>150</sup> and elsewhere,<sup>151</sup> patients with disorders of consciousness are routinely *segregated* in chronic care where they are unable to get adequate medical treatment or rehabilitation. They struggle for these services and a proper diagnosis, which is accurate and captures the nuances of an often subtle recovery process.

#### V. FROM A RIGHT TO DIE TO A RIGHT TO CARE: IDEOLOGY, DISABILITY LAW, AND DISORDERS OF CONSCIOUSNESS

While there remain formidable clinical and operational barriers to the diagnosis and treatment of patients with disorders of consciousness, the greatest challenge is one of ideology. This transcends science and reflects a deep cultural divide in society. Patients in the vegetative state, and more generally those with disorders of consciousness, have been thrust into the debate over the right to die.

The appropriation of these patients as proxies in a culture war pitting a pro-life position against one that is pro-choice occurs at the expense of this very vulnerable cohort. In his *Cruzan* dissent, Justice Brennan, arguing for the rights of families to make decisions on behalf of their loved ones, noted how these patients become victims.<sup>152</sup> Citing the New Jersey Supreme Court and the primacy of the family, Justice Brennan stated, “It is . . . [the families] who treat the patient as a person, rather than as a symbol of a cause.”<sup>153</sup>

This was particularly salient in the debate over Terri Schiavo, whose diagnosis became an object of contention in Florida and then national

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147. See SUSAN P. MATTERN, *GALLEN AND THE RHETORIC OF HEALING* 174, 200 (2008); see also Zoe M. Adams & Joseph J. Fins, *Penfield's Ceiling: Seeing Brain Injury Through Galen's Eyes*, 89 *NEUROLOGY* 854, 856 (2017).

148. Joseph J. Fins & Nicholas D. Schiff, *Differences that Make a Difference in Disorders of Consciousness*, 8 *AM. J. BIOETHICS NEUROSCIENCE* 131, 131 (2017).

149. JEAN BÉRUBÉ ET AL., *THE MOHONK REPORT: A REPORT TO CONGRESS IMPROVING OUTCOMES FOR INDIVIDUALS WITH DISORDERS OF CONSCIOUSNESS* (2006).

150. See FINS, *RIGHTS COME TO MIND*, *supra* note 24, at 288.

151. See, e.g., Joseph J. Fins, *Disorders of Consciousness and Disordered Care: Families, Caregivers, and Narratives of Necessity*, 94 *ARCHIVES PHYSICAL MED. & REHABILITATION* 1934, 1936 (2013).

152. *Cruzan v. Dir., Mo. Dep't. of Health*, 497 U.S. 261, 328–30 (Brennan, J., dissenting).

153. *Id.* at 328 (quoting *In re Jobes*, 529 A.2d 434, 445 (N.J. 1987)).

politics.<sup>154</sup> Regrettably, the assessment of these patients has become a litmus test of one's political predilections and not an exercise in clinical discernment. In an article entitled *Neurological Diagnosis is More than a State of Mind: Diagnostic Clarity and Impaired Consciousness*, which I co-authored with Plum in 2003, I noted that, "[w]hile a diverse society can ascribe differing meaning to life in a permanent vegetative state, these valuations should [not] undermine an accurate diagnosis . . . ."<sup>155</sup>

Sadly, the implications of a vegetative diagnosis have distorted the diagnostic process itself. To be seen as vegetative is to be seen as undeserving of medical care and even unworthy of one's legal rights. To counter this, for example, advocates for Terri Schiavo sought to assert that she was not vegetative but, in fact, minimally conscious by means of a highly edited video of Ms. Schiavo from her nursing home that appeared to indicate that the random eye movements seen in the wakeful unresponsive state were purposeful.<sup>156</sup> The rationale for these diagnostic excursions was that if she could be demonstrated as conscious, Ms. Schiavo's life would be more valued and more worthy of protection. Such was the argument of House and Senate legislators with medical degrees, among them Senate Majority Leader Bill Frist, a cardiothoracic surgeon experienced in transplant medicine and certainly skilled in these clinical distinctions.<sup>157</sup>

Shortly after Ms. Schiavo died and her autopsy results were released, I commented on NPR about this mix of diagnostics and politics noting, "We all should be cautious about talking about patients we've never examined, and diagnosis by long distance is problematic. And I think that the doctors in Congress who were making diagnosis were dealing with the body politic and not with a particular patient."<sup>158</sup>

Regrettably, some of this ideological posturing has its roots in the opinions proffered in *Cruzan* and in the discourse of that era.<sup>159</sup> Death and dying were in the news and at the core of the culture of life debate.<sup>160</sup> Proponents on both sides of the question were prone to excess as society

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154. See Fins, *Affirming the Right to Care, Preserving the Right to Die*, *supra* note 21, at 170.

155. Fins & Plum, *supra* note 22, at 1354.

156. See Fins, *Affirming the Right to Care, Preserving the Right to Die*, *supra* note 21, at 172.

157. See Sheryl Gay Stolberg, *Legislators with Medical Degrees Offer Opinions on Schiavo Case*, N.Y. TIMES (Mar. 23, 2005), <https://www.nytimes.com/2005/03/23/politics/legislators-with-medical-degrees-offer-opinions-on-schiavo-case.html> [<https://perma.cc/6HKS-R775>].

158. See Jon Hamilton, *Schiavo Autopsy: Damage, No Abuse*, NPR (June 15, 2005, 12:00 AM), <https://www.npr.org/templates/story/story.php?storyId=4705007> [<https://perma.cc/E2QA-W29U>].

159. See Joseph J. Fins, *Death and Dying in the 1990s: Intimations of Reality and Immortality*, 23 GENERATIONS 81, 82–83 (1999).

160. The culture war over death and dying, which began in the 1990s with *Cruzan*, would continue in the debate over physician assisted suicide in *Quill v. Vacco*, 521 U.S. 793 (1997), and *Washington v. Glucksberg*, 521 U.S. 702 (1997), which both reached the Supreme Court in 1997 from the Second and Ninth Circuits respectively. These tensions would continue in the Florida deliberations over Terri Schiavo in 2003 and on the national

tried to reign in the promise and peril of advancing medical technology. Complex issues were reduced to questions of choice or human dignity, often missing the nuance of what the philosopher and bioethicist Daniel Callahan aptly called the troubled middle in between these dichotomous perspectives.<sup>161</sup>

It was in this ideological cauldron that *Cruzan* was decided, contributing in part to the rhetorical excess of that period. A case in point is Justice Stevens's *Cruzan* dissent. While I agree with his opinion in large part, and fully endorse the right of family members to make decisions on behalf of their loved ones, I was taken aback by how he justified his point. Perhaps in his zest to assert an argument for dominion over life's end, Justice Stevens asks the provocative question of what sort of life Ms. Cruzan was living, if she was living at all.<sup>162</sup> He then asked whether if she was not living in the way that other citizens do, should she be entitled to the same rights enjoyed by the rest of us?<sup>163</sup> Justice Stevens wrote:

But for patients like Nancy Cruzan who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is "life" as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence.<sup>164</sup>

While this line of argument—denying rights to a vulnerable class—is constitutionally chilling, Justice Stevens's argument is not out of line with that of the Cruzan family, who clearly loved their daughter. Her family chose three dates for Ms. Cruzan's tombstone: when she was "born," when she "departed," and when she was "at peace."<sup>165</sup> The date of her departure was the night of her accident. She was at peace when she died, but in their view she had departed nearly eight years earlier.<sup>166</sup> The family, which has also marked the tombstone with "most loved, daughter-sister-aunt,"<sup>167</sup> felt that she had left them when she became vegetative.

Nonetheless, in asserting a right to die and arguing that "Missouri asserts an interest in Nancy Cruzan's life in opposition to Nancy Cruzan's own interests,"<sup>168</sup> Justice Stevens argued that Ms. Cruzan was not alive as we understand the word "alive" to mean.<sup>169</sup> He explained, "Life, particu-

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stage in 2005. See Fins, *Affirming the Right to Care, Preserving the Right to Die*, *supra* note 21, at 170.

161. See Daniel Callahan, *When Self-Determination Runs Amok*, 22 HASTINGS CTR. REP. 52, 52–53 (1992).

162. *Cruzan v. Dir., Mo. Dep't. of Health*, 497 U.S. 261, 345 (1990) (Stevens, J., dissenting).

163. *See id.*

164. *Id.*

165. WALTER GLANNON, *BIOETHICS AND THE BRAIN* 169 (2007).

166. *See id.*; see also Andrew H. Malcom, *Nancy Cruzan: End to Long Goodbye*, N.Y. TIMES (Dec. 29, 1990), <https://www.nytimes.com/1990/12/29/us/nancy-cruzan-end-to-long-goodbye.html>. [<https://perma.cc/XGN6-BAJT>].

167. LILA PERL, *SUPREME COURT MILESTONES: CRUZAN V. MISSOURI: THE RIGHT TO DIE* 79 (2008).

168. *Cruzan*, 447 U.S. at 345 (Stevens, J., dissenting).

169. *Id.* at 345–46.

larly human life, is not commonly thought of as a merely physiological condition or function. Its sanctity is often thought to derive from the impossibility of any such reduction.”<sup>170</sup> He concluded, “[T]he idea of life is not conceived separately from the idea of a living person.”<sup>171</sup>

Paradoxically, in making this heart-felt defense of Ms. Cruzan’s interests, Justice Stevens seems to have abridged other of Ms. Cruzan’s fundamental rights enumerated in the Declaration of Independence and the Constitution. His dissent seems to say that the rights enjoyed by all citizens did not apply to Ms. Cruzan because she had either ceased to live in the conventional sense or her diminished life had ceased to make a claim on these rights.<sup>172</sup> Indeed, in an effort to secure a right to refuse unwanted and disproportionate treatment, Justice Stevens actually seems to strip Ms. Cruzan of the rights of citizenship, implying that her life, as he understood it, did not comport with the protections and liberty interests espoused in our nation’s foundational documents.

Justice Stevens’s argumentation, however, is internally inconsistent. To narrowly refute the Court’s decision to uphold the Missouri ruling, he made a broader claim about the constitutional rights of the incompetent which would seem to contradict his earlier argument that negated those rights when he questioned whether the “mere persistence of their bodies is ‘life’ as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence.”<sup>173</sup> As he reached his summation he asserted, “the Court’s deference [to Missouri] seems ultimately to derive from the premise that chronically incompetent persons have no constitutionally cognizable interests at all, and so are not persons within the meaning of the Constitution. Deference of this sort is patently unconstitutional.”<sup>174</sup>

I would concur but the damage had already been done to the standing of the chronically incompetent by the assertion that patients in the vegetative state were not alive consistent with the self-evident Jeffersonian truths about the unalienable rights of equality, life, liberty, and the pursuit of happiness. That is, by struggling to assert a right of self-determination against the categorical approach of Missouri and the Court, Justice Stevens went too far and paradoxically diminished more essential dimensions of citizenship. It is true that the provision of treatment as desired by Missouri and upheld by the Court would violate Ms. Cruzan’s liberty interests. But did that assertion come at the cost of a greater degradation—a more global assault—on her rights and those of people like her?

If we contextualize Justice Stevens’s argument against the medical facts and take it to its logical conclusion, his comments about “‘life’ as that word is commonly understood, or as it is used in both the Constitution

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170. *Id.*

171. *Id.* at 347.

172. *See id.* at 345.

173. *Id.*

174. *Id.* at 354.



and the Declaration of Independence”<sup>175</sup> becomes especially troubling. If, as noted previously, 41% of patients with traumatic brain injuries thought to be vegetative in chronic care facilities are in fact minimally conscious,<sup>176</sup> what of their lives and their inner lives? What of patients who have covert consciousness or CMD whose lives can be diminished because of a failure to identify what might not be readily apparent?<sup>177</sup> What of their rights short of a search for what we have described as these *hidden minds*?<sup>178</sup>

A more salubrious and constitutionally sound approach is advanced by Justice Brennan in his dissent. He properly asserted Ms. Cruzan’s constitutional rights and asked how they could best be applied in context. He wrote, “Nor does the fact that Nancy Cruzan is now incompetent deprive her of her fundamental rights. . . . [T]he question is not whether an incompetent has constitutional rights, but how such rights may be exercised.”<sup>179</sup> And herein lies the essential question: how do we exercise rights for these patients that seem fundamentally at odds with each other and which cross the ideological boundaries of the culture wars?

During the debate over Ms. Schiavo, while strongly advocating for the right of her husband to make decisions on her behalf as her legal surrogate and based on Ms. Schiavo’s previously articulated preferences, I also argued that we as a society needed to do more.<sup>180</sup> We needed to both “preserve the right to die . . . and affirm[ ] the right to care” for those who sought those interventions.<sup>181</sup> I believed then, and now, that this was truly the “choice” position, nesting authority to make care decisions with families, properly informed about the burdens and benefits of treatment and their likelihood for success.

175. *Id.* at 346.

176. Schnakers et al., *supra* note 56, at 37.

177. See Joseph J. Fins, *Neuroethics and Disorders of Consciousness: Discerning Brain States in Clinical Practice and Research*, 18 *AMA J. ETHICS* 1182, 1186 (2016).

178. See Joseph J. Fins & Nicholas D. Schiff, *In Search of Hidden Minds*, 27 *SCI. AM. MIND* 44, 44–51 (2016).

179. *Cruzan*, 497 U.S. at 308–09 (Brennan, J., dissenting).

180. For samples of my interviews regarding the matter, see *Matters of Life and Death* (CNN television broadcast Aug. 29, 2001); *Evening News with John Roberts* (CBS television broadcast Oct. 12, 2003); *Good Morning America* (ABC News television broadcast Oct. 15, 2003); *Evening News with Dan Rather* (CBS television broadcast Oct. 15, 2003); *Good Morning America* (ABC News television broadcast Oct. 22, 2003); *Evening News with Dan Rather* (CBS television broadcast Oct. 22, 2003); *News Night with Aaron Brown* (CNN television broadcast Oct. 22, 2003); *Simply Put* (Bloomberg Radio broadcast Oct. 26, 2003); *Connected Coast to Coast with Ron Reagan and Monica Crowley* (MSNBC television broadcast Mar. 21, 2005); *CBS Evening News* (CBS Evening News television broadcast Mar. 21, 2005); *WCBS-TV News* (WCBS-TV television broadcast Mar. 21, 2005); *To the Point* (PRI/NPR radio broadcast Mar. 21, 2005); *Lou Dobbs Tonight* (CNN television broadcast Mar. 21, 22, 24, & 31, 2005); *Sunday Morning* (CBS television broadcast Mar. 27, 2005). My opinions were also featured in print in *Nature*, the *New York Times*, the *New York Times Week in Review*, the *New York Times: Science Times*, the *Chicago Tribune*, the *Boston Globe*; *Reuters*, *Time*, *Newsday*, ABC, and HealthDay News.

181. See Fins, *Affirming the Right to Care, Preserving the Right to Die*, *supra* note 21, at 170.

In the context of patients who were permanently vegetative, as was Ms. Schiavo following severe anoxic brain injury and cardiac arrest, the prospects for recovery are essentially nil, as Ms. Schiavo's subsequent autopsy attested.<sup>182</sup> For patients with anoxic injury in the vegetative state, asserting a right to care is essentially arguing for ongoing nursing care and the provision of artificial nutrition and hydration. But advocacy for patients with traumatic brain injury who have a more favorable prognosis and all those who have been misdiagnosed or have covert consciousness or cognitive CMD may result in meaningful recovery and, notably, the identification of individuals who may be able to reconnect with their families and their communities.

Returning to the lineage of the right to die, epitomized by the rhetoric of Justice Stevens's dissent, is the irony that in establishing "one set of rights we have trampled on the rights of others."<sup>183</sup> As I have written previously:

In establishing the right to die . . . we have marginalised conscious individuals and deprived them of their right to a self. They have been segregated from the medical mainstream, deprived of adequate rehabilitation, all with the consequence that we have kept them from being more fully reintegrated into civic community. By not adequately identifying consciousness when it exists and failing to foster it when it does, we have perpetuated a kind of neuronal segregation.<sup>184</sup>

Elsewhere, I have argued that by denying patients with disorders of consciousness proper diagnosis, treatment, and rehabilitation, we are precluding their maximal integration back into their families and their communities. I have maintained that this amounts to segregation and, as such, we are in violation of the Americans with Disabilities Act (ADA)<sup>185</sup> and the U.N. Convention on the Treatment of Persons with Disabilities.<sup>186</sup>

While asserting segregation may seem to be a stretch, in upholding the ADA in *Olmstead vs. L.C. ex rel. Zimring*, Justice Ginsburg, writing for the Court, called for overcoming this segregation, noting, "Congress explicitly identified unjustified 'segregation' of persons with disability as a 'for[m] of discrimination.'"<sup>187</sup> Nonetheless, many patients with disorders

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182. See Joseph J. Fins & Nicholas D. Schiff, *The Afterlife of Terri Schiavo*, 35 HASTINGS CTR. REP. 8, 8 (2005).

183. Joseph J. Fins, *Bring Them Back*, AEON (May 10, 2016), <https://aeon.co/essays/thousands-of-patients-diagnosed-as-vegetative-are-actually-aware> [<https://perma.cc/DT6U-MW7N>] [hereinafter Fins, *Bring Them Back*].

184. *Id.*

185. Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (2012); see also Joseph J. Fins & Megan S. Wright, *Rights Language and Disorders of Consciousness: A Call for Advocacy*, 32 BRAIN INJURY 670, 670–71 (2018); Megan S. Wright et al., *Severe Brain Injury, Disability, and the Law: Achieving Justice for a Marginalized Population*, 45 FLA. ST. U. L. REV. 313, 329–31 (2018); Fins, *Brain Injury and the Civil Right We Don't Think About*, *supra* note 145.

186. Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3.

187. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999) (citing 42 U.S.C. § 12101(a)(2)).

of consciousness, who are segregated from the medical mainstream, improperly diagnosed, and neglected, do not even fulfill the separate but equal mandate enconced in *Plessy v. Ferguson*.<sup>188</sup>

It may seem hyperbolic to view this as segregation but the exclusion and neglect of patients with disorders of consciousness is tragically systematic. It is rooted in biases that have their origins in the virtuous pursuit of a right to die, of self-determination. But in reviewing this record, we can see there have been unintended consequences of this march to progress for conscious beings who are wholly dependent upon others and vulnerable. Neuroscience now has the ability to identify them and give them voice through neuroprosthetics, drugs, neuromodulation, and rehabilitation. I have asserted that this should be the civil rights mandate of our era.<sup>189</sup>

Overcoming segregation for these patients is not merely a question of physical reintegration into their communities. Rather, through the identification of consciousness when it exists and the provision of the means to foster and restore communication, we can help to overcome the barriers erected by injury and society and reintegrate individuals back into the nexus of their families and communities.

Communication is the critical issue, if we consider how we appreciate the consciousness of others.<sup>190</sup> It is well appreciated that the only consciousness we can know is our own. Given this, the only way to *infer* the consciousness of others is through the restoration of functional communication. This is how we know the other is there. Note the cognates: community and communication. Reintegration, and the overcoming of the segregation of these individuals into civil society, is achieved through affirming their right to care and restoring functional communication. These efforts begin with eschewing ideological vestiges of the right-to-die movement and corrosive rhetoric that diminishes this possibility.

Neuroscience has provided us with the ability to identify patients, once thought vegetative, who are indeed conscious. And now that we have the means to appreciate that these people exist, we are morally obliged not to look away. We now can appreciate that the neglect, marginalization, and segregation suffered by these individuals is unjustifiable and wrong. In the majority opinion in *Obergefell v. Hodges*, which decriminalized gay marriage, Justice Kennedy aptly wrote, “[N]ew insights and societal understanding can reveal unjustified inequality within fundamental institutions that once passed unnoticed and unchallenged.”<sup>191</sup> What was true in that landmark civil rights case will, I hope, someday be written by another court for patients with disorders of consciousness whose prospects

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188. See *Plessy v. Ferguson*, 163 U.S. 537, 547 (1896); see also FINS, RIGHTS COME TO MIND, *supra* note 24, at 298; Fins, *Bring Them Back*, *supra* note 183.

189. See FINS, RIGHTS COME TO MIND, *supra* note 24, at 305–08; see also Fins, *Brain Injury and the Civil Right We Don't Think About*, *supra* note 145.

190. See FINS, RIGHTS COME TO MIND, *supra* note 24, at 272.

191. *Obergefell v. Hodges*, 135 S. Ct. 2584, 2590 (2015).