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# Advances in Neuroimaging and the Vegetative State: Implications for End-of-Life Care

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**ADVANCES IN NEUROIMAGING  
AND THE VEGETATIVE STATE:  
IMPLICATIONS FOR END-OF-LIFE CARE**

*Maxine H. Harrington\**

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**I. INTRODUCTION**

Severely brain damaged patients represent major ethical and legal challenges in end-of-life care. In particular, the vegetative state has featured significantly in the origins and evolution of the “right to die” movement. The first significant end-of-life case was *Quinlan*, where the New Jersey Supreme Court, citing Quinlan’s constitutional right to privacy, permitted her father to

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withdraw her ventilator.<sup>1</sup> The right to die movement reached its apex in 1990, when in *Cruzan*, the United States Supreme Court assumed (without deciding) that an incompetent person had a constitutionally protected liberty interest in refusing life-prolonging treatment.<sup>2</sup> The politically contentious *Schiavo* case engendered a national discussion about the appropriateness of withdrawing artificial nutrition and hydration at the end of life.<sup>3</sup> These three seminal cases featured young women in a “persistent” vegetative state and defined the boundaries of the right to withhold or withdraw treatment from those with severely impaired consciousness.

The *Quinlan* case, in particular, marked a turning point, as it allowed physicians, courts, legislatures, and the public to view the vegetative state as a meaningless, bleak existence of irreversible unconsciousness, justifying the decision to forego life-sustaining treatment. Recently, however, sophisticated neuroimaging studies have challenged the decades-old assumption that all vegetative patients lack capacity for conscious thought. The evolving science has promise to transform the evaluation and treatment of patients in a vegetative state and its related disorder of consciousness—the minimally conscious state.

## II. DISORDERS OF CONSCIOUSNESS

Disorders of consciousness arise from severe brain injury most commonly caused by massive head trauma or a nontraumatic event such as a cardiac arrest that results in an anoxic injury to the brain.<sup>4</sup> Consciousness has two main components: the level of consciousness, which includes wakefulness or arousal, and the content of consciousness, which is awareness.<sup>5</sup> Awareness can be divided into awareness of self and awareness of the environment.<sup>6</sup> After a serious brain insult, one or both of these components may be compromised, leading to a disorder of consciousness. Severe disorders of consciousness include coma, the vegetative state, and the minimally conscious state.

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<sup>1</sup> In re *Quinlan*, 355 A.2d 647, 664 (N.J. 1976), cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976).

<sup>2</sup> *Cruzan v. Dir., Missouri Dep’t of Health*, 497 U.S. 261, 279–80 (1990).

<sup>3</sup> See, e.g., Terry Schiavo’s life, death sparked national debate, CNN U.S. News, March 31, 2005, <http://www.cnn.com/2005/US/03/31/obit.schiavo/> (last visited Feb. 25, 2013); see also *Bush v. Schiavo*, 885 So. 2d 321, 332 (Fla. 2004) (holding that statute authorizing governor to issue a stay of the withdrawal of nutrition and hydration from a vegetative patient was unconstitutional under the separation of powers doctrine).

<sup>4</sup> JAMES L BERNAT, *ETHICAL ISSUES IN NEUROLOGY* 288, 295 (3d ed. 2008).

<sup>5</sup> Steve Majerus et al., *Behavioral Evaluation of Consciousness in Severe Brain Damage*, 150 *PROG. BRAIN RES.* 397, 397 (2005), available at [http://espra.risc.cnrs.fr/majerus\\_PBR\\_vol150\\_397\\_413.pdf](http://espra.risc.cnrs.fr/majerus_PBR_vol150_397_413.pdf).

<sup>6</sup> *Id.*

### A. Coma

Coma is a state of unwakefulness (eyes-closed) and unawareness.<sup>7</sup> Patients in a coma are unable to be aroused with stimuli.<sup>8</sup> It is usually a temporary, acute state that can last days to weeks.<sup>9</sup> Patients may devolve from coma to brain death, which is defined as the irreversible cessation of all functions of the brain,<sup>10</sup> or may fully recover to a conscious state. In other cases, recovery may not advance beyond a severe disability with little or no consciousness.

### B. Vegetative State

What Patients may emerge from coma into a condition of “wakefulness without awareness,” or the vegetative state (VS).<sup>11</sup> Patients in a VS, unlike those who are brain dead, have preserved or partially preserved hypothalamic and brain stem functions necessary for survival.<sup>12</sup> They open their eyes and often breathe on their own but, due to loss of cortical or higher brain function, are incapable of purposeful, voluntary, reproducible movement in response to stimuli.<sup>13</sup> When stimuli-induced, vegetative patients exhibit only reflex or automatic movements, such as posturing in response to pain or eye-opening when subjected to a loud noise.<sup>14</sup> Many individuals in this condition live for an extended period of time as long as they receive sustenance; they are not terminally ill.<sup>15</sup>

The term persistent vegetative state was coined in 1972 by Jennett and Plum to describe patients whose “vegetative, mindless state” lasted longer than a few weeks.<sup>16</sup> In 1994, the Multi-Society Task Force on PVS defined the temporal boundaries of the vegetative state.<sup>17</sup> The persistent vegetative state was deemed permanent if it lasted more than three months

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<sup>7</sup> Steven Laureys et al., *Brain Function in Coma, Vegetative State, and Related Disorders*, 3 LANCET NEUROLOGY, 537, 538 (2004).

<sup>8</sup> Luaba Tshibanda et al., *Neuroimaging After Coma*, 52 NEURORADIOLOGY 15, 15 (2010).

<sup>9</sup> *Id.*

<sup>10</sup> UNIF. DETERMINATION OF DEATH ACT § 1, 12 U.L.A. 781 (2008).

<sup>11</sup> Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 1 LANCET 734, 734 (1972).

<sup>12</sup> The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (1)*, 330 N. ENG. J. MED 1499, 1500 (1994).

<sup>13</sup> *Id.*

<sup>14</sup> Joseph J. Fins et al., *Neuroimaging and Disorders of Consciousness: Envisioning an Ethical Research Agenda*, 8 AM. J. BIOETHICS 3, 4 (2008).

<sup>15</sup> American Academy of Neurology, *Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient*, 39 NEUROLOGY 125, 125 (1989).

<sup>16</sup> Jennett & Plum, *supra* note 11, at 736.

<sup>17</sup> The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (2)*, 330 N. ENG. J. MED 1572, 1575 (1994).

for those patients with nontraumatic brain injury and more than twelve months for those with traumatic brain injury.<sup>18</sup> The Task Force concluded that recovery after these times was rare and almost always involved moderate to severe disability.<sup>19</sup>

There has been criticism of the semantics surrounding the vegetative state. Some clinicians object to the term “vegetative”<sup>20</sup> because in the minds of many lay people (and some professionals), it implies the patient is a “vegetable” and therefore, subhuman.<sup>21</sup> For that reason, the European Task Force on Disorders of Consciousness recently recommended that the term vegetative state be changed to “unresponsive wakefulness syndrome” (UWS).<sup>22</sup> Further, PVS, an abbreviation for persistent vegetative state, is often confused as the acronym for permanent vegetative state, leading some groups and authors to avoid the terms persistent or permanent when referring to the vegetative state.<sup>23</sup> Finally, many clinicians use the terms persistent and permanent interchangeably.<sup>24</sup> However, persistent is a diagnosis of a disability of uncertain duration, while permanent is a prognosis and implies irreversibility.<sup>25</sup> For these reasons, many neurologists simply describe the syndrome as the vegetative state or VS, a term that will be used in this article.

There is also some confusion in legal and medical circles as to the implications of a VS diagnosis. Although by definition, VS patients are unaware and lack the ability to perceive pain,<sup>26</sup> some courts have allowed juries to award damages to VS patients for conscious pain and suffering.<sup>27</sup>

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<sup>18</sup> *Id.*

<sup>19</sup> *Id.*

<sup>20</sup> The term vegetative was chosen as it refers to the preserved vegetative functions of patients, including sleep-wake cycles, respiration, digestion, and thermoregulation. Marie-Aurélié Bruno et al., *From Unresponsive Wakefulness to Minimally Conscious PLUS and Functional Locked-In Syndromes: Recent Advances in Our Understanding of Disorders of Consciousness*, 258 J. NEUROLOGY 1373, 1373–74 (2011).

<sup>21</sup> *Id.* at 1374 (noting tendency of laypersons to use the word “vegetable” to refer to those with severe disorders of consciousness); see also BERNAT, *supra* note 4 at 288 (opining that “the term ‘vegetative’ was an unfortunate choice because of its unintended similarity to the pejorative term ‘vegetable’ . . .”).

<sup>22</sup> Steven Laureys et al., *Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome*, 8 BMC MEDICINE 68, 69 (2010), available at <http://www.biomedcentral.com/content/pdf/1741-7015-8-68.pdf>.

<sup>23</sup> See Olivia Gosseries et al., *Disorders of Consciousness: What’s in a Name?*, 28 NEUROREHABILITATION 3, 4 (2011) (preferring to avoid use of the terms persistent or permanent); see also BERNAT, *supra* note 4 at 289 (stating that it is best to avoid the modifier persistent or permanent when referring to the vegetative state).

<sup>24</sup> BERNAT, *supra* note 4 at 288.

<sup>25</sup> The Multi-Society Task Force on PVS, *supra* note 12 at 1501.

<sup>26</sup> See American Academy of Neurology, *supra* note 15 at 125 (stating that VS patients cannot experience pain).

<sup>27</sup> See, e.g., *Banks ex rel. Banks v. Sunrise Hosp.*, 102 P.3d 52, 64 (Nev. 2004) (allowing the jury to award damages for conscious pain and suffering of a patient in a persistent vegetative state based on a nurse’s testimony that the patient was able to respond to his environment); *Maracle v. Curcio*, 806 N.Y.S.2d 839, 840–841 (N.Y. App. Div. 2005)

Other courts have referred to vegetative patients as comatose,<sup>28</sup> or terminally ill<sup>29</sup> (although most are not). And it is not unusual for misunderstandings to exist about the difference between the VS and brain death,<sup>30</sup> even among neurologists.<sup>31</sup> Although the nomenclature in this area is confused, the essence of the permanent VS is thought to be state of total unconsciousness—of nothingness—from which no return is possible.

### C. Minimally Conscious State

Patients may emerge from coma or may transition from the VS to a state of partial awareness, known as the minimally conscious state (MCS).<sup>32</sup> The condition of partial consciousness has been observed for years, but the diagnostic criteria for MCS were developed only a decade ago by the Aspen Neurobehavioral Conference.<sup>33</sup> The MCS is defined as a syndrome in which the person has intermittent but reproducible evidence of discernible awareness of self or the environment.<sup>34</sup> Behaviors exhibited by patients in MCS include following simple commands, gesturing or verbalizing yes or no to questions, manipulating objects, purposeful blinking or smiling (not reflexive), or intelligible verbalization.<sup>35</sup> MCS may also be categorized by the level of behavioral responses: MCS+ describes higher functioning patients, while MCS- refers to minimal or low-level responses.<sup>36</sup>

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(affirming trial court's refusal to dismiss claim for conscious pain and suffering because the patient, "although in a vegetative state, had the requisite level of awareness necessary for such an award").

<sup>28</sup> See, e.g., *People v. Haley*, 960 N.E.2d 670, 677 (Ill. App. Ct. 2011) (citing evidence that if the patient had survived, he would have been in a "comatose vegetative state"); *Gray v. Romeo*, 697 F. Supp. 580, 582 (D. R.I. 1988) (describing a persistent vegetative state patient as being in "a type of comatose state").

<sup>29</sup> See, e.g., *In re AB*, 768 N.Y.S.2d 256, 272 (N.Y. Sup. Ct. 2003) (referring to infant in a persistent vegetative state as terminally ill).

<sup>30</sup> See, e.g., Stephen G. Calabresi, *The Terri Schiavo Case: In Defense Of the Special Law Enacted By Congress and President Bush*, 100 NW. U. L. REV. 151, 154 (2006) (criticizing the failure of the courts in the *Schiavo* case to order brain scans because "there was no hard evidence that Mrs. Schiavo was truly brain-dead at the time that tube was removed.").

<sup>31</sup> See Ari R. Joffe et al., *A Survey of American Neurologists About Brain Death: Understanding the Conceptual Basis and Diagnostic Tests for Brain Death*, 2 ANNALS OF INTENSIVE CARE 1, 3 (2012), available at <http://www.annalsofintensivecare.com/content/pdf/2110-5820-2-4.pdf> (reporting that almost half of neurologists surveyed understood brain death as the loss of higher brain functions or permanent loss of consciousness).

<sup>32</sup> J.T. Giacino et al., *The Minimally Conscious State Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 349–351 (2002), available at <http://www.neurology.org/content/58/3/349.full>.

<sup>33</sup> *Id.* at 350.

<sup>34</sup> *Id.* at 351.

<sup>35</sup> *Id.*

<sup>36</sup> Bruno, *supra* note 20, at 1373.

### D. Locked-in Syndrome

Locked-in syndrome (LIS) is not a disorder of consciousness, but may appear as one.<sup>37</sup> A person with LIS has preserved consciousness without the ability to move or communicate, except, in most cases, by voluntary vertical eye movements and blinking.<sup>38</sup> The locked-in syndrome was brought to the public's attention in Jean-Dominique Bauby's autobiographical work, *The Diving Bell and the Butterfly*.<sup>39</sup> Bauby, who was in LIS and fully conscious, wrote the book one letter at a time by blinking his left eye.<sup>40</sup>

The classical locked-in state is characterized by total immobility that prevents movement or speech, preserved cognitive functioning, and a code for communicating that uses eye movements or blinking.<sup>41</sup> In some patients, the syndrome is considered incomplete because the patient has some remnants of voluntary motion.<sup>42</sup> Total LIS occurs in the presence of complete immobility, including eye movements.<sup>43</sup>

### E. Diagnostic Challenges

Differentiating between these three syndromes is very challenging, particularly in those patients who have limited or inconsistent motor ability from which consciousness may be inferred.<sup>44</sup> Studies performed during the past two decades confirm that standard clinical diagnosis of the vegetative state may be erroneous in more than forty percent of patients.<sup>45</sup> The high rate

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<sup>37</sup> See Caroline Schnakers et al., *Detecting Consciousness In a Total Locked-In Syndrome: An Active Event-Related Paradigm*, 15 NEUROCASE 271, 272 (2009) (noting that difficulties in diagnosis of LIS occur because of behavioral similarities to VS).

<sup>38</sup> Nick Chisholm & Grant Gillett, *The Patient's Journey: Living With Locked-In Syndrome*, 331 BRIT. MED. J. 94, 95–96 (2005).

<sup>39</sup> JEAN-DOMINIQUE BAUBY, *THE DIVING BELL AND THE BUTTERFLY: A MEMOIR OF LIFE IN DEATH* (Jeremy Leggatt trans., Vintage International 1997).

<sup>40</sup> Steven Laureys et al., *The Locked-In Syndrome: What Is It Like To Be Conscious But Paralyzed and Voiceless?*, in 150 PROG. BRAIN RES. 495, 497 (Steven Laureys ed., 2005), available at [http://www.coma.ulg.ac.be/papers/LIS/2005\\_PBR\\_vol150\\_495\\_511.pdf](http://www.coma.ulg.ac.be/papers/LIS/2005_PBR_vol150_495_511.pdf).

<sup>41</sup> *Id.* at 497.

<sup>42</sup> *Id.*

<sup>43</sup> *Id.*

<sup>44</sup> Steven Laureys et al., *supra* note 7, at 537.

<sup>45</sup> See Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35 (2009), available at <http://www.biomedcentral.com/1471-2377/9/35> (finding forty-one percent of VS patients to be in MCS); Keith Andrews et al., *Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit*, 313 BRIT. MED. J. 13, 14 (1996) (concluding that forty-three percent of patients in VS were misdiagnosed); Nancy L. Childs et al., *Accuracy of Diagnosis of Persistent Vegetative State*, 43 NEUROLOGY 1465, 1466 (1993) (reporting that thirty-seven percent of those labeled in VS had some level of awareness); Donald D. Tresch et al., *Clinical Characteristics of Patients in*

of diagnostic errors has persisted despite improved behavioral testing standards.<sup>46</sup> In most of these cases, patients are found to be in MCS rather than VS, but some misdiagnosed patients are in LIS.<sup>47</sup>

“Consciousness is at the heart of the distinction” between the vegetative, minimally conscious, and locked-in, states.<sup>48</sup> There is, however, no objective test for measuring consciousness.<sup>49</sup> Diagnostic errors occur because the examiner can only infer the lack of awareness in a person by observation of the person’s behavior and the ability to signal consciousness through motor or verbal responses.<sup>50</sup> Distinguishing VS from MCS depends on “meaningful” or “purposeful” responses to commands or stimuli, terms that require subjective interpretation on the part of the examiner.<sup>51</sup> There are multiple bedside assessment tools used for diagnosing the level of consciousness, some of which are less reliable than others.<sup>52</sup>

Patients with disorders of consciousness may confuse examiners because of temporal conditions such as sedative medication.<sup>53</sup> Many of the misdiagnosed may be blind or severely visually impaired, making it difficult to assess purposeful eye tracking.<sup>54</sup> Others may be deaf or hearing-impaired, confounding verbal command testing.<sup>55</sup> Finally, the examiner’s and treatment team’s experience, skill, and length of assessment affect their ability to draw accurate conclusions from the patient’s behavior.<sup>56</sup>

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*the Persistent Vegetative State*, 151 ARCHIVES INTERNAL MED. 930, 930 (1991) (concluding that eighteen percent of those diagnosed in the persistent vegetative state were aware of themselves or their environment).

<sup>46</sup> See Gosseries, *supra* note 23, at 4 (noting that despite the publication of diagnostic criteria for VS and MCS, the high rate of diagnostic error has not changed).

<sup>47</sup> See Laureys et al., *supra* note 40, at 499–500 (describing two poignant cases where LIS patients were mistakenly diagnosed in the vegetative state).

<sup>48</sup> Martha Farah, *That Little Matter of Consciousness*, 8 AM. J. BIOETHICS 17, 17 (2009).

<sup>49</sup> Majerus, *supra* note 5, at 397. Further, there is a debate in neurology about the nature of consciousness itself. See Carl E. Fisher & Paul S. Appelbaum, *Diagnosing Consciousness, Neuroimaging, Law, and the Vegetative State*, 38 J. L. MED. & ETHICS 374, 375 (2010) (explaining that although there are established criteria for impaired consciousness, there is little agreement on what defines consciousness).

<sup>50</sup> Multi-Society Task Force on PVS, *supra* note 12, at 1501; see also Majerus, *supra* note 5, at 398 (“Clinically, we are limited to the appraisal of the patient’s capacity to perceive the external world and to voluntarily interact with it (i.e., perceptual awareness.)”); Martin M. Monti et al., *Neuroimaging and the Vegetative State Resolving the Behavioral Assessment Dilemma?*, 1157 ANN. N.Y. ACAD. SCI. 81, 83 (2009) (stating that the differentiation between consciousness and unconsciousness is the ability of the patient to signal awareness).

<sup>51</sup> Majerus et al., *supra* note 5, at 399.

<sup>52</sup> See generally *id.* at 402–11 (describing a number of tests used to assess consciousness).

<sup>53</sup> Monti et al., *supra* note 50, at 85 (noting that diagnostic errors can occur due to the failure to exclude such factors as sedatives, range of motion, posture, and nutrition).

<sup>54</sup> *Id.*

<sup>55</sup> *Id.*

<sup>56</sup> Majerus et al., *supra* note 5, at 401–02.



In patients who have complete LIS and who are immobile (except perhaps for blinking and eye movements) and unable to speak, preservation of consciousness is often difficult to detect at the bedside.<sup>57</sup> Discerning purposeful eye blinking from spontaneous or reflex eye blinking requires repeated observation under different conditions.<sup>58</sup> In patients with total LIS without eye movements, rates of misdiagnosis may be particularly high.<sup>59</sup> Without careful surveillance, locked-in patients may be mistakenly considered to be in a vegetative or minimally conscious state.<sup>60</sup>

Further, once labeled with the term vegetative, it is frequently difficult to change the diagnosis as caretakers may not notice subtle changes in the level of consciousness.<sup>61</sup> One well-publicized case demonstrates the tenacity of the VS label. Nineteen years after a traumatic brain injury, Terry Wallis began to speak.<sup>62</sup> During those years, Wallis was described as being in a VS.<sup>63</sup> A subsequent review of his medical records showed that he had emerged from VS to MCS.<sup>64</sup> Interestingly, scientists later discovered axonal regrowth in Wallis' brain, indicating that such regrowth may play a role in late recovery of function in patients with severe brain injuries.<sup>65</sup>

### F. Prognosis

Studies have emphasized the importance of distinguishing between these three states because of the differing potential for patient improvement. While unresponsive patients in the VS have been thought to have little to no chance of recovery after one year, there are no such temporal boundaries for improvement or recovery for those in MCS.<sup>66</sup> Patients with MCS have significantly more favorable outcomes than patients in the VS, particularly those with traumatic brain injuries.<sup>67</sup> Although many MCS patients will

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<sup>57</sup> Chisolm & Gillett, *supra* note 38, at 95–96; *see also* Laureys, *supra* note 40, at 499 (noting that in a majority of cases, it is a relative of the LIS patient and not the physician who first realizes the patient is conscious and able to communicate through eye movements).

<sup>58</sup> Majerus et al., *supra* note 5, at 400.

<sup>59</sup> Schnakers et al. *supra* note 37, at 272.

<sup>60</sup> Laureys et al., *supra* note 40, at 499.

<sup>61</sup> Bruno et al., *supra* note 20, at 1374.

<sup>62</sup> Joseph J. Fins, *Neuroethics, Neuroimaging, and Disorders of Consciousness: Promise or Peril?*, 122 TRANSACTIONS AM. CLINICAL CLIMATOLOGICAL ASS'N 336, 341 (2010).

<sup>63</sup> *Id.*

<sup>64</sup> *Id.*

<sup>65</sup> *Id.*

<sup>66</sup> Giacino et al., *supra* note 32, at 352 (declaring that it is not known how many patients will emerge from MCS more than one year post-injury).

<sup>67</sup> *Id.*; *see also* Dominic Wilkinson & Julian Savulescu, *Is It Better To Be Minimally Conscious Than Vegetative?*, J. MED. ETHICS (2012), available at <http://jme.bmj.com/content/early/2012/08/31/medethics-2012-100954.short> (citing studies showing that half of MCS patients developed signs of functional recovery by 12 months and that one-third of patients who had been in MCS more than one year showed continued improvement over the next five years).

remain in MCS with severe disabilities, others may progress to a state where they can functionally communicate.<sup>68</sup>

The prognosis of patients with LIS varies with the extent of the brain lesion.<sup>69</sup> Some patients with locked-in syndrome may exhibit good functional outcomes, including limited motor recovery, with the benefit of rehabilitation.<sup>70</sup> In these LIS patients, a misdiagnosis of VS or MCS can be particularly harmful, delaying or depriving conscious individuals of adequate therapeutic measures designed to provide a useful recovery and improved quality of life.<sup>71</sup>

### G. Pain Perception

The importance of distinguishing between these disorders also relates to patients' perception of pain. Pain is thought to be a phenomenon of the conscious state.<sup>72</sup> LIS patients are conscious and can experience pain. Those patients in a VS or MCS pose a challenge for clinicians determining the patient's level of pain perception solely through behavior assessments.<sup>73</sup> Patients in a VS are thought to be unable to perceive pain and are not routinely administered potent analgesics, even when end-of-life care is withdrawn.<sup>74</sup> There are no guidelines for the treatment of pain in MCS patients,<sup>75</sup> although there have been recommendations to treat all MCS patients with analgesics since they have, by definition, some evidence of the ability to be conscious of pain.<sup>76</sup>

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<sup>68</sup> Laureys, *supra* note 7, at 539.

<sup>69</sup> José León-Carrión et al., *The Locked-In Syndrome: A Syndrome Looking for a Therapy*, 16 BRAIN INJURY 571, 579 (2002) (stating that LIS caused by traumatic damages to the brain stem may be transient and portend a better prognosis than LIS that is secondary to an occlusion of the basilar artery).

<sup>70</sup> *Id.* at 578.

<sup>71</sup> *Id.* at 575; *see also* Laureys et al., *supra* note 40, at 499 (reporting average delays in diagnosis of LIS patients of seventy-eight days; several patients were not correctly diagnosed for more than four years).

<sup>72</sup> *See* American Academy of Neurology, *supra* note 15, at 125 (stating that VS patients lack the capacity to experience pain and suffering); *see also* Nada Gligorov, *Unconscious Pain*, 8 AM. J. BIOETHICS 27, 27 (2008) (describing the standard view that "pain (is) an exclusively conscious state . . .").

<sup>73</sup> *See* Mélanie Boly et al., *Perception of Pain In the Minimally Conscious State With PET Activation: An Observational Study*, 7 LANCET NEUROLOGY 1013, 1013 (2008), available at [http://www.coma.ulg.ac.be/papers/vs/Pain\\_MCS\\_LancetNeuro08.pdf](http://www.coma.ulg.ac.be/papers/vs/Pain_MCS_LancetNeuro08.pdf).

<sup>74</sup> *See* Fins, *supra* note 14, at 8 (stating that pain treatment is not generally used in VS patients, and that Schiavo died without receiving strong opiates).

<sup>75</sup> Boly et al., *supra* note 73, at 1013.

<sup>76</sup> Boly et al., *supra* note 73, at 1018 ("[T]he results of the study should prompt the use of analgesics in patients in MCS . . .").

### III. RECENT ADVANCES IN NEUROIMAGING

Neuroimaging holds promise as an aid in diagnosing disorders of consciousness, principally in those who are unable to produce any meaningful behavioral response.<sup>77</sup> In particular, positron emission tomography (PET),<sup>78</sup> and, more recently, functional magnetic resonance imaging (fMRI),<sup>79</sup> have been used in an attempt to assess the level of cognition of patients with serious brain disorders and to distinguish the VS from the MCS. Functional neuroimaging is distinguished from structural imaging, such as computer tomography (CT) or traditional MRI scans, which produce only pictures of the brain.<sup>80</sup> Functional brain scans measure the brain's activity both at rest and in response to commands.<sup>81</sup>

Using electrophysiology, alone or in conjunction with fMRI, also shows promise in both the differential diagnosis and prognosis of disorders of consciousness.<sup>82</sup> Electrophysiological measures such as evoked potentials (EPs)<sup>83</sup> and event-related potentials (ERPs)<sup>84</sup> derived from electroencephalography (EEG) may have a role in detecting covert awareness in impaired patients.<sup>85</sup> Using this technology to assess consciousness may have even wider application in clinical practice as EEGs have been used at the bedside for many years.

Brain imaging studies during the past decade have challenged assumptions about the diagnostic categories of disorders of consciousness and their immutability.<sup>86</sup> Although a number of studies utilizing these techniques have been performed over the past decade, only selected case reports will be described.<sup>87</sup>

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<sup>77</sup> See Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 588 (2010) (asserting that neuroimaging is most helpful in those who exhibit no motor response evidencing awareness).

<sup>78</sup> Positron emission tomography (PET) measures the metabolic activity in the brain after the patient has been administered radioactive elements. Fisher & Appelbaum, *supra* note 49, at 376.

<sup>79</sup> Functional magnetic resonance imaging (fMRI) records changes in blood oxygenation in the brain using magnetic fields. Fisher & Appelbaum, *supra* note 49, at 376.

<sup>80</sup> Jodie R. Gawryluk et al., *Improving the Clinical Assessment of Consciousness With Advances in Electrophysiological and Neuroimaging Techniques*, 10 BMC NEUROLOGY 1, 3 (2010), available at <http://biomedcentral.com/1471-2377/10/11>.

<sup>81</sup> Tshibanda et al., *supra* note 8, at 18.

<sup>82</sup> Gawryluk et al., *supra* note 80, at 6.

<sup>83</sup> Evoked potentials refer to basic sensory processing responses seen on EEG recordings. Gawryluk et al., *supra* note 80, at 3.

<sup>84</sup> Event-related potentials are used to assess higher-level cognitive functions, such as memory or language. Gawryluk et al., *supra* note 80, at 3.

<sup>85</sup> Gawryluk et al., *supra* note 80, at 1-2 (suggesting that electrophysiology addresses the need for better diagnosis of consciousness).

<sup>86</sup> Fins et al., *supra* note 14, at 4.

<sup>87</sup> For a summary of other studies, see Bruno et al., *supra* note 20, at 1381-82, Table 3.

### A. Functional Neuroimaging to Detect Covert Awareness

In 2006, Adrian Owen and colleagues published a provocative report that appeared to demonstrate the ability of a VS patient to respond to auditory commands.<sup>88</sup> A twenty-three year old woman in a VS for five months was asked to imagine playing tennis and walking through her home.<sup>89</sup> On fMRI, there was significant activation in the same areas of the brain observed in healthy volunteers asked to perform the same tasks.<sup>90</sup> The authors concluded that the responses of the patient “confirmed beyond any doubt that she was aware of herself and her surroundings.”<sup>91</sup>

An even more compelling fMRI study was reported in 2010 with fifty-four subjects, twenty-three who were in a VS and thirty-one in an MCS.<sup>92</sup> The patients were evaluated on their performance of motor and spatial imagery tasks against healthy controls.<sup>93</sup> The investigators found five subjects who were able to willfully modulate their brain activity in ways that closely matched the pattern of healthy controls, indicating preserved, but undetected, awareness.<sup>94</sup> Of the five that exhibited such responses, four had been diagnosed in a VS for periods ranging from two months to five years.<sup>95</sup> After further clinical assessment, two of these patients were found to show some signs of functional response, indicating a diagnosis of MCS.<sup>96</sup> Two patients, however, remained behaviorally in a VS.<sup>97</sup>

One patient in this group, who had been in a VS for five years, also underwent a communication task using fMRI.<sup>98</sup> He was asked specific yes or no questions and instructed to think of one type of imagery for yes and another for no.<sup>99</sup> Remarkably, the patient responded accurately to five out of six autobiographical questions he was asked, such as “Is your father’s name Alexander?” (yes) and “Is your father’s name Thomas?” (no).<sup>100</sup> The authors concluded that although it was impossible to establish any communication

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<sup>88</sup> Adrian M. Owen, et al., *Detecting Awareness in the Vegetative State*, 313 SCIENCE 1402, 1402 (2006).

<sup>89</sup> *Id.*

<sup>90</sup> *Id.*

<sup>91</sup> *Id.*

<sup>92</sup> Martin M. Monti, et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 580 (2010).

<sup>93</sup> *Id.* at 580.

<sup>94</sup> *Id.* at 585.

<sup>95</sup> *Id.* at 583.

<sup>96</sup> *Id.* at 585.

<sup>97</sup> *Id.*

<sup>98</sup> Martin M. Monti, et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED., at 580.

<sup>99</sup> *Id.* at 585.

<sup>100</sup> *Id.*

with the patient at the bedside, there was “clear evidence that the patient was aware and able to communicate. . . .”<sup>101</sup>

A recent electrophysiological study concluded that a subset of VS patients may have the ability to “follow” movement commands.<sup>102</sup> Using motor imagery, sixteen patients confirmed with a diagnosis of VS were instructed to imagine squeezing the right hand or wiggling the toes, alternating with relaxation.<sup>103</sup> EEG responses were recorded during the tasks.<sup>104</sup> Three of the sixteen patients (or nineteen percent) were repeatedly and reliably able to generate appropriate EEG responses.<sup>105</sup> The investigators noted that even though these patients were not misdiagnosed as vegetative, experienced evaluators had not been able to identify the “actual condition” of these individuals using standard behavioral assessments.<sup>106</sup> Of particular concern, however, is that only seventy-five percent of healthy controls could demonstrate motor awareness in the task, leading some experts to criticize the data as unreliable.<sup>107</sup>

### ***B. Functional Neuroimaging to Distinguish Disorders of Consciousness***

Functional neuroimaging of auditory processing has also been used to distinguish the VS from the MCS. In MCS patients subjected to complex auditory stimuli, brain imaging showed widespread activation upon the presentation of cries or the patient’s own name.<sup>108</sup> Although MCS patients showed responses in auditory processing areas similar to healthy controls, no significant activation in higher order associative areas was found in VS patients.<sup>109</sup>

Another group of MCS patients was scanned while recordings of either meaningful speech or backwards speech were played.<sup>110</sup> The MCS subjects showed patterns of brain activity that were “remarkably similar” to

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<sup>101</sup> *Id.* The patient later underwent extensive behavior testing and was found to exhibit some responses indicative of MCS rather than VS, but there was no way to determine how long such responses were apparent. *Id.*

<sup>102</sup> Damian Cruse, et al., *Bedside Detection of Awareness in the Vegetative State: A Cohort Study*, 378 LANCET 2088, 2091 (2011).

<sup>103</sup> *Id.* at 2089-90.

<sup>104</sup> *Id.*

<sup>105</sup> *Id.* at 2091.

<sup>106</sup> *Id.* at 2092.

<sup>107</sup> See, e.g., Andrew M. Goldfine et al., Correspondence, *Bedside Detection of Awareness In the Vegetative State*, 379 LANCET 1701, 1701 (2012) (stating that known alterations of brain function in VS and MCS patients along with the weak EEG signals in healthy controls raised concerns about the study’s findings).

<sup>108</sup> Mélanie Boly et al., *Cerebral Processing of Auditory and Noxious Stimuli in Severely Brain Injured Patients: Differences Between VS and MCS*, 15 NEUROPSYCHOLOGICAL REHAB. 283, 286 (2005).

<sup>109</sup> *Id.*

<sup>110</sup> N.D. Schiff, et al., *fMRI Reveals Large-Scale Network Activation in Minimally Conscious Patients*, 64 NEUROLOGY 514, 515–16 (2005).

those demonstrated by healthy controls,<sup>111</sup> suggesting that language comprehension was preserved, at least to some degree, in these patients, distinguishing them from VS patients.<sup>112</sup>

In a study utilizing PET scanning that compared VS and MCS patients, the authors found significant changes in brain function in the MCS patients during noxious stimulation.<sup>113</sup> The higher-order areas of the brain associated with the pain matrix activated in MCS patients by unpleasant stimulation were substantially similar to the areas activated in healthy controls.<sup>114</sup> In contrast, activation in those same areas was not seen in VS patients.<sup>115</sup> The ability to perceive pain, therefore, is one more reason to distinguish most VS patients from those in an MCS.

Electrophysiological approaches have also shown promise as a tool in determining diagnosis and prognosis in those with impaired consciousness.<sup>116</sup> Such results may enable clinicians to predict future functional improvement at an earlier point in time rather than relying solely on behavioral assessments that can lead to a delayed diagnosis.<sup>117</sup> For example, using auditory cognitive ERPs, covert signs of awareness were detected in a total LIS patient who appeared behaviorally comatose.<sup>118</sup> The patient was presented names, including her own name, and asked to either count one target unfamiliar name or her own name.<sup>119</sup> The patient's responses to this auditory stimulus, recorded by EEG, indicated that the patient was able to consciously detect her own name.<sup>120</sup> Fourteen days after testing was completed, the first signs of consciousness were behaviorally observed.<sup>121</sup> The patient was transferred to a rehabilitation unit where she progressively improved.<sup>122</sup>

### C. Limitations of the Studies

What can we infer about these patients? Does an individual whose scan shows islands of activity unequivocally possess a higher functioning brain? If the findings are negative, does that indicate a complete absence of consciousness? Before reaching such hasty conclusions, we need to

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<sup>111</sup> *Id.* at 519.

<sup>112</sup> *Id.* at 520.

<sup>113</sup> Boly et al., *supra* note 73, at 1017.

<sup>114</sup> *Id.* at 1018.

<sup>115</sup> *Id.* This does not mean that VS patients may not experience pain; only that the technique failed to detect activation of areas of the brain associated with the conscious perception of pain. *Id.* at 1019.

<sup>116</sup> See Gawryluk et al., *supra* note 80, at 6 (citing studies that demonstrated the usefulness of ERPs in LIS patients).

<sup>117</sup> *Id.*

<sup>118</sup> Schnakers et al., *supra* note 37, at 272.

<sup>119</sup> *Id.* at 273.

<sup>120</sup> *Id.* at 275–76.

<sup>121</sup> *Id.* at 272.

<sup>122</sup> *Id.* at 272.

acknowledge the limitations of functional neuroimaging and the realities of what it can accomplish.

### ***1. Research and Methodological Limitations***

Studies using sophisticated brain scans to detect covert awareness in patients in a VS, MCS, or LIS have been performed on a small number of patients in only a few research centers. Neuroimaging as an aid in diagnosis and prognosis is still in its infancy and it may be years before such research is translated into a clinical setting.<sup>123</sup> Although EEGs are in routine use and are more transportable and cheaper than fMRI, ERPs to assess consciousness are also in the investigational stages.<sup>124</sup> Large, multi-center studies with standardized protocols will be necessary to validate the results of these studies.<sup>125</sup>

There are also methodological limitations to fMRI. Analyzing neuroimaging data in patients with impaired consciousness is challenging.<sup>126</sup> Some brain lesions may interfere with the ability to follow commands even though the patient may have some cognitive ability.<sup>127</sup> Using fMRI to detect evidence of consciousness requires prolonged attention.<sup>128</sup> Since consciousness may be episodic or inconsistent in some patients, repeated testing may be necessary.<sup>129</sup> Other drawbacks are technical, including the possibility of false positives or misinterpretation of scan results due to patient movement.<sup>130</sup> Some patients have metal implants, making them inappropriate candidates for fMRI, although suitable for EEG studies.<sup>131</sup>

### ***2. Interpretation of Positive Findings***

Positive findings of brain activity in the VS patient indicate several possibilities: the patient has only automatic responses and no evidence of awareness, the patient has minimal consciousness, i.e., is in an MCS rather

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<sup>123</sup> Fins et al., *supra* note 14, at 5.

<sup>124</sup> *Id.*

<sup>125</sup> Haibo Di et al., *Neuroimaging Activation Studies In the Vegetative State: Predictors Of Recovery?*

8 CLINICAL. MED. 502, 506 (2008), available at [http://www.coma.ulg.ac.be/papers/vs/ClinMed\\_VS\\_2008.pdf](http://www.coma.ulg.ac.be/papers/vs/ClinMed_VS_2008.pdf).

<sup>126</sup> Monti et al., *supra* note 50, at 87 (noting the difficulty and complexity of acquiring and analyzing fMRI data in this population).

<sup>127</sup> León-Carrión et al., *supra* note 69, at 565.

<sup>128</sup> *Id.*

<sup>129</sup> *Id.* (stating that patients may present only transient activity in response to instructions); see also Monti et al., *supra* note 50, at 88 (recommending that patients with a negative response be subjected to repeat testing at different times of the day or to testing with different modalities).

<sup>130</sup> Laureys et al., *supra* note 7, at 544.

<sup>131</sup> Cruse et al., *supra* note 102, at 2088.

than in a VS, or the patient is fully conscious and actually in complete LIS.<sup>132</sup> The researchers who report activity in the areas of the brain that process consciousness appear confident that the subjects possess subjective awareness of themselves and their environment.<sup>133</sup> Others, however, caution that normal or near-normal activation in response to stimulation cannot be considered as proof of consciousness in these patients.<sup>134</sup>

In particular, there is skepticism of brain imaging used to demonstrate command-following. The Owen and Monti studies assume that patients who demonstrate patterns of activity on scans when asked to imagine activities or follow commands through imagery have conscious awareness. Concerns have been raised that these studies are flawed and that their findings are not proof of the presence of awareness but may only reflect unconscious automatic reactions.<sup>135</sup> Even healthy individuals, studies show, are capable of subconsciously processing sensory information without awareness.<sup>136</sup> In addition, reports demonstrating speech recognition in MCS patients may be dissociative of actual consciousness.<sup>137</sup> Such patients may be responding to stimuli but are not aware they are doing so. In other words, the “light’s on, but is anybody home?”<sup>138</sup>

Further, the results may highlight only the misdiagnosis of disorders of consciousness. In other words, the studies may indicate that a few patients diagnosed in a VS may actually be in or emerging into an MCS state.<sup>139</sup> Nevertheless, this could implicate a sizable number of patients. Although

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<sup>132</sup> D.J. Wilkinson et al., *Functional Neuroimaging and Withdrawal of Life-Sustaining Treatment from Vegetative Patients*, 35 J. MED. ETHICS 508, 509 (2009), available at <http://jme.bmj.com/content/35/8/508.full.pdf+html>.

<sup>133</sup> See *supra* text accompanying notes 91, 101, 106.

<sup>134</sup> E.g., M. Boly et al., *When Thoughts Become Action: An fMRI Paradigm to Study Volitional Brain Activity In Non-Communicative Brain Injured Patients*, 36 NEUROIMAGE 979, 980 (2007), available at <http://www.wbic.cam.ac.uk/Members/cric/research/documents/boly-neuroimage-2007.pdf/view> (opining that the ability to respond to sensory stimulation is not proof of the presence of awareness).

<sup>135</sup> See Daniel L. Greenberg, *Comment on “Detecting Awareness in the Vegetative State,”* 315 SCIENCE 1221 (2007) (stating that Owen’s single case study suffered from “substantial flaws” and that it was not clear the tennis-imagining patient made any conscious decisions); see also Nachev Parashkev & Husain Masud, *Comment on “Detecting Awareness in the Vegetative State,”* 315 SCIENCE 1221 (2007) (arguing that Owen was making “radical inferences” in interpreting data); see also Tshibanda et al., *supra* note 8 at 19–20 (stating that the only thing that can be inferred from fMRI studies is that some patients can process sensory stimuli).

<sup>136</sup> See Neil Levy, *Going Beyond the Evidence*, 8 AM. J. BIOETHICS 19, 20 (2009) (noting that even normal persons engage in mental tasks that are not conscious).

<sup>137</sup> See Farah, *supra* note 48, at 18 (asserting that brain damage leads to dissociation between cognition and awareness).

<sup>138</sup> Robert Burton, *The Light’s On, But Is Anybody Home*, SALON (Sept. 25, 2007), available at [http://www.salon.com/2007/09/25/is\\_she\\_conscious/](http://www.salon.com/2007/09/25/is_she_conscious/); see also Fisher & Appelbaum, *supra* note 49, at 381 (stating that it may not be reasonable to assume that activity in a brain region is associated with cognitive functioning).

<sup>139</sup> Tshibanda et al., *supra* note 8, at 21.



estimates vary widely, there may be more than 35,000 adult VS patients in the United States<sup>140</sup> and even more in MCS.<sup>141</sup>

Moreover, the studies should not be exaggerated to suggest that all VS patients retain some semblance of consciousness. Only a small proportion of VS patients, most of whom suffered a traumatic insult, have demonstrated covert awareness. Those who suffered a nontraumatic (anoxic) injury or who have been in a VS for more than one year are less likely to have the potential for normal brain activation on neuroimaging.<sup>142</sup>

Further research may validate these early findings but, for now, it may be premature to conclude that activation in some areas of the brain, when given imagery or auditory tasks, definitively equates with consciousness.<sup>143</sup> Although the research is promising, the results are not yet reliable enough for widespread use in clinical practice.

### 3. Interpretation of Negative Findings

Negative findings, or the absence of brain activation, in severely brain-injured patients also need to be approached cautiously. From the studies conducted so far, it is not possible to conclude emphatically that negative findings reflect the absence of cognition.<sup>144</sup> Some patients may have been transiently unconscious or asleep during testing or the tasks may have been too complex due to deficits in language comprehension, memory, or decision making.<sup>145</sup> The choice of experiment is also crucial to understanding the results. For example, if a patient has abnormal auditory pathways, the use of auditory stimuli to provoke a response is inappropriate.<sup>146</sup> Methodological limitations, discussed previously, may also limit the usefulness of negative findings.<sup>147</sup> Most important, studies have demonstrated false negatives even

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<sup>140</sup> See Fins et al., *supra* note 14, at 4 (citing to a study estimating a prevalence of VS adults in the United States between 40 and 168 per million population).

<sup>141</sup> *Id.*

<sup>142</sup> Adrian M. Owen et al., *Using Functional Magnetic Resonance Imaging to Detect Covert Awareness in the Vegetative State*, 64 ARCHIVES NEUROLOGY 1098, 1101 (2007).

<sup>143</sup> See Levy, *supra* note 136, at 20 (questioning whether the patient in Owen's 2006 study was misdiagnosed as VS instead of MCS—if anything, the task was so complex that if the study provided evidence of consciousness, the response was indicative of full-blown consciousness).

<sup>144</sup> See Owen, *supra* note 88, at 1402 (emphasizing that negative findings cannot be used as evidence of a lack of awareness).

<sup>145</sup> Monti et al., *supra* note 92, at 588; see also Owen et al., *supra* note 142, at 1101 (noting that patients may be asleep or may not have understood or heard the commands, leading to false negative results).

<sup>146</sup> Laureys, *supra* note 7, at 544.

<sup>147</sup> See *supra* Part II.C.1.

in healthy volunteers.<sup>148</sup> Thus, “negative findings should never be taken as evidence for a lack of mental activity.”<sup>149</sup>

#### IV. LEGAL AND ETHICAL IMPLICATIONS

The prospect of a subset of VS patients with undetected consciousness raises legal and ethical ramifications for end-of-life decision making. Does having covert signs of awareness give a patient greater legal or moral status such that it is inappropriate to remove life-sustaining treatments, such as artificial nutrition and hydration?<sup>150</sup> Or, is the ability to perceive suffering without the ability to express it a life not worth living?

##### *A. Effect on the Legal System*

Both legislatures and courts have been influenced by a view of the VS as an irreversible, meaningless existence. As a result of the emerging consensus after *Quinlan* that incompetent vegetative patients had a right to forego life-sustaining care, all states enacted advance directive statutes.<sup>151</sup> Under these laws, patients, while competent, may execute a directive setting out their wishes regarding end-of-life care; they may also designate a health care agent to make decisions for them when they lack decision-making capacity.<sup>152</sup> In the absence of an advance directive, family members or other surrogates are instructed to make decisions based on the patient’s preferences expressed while the patient was competent, a doctrine known as substituted judgment.<sup>153</sup> In some states, if the patient’s wishes cannot be discerned, a decision about life-sustaining treatments may be made under a best-interest standard.<sup>154</sup> Most states allow surrogates and health care providers to make end-of-life decisions in the clinical setting, but a few require court approval in the absence of an advance directive.<sup>155</sup>

<sup>148</sup> Monti, *supra* note 50, at 87; *see also* Cruse, *supra* note 102, at 2093 (noting that three healthy volunteers could not produce significant EEG responses).

<sup>149</sup> Monti, *supra* note 50, at 88.

<sup>150</sup> *See id.* at 383; *see also* Barbara A. Wilson et al., *Neuropsychological Assessment and Management of People in States of Impaired Consciousness: An Overview of Some Recent Studies*, 9 BRAIN IMPAIRMENT 28, 29 (describing a case where a woman was found to be misdiagnosed in VS while undergoing assessment to determine if feeding and hydration should be withdrawn. In a follow-up ten years later, she was living in the community with constant support, but able to speak, initiate conversation, use an electric wheelchair, drink through straw, and eat food).

<sup>151</sup> ALAN MEISEL & KATHERINE L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* § 7.10 (3d ed. 2004 & Supp. 2005-2012).

<sup>152</sup> *Id.*

<sup>153</sup> *Id.* at § 4.02 (discussing the substituted judgment standard).

<sup>154</sup> *Id.* at § 4.07 (explaining the best interests standard).

<sup>155</sup> *Id.* at § 3.03 (addressing the different settings in which end-of-life decisions are made).

Many advance directive statutes limit the class of persons from whom life-sustaining care may be withheld or withdrawn to those in a terminal illness or permanent unconsciousness, i.e., a permanent vegetative state.<sup>156</sup> For example, in Pennsylvania, a surrogate may authorize the withdrawal of life-sustaining procedures only from an incompetent patient who has an end-stage disease or is “permanently unconscious.”<sup>157</sup> Permanently unconscious is defined as:

A medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, an irreversible vegetative state or irreversible coma.<sup>158</sup>

Florida allows withdrawal or withholding of treatment by a surrogate when the patient is diagnosed in a persistent vegetative state, which is defined as “a permanent and irreversible condition of unconsciousness in which there is [an] absence of voluntary action or cognitive behavior [and] an inability to communicate or interact purposefully with the environment.”<sup>159</sup> Although advance directive statutes do not supplant common law rights, they may constrain the right of patients and surrogates to forgo life-sustaining care in disorders of consciousness other than an irreversible coma or permanent vegetative state.<sup>160</sup>

Many courts, beginning with *Quinlan*, have also approached VS patients differently than other impaired individuals when confronted with requests to end life support. Judicial opinions largely reflect the clinical assumption that VS involves a “special category of patients.”<sup>161</sup> In authorizing the withholding or withdrawal of life-sustaining care, most courts would probably agree that VS is a condition where “(p)ersonality, memory, purposive action, social interaction, sentience, thought, and even emotional states are gone.”<sup>162</sup> Thus, the VS has become an important diagnostic predicate on which to base legal decisions allowing caretakers or surrogates to forego life-sustaining care.

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<sup>156</sup> *Id.* at §§ 7.06 [A], 8.03.

<sup>157</sup> 20 PA. CONS. STAT. ANN. §§ 5456, 5461, 5462 (2005).

<sup>158</sup> 20 PA. CONS. STAT. ANN. § 5422 (2005).

<sup>159</sup> FLA. STAT. ANN. § 765.101(12) (West 2010).

<sup>160</sup> Some advance directive statutes allow withdrawal of care from patients in an end-stage condition, which includes advanced Alzheimer’s disease. Meisel & Cerminara, *supra* note 151, at § 7.06 [A] [2].

<sup>161</sup> *In re Conroy*, 486 A.2d 1209, 1228 (N.J. 1985).

<sup>162</sup> *In re Jobes*, 529 A.2d 434, 438 (N.J. 1987) (quoting PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 174-75 (1983)).

On the other hand, courts have been careful to distinguish the VS patient from the MCS patient, who has been conferred greater moral and legal status.<sup>163</sup> Several cases illustrate the tendency of courts to require heightened procedural protections before life-sustaining care can be withdrawn from non-VS patients. In *In re Martin*, the patient was described as having minimal voluntary movements and consciousness to some extent, but unable to communicate in any meaningful way.<sup>164</sup> The patient's wife sought a court order to terminate all medical treatment, including artificial nutrition and hydration, which was opposed by the patient's mother and sister.<sup>165</sup> The court considered, but rejected, a best interests (objective) standard for terminating treatment in favor of a subjective or substituted judgment standard.<sup>166</sup> Indicating, however, that the objective standard might be appropriate for a VS patient, the court stated: "In the cases that have applied a more objective test or suggested a more objective test would be proper, the patient generally has been comatose or in a persistent vegetative state."<sup>167</sup> The court did not explain, however, why there should be a distinction between vegetative and minimally conscious patients when choosing the appropriate test to apply in terminating life support.

Similarly, in *Conservatorship of Wendland*, the spouse conservator sought to withdraw tube feedings from her husband who was in MCS.<sup>168</sup> Because the patient was intermittently conscious, the conservator was required to present clear and convincing evidence of his wishes to refuse life-sustaining treatment or that it was in his best interests to end his life, a burden that could not be met in this case.<sup>169</sup> The court was careful to distinguish the right of surrogates to withdraw treatment from a person in an MCS from one in a VS. The high evidentiary standard of clear and convincing evidence would not be required for "permanently unconscious patients, including those who are comatose or in a persistent vegetative state."<sup>170</sup>

More recently, the Pennsylvania Supreme Court had the opportunity to consider whether a guardian could exercise the right to refuse life-sustaining treatment on behalf of a profoundly retarded, never-competent

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<sup>163</sup> It is questionable whether there should be sharp distinctions drawn between VS and MCS patients in end-of-life care. See Lawrence J. Nelson and Ronald E. Cranford, *Michael Martin and Robert Wendland: Beyond the Vegetative State*, 15 J. CONTEMP. HEALTH L. & POL'Y 427, 446-47 (1999) (arguing that there are no valid legal or clinical reasons to treat MCS patients differently than VS patients).

<sup>164</sup> *In re Martin*, 538 N.W. 2d 399, 402-03 (1995), *cert. denied sub nom. Martin v. Martin*, 516 U.S. 1113 (1996).

<sup>165</sup> *Id.* at 402.

<sup>166</sup> *Id.* at 408-09.

<sup>167</sup> *Id.* at 408.

<sup>168</sup> *In re Conservatorship of Wendland*, 28 P.3d 151,155 (Cal. 2001).

<sup>169</sup> *Id.* at 166.

<sup>170</sup> *Id.* at 175; see also *In re L.W.*, 482 N.W.2d 60, 67-68 (Wis. 1992) (refusing to require clear and convincing proof of the wishes of an individual in VS).

patient.<sup>171</sup> The court concluded that, unless authorized by an advance directive, life-preserving care must be provided to an individual who has neither an end-stage medical condition nor is permanently unconscious.<sup>172</sup>

Case law and advance directive statutes reflect a broad societal view that patients in a VS or in a state of permanent unconsciousness are presumed to be in the category of persons for whom life-sustaining procedures can be ethically withheld or withdrawn. Patients in a VS have been not only clinically but also legally marginalized; they are among the “almost dead.”<sup>173</sup> But the emerging neuroscience indicates there may be more blurring of the line between conscious and unconscious than previously thought.<sup>174</sup> If functional imaging to detect hidden awareness gains widespread clinical acceptance, the evolving neuroscience may have a far-reaching effect on how legal bodies define consciousness and approach end-of-life decisions for this vulnerable population.<sup>175</sup> If nothing else, the new data on undetected consciousness should alert legislators and courts to reconsider or question the inviolability of the VS diagnosis. Accurate diagnosis of these patients is critical, as, under existing law, patients who demonstrate some level of consciousness may move “from the ‘possibly allowed to die’ category to the ‘not generally allowed to die’ category.”<sup>176</sup>

### ***B. Effect on End-of-Life Decisions By Surrogates and Healthcare Providers***

Advances in neuroimaging have the potential to alter end-of-life conversations between patients, their families, and their caretakers. Even if a patient has an advance directive, such as a living will, it is unlikely the patient will have considered the possibility that consciousness may exist on a

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<sup>171</sup> In re D.L.H., 2 A.3d 505, 506 (Pa. 2010), *aff’g on other grounds* 967 A.2d 971 (Pa. Super. Ct. 2009).

<sup>172</sup> *Id.* at 515; *see also* Woods v. Commonwealth, 142 S.W.3d 24, 42 (Ky. 2004) (construing state statute to allow the withholding or withdrawal of life-sustaining care only in patients who are permanently unconscious or in a persistent vegetative state, or who are expected to die within a few days); In re Edna M.F., 563 N.W. 2d 485, 491–92 (Wis. 1997), *cert. denied sub nom.* Spahn v. Wittman, 522 U.S. 951 (1997) (refusing to allow guardian to withdraw care from a patient who was not in a persistent vegetative state).

<sup>173</sup> Some have argued that brain death should include those in VS because they lack the consciousness required for a person to be considered living. *See, e.g.*, Robert M. Veatch, *The Dead Donor Rule: True By Definition*, 3 AM. J. BIOETHICS 10, 10-11 (2003).

<sup>174</sup> Fisher & Appelbaum, *supra* note 49, at 377. For a helpful summary of definitions of unconsciousness used in state statutes, *see id.* at 383, Table 1.

<sup>175</sup> *See id.* at 382 (arguing that statutory language used to define neurological conditions and behaviors should be updated in light of neuroscientific advances).

<sup>176</sup> David Cyranoski, *Neuroscience: The Mind Reader*, 486 NATURE 178, 180 (2012), *available at* <http://www.nature.com/news/neuroscience-the-mind-reader-1.10816>; *see also, e.g.*, In re Riley M, No. A-96-409, 1997 WL 133169, at \*3 (Neb. Ct. App. March 25, 1997). In Riley, the court approved a DNR (“do not resuscitate”) order for a two-year old in a persistent vegetative state. While an appeal was pending, the diagnosis was changed because of “marked changes” in the child’s condition making the DNR order inappropriate.

continuum. In most cases, therefore, families and other surrogates will be called on to choose whether life-supporting care should be terminated. The emerging science will heighten expectations for some family members, and perhaps even exaggerate those expectations. For others, the lack of objective signs of awareness on brain imaging will be intensely disappointing.

Families are often faced with end-of-life options days or weeks after a serious brain injury. At that point, however, it is impossible to predict with any confidence whether the patient will evolve to MCS or a functional recovery.<sup>177</sup> Later on, when the diagnosis is clear, decisions to end a family member's life become more difficult as the patient may be breathing on his own and the choice is often whether to remove a feeding tube. Reliable diagnoses and prognoses are, therefore, profoundly important as families or other caretakers consider whether to forego end-of-life procedures. Ethical responsibilities require that families be provided with the full range of choices available in determining whether to withhold or withdraw life-sustaining treatment. "They are entitled to support and the exchange of information that is both scientifically accurate and compassionately communicated."<sup>178</sup>

If neuroimaging lives up to its potential, it could be a valuable aid in assessing early signs of consciousness in patients who are aware but cannot demonstrate any motor behavior reflecting an ability to understand commands or communicate.<sup>179</sup> For example, studies indicating that MCS patients have the ability to process language and speech, which one prominent neurologist has called "spine-chilling,"<sup>180</sup> are significant because these patients have often been conflated with those in a VS and shunted off to chronic care facilities without benefit of meaningful treatment and rehabilitation.<sup>181</sup>

Families may also be provided with better prognostic information.<sup>182</sup> If the developing science can be adapted for bedside use, it may help to identify those patients who will emerge from a VS and respond to rehabilitation intended to improve their mental state. Several studies have shown that those few patients who exhibit signs of consciousness on imaging are more likely later to exhibit behavioral signs of awareness.<sup>183</sup> For example, one study demonstrated that the higher the level of speech

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<sup>177</sup> See generally BERNAT, *supra* note 4, at 296–298 (discussing the limits of prognostication in the VS and MCS states).

<sup>178</sup> Fins et al., *supra* note 14, at 9.

<sup>179</sup> See Tshabanda et al., *supra* note 8, at 20 (concluding that the new imaging studies may be used to detect signs of consciousness that cannot be discerned in a conventional assessment).

<sup>180</sup> Fins, *supra* note 62, at 341.

<sup>181</sup> *Id.* at 342.

<sup>182</sup> Tshabanda et al, *supra* note 8, at 21 (suggesting that fMRI could be a marker of prognosis).

<sup>183</sup> See Di et al., *supra* note 125, at 506 (reviewing fifteen studies and concluding that early activation of brain activity is a reliable marker of recovery).

processing demonstrated by VS patients on fMRI, the more likely they were to show improvement in their behavioral assessment six months later, often leading to a changed diagnosis.<sup>184</sup>

Functional neuroimaging may also aid in assessing the effect of treatment (as yet experimental) in those with impaired consciousness.<sup>185</sup> There have been reports that certain drugs, such as amantadine or zolpidem (Ambien), may temporarily improve awareness in VS and MCS patients.<sup>186</sup> Not all patients respond to these drugs, however, and neuroimaging may prove to be useful in selecting appropriate patients for these therapies.

Early diagnosis of patients with some level of consciousness is particularly important for proper pain management.<sup>187</sup> A correct diagnosis may also guide clinicians to determine when pain relief should be provided for patients in whom life-sustaining procedures patients are withdrawn.<sup>188</sup> Some authors have raised the possibility of using functional neuroimaging to ask patients if they are feeling pain.<sup>189</sup> Even if such communication cannot be established, the possibility of covert awareness in a minority of patients and the high rate of diagnostic error suggest that all patients with impaired consciousness, even those in an apparent VS, should receive pain medication.<sup>190</sup>

More worrisome, if neuroscience progresses to the point where clinicians using sophisticated brain imaging can communicate with a patient who is unresponsive behaviorally, the next stage may be asking the patient whether life-sustaining treatment should be continued or withdrawn.<sup>191</sup> This would be a precarious step. The doctrine of informed consent requires patients to be competent to make health care decisions. Competency encompasses not only the ability to communicate a choice, but also the

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<sup>184</sup> M. R. Coleman et al., *Towards the Routine Use of Brain Imaging to Aid the Clinical Diagnosis of Disorders of Consciousness*, 132 *BRAIN* 2541, 2550 (2009) (reporting that all but one out of eight VS patients who demonstrated a high level of auditory processing during fMRI showed behavioral evidence of emergence to MCS six months later).

<sup>185</sup> Di et al., *supra* note 125, at 506.

<sup>186</sup> See, e.g., Caroline Schnakers et al., *Measuring The Effect Of Amantadine In Chronic Anoxic Minimally Conscious State*, 79 *J. NEUROLOGY NEUROSURGERY & PSYCHIATRY* 225, 226 (2008) (demonstrating the beneficial effect of amantadine in a single patient); see also, e.g., Ralf Class & Wally Nel, *Drug Induced Arousal From the Permanent Vegetative State*, 21 *NEUROREHABILITATION* 23, 24–25 (2006) (reporting arousal in three patients in a permanent vegetative state with zolpidem).

<sup>187</sup> See Laureys et al., *supra* note 40, at 506 (stressing the importance of early diagnosis and pain management in LIS patients).

<sup>188</sup> Fins et al., *supra* note 14, at 6 (suggesting that neuroimaging could be helpful in assessing pain in individuals who have lost the ability to communicate).

<sup>189</sup> Monti et al., *supra* note 92, at 589.

<sup>190</sup> See Caroline Schnakers & Nathan D. Zasler, *Pain Assessment and Management in Disorders of Consciousness*, 20 *CURRENT OPINION IN NEUROLOGY* 620, 624 (2007) (suggesting that all patients in VS or MCS receive analgesics).

<sup>191</sup> See Fisher & Appelbaum, *supra* note 49, at 380 (envisioning using neuroimaging methods to ask a patient if he wants to be removed from life support).

ability to understand relevant information and to appreciate treatment alternatives and their consequences.<sup>192</sup>

Brain scans alone cannot demonstrate competency and the cognitive and emotional abilities to make such a complex decision may be out of reach of these patients. Making an autonomous choice requires not only comprehension but also the ability to judge the worth of treatment in accordance with one's own values and personal conscience. It is only speculation whether patients who can minimally communicate via neuroimaging possess that kind of sophisticated reasoning ability.

There are also risks in accepting technology as the final word in assessing consciousness. Some families will almost surely request fMRI or electrophysiological studies to confirm or challenge the VS diagnosis. Assuming a dispute among family members or refusal by the attending physician to order functional imaging, it is conceivable that there could be court proceedings initiated to compel such testing. Indeed, that request was made in the *Schiavo* case, where the parents retained experts who testified that Schiavo was in an MCS rather than a VS.<sup>193</sup> The court had before it CT scans of the brain that demonstrated structural defects, but refused to order an fMRI, which the parents hoped would demonstrate evidence of conscious activity.<sup>194</sup>

In 2005, at the time of the *Schiavo* case, and even today, fMRI suggestions of consciousness in an otherwise behaviorally unresponsive patient are not ready for the spotlight of the courtroom. It is unlikely that this emerging technology would meet the standards for scientific reliability established in federal and state courts under *Daubert*<sup>195</sup> and its progeny.<sup>196</sup> If the studies are validated in larger clinical populations, however, they can be expected to provoke courtroom controversies over diagnosis in end-of-life care.

Outside the realm of family disputes, there may be overreliance on the diagnostic use of advanced neuroimaging techniques. The means to determine whether conscious functions of the brain have irreversibly ceased have largely been behavioral observations, which as previously noted, can be challenging.<sup>197</sup> Technical "answers" to whether a patient has undetected consciousness may be tantalizingly persuasive to family members and clinicians, even if the science is still elusive. In a recent case pending in British Columbia, the parents of a man diagnosed in VS have asked the court

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<sup>192</sup> See Jessica Wilen Berg et al., *Constructing Competence; Formulating Standards of Legal Competence to Make Medical Decisions*, 48 RUTGERS. L. REV. 345, 351 (discussing Appelbaum and Grisso's competence standards).

<sup>193</sup> Order at 4-6, In re Schiavo, No. 90-2908-GD-003 (Fla. Pinellas Cnty. Ct. March 9, 2005), available at <http://abstractappeal.com/schiavo/trialctorder030905.pdf>.

<sup>194</sup> *Id.*

<sup>195</sup> *Daubert v. Merrell-Dow Pharmaceuticals*, 509 U.S. 579 (1993).

<sup>196</sup> See Fisher & Appelbaum, *supra* note 49, at 381-82 (discussing the admissibility of neuroimaging data).

<sup>197</sup> See *supra* Part II.C.



to keep their son alive so that he can participate in one of Owen's studies to assess covert consciousness in severely brain-damaged patients.<sup>198</sup> The well-known "CSI effect" informs us that lay people have high expectations for scientific, objective evidence, including fMRI.<sup>199</sup> The presence or hope of conscious activity on brain scans or EEGs may lead not only families, but also health care providers, down the path of overreliance on neuroimaging technology, without consideration of its limitations and experimental posture. False hope for the families of those with severe brain injuries like VS may be worse than no hope at all.

On the other hand, if brain scans can reliably rule out conscious thoughts or perceptions, does that render the withdrawal or withholding of life-sustaining procedures even more ethically justifiable? The absence of any conscious activity on neuroimaging may give voice to the notion that further treatment is medically "futile." The debate about end-of-life care has gradually shifted from the right to refuse life-sustaining treatment the patient or surrogate deems futile to the obligation to provide care the physician deems futile.<sup>200</sup> These reverse end-of-life cases raise questions about whether the surrogate of an incompetent VS patient has the right to demand life-preserving care over the health care provider's objections.<sup>201</sup> If functional neuroimaging tests repeatedly demonstrate a complete lack of brain activity diagnostic of awareness, the findings may give health care providers further persuasive tools to contend that life-prolonging care is futile.

The concept of futility also raises broader issues concerning the just allocation of healthcare resources. Some commentators argue that society should not use finite resources to keep alive those who are in a VS and unable to meaningfully interact with their environment, caretakers, and family.<sup>202</sup> Veatch and Spicer propose that if there is community consensus, reimbursement for life-sustaining care of those in a persistent vegetative state

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<sup>198</sup> Ian Mulgrew, *Family Fights Over of Severely Brain Injured Man*, VANCOUVER SUN, Dec. 5, 2012, available at <http://www.vancouversun.com/health/Family+fighters+over+fate+severely+brain+injured/7653097/story.html#ixzz2EC1HfuPR>.

<sup>199</sup> See David P. McCabe et al., *The Influence of fMRI Lie Detection Evidence on Juror-Decision-Making*, 29 BEHAV. SCI. & L. 566, 574 (reporting that fMRI evidence indicating the defendant is lying may be more persuasive to potential jurors than other evidence of lying).

<sup>200</sup> See generally Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor To Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 8–10 (2007).

<sup>201</sup> *Id.*

<sup>202</sup> See, e.g., Jacob M. Appel, *Rational Rationing vs. Irrational Rationing: The Struggle for the Legacy of Reuben Bentancourt*, HUFFINGTON POST (June 23, 2010), [http://www.huffingtonpost.com/jacob-m-appel/rational-rationing-vs-irr\\_b\\_622057.html](http://www.huffingtonpost.com/jacob-m-appel/rational-rationing-vs-irr_b_622057.html) (arguing that VS patients should be viewed differently than other patients and that scarce resources should not be committed to prolonging their lives); see also Catherine Constable, *Withdrawal of Artificial Nutrition and Hydration for Patients in a Permanent Vegetative State: Changing Tack*, 26 BIOETHICS 157, 162 (2012) (arguing there should be a presumption to withdraw life-sustaining in VS patients, in part because resources should be allocated to those who can benefit from them).

should end at three months of care.<sup>203</sup> Batavia argues that a rationing scheme based on medical futility should focus on the permanently unconscious, defined as a lack of consciousness for one year.<sup>204</sup> In today's cost-conscious health care environment, it is possible to envision a rationing agenda that relies on adjuvant neuroimaging to "rule out" consciousness in an effort to justify an end of funding for life-prolonging care.

Finally, the presence of sensory or cognitive processing in the lives of seriously brain-damaged individuals raises larger philosophical questions about the impact this small subset of VS patients with covert consciousness will have on end-of-life decisions. Is the ability to follow simple commands indicative of a "meaningful" life? Can families or other surrogates discern whether the patient would have wanted to opt for any life, or object to the "prison" of MCS?<sup>205</sup> In fact, given the likelihood that patients with minimal or intermittent awareness experience pain, it may be worse to be partially conscious. Further, there is no assurance, even with aggressive care, that a person in a VS who demonstrates minimal awareness will ever be able to achieve a recovery beyond a severe disability.<sup>206</sup> What good is knowing an individual has islands of brain activity if there is little or no possibility he will emerge from that state to be able to interact with his caretakers or family? Indeed, some might conclude that a state of partially preserved cognition without a means of expression is a "life worse than death."<sup>207</sup> A better understanding of consciousness will inform this debate.

## V. CONCLUSION

Functional neuroimaging needs to be cautiously interpreted, but may open a window into how much awareness is possible in a person in a vegetative or minimally conscious state. The data are preliminary and families need transparency about the limits of diagnosing or prognosticating on the basis of brain scans alone. At the very least, patients and their families should be informed of the shortcomings of the neuroscience and that case reports of awareness in a very small proportion of VS and MCS patients are investigational and unlikely to predict whether a particular individual will benefit from high-tech neuroimaging tools. Inevitably, as the technology advances, the ability to assess cognitive awareness will improve, leading to

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<sup>203</sup> Robert M. Veatch & Carol Mason Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J. L. & MED. 15, 30 (1992).

<sup>204</sup> Andrew I. Batavia, *Disability Versus Futility in Rational Health Care Services: Defining Medical Futility Based on Permanent Unconsciousness—PVS, Coma and Anencephaly*, 20 BEHAV. SCI. & L. 219, 229 (2002).

<sup>205</sup> Robert T. Knight, *Consciousness Unchained: Ethical Issues and the Vegetative State and Minimally Conscious State*, 8 AM. J. BIOETHICS 1, 1 (2008).

<sup>206</sup> See Wilkinson et al., *supra* note 132 at 509 (stating there are no reports of VS patients identified as conscious on neuroimaging who made a recovery to functional independence).

<sup>207</sup> *Id.* at 510.

better diagnoses and outcomes in those with disorders of consciousness. This should help patients, families, physicians, and the courts, when necessary, to make better end-of-life decisions.