

## FEEDING THE DEAD? RETHINKING ROBERT RAKESTRAW ON THE PERSISTENT VEGETATIVE STATE

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This year marks the tenth anniversary of the death of Terri Schiavo, a Florida woman whose plight ignited an intense national debate over the practice of withholding artificial nutrition and hydration (ANH) from individuals diagnosed as being in a persistent vegetative state (PVS). According to public opinion surveys that stretch back to the early 1990s, the majority of evangelical Christians are opposed to indefinite ANH in the case of PVS.<sup>1</sup> Few have been willing to publicly stake that position to the claim frequently advanced by secular ethicists that patients deemed persistently vegetative are, in fact, dead. Among those who have, however, is Robert V. Rakestraw, who, in a 1992 *JETS* essay that continues to be reprinted in his widely used introductory text on Christian ethics, argued that vegetative patients are “theologically dead” on account of a “completely and permanently destroyed” cerebral cortex.<sup>2</sup>

Though advocating a “major redefinition of death” with significant theological and ethical implications, Rakestraw’s essay surprisingly garnered no response in *JETS*. Indeed, one has to search far and wide for an engagement of his proposal. Biola ethicist Scott Rae cites Rakestraw’s proposal in multiple publications, but the engagement is brief as Rae is chiefly focused in those efforts to deliver a philosophical critique against the larger target of personhood bioethics.<sup>3</sup> More substantial is

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<sup>1</sup> James Lindgren, “Death by Default,” *Law and Contemporary Problems* 56/3 (1993) 205–7; “A Majority (53%) of Those Who Call Themselves Evangelicals Support Removing the Feeding Tube, 41% Oppose Removal of the Feeding Tube,” *Time Magazine* U.S. (March 27, 2005), <http://www.time.com/time/printout/0,8816,1042435,00.html#>.

<sup>2</sup> Robert V. Rakestraw, “The Persistent Vegetative State and the Withdrawal of Nutrition and Hydration,” *JETS* 35/3 (1992) 389–405; David K. Clark and Robert Vincent Rakestraw, *Readings in Christian Ethics*, vol. 2: *Issues and Applications* (Grand Rapids: Baker, 1994) 116–31.

<sup>3</sup> J. P. Moreland and Scott B. Rae, *Body & Soul: Human Nature & the Crisis in Ethics* (Downers Grove, IL: InterVarsity, 2000) 318–19, 378–79 n. 46; Scott B. Rae, “Views of Human Nature at the Edges of Life: Personhood and Medical Ethics,” in *Christian Perspectives on Being Human: A Multidisciplinary Approach to Integration* (ed. James Porter Moreland and David M. Ciochi; Grand Rapids: Baker, 1993) 250–51. Writing with J. P. Moreland, Rae identifies as Rakestraw’s chief error a depiction of the human person as a “property-thing”—i.e. as a conglomerate of externally related parts that lacks an internal ordering or unity. Working from a property-thing view of human nature, one is hard-pressed, Moreland and Rae contend, to explain numerous aspects of reality that include continuity of personal identity across physical change. If the property-thing view holds, then “person” is really nothing more than a construct to signify a temporary ordering of material—each change in physical appearance or function entails a change in personal identity. The reality, however, is that we remain who we are over time even as our bodies undergo change. If that were not the case, we would, Moreland and Rae contend, have to sur-

the interaction from Dónal O'Mathúna in a 1996 essay published in *Philosophia Christi*.<sup>4</sup> O'Mathúna's critique was chiefly theological, but he also raised in bare-bones fashion a separate objection that, more fully developed, proves devastating to Rakestraw's argument. Specifically, it is the challenge of empirical warrant, and in this essay, we shall develop the objection, arguing that in constructing his ethical analysis, Rakestraw relied upon a severely flawed analysis of the medical data—judged both by sources available at the time of his writing and by more recent research. The conclusions reached are significant for any approach to the ANH-PVS question that grants decisive influence to the claim that PVS patients are, *en masse*, permanently unconscious.

### I. FRAMING THE ISSUE

Writing in 1992, Rakestraw extended an argument he offered one year prior in a lay-level publication while debate over the ethics of withdrawing ANH from vegetative patients was raging in the wake of the United States Supreme Court's decision concerning Nancy Cruzan.<sup>5</sup> In that case, the Court affirmed with some constraints ANH withdrawal as a legal option in the case of PVS, and in so doing it infuriated many pro-life advocates who viewed the practice as categorically immoral. Rakestraw did not share the latter group's opinion and makes that fact abundantly clear in the opening paragraph of his 1992 essay as he complains of those who in opposing ANH withdrawal "wrongly allege the intention to kill ... on the part of all who allow the practice."<sup>6</sup> In error, he contends, they view the practice as "euthanasia" and so conflate it with "the deliberate termination of the lives of conscious yet severely disabled persons."

At the outset, then, Rakestraw gives his reader some indication of where he will land on the ANH-PVS issue, but with his next preliminary move, he lays his position bare. Surveying the moral terrain, he identifies only two possible positions on the moral question, one of which he has just rejected. The only alternative to the euthanasia approach, he insists, is to view ANH withdrawal as ceasing ministrations to the dead.<sup>7</sup> In removing the feeding tube, either we commit homicide or we

render belief in such bedrock notions as selfness—an "I" that transcends, interprets, and unifies bodily experiences—and also personal responsibility for only if personal identity is maintained over time can one truly be accountable for past actions.

<sup>4</sup> Dónal P. O'Mathúna, "Responding to Patients in the Persistent Vegetative State," *Philosophia Christi* 19/2 (1996) 62–74. According to O'Mathúna, Scripture gives no credence to the notion of a human being devoid of the *imago Dei*. He writes,

The image of God passages were not written to show which humans are images and which are not. They state that humans are images of God because God created us as such (Gen 1:26–27)... . Because we are images of God, we have some unique attributes, including rational, relational, moral and spiritual capacities. We are not images of God because we have these capacities. All humans are images of God, and because of this, these types of activities are part of what it means to be human.

<sup>5</sup> Robert V. Rakestraw, "When Does Death Come? Is It Ethical to Deprive Food and Water from Patients in a Persistent Vegetative State?" *The Standard* 81/10 (1991) 24–27; *Cruzan v. Missouri Department of Health*, 497 U.S. 261 (1990).

<sup>6</sup> Rakestraw, "Persistent Vegetative State" 389.

<sup>7</sup> *Ibid.* 390.

initiate the proper disposition of mortal remains. Inclined to the latter view, Rakestraw devotes the remainder of the essay to arguing that vegetative patients are, in some real sense, deceased. On this proposition, he believes, the morality of ANH withdrawal truly hinges. As he states, “If we can determine that the PVS individual is dead, then we need not hesitate to withdraw food and water. If on the other hand the patient is alive, we must not take his or her life.”<sup>8</sup>

Rakestraw is fully aware that in retaining brainstem function sufficient to undergird spontaneous breathing and circulation, patients diagnosed as vegetative do not meet accepted criteria for declaring death (i.e. they are not dead according to cardiopulmonary or whole-brain standards). He insists, however, that careful ethical reflection reveals a “neocortical” standard as the better approach and to argue the point, he draws first on ethicist Robert Veatch’s proposal that life and death are best understood in relation to our status as human *persons*.

At the core of human personhood, Veatch argued, is the “embodied capacity for social interaction.”<sup>9</sup> Absent that capacity, one cannot, he maintained, truly be alive. For Rakestraw the theologian, “social interaction” fails to fully capture the essence of our personhood—better it is, he asserts, to think in terms of the capacity to image God. With Veatch, however, he agreed that the core capacity presumes consciousness and that such, in turn, requires a functioning cerebral cortex. With a neocortex destroyed by disease or injury, the person, they claim, is dead. In Rakestraw’s words, “Neocortical destruction is both a necessary and sufficient condition for declaring an individual dead theologically” and such, he maintains, is precisely the situation for PVS patients.<sup>10</sup>

## II. A NEOCORTEX “COMPLETELY AND PERMANENTLY DESTROYED”

Briefly summarized, Rakestraw’s argument is as follows:

(P1) To be alive (not dead), a human being must be a human person.

(P2) To be a human person, one must image God.

(P3) To image God, one must be self-aware and self-directing or at least have the potential for such.

(P4) A functioning neocortex is a necessary condition for self-awareness and self-direction.

(C1) Therefore, to be alive, one must have a functioning neocortex or at least the potential for such.

(P5) In the situation of PVS, the neocortex is “completely and permanently destroyed.”<sup>11</sup>

(C2) Therefore, patients in a PVS cannot be alive—i.e., they are dead.

Clearly, there is much packed into premises P1–P4 and to some of the questions raised therein, the philosophical and theological critiques of Rae and

<sup>8</sup> Ibid. 394.

<sup>9</sup> Ibid. 396.

<sup>10</sup> Ibid. 402.

<sup>11</sup> Ibid. 401.

O'Mathúna apply. The focus of the present treatment, however, concerns Rakestraw's empirical warrant—specifically, the claim of complete neocortical destruction (P5).

In characterizing the PVS, Rakestraw begins with a description first advanced by physicians Bryan Jennett and Fred Plum in 1972.<sup>12</sup> He states, “The persistent vegetative state may be defined loosely as a condition in which there is no awareness of the self or the surroundings though the patient appears at times to be awake.”<sup>13</sup> “Wakefulness without awareness” is the claim and per Jennett and Plum such reflects a “cerebral cortex [that] is out of action.”<sup>14</sup> Working from that narrative, Rakestraw believed it appropriate to declare PVS a post-mortem state by neocortical standard provided it could be established that the condition is truly irreversible. In other words, the determination hinged upon the ability to clinically distinguish a dead neocortex from one that was not, and on that issue Rakestraw turned to general surgeon and fellow evangelical, Kenneth Schemmer.<sup>15</sup>

Also an advocate for a higher-brain standard for determining death, Schemmer understood the clinical challenge to the approach. He comments,

Part of the dilemma we face in patients with a permanent loss of consciousness occurs precisely because of that unconsciousness. Is the patient's cortex dead (so there is no hope of ever recovering)? Could they be unconscious but recoverable? Or could they actually be conscious but unable to communicate by usual ways as we saw in the locked-in syndrome?<sup>16</sup>

Working strictly from a clinical (bedside) neuro-examination, these distinctions, Schemmer conceded, “could not be made with certainty,” but in two novel diagnostic technologies he believed the problem was solved. First, he pointed to the use of Positron Emission Tomography (PET) to measure cerebral metabolic activity and blood flow reported by Plum and his colleagues at Cornell Medical Center.<sup>17</sup> With David Levy as their lead author, these investigators reported no overlap in metabolic data between vegetative and non-vegetative patients, and for Schemmer, the finding was most significant. As Rakestraw relates,

What this means, according to Schemmer, is that for the first time since we began connecting people to machines that replace their vital organs we can now determine whether we are keeping a *person* alive or keeping a *body* functioning.

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<sup>12</sup> Bryan Jennett and Fred Plum, “Persistent Vegetative State after Brain Damage: A Syndrome in Search of a Name,” *Lancet* 7753 (1972) 734–37.

<sup>13</sup> Rakestraw, “Persistent Vegetative State” 392.

<sup>14</sup> Jennett and Plum, “Persistent Vegetative State” 734.

<sup>15</sup> Rakestraw, “Persistent Vegetative State” 397–99.

<sup>16</sup> Kenneth E. Schemmer, Dave Jackson, and Neta Jackson, *Between Life and Death: The Life-Support Dilemma* (Wheaton, IL: Victor, 1988) 56–59.

<sup>17</sup> For the original report, see David E. Levy, John J. Sidtis, David A. Rottenberg and others, “Differences in Cerebral Blood Flow and Glucose Utilization in Vegetative Versus Locked-in Patients,” *Annals of Neurology* 22/6 (1987) 673–82.

He calls this a “welcome breakthrough” that “may provide us with our first truly ethical release from one aspect of the life-support dilemma.”<sup>18</sup>

Significant as Levy’s findings were, Schemmer recognized their technique offered no practical solution to the ANH-PVS conundrum because of the high cost and relative inaccessibility of PET scanners. What was needed was “a cheaper and widely available test” and such, he believed, materialized in the Pulsed Doppler Ultrasound (PDU) technique developed by Peter Ahmann at Emory University School of Medicine.<sup>19</sup>

From Ahmann’s 1987 report of a particular pattern of blood flow within the common carotid arteries of nineteen infants declared brain dead, Schemmer concluded the PDU procedure to be “accurate by itself” in establishing neocortical death.<sup>20</sup> With vegetative patients clearly in view, he explained, “This is to say that when the characteristic brain death waveform is present, *even though the brain stem may be functioning and sustaining heart and lung action* [i.e. the vegetative state], the cortex is reliably dead.”<sup>21</sup> Clearly impressed, Rakestraw comments

Schemmer calls this “a landmark discovery: the actual clinical point of death of the human being can now be identified technologically with *certainty*.” In his view we no longer need to worry about pulling the plug too soon. “When a patient has all the clinical evidence of permanent loss of consciousness over a period of time, we can now obtain a PDU test and a confident determination of brain death.”<sup>22</sup>

In Schemmer’s assessments, Rakestraw found confidence for asserting neocortical death as a definitive feature of the vegetative condition. He comments, “Undoubtedly these data will be scrutinized and further research will be done to explore the ramifications of the findings for PVS cases. At the present time, however, there appear to be increasingly reliable scientific criteria for establishing the *totality* and *permanence* of neocortical destruction in PVS individuals.”<sup>23</sup>

### III. THE CLAIM OF NEOCORTICAL DEATH EXAMINED

In their seminal 1972 article describing the PVS, Jennett and Plum expressed hope that later research would yield “reliable predictive criteria” for identifying patients with no chance of recovery from the “vegetative mindless state,” and by Schemmer’s assessment, medical science had finally delivered in the PET and PDU procedures. Concerning PET, Schemmer believed he had found in Levy’s report solid warrant for declaring “complete cortical death” a feature of the vegetative

<sup>18</sup> Rakestraw, “Persistent Vegetative State” 398 (italics his).

<sup>19</sup> See P. A. Ahmann, T. A. Carrigan, D. Carlton, et al., “Brain Death in Children: Characteristic Common Carotid Arterial Velocity Patterns Measured with Pulsed Doppler Ultrasound,” *The Journal of Pediatrics* 110/5 (1987) 723–28.

<sup>20</sup> Schemmer, Jackson, and Jackson, *Between Life and Death* 57.

<sup>21</sup> Italics mine.

<sup>22</sup> Rakestraw, “Persistent Vegetative State” 398 (italics mine).

<sup>23</sup> *Ibid.* 399 (italics mine).

condition, but the data indicated otherwise as all seven vegetative patients studied exhibited continued, though diminished, neocortical blood flow and metabolic activity.<sup>24</sup> Levy conceded as one possible interpretation that “all parenchymal elements, including neurons, glia, and blood vessels, are spared and functioning.” That interpretation comports with numerous reports issued before and after Levy’s publication of neocortical preservation in the brains of PVS patients examined post-mortem.<sup>25</sup>

Similar to Levy’s study, clinical investigations led by Anne DeVolder at Belgium’s University of Louvain and reported in 1990 also demonstrated on PET scan continued cerebral metabolic activity in vegetative patients.<sup>26</sup> More significantly, she identified overlap in the data between vegetative and non-vegetative patients contra the finding of Levy. With the data averaged across five neocortical regions within each patient, “the [two] most affected conscious patients ... had lower [mean] metabolism than the vegetative subject with the highest metabolic values.” Examining the data closely, the overlap appears even more extensive than what DeVolder reports as six of the seven vegetative patients studied had at least one of the five regional rate measurements exceed the lowest corresponding value for patients identified as conscious.<sup>27</sup>

Since the Louvain report, subsequent research from Plum’s group has further challenged the narrative of complete cortical death. In a 2002 paper with Nicholas Schiff as the lead author, the Cornell researchers reported on three vegetative patients with unexpectedly high cerebral metabolic activity who also manifested activities believed to require cerebral processing.<sup>28</sup> Interpreting the data, Schiff proposed that in at least some vegetative patients, there can exist “isolated remnants of functional brain networks” that include regions of preserved neocortex. In other words, at least some vegetative patients retain a neurally active neocortex.

With respect to PDU, Schemmer believed the technique would greatly facilitate the differentiation of PVS patients from chronically unresponsive individuals who retain the capacity for cognition, but there again he was reaching beyond the

<sup>24</sup> Levy, Sidtis, Rottenberg, et al., “Differences in Cerebral Blood Flow” 676. Metabolic rate in vegetative patients was 60 percent lower than in normal volunteers. The reduction in cortical blood flow paralleled the decrease in metabolic rate with the vegetative group registering a 49% reduction as compared with six healthy volunteers.

<sup>25</sup> For a survey regarding post-mortem findings in PVS patients, see Bryan Jennett, *The Vegetative State: Medical Facts, Ethical and Legal Dilemmas* (Cambridge: Cambridge University Press, 2002) 52–53. Jennett notes in this discussion that when he and his colleagues at the University of Glasgow examined the brains of forty-nine vegetative patients, “The cerebral cortex was completely normal in seven cases and in 21 others was affected only by minor traumatic contusions.”

<sup>26</sup> Anne G. DeVolder, André M. Goffinet, Anne Bol, et al., “Brain Glucose Metabolism in Postanoxic Syndrome. Positron Emission Tomographic Study,” *Archives of Neurology* 47/2 (1990) 197–204.

<sup>27</sup> *Ibid.* 200. See Table 3. In this table, DeVolder lists the metabolic data corresponding to the five neocortical regions studied. The most significant overlap of data between patients deemed vegetative and those measurably conscious involved the frontomesial cortex wherein absolute metabolic rate was higher for six vegetative patients than for one conscious patient identified by DeVolder as “Patient 12.”

<sup>28</sup> Nicholas D. Schiff, Urs Ribary, Diana R. Moreno, et al., “Residual Cerebral Activity and Behavioural Fragments Can Remain in the Persistently Vegetative Brain,” *Brain* 125/6 (2002) 1210–34.

data. Most significantly, the characteristic pressure waveform that Ahmann identified and of which Schemmer asserted will free us from anxiety over “pulling the plug too soon” was observed not in individuals deemed vegetative but in patients who met the clinical criteria of *whole* brain death (i.e. irrecoverable loss of *all* brain function and not just neocortical).<sup>29</sup> If there were any vegetative patients to be found in Ahmann’s study, it would have been in its poorly-described comparison group of eighteen patients “who, in the opinion of the attending physician, were likely to become brain dead in the immediate future” but instead became “neurologically stable.”<sup>30</sup> None of these patients exhibited the brain death waveform (BDWF), and fifteen of them had completely normal PDU waveforms.<sup>31</sup>

At the very least, Ahmann’s study provided no positive evidence to support the characterization of vegetative patients as neocortically dead. Indeed, with Levy’s study showing continued cerebral perfusion in vegetative patients near 50 percent of normal, there was good reason to believe the PDU approach would *not* be helpful in furthering Schemmer’s goal of screening chronically unresponsive patients for the vegetative condition because in order for the BDWF to occur, blood flow to the cerebrum must be interrupted.<sup>32</sup> In extrapolating Ahmann’s data to the vegetative state, Schemmer was clearly assuming rather than proving “complete cortical death” to be a definitive feature of PVS.

Compounding the error, Schemmer’s analysis failed to note the marked insensitivity of Ahmann’s technique—thirteen of the study’s 32 patients (40%) who met the clinical criteria for (whole) brain death failed to exhibit the BDWF. If the PDU technique was truly “accurate by itself” as Schemmer claimed, then the patients deemed brain dead but exhibiting no BDWF were not truly brain dead. Ahmann offered no such concession and neither did Schemmer, and perhaps rightly so as five of these patients failed to evidence cerebral blood flow when studied with a more sensitive technique (radionuclide cerebral angiography).<sup>33</sup> Convinced that

<sup>29</sup> Ahmann, Carrigan, Carlton, et al., “Brain Death in Children” 724. The clinical criteria for (whole) brain death employed by Ahmann and his colleagues included “absent spontaneous respiration, dilated and unreactive pupils, absent corneal reflexes, absent eye movements, . . . and flaccidity with unresponsiveness to noxious stimuli.”

<sup>30</sup> *Ibid.* “Neurologically stable” does not imply a return to normality but rather, it means a halting of the deterioration in neuro-clinical signs.

<sup>31</sup> The three patients in the comparison group with abnormal PDU waveforms were reported to be “nearly brain dead” with two *in extremis* and the third dying from cardiopulmonary arrest some time after the PDU study—i.e. they did not present the clinical picture of the vegetative patient.

<sup>32</sup> Ahmann explains the theory underlying his diagnostic innovation: “The flow in the common carotid simply reflects the sum of the low-resistance high-flow internal carotid [which branches to form anterior and middle cerebral arteries] and the high-resistance low-flow external carotid circulation. The flow through the common carotid artery after the loss of cerebral perfusion is consequently that which perfuses the external carotid artery; the measured brain death waveform is like that found in a peripheral artery.” See Ahmann, Carrigan, Carlton, et al., “Brain Death in Children” 727.

<sup>33</sup> Of the thirty-two patients diagnosed as clinically brain dead, fourteen had cerebral blood flow evaluated with radionuclide angiography (RA). Thirteen were judged to have no cerebral blood flow, including eight with and five without the BDWF on PDU evaluation. In one infant diagnosed as clinically brain dead, retained cerebral blood flow was documented using RA at fourteen and thirty-nine hours following diagnosis.

these patients truly were brain dead, Ahmann postulated that further refinement of the carotid PDU technique would enable detection of a “no cerebral flow’ velocity pattern” in these types of cases. To date, that projection has yet to be experimentally confirmed, and, more significant to Rakestraw’s analysis, neither has Schemmer’s claim that PDU would simplify the diagnostic assessment of unresponsive patients with functioning brainstems.

In considering, then, the data available to Rakestraw in 1992 and more recently, we may conclude that “complete neocortical destruction” and “cerebral death” are inaccurate descriptors when globally attributed to patients who meet the clinical criteria for the vegetative state. Much like the term “apallic”—meaning, “without cerebral cortex”—which Jennett and Plum rejected in 1972, the rhetoric of “death” and “complete destruction” conveys as fact a disproven pathology.<sup>34</sup> Retained neocortical viability appears to be the norm in vegetative patients and according to Schiff’s report, it is sufficient in at least some of these individuals to undergird neural activity.

#### IV. “PERMANENTLY UNCONSCIOUS?”

Largely obscured by Rakestraw’s appeal to the narrative of complete cortical destruction is the more fundamental claim that PVS patients are permanently unconscious. Stripping away the former, his argument may thus be reformulated as

(P1) To be alive (not dead), a human being must be a human person.

(P2) To be a human person, one must image God.

(P3) To image God, one must be self-aware and self-directing or at least have the potential for such.

(P4) To be self-aware and self-directing, one must be conscious.

(C1) Therefore, to be alive, one must be conscious or at least have the potential for such.

(P5) Patients in a PVS are permanently unconscious.

(C2) Therefore, patients in a PVS cannot be alive—i.e. they are dead.

Probing the reformulated empirical premise (P5), we may first ask, “Are PVS patients unconscious?” and then secondly, “If PVS patients are unconscious, is their condition permanent?” Respectively, the questions reflect the concerns of diagnostic and prognostic accuracy, and given the severe offense Rakestraw believed would be committed in withholding ANH from a patient still cognitive, he concluded we must on both issues be sure. If we err, we should, he asserted, “err on the side of keeping someone physically alive when the spirit may be gone rather than risk killing a person.”<sup>35</sup>

1. *The problem of misdiagnosis.* Largely on the basis of Schemmer’s analysis, Rakestraw was convinced that the risk of misdiagnosing a severely debilitated but still conscious patient as vegetative was negligible. The published literature, however, tells a different story. Misdiagnosis of the PVS is an intractable and well-

<sup>34</sup> Jennett and Plum, “Persistent Vegetative State” 736.

<sup>35</sup> Rakestraw, “Persistent Vegetative State” 405.

documented phenomenon that first surfaced in the medical literature as an incidental finding in a 1991 report from geriatrician Donald Tresch at the Medical College of Wisconsin.<sup>36</sup> While working to identify a study group of PVS patients from several regional nursing homes, Tresch and his fellow researchers found that 11 of 62 prospective subjects (18%) had “some awareness of their environment, with some of the patients demonstrating volitional movements.”

Two years after Tresch’s report was published, Nancy Childs from the Healthcare Rehabilitation Center in Austin, Texas, reported finding evidence of consciousness in 18 of 49 patients (37%) referred to her institution with a diagnosis of coma or PVS.<sup>37</sup> These were not patients believed to be unconscious at admission who subsequently recovered cognitive function while receiving rehabilitation therapy; rather, they were patients for whom evidence of consciousness was identified within hours or days of arriving at the rehabilitation center, thus discrediting the referring physician’s diagnosis.<sup>38</sup> To explain the diagnostic errors, Childs posited a combination of “confusion in the terminology used to describe alterations in states of consciousness” and referring clinicians “untutored in assessment of consciousness.”

Similar to Childs’s experience, Keith Andrews from London’s Royal Hospital for Neurodisability (RHN) reported in 1996 a very high rate (43%) of misdiagnosis across a cohort of forty patients referred as vegetative to his institution over a four-year period.<sup>39</sup> Working against Childs’s hypothesis, however, Andrews observed that most of the misdiagnoses he and his colleagues identified were “made by a neurologist, neurosurgeon, or rehabilitation specialist—all of whom could have been expected to have experience of vegetative state.”<sup>40</sup> Almost a decade later, researchers at RHN were still reporting a high error rate with 28 percent of patients declared vegetative by the referring physician demonstrating awareness on first examination at RHN and 45 percent by a third examination conducted within four months of admission.<sup>41</sup> Five years subsequent to that report, researchers from the

<sup>36</sup> Donald D. Tresch, Farrol H. Sims, Edmund H. Duthie, et al., “Clinical Characteristics of Patients in the Persistent Vegetative State,” *Archives of Internal Medicine* 151/5 (1991) 930–32.

<sup>37</sup> Nancy L. Childs, Walt N. Mercer, and Helen W. Childs, “Accuracy of Diagnosis of Persistent Vegetative State,” *Neurology* 43/8 (1993) 1465–67.

<sup>38</sup> According to Childs et al., “50% (9 of 18) [of the misdiagnoses] were identified within the first day of admission and 78% (14 of 18) by the third day.”

<sup>39</sup> Keith Andrews, Lesley Murphy, Ros Munday, and Clare Littlewood, “Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit,” *British Medical Journal* 313/7048 (1996) 13–16. In this report, misdiagnosis of the vegetative state was identified in seventeen of forty patients. In fifteen of the misdiagnosed patients (88%), cognition was identified within sixteen days of arrival despite these patients being considered vegetative for an average of twenty-four months prior to admission.

<sup>40</sup> *Ibid.* 14.

<sup>41</sup> H. Gill-Thwaites and R. Munday, “The Sensory Modality Assessment and Rehabilitation Technique (Smart): A Valid and Reliable Assessment for Vegetative State and Minimally Conscious State Patients,” *Brain Injury* 18/12 (2004) 1255–69. Gill-Thwaites and Munday comment, “Of these [sixty] subjects [referred as vegetative], 28% demonstrated [awareness] in the first assessment (week 1 of admission). It is reasonable to assume that they had been misdiagnosed. This figure does not take account of those patients who required time to settle into the unit, develop rapport with the staff and medical

Coma Science Group at the University of Liege signaled no abatement of the problem as they reported finding evidence of cognition in 18 of 44 patients (41%) assessed as vegetative no more than twenty-four hours prior by other clinicians employing standard behavioral assessments.<sup>42</sup>

Despite heightened awareness of the issue, PVS misdiagnosis is a persistent problem. Compounding the situation, recent studies employing sophisticated brain imaging techniques suggest the error rate may be even higher than what the above-mentioned reports indicate. To explain, in those reports, misdiagnoses were identified on behavioral examination—long the standard for diagnosing disorders of consciousness—but beginning with a 2006 report from Adrian Owen at Cambridge University, researchers have with the aid of magnetic resonance imaging (MRI) come to recognize a subset of wakeful, post-comatose patients who are conscious at some level but, unlike classically “locked-in” patients, are completely unable to demonstrate any outward signs of such.<sup>43</sup> Relating the discovery of this “covert awareness” in a woman repeatedly assessed as vegetative for six months following a vehicular accident, Owen wrote,

The patient was given spoken instructions to perform two mental imagery tasks at specific points during the [MRI] scan. One task involved imagining playing a game of tennis and the other involved imagining visiting all of the rooms of her house, starting from the front door. During the periods that she was asked to imagine playing tennis, significant activity was observed in the supplementary motor area [of the cerebral cortex]. In contrast, when she was asked to imagine walking through her home, significant activity was observed in the parahippocampal gyrus, the posterior parietal cortex, and the lateral premotor cortex. *Her neural responses were indistinguishable from those observed in healthy volunteers performing the same imagery tasks.*<sup>44</sup>

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status to be stabilized. Therefore, the figure of possible misdiagnosis may have been greater.” Indeed, reflecting two years later, Gill-Thwaites stated the conviction that all twenty-seven patients (45%) demonstrating awareness by third examination in her 2004 report were non-vegetative at admission (Helen Gill-Thwaites, “Lotteries, Loopholes and Luck: Misdiagnosis in the Vegetative State Patient,” *Brain Injury* 20/13 (2006) 1321).

<sup>42</sup> C. Schnakers, A. Vanhaudenhuyse, J. Giacino, et al., “Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment,” *BMC Neurology* 9 (2009) 35.

<sup>43</sup> Damian Cruse, Srivas Chennu, Davinia Fernandez-Espejo, et al., “Detecting Awareness in the Vegetative State: Electroencephalographic Evidence for Attempted Movements to Command,” *PLoS One* 7/11 (2012) e49933; Adrian M Owen and Martin R Coleman, “Detecting Awareness in the Vegetative State,” *Annals of the New York Academy of Sciences* 1129 (2008) 130–38; Adrian M Owen, Martin R Coleman, Melanie Boly, et al., “Detecting Awareness in the Vegetative State,” *Science* 313/5792 (2006) 1402; C. Schnakers, J. T. Giacino, M. Lovstad, et al., “Preserved Covert Cognition in Noncommunicative Patients with Severe Brain Injury?,” *Neurorehabilitation and Neural Repair* (2014) doi:10.1177/1545968314547767. By the classical description, patients who are “locked-in” are fully conscious and able to communicate via eye blinks and changes in eyeball position. On account of severe paralysis that renders them immobile and unable to speak, they are often misdiagnosed as vegetative. See Jennett, *Vegetative State* 20–21.

<sup>44</sup> Owen, Coleman, Boly, et al., “Detecting Awareness in the Vegetative State” 1402 (my italics). Even more amazing, Owen’s group working in collaboration with researchers from the University of

Along with Owen's research group now stationed at Canada's Western University, the Coma Science Group led by Steven Laureys at Liege has been on the leading edge of this newest wave of PVS research. In a recent paper, Laureys's group reported detection of covert awareness using PET and MRI in 13 of 41 patients (31%) he and his colleagues had confirmed as meeting the standard (behavioral) criteria for PVS.<sup>45</sup> Combining these findings with the group's prior report of misdiagnosis attaching to errant behavioral assessments, the Liege experience suggests it is more likely than not that when a post-comatose patient is tagged with a diagnosis of PVS, he or she is actually conscious at some level.<sup>46</sup> To be clear, Laureys and Owen do not dispute that some unresponsive, wakeful patients may truly be unconscious. But their research extends the point demonstrated well in the earlier reports that clinicians can, and often do, err when declaring wakeful, post-comatose patients to be completely unaware.

Now, one may counter that the problem of misdiagnosis is solvable—specifically, that unresponsive post-comatose patients simply be directed to facilities like those at Royal Hospital, Liege, or Western for verification of diagnosis. There are, however, very few of these specialized centers in the world and certainly too few in the United States to accommodate an estimated 30,000 PVS patients.<sup>47</sup> The reality, as Jennett observed in 2002, is that these patients are distributed across a wide variety of institutions including “acute hospitals, geriatric or young chronic sick units, mental hospitals, rehabilitations units, nursing homes, and charitable care facilities.”<sup>48</sup> Physicians and caregivers in most of these facilities typically have little experience working with highly debilitated, post-comatose patients and as a result, they are more apt to miss subtle signs of consciousness. And with the novel clinical methods presently confined to specialty centers possessing high-end scanners and robust neuroclinical research budgets, most patients “covertly aware” will continue to evade detection. In practice, then, we may expect that in positing the PVS diagnosis as the lynchpin for withdrawing ANH, patients retaining cognitive capacity will, contra Rakestraw's intention, be denied treatment.

Liege later reported two-way communication with one covertly aware patient (see M. M. Monti, A. Vanhaudenhuyse, M. R. Coleman, et al., “Willful Modulation of Brain Activity in Disorders of Consciousness,” *The New England Journal of Medicine* 362/7 (2010) 579–89).

<sup>45</sup> J. Stender, O. Gosseries, M. A. Bruno, et al. “Diagnostic Precision of PET Imaging and Functional MRI in Disorders of Consciousness: A Clinical Validation Study,” *Lancet* 384/9942 (2014) 514–22. In this paper and others delivered by his group since 2010, Laureys employs the term “unresponsive wakefulness syndrome” as a preferred substitute for “vegetative state.” For a defense of this shift in terminology, see S. Laureys, G. G. Celesia, F. Cohadon, et al., “Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome,” *BMC Medicine* 8 (2010) 68.

<sup>46</sup> If 41 percent of patients receiving the diagnosis of PVS can be demonstrated on behavioral examination as non-vegetative and of the remaining individuals (59%) covert awareness is detected in 31 percent, then the overall misdiagnosis rate would be 59 percent (41% + [59%\*0.31]).

<sup>47</sup> Jennett, *Vegetative State* 36. The estimate of 30,000 PVS patients in the United States is based on an approximate population of 300 million and a mid-range estimate of 100 PVS patients per million population drawn from Jennett's review of the literature.

<sup>48</sup> *Ibid.* 33.

2. *The problem of "late recovery."* Working from the premise that medical science had established complete neocortical destruction as a definitive feature of the vegetative condition, Rakestraw believed we could say with confidence that "correctly diagnosed" patients are *permanently* unconscious—i.e. that recovery of consciousness was a medical impossibility. The reality, however, is that some post-comatose patients who repeatedly meet the established criteria for PVS over an extended period of time eventually manifest signs of consciousness. These are not patients deemed misdiagnosed, but rather, they are individuals whose condition clinicians judge to progress over time from an unconscious to a conscious state. In describing their condition, Jennett comments "these late recoveries are almost always to very severe disability. Most patients remain totally dependent, some reaching only the minimally conscious state or a little better. Many continue to require tube feeding and are able to communicate only by gesture or coded movements because they cannot speak."<sup>49</sup> In other words, these patients are typically highly debilitated, yet they are nonetheless demonstrably conscious at some level.

Before Rakestraw wrote in 1992, numerous reports of vegetative patients regaining cognitive function had already appeared in the clinical literature.<sup>50</sup> With the duration between PVS diagnosis and recovery varying in those publications, debate arose over the question of when, if at all, the condition might be declared irreversible. Addressing that issue, Plum and nine other neuro-medical experts working in 1994 as the Multi-Society Task Force on PVS (MSTF) recommended from their review of the literature that the vegetative state be declared "permanent" if persisting beyond twelve months post-trauma or three months following non-traumatic (anoxic) injury.<sup>51</sup>

Beyond its chosen time points, there were, the MSTF acknowledged, documented recoveries. Out of 434 adults with traumatic brain injuries that met its inclusion criterion for review (vegetative at one month post-injury), the MSTF identified seven as having recovered consciousness twelve months or more after trauma. Calculating the incidence of these "late" recoveries to be 1.6 percent (7÷434), they concluded the phenomenon to be "exceedingly rare." Disability advocate Chris Borthwick, however, has keenly observed that since only 65 of the 434 patients were alive and vegetative at twelve months, the incidence of late recovery (i.e. recovery after twelve months per the MSTF) should have been reported as just over

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<sup>49</sup> Ibid. 65.

<sup>50</sup> See, e.g., H. S. Levin, C. Saydjari, H. M. Eisenberg, et al., "Vegetative State after Closed-Head Injury. A Traumatic Coma Data Bank Report," *Archives of Neurology* 48/6 (1991) 580–85. Levin and his colleagues reported at least partial cognitive recovery by six months in 34 of 84 patients (40%) rendered vegetative by traumatic brain injury. At one year, the rate was 52 percent and by two years, it rose to 58 percent. Reviewing the literature in his 2002 book on the vegetative state, Jennett identified several reports of cognitive recovery in vegetative patients dating back to 1977 (*Vegetative State* 57–65).

<sup>51</sup> The Multi-Society Task Force on the Persistent Vegetative State, "Medical Aspects of the Persistent Vegetative State (Second of Two Parts)," *New England Journal of Medicine* 330/22 (1994) 1575.

10 percent (7÷65), and given that figure, he concluded the attribution of rarity to be inaccurate and misleading.<sup>52</sup>

Since the MSTF report was released, research addressing the issue of late recovery has been slow to accrue, but recently published studies suggest Borthwick was on the right track. In 2010, clinical researchers from Telese, Italy, reported late recoveries averaging 17.2 months post-injury in 10 of 50 (20%) patients prospectively studied for an average of 25.7 months following admission to their neurorehabilitation facility.<sup>53</sup> Two years later, a multi-center longitudinal analysis with five-year follow-up on 37 vegetative patients receiving inpatient rehabilitation following traumatic brain injury revealed eight late recoveries (22%) with half occurring after two years.<sup>54</sup> The following year, the Telese researchers reported again on late recovery but with a focus on patients with non-traumatic injuries.<sup>55</sup> With 9 of their 43 patients (21%) experiencing a recovery of consciousness beyond the MSTF permanency cutoff, they concluded with echoes of Borthwick that “late recovery cannot be considered as an exception.”

For Jennett and many others, late recovery is not a serious issue because they judge the quality of life that typically results to be so poor as to warrant discontinuation of life-prolonging treatment.<sup>56</sup> Indeed, some assert that to recover to a minimally conscious state would be a fate worse than permanent vegetation.<sup>57</sup> For Rakestraw, however, who settles the ANH-PVS issue solely on the question of whether or not the patient retains a capacity “however slight” for consciousness, late recoveries present the same problem as misdiagnosed patients—specifically, that patients alive by his own criterion would be denied life-sustaining treatment and thus, by his moral reckoning, be killed without justification.<sup>58</sup>

<sup>52</sup> Christian J. Borthwick, “The Permanent Vegetative State: Ethical Crux, Medical Fiction?,” *Issues in Law & Medicine* 12/2 (1996) 167–85.

<sup>53</sup> A. Estraneo, P. Moretta, V. Loreto, et al., “Late Recovery after Traumatic, Anoxic, or Hemorrhagic Long-Lasting Vegetative State,” *Neurology* 75/3 (2010) 239–45. Patients exhibiting late recovery in this study included six with traumatic brain injury, three with anoxic injury, and one with cerebral aneurysm. The range between disease onset and detection of consciousness was 14 to 28 months.

<sup>54</sup> R. Nakase-Richardson, J. Whyte, J. T. Giacino, et al., “Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Programs,” *Journal of Neurotrauma* 29/1 (2012) 59–65.

<sup>55</sup> A. Estraneo, P. Moretta, T. Terme, and L. Trojano, “Predictors of Recovery of Responsiveness in Prolonged Anoxic Vegetative State,” *Neurology* 80/5 (2013) 464–70.

<sup>56</sup> Commenting in 1992 on the case of vegetative patient Tony Bland, Jennett reveals his criteria for when to continue life-prolonging treatment, stating, “Treatment is justified only if there is a reasonable probability of *meaningful* recovery and of regaining life as a *social person* or if, in the words of the BMA’s medical ethics committee, “it makes possible a *decent* life in which a patient can reasonably be thought to have a *continued interest*.” A typical recovery from the vegetative state will not satisfy his requirements, and so he observes, “The recovery of a limited degree of awareness may indeed be worse than non-sentience for the patient, whatever satisfaction it may bring to the carers.” Bryan Jennett, “Letting Vegetative Patients Die,” *British Medical Journal* 305/6865 (1992) 1305 (my italics).

<sup>57</sup> A. Demertzi, D. Ledoux, M. A. Bruno, et al., “Attitudes Towards End-of-Life Issues in Disorders of Consciousness: A European Survey,” *Journal of Neurology* 258/6 (2011) 1058–65.

<sup>58</sup> Rakestraw, “Persistent Vegetative State” 401.

To deflect the concern, Rakestraw might contend that prior to recovery, the patient is truly bereft of cognitive capacity and thus dead. If so, then in the words of physician Peter Emmett, a former graduate student under Rakestraw, cognitive recovery is a “Lazarus event.”<sup>59</sup> Rakestraw seems to agree as he comments, “turning the individual over to God’s providence [by disconnecting the feeding tube] ... we may hope beyond all reason for hope that God will yet quicken the loved one.”<sup>60</sup> Yet, even if certain occurrences of cognitive recovery may indeed be miraculous, the general phenomenon can be explained without recourse to resurrection. As researchers from Boston University School of Medicine state, “The natural history of recovery from brain injury typically consists of a period of impaired consciousness, a subsequent period of confusion and amnesia, followed by a period of post-confusional recovery of function. Patients with more severe injuries may have more prolonged episodes of unconsciousness or minimal consciousness and may not fully evolve through this continuum of recovery.”<sup>61</sup> Understanding late recovery as movement along a continuum of pathologic brain disturbance that begins with coma and passes slowly through the vegetative state, there seems little need to posit for each and every occurrence a raising of the dead.

## V. CONCLUSION

Without question, an “ethical release” would be roundly received by all who must grapple with the question of indefinite ANH for individuals diagnosed as being in a PVS, and toward that end, a declaration of death would seem most expeditious. Yet, the notion that a patient who still moves, breathes, and reacts is dead is not one easily accepted, and so Rakestraw, presuming PVS would be the paradigmatic case, labored to win fellow evangelicals over to a neocortical concept of death.

Even in 1992, however, the claim of complete neocortical destruction constituting a definitive feature of the PVS was evidentially suspect, and with studies since then confirming neocortical preservation and functioning in patients who consistently meet the diagnostic criteria for PVS, the proposition may be dismissed without reservation. More significantly, the accrued research presents a serious obstacle not just for Rakestraw but for many other ethicists whose analyses of the ANH-PVS issue proceed on the notion that we are dealing *en masse* with permanently unconscious patients. The consistent judgment of science commenting upon science is that a large percentage of patients branded as persistently vegetative are not truly vegetative (i.e. they are cognitive at some level), and of those declared permanently vegetative after repeated examinations, roughly one or two out of ten will, given the opportunity, transition to at least a minimally conscious state.

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<sup>59</sup> Peter Alan Emmett, “The Image of God and the Ending of Life,” *Asbury Theological Journal* 47/1 (1992) 59.

<sup>60</sup> Rakestraw, “Persistent Vegetative State” 404.

<sup>61</sup> D. I. Katz, M. Polyak, D. Coughlan, et al., “Natural History of Recovery from Brain Injury after Prolonged Disorders of Consciousness: Outcome of Patients Admitted to Inpatient Rehabilitation with 1–4 Year Follow-Up,” *Progress in Brain Research* 177 (2009) 73–88.

Perhaps medical science will eventually deliver an accurate and widely accessible technique for identifying among post-comatose patients those who are truly unconscious and will remain as such however long ANH continues.<sup>62</sup> For the time being, however, we do well, as Borthwick suggested a decade ago, to “frame our opinions and our procedures in ways that can accommodate a high element of uncertainty [as to the cognitive status of patients declared vegetative].”<sup>63</sup> This is not to claim that all patients diagnosed as persistently vegetative are, in fact, conscious or at least possessing of the capacity to recover cognitive function. Nor is it to demand of physicians absolute certainty in their diagnostic and prognostic judgments. Nor is it to argue for indefinite ANH—only if one first accepts Rakestraw’s binary construct of the moral options would that conclusion flow from a rejection of the PVS-death thesis. Rather, the above analysis leads us to a more modest conclusion. At the level of concrete action, it is to acknowledge that when pastors, chaplains, and ethicists are called to render guidance on the question of continued care for an individual diagnosed as persistently vegetative, there exists a significant possibility their task will concern a patient who, unbeknownst to all gathered around the bedside, is conscious at some level or may become so if further sustained. If, then, release from the concern of “pulling the plug too soon” on ANH is truly in the offing as Rakestraw supposed, it will not be found in the narrative of permanent unconsciousness.<sup>64</sup>

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<sup>62</sup> Eliminating all diagnostic and prognostic errors would deliver no guarantee of success for the PVS-death thesis as weighty theological and philosophical objections remain. To the concerns raised by Rae and O’Mathúna mentioned above, other negative evaluations of the personhood distinction may be added including the critique of ethicist Gilbert Meilaender offered in a number of works that include a 1984 essay cited by Rakestraw in his *JETS* article. See Gilbert Meilaender, “On Removing Food and Water: Against the Stream,” *Hastings Center Report* 14/6 (1984) 12; Rakestraw, “Persistent Vegetative State” 389.

<sup>63</sup> Chris Borthwick, “Ethics and the Vegetative State,” *Neuropsychological Rehabilitation* 15/3 (2005) 262.

<sup>64</sup> Ethicists addressing the ANH-PVS question routinely adopt the narrative of permanent unconsciousness, and generally without any critical evaluation of the empirical evidence. For proponents of ANH withdrawal, the narrative is typically a critical element in the moral analysis because, with few exceptions, they identify consciousness as ethically determinative. This is true whether the appeal is made to the personhood distinction, to quality of life, or to a right to refuse (by proxy) treatment deemed medically futile. For a deeper discussion of the issue and a defense of ANH withdrawal that proceeds *sans* the narrative of permanent unconsciousness, see Erik M. Clary, “On the Ethics of Withdrawing Artificial Nutrition and Hydration from Patients Diagnosed as Being in a Persistent Vegetative State: An Analysis of Prior Evangelical Treatments and a Proposal” (Ph.D. diss., Southeastern Baptist Theological Seminary, 2015). The author is grateful for the feedback received in that forum and also for the thoughtful reviews of Daniel Heimbach and Mark Liederbach.