



COMMENTARY

Ethical, Palliative, and Policy Considerations in Disorders of Consciousness

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Abstract

This essay complements the scientific and practice scope of the American Academy of Neurology Guideline on Disorders of Consciousness by providing a discussion of the ethical, palliative, and policy aspects of the management of this group of patients. We endorse the renaming of “permanent” vegetative state to “chronic” vegetative state given the increased frequency of reports of late improvements but suggest that further refinement of this class of patients is necessary to distinguish late recoveries from patients who were misdiagnosed or in cognitive-motor dissociation. Additional nosologic clarity and prognostic refinement is necessary to preclude overestimation of low probability events. We argue that the new descriptor “unaware wakefulness syndrome” is no clearer than “vegetative state” in expressing the mismatch between apparent behavioral unawareness when patients have covert consciousness or cognitive motor dissociation. We advocate routine universal pain precautions as an important element of neuropalliative care for these patients given the risk of covert consciousness. In medical decision-making, we endorse the use of advance directives and the importance of clear and understandable communication with surrogates. We show the value of incorporating a learning health care system so as to promote therapeutic innovation. We support the Guideline’s high standard for rehabilitation for these patients but note that those systems of care are neither widely available nor affordable. Finally, we applaud the Guideline authors for this outstanding exemplar of engaged scholarship in the service of a frequently neglected group of brain-injured patients.

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For a patient population long marginalized by an uninterested health care system,¹ Practice Guideline: Disorders of Consciousness² is a landmark publication. Through the rigorous application of evidence-based criteria to the available literature, the Guideline demonstrates that patients with disorders of consciousness (DoC) comprise a population at risk, vulnerable to misdiagnosis and to medical mismanagement that can negatively affect their access to ongoing care, rehabilitation, and pain and symptom management. To address this problem, the Guideline affirmatively calls for the provision of skilled care by knowledgeable practitioners—a standard of care that is currently unavailable to most patients except those few who are lucky enough to gain admission to the small number of elite specialized rehabilitation centers. By articulating this aspirational standard of care and laying bare the deficits of current practices, the Guideline provides a useful metric

by which society should work to meet its normative obligations to patients with severe brain injury.

In this commentary, we address the ethical, palliative, and policy aspects of the Guideline. When the Guideline was first envisioned, these topics were intended to constitute a companion report, but that effort was abandoned to prioritize an analytical review of the literature. While we understand the reasons for this choice, a full consideration of the Guideline is incomplete without addressing the broader ethical implications for patient care and institutional reform. We address this gap here to lay the foundation for a subsequent multisociety consensus statement on the ethical and policy considerations for the care of patients with disorders of consciousness.

Diagnostic nomenclature, ethics, and ideology

It is a welcome relief to codify and not revisit the category of the minimally conscious state (MCS),³ whose designation

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dramatically enriched the research and clinical landscape by giving a name to a cohort of patients who previously had been grouped within the vegetative state (VS) and whose diagnosis remains confused with it. The Guideline adds a level of refinement by introducing the term chronic vegetative state to replace permanent vegetative state, which the Multi-Society Task Force on PVS (MSTF)⁴ had codified as a prognostic refinement of the term persistent vegetative state, coined earlier by Jennett and Plum.⁵

This new term represents a justified refinement in our thinking. Nonetheless, we comment upon how changes in the nomenclature of the VS may be received in the bioethics community and in society at large given the etymologic origins of the term vegetative state⁶ and the place that the VS has played within American jurisprudence in the evolution of the right to refuse life-sustaining treatment.⁷ Based on Dr. Plum's testimony, Judge Hughes found that there was no state interest to "compel Karen (Quinlan) to endure the unendurable only to vegetate a few more measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life."⁸ The futility of the VS became the moral and legal warrant to remove Quinlan's respirator. Thereafter, the VS was linked to the right to die and to the culture wars that later played out in the public debates over removing the feeding tubes of VS patients Nancy Cruzan⁹ and Teresa Schiavo.^{10–12}

Now based on evidence of late improvements from the VS as well as a reanalysis of the small sample size that led the MSTF to overestimate its permanence, the Guideline acknowledges that perhaps 20% of vegetative patients will evolve into MCS, far outside of the MSTF temporal prognostic boundaries. This reassessment has led the Guideline authors to redesignate this group as the chronic VS.

While this redesignation seems warranted on clinical and epidemiologic grounds, it will create repercussions beyond the house of medicine given that the right to refuse lifesustaining treatment initially was predicated upon the irreversibility of the VS.¹³ With the change from "permanent" to "chronic" VS, we can imagine commentators revisiting contentious cases like Schiavo. If 20% of VS patients have late improvements, how certain can we be that patients like Schiavo might not have improved? When argued from an ideologic stance, objective evidence about etiology of injury or autopsy data will do little to assuage skeptics. Of course, this is not a reason to eschew improved diagnostic schemata, but this issue may be an unintended consequence that the medical profession will need to address and mitigate.

To that end, we urge additional prognostic refinement clarifying which vegetative patients might make late improvements. This clarity would help minimize the conceptual vulnerability of too broad a category in which 80% of patients will remain permanently vegetative. To this end, we envision several additional nosologic distinctions, each with its own ethical valence.^{14,15}

The first group is patients who were simply misdiagnosed, a common situation given the known high prevalence of diagnostic errors.¹⁶ To minimize diagnostic error, neurologists should

perform a thorough neurologic examination specifically targeting evidence of awareness, such as by employing the Coma Recovery Scale—Revised.¹⁷ A second group is those who underwent a state change from appearing behaviorally vegetative to being overtly minimally conscious after treatment with a drug (such as zolpidem)¹⁸ or neurostimulation (with deep brain stimulation, transcranial magnetic stimulation, or vagal nerve stimulation).^{19–21} These patients might be better understood as MCS patients with largely intact neural networks that had been underactivated, leading to a vegetative appearance until they were stimulated. A third category is patients with cognitive—motor dissociation (CMD) in whom the behavioral examination was dissociated from detected volitional responsiveness.²² Patients in this group span a range of functional statuses from MCS to those with complete awareness in the locked-in syndrome.²³ A fourth group is those patients who underwent late structural changes recreating network responses necessary for consciousness.^{24,25} Further complicating this framework, patients in this fourth group could either manifest behavioral evidence of consciousness or evolve to CMD.

Given the relationship of permanence to the right to refuse life-sustaining therapy, we emphasize that only patients in the fourth category have true late improvements. The others had been mistakenly classified as vegetative because of misdiagnosis, absence of pharmacologic or electrical stimulation, or CMD. Contrasting the delayed diagnosis of MCS or CMD against late improvement beyond the VS can help temper societal expectations about miracle recoveries for the vast majority of vegetative patients who will never regain consciousness.

Covert consciousness and the unresponsive wakefulness syndrome

In an effort to counter false-negative bedside examinations that fail to identify covert consciousness, the Guideline calls for the use of ancillary multimodal evaluation with neuroimaging and electrophysiologic testing. The authors' willingness to turn to measures whose test characteristics have not been determined fully speaks to the ethical importance of avoiding type II error: failing to identify consciousness when it is present. While nonbehavioral assessment is less sensitive than the highly validated Coma Recovery Scale—Revised,¹⁷ we fully endorse the use of ancillary assessment tools when doubt remains about the diagnosis. Nonbehavioral assessment may be more specific and identify patients whose consciousness might otherwise lack detection.²⁶ Given that consciousness is an irreducible component of personhood, the use of these additional modalities contributes to respect for persons, a central tenet of the Belmont Report.²⁷

Given the importance placed upon the detection of covert consciousness, we were puzzled by the Guideline's adoption of the behavioral term unresponsive wakefulness syndrome. This term, accepted in Europe to replace VS, is a bedside description that obscures nonobserved biological differences underwriting consciousness. As we recognize the clinical and ethical significance of covert consciousness, the endorsement of this descriptive category seems regressive because it fails to connote the underlying pathophysiology, just as does the term VS. Functional neuroimaging demonstrating covert consciousness in some patients showed that the behavioral "phenotype" of unresponsive wakefulness may not always correlate with the underlying "genotype." This diagnostic error is analogous to that of persisting in the belief that all the generations of colored peas in Mendel's

List of abbreviations:

CMD	cognitive—motor dissociation
DoC	disorders of consciousness
MCS	minimally conscious state
MSTF	Multi-Society Task Force on PVS
VS	vegetative state

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