

Ethics and the 2018 Practice Guideline on Disorders of Consciousness

A Framework for Responsible Implementation

Andrew Peterson, MA, PhD, Michael J. Young, MD, MPhil, and Joseph J. Fins, MD, MACP

Neurology® 2022;98:712-718. doi:10.1212/WNL.0000000000200301


Correspondence

Dr. Peterson
apeter31@gmu.edu

Abstract

The 2018 practice guideline on disorders of consciousness marks an important turning point in the care of patients with severe brain injury. As clinicians and health systems implement the guideline in practice, several ethical challenges will arise in assessing the benefits, harms, feasibility, and cost of recommended interventions. We provide guidance for clinicians when interpreting these recommendations and call on professional societies to develop an ethical framework to complement the guideline as it is implemented in clinical practice.

RELATED ARTICLE

 **Editorial**
Ethical Guidance for
Neuroprognostication in
Disorders of
Consciousness
Page 701

Introduction

The 2018 practice guideline on disorders of consciousness (DoC), developed by the American Academy of Neurology (AAN), the American Congress of Rehabilitation Medicine (ACRM), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), marks an important turning point in the care of patients with severe brain injury.¹ The product of a 5-year evidence-base review,² the guideline calls for improved standards of care aligned with discoveries in clinical neuroscience. It is a historic and aspirational document that challenges the prevailing nihilism encountered by this marginalized population.³

Yet, as clinicians and health systems implement the guideline, several key ethical challenges will arise. Some recommendations in the guideline instruct clinicians to weigh the “benefits,” “harms,” “feasibility,” and “costs” of interventions, allowing for individual clinical judgment during implementation (Table 1). The flexibility of clinical judgment corresponds to the priority level of the recommendations. Recommendations with high priority have a strong evidence base and allow for little to no flexibility. Recommendations with a weaker evidence base have a lower priority level and allow for greater flexibility (Table 2). Despite the comprehensive nature of the recommendations, clinicians are not given guidance in how to interpret these value-laden terms.

Although the guideline urges caution in neuroprognostication, especially in the acute phase of care, ambiguity in language could perpetuate clinical nihilism about patients with DoC. Nihilism about the cost of care relative to the quality of recovery could lead to premature withdrawal of life-sustaining measures in patients who might otherwise have fulfilling lives. For patients with a prolonged DoC, nihilism about feasibility could excuse “warehousing” of patients in suboptimal, long-term custodial care, instead of providing them the rehabilitation they need. These errors of omission and commission would fail to meet the goals of the guideline in improving patient care.

From the Institute for Philosophy and Public Policy (A.P.), George Mason University, Fairfax, VA; Penn Program on Precision Medicine for the Brain (A.P.), University of Pennsylvania, PA; Department of Neurology and Edmond J. Safra Center for Ethics (M.J.Y.), Harvard University, Boston, MA; Division of Medical Ethics (J.J.F.), Weill Cornell Medical College, Cornell University, New York, NY; and Solomon Center for Health Law & Policy (J.J.F.), Yale Law School, New Haven, CT.

Go to [Neurology.org/N](https://www.neurology.org/N) for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License 4.0 (CC BY-NC-ND), which permits downloading and sharing the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Glossary

AAN = American Academy of Neurology; ACRM = American Congress of Rehabilitation Medicine; DoC = disorders of consciousness; NIDILRR = National Institute on Disability, Independent Living, and Rehabilitation Research.

We propose an ethical framework to assist clinicians when addressing this uncertainty (Table 3). Whereas the assessment of benefit, harm, feasibility, and cost will vary with each recommendation and care trajectory of individual patients, general ethical guidance could mitigate uneven and potentially ad hoc implementation of the recommendations. We hope our analysis will lead to a more robust, multisociety ethical framework that can assist in translating the ethos of the guideline into clinical practice.

Benefits and Harms

The guideline's recommendations carry different potential benefits and harms, which may be contingent upon a patient's stage of care, medical history, or previously expressed wishes. One of the greatest potential harms is the framing effect of "prognostic pessimism."⁴ As such, recommendation 3 of the guideline emphasizes that "when discussing prognosis with caregivers of patients with a

DoC during the first 28 days post injury, clinicians must avoid statements that suggest these patients have a universally poor prognosis." Yet the guideline does not provide direction on how to approach or formulate nonuniversal statements of prognosis that influence decision-making in particular cases.

Surrogates are likely to be more interested in, and swayed by, individualized prognostic statements than by general statements concerning the broader patient population.⁵⁻⁷ As formulated, the guideline only speaks to what clinicians should not say, rather than what they might say about a particular patient's potential for recovery. Without this additional specificity, the guideline leaves room for clinicians to import undue prognostic pessimism, even if it is generally acknowledged that patient cohorts do not have a categorically poor prognosis.

Because many decisions to withdraw treatment following severe brain injury occur within the first 72 hours of injury,^{8,9}

Table 1 Selected Recommendations Containing Flexibility for Clinical Judgment^a

Clinical context	Recommendation
Overall care of adult patients with DoC	Recommendation 2a: Clinicians should use standardized neurobehavioral assessment measures that have been shown to be valid and reliable (such as those recommended by the ACRM) to improve diagnostic accuracy for the purpose intended (Level B based on importance of outcomes and feasibility).
	Recommendation 2b: To reduce diagnostic error in individuals with prolonged DoC after brain injury, serial standardized neurobehavioral assessments should be performed with the interval of reassessment determined by individual clinical circumstances (Level B based on cogency, feasibility, and cost relative to benefit).
	Recommendation 2d: Clinicians should identify and treat conditions that may confound accurate diagnosis of a DoC prior to establishing a final diagnosis (Level B based on feasibility and cost).
	Recommendation 2e: In situations where there is continued ambiguity regarding evidence of conscious awareness despite serial neurobehavioral assessments, or where confounders to a valid clinical diagnostic assessment are identified, clinicians may use multimodal evaluations incorporating specialized functional imaging or electrophysiologic studies to assess for evidence of awareness not identified on neurobehavioral assessment that might prompt consideration of an alternate diagnosis (Level C based on assessment of benefit relative to harm, feasibility, and cost relative to benefit).
	Recommendation 2f: In situations where there is no behavioral evidence of consciousness on clinical examination but functional neuroimaging or electrophysiologic testing suggests the possibility of preserved conscious awareness, frequent neurobehavioral reevaluations may be conducted to identify emerging signs of conscious awareness (Level C based on feasibility) and decisions to reduce the intensity of rehabilitation treatment may be delayed for those individuals receiving active rehabilitation management (Level C based on variation in patient preferences and cost relative to net benefit), with the length of time over which these are done determined by an agreement between the treating clinician and the health care proxy given the lack of evidence to provide guidance.
Prognosis of adults with DoC	Recommendation 5: Clinicians may assess for the presence of higher-level activation of the auditory association cortex using BOLD fMRI in response to a familiar voice speaking the patient's name to assist in prognostication regarding 12-month (postscan) recovery of consciousness for patients in traumatic vegetative state 1–60 months postinjury (Level C based on feasibility, cost).
	Recommendation 6: Clinicians should perform the CRS-R (Level B) and may assess SEPs (Level C based on feasibility) to assist in prognostication regarding recovery of consciousness at 24 months for patients in nontraumatic postanoxic vegetative state.

Abbreviations: ACRM = American Congress of Rehabilitation Medicine; BOLD = blood oxygenation level–dependent; CRS-R = Coma Recovery Scale–Revised; DoC = disorders of consciousness; SEP = somatosensory evoked potential.

^a Language directly represents the recommendation tables included in the practice guideline.¹

Table 2 Priority Levels of Practice Guideline Recommendations^a

Priority level	Description
Level A	Level A recommendations represent the strongest priority level and contain the verb “must.” Level A recommendations can be interpreted as mandates and are exceedingly rare in clinical guidelines. Three recommendations and subrecommendations in the practice guideline have Level A designations (Recommendations 3, 9, and 11). These recommendations instruct clinicians to avoid statements of universally poor prognosis, to guide families in specifying the goals of care, and to become familiar with family and patient preferences.
Level B	Level B recommendations represent a lower priority than Level A recommendations but are still supported by strong evidence and “associated with confidence in the rationale and a favorable benefit–risk profile.” ¹ They contain the verb “should.” Eighteen recommendations and subrecommendations in the practice guideline have Level B designations (Recommendations 1, 2a–2d, 4–8, 10, and 12–18). These recommendations pertain to the use of evidence-based methods to diagnose, prognosticate, and manage patients with DoC. The guideline instructs clinicians to judge the benefits, harms, feasibility, and costs of implementing most Level B recommendations.
Level C	Level C recommendations “represent the lowest allowable [priority] level that the AAN considers useful within the scope of clinical practice and can accommodate the highest degree of practice variation.” ¹ These recommendations are supported by sparse evidence and contain the verb “may.” Four of the recommendations and subrecommendations in the practice guideline have Level C designations (recommendations 2e, 2f, 5, and 6). These recommendations pertain to the use of specialized neuroimaging assessment for diagnosis and prognostication of DoC. The guideline instructs clinicians to judge the benefits, harms, feasibility, and costs of implementing all Level C recommendations.

Abbreviations: AAN = American Academy of Neurology; DoC = disorders of consciousness.

^a Priority levels are representative of the language in the practice guideline.¹

prognostic pessimism predominately affects patients in acute care. But this attitude can extend across the disease trajectory. Families may be gripped by a penumbra of fear throughout stages of care, amplifying or distorting interpretations of clinicians’ advice owing to anxiety. Pessimistic attitudes about quality of life with a disability can have profound downstream consequences for patients with DoC, as they can frame choices for families and lead to the belief that there is little benefit to continued aggressive therapy. Even for well-intentioned clinicians, latent pessimism could emerge in family consults through body language, tone, and terminology, or in failing to acknowledge a family’s values or concerns.^{10–12} Clinicians might also succumb to a kind of ambiguity aversion: the feeling that families need prognostic certainty in a clinical situation that is inherently uncertain. An

aversion to ambiguity can drive biases and premature clinical decisions.^{13,14}

In the face of uncertainty and fear, clinicians must provide guidance to families struggling to make ethically fraught decisions. Rather than avoid uncertainty, clinicians should embrace it, transparently communicate its source and scope, and explain that uncertainty often wanes with time. Neuroprognostication is, in this way, like predicting hurricanes.¹⁵ When a tropical depression forms off the coast of Africa in the Atlantic, the trajectory and severity of the storm is largely unknown. However, as the hurricane grows closer to North America, this “cone of uncertainty” narrows, allowing municipalities to prepare. National weather alerts are designed to calibrate this uncertainty and provide additional specificity about landfall as the storm evolves.

Table 3 Ethical Challenges for Implementing the Guideline

Terms in guideline	Ethical challenge	Potential guidance
“Harms and benefits”	Harms and benefits of interventions are difficult to assess in this population, and clinicians might experience ambiguity aversion when communicating with families. Value-laden judgments about quality of life might be confused with discussions of harms and benefits.	<ul style="list-style-type: none"> • Manage prognostic and diagnostic uncertainty by meeting frequently with families, tracking discussions, and framing improvements with clinical milestones. • Distinguish quality of life judgments from discussions of harm and benefits. • Be attentive to how these issues are discussed and interpreted in family meetings (e.g., through body language or framing effects).
“Feasibility”	Feasibility is an objective claim about the inability to implement an intervention due to uncontrollable factors. Feasibility could be confused with value-laden judgments of practicality, which involve tradeoffs of cost, benefit, and harms.	<ul style="list-style-type: none"> • Acknowledge that feasibility is different from practicality. • Adopt a consensus-based definition of feasibility, or defer to independent, multidisciplinary committees to evaluate feasibility concerns. • Adopt hub-and-spoke care delivery to ensure patients have access to resources at specialized medical centers.
“Cost”	Judgments about cost pertain to issues of fairness and distributive justice. Cost considerations may involve implicit or explicit tradeoffs in allocating resources between 2 or more patients.	<ul style="list-style-type: none"> • Adopt a principle of prospective benefit, according to which the cost of an intervention is compared to the expected benefit to the patient. • Prioritize diagnostic interventions, as these may optimize treatment allocation decisions longitudinally. • Acknowledge that the meaning of “benefit” may differ among families and cultures and this may influence how costs are evaluated. • Avoid conflating cost considerations with futility.

If a hurricane remains far off shore and there is a large chance it could change course, making landfall in the Carolinas rather than in Florida, it would be premature—even irresponsible—to evacuate Miami. By the same token, withdrawing treatment after brain injury without sufficient prognostic information might also be premature if there remains a significant chance of a good recovery. Gaps left by this uncertainty can be filled with biases and undue pessimism, potentially leading to worse outcomes.

In such situations, uncertainty needs to be managed, not ignored. Discussions with families following brain injury should be frequent and tracked, and patient wishes as known by the family need to be framed against important clinical milestones, such as transitions between diagnostic categories. This allows clinicians to acknowledge prognostic uncertainty while mapping out for families how the “cone of uncertainty” narrows over time. Clinicians might also adopt evidence-based approaches to debiasing framing effects, such as listing the advantages and disadvantages of an intervention prior to making a decision,¹⁶ describing the range of potential outcomes and not focusing exclusively on the desired or predicted outcome, or using visual charts when describing the numerical chances of recovery.¹⁷

Finally, when discussing how the guideline’s recommendations might be beneficial or harmful, clinicians should avoid conflating this with quality of life assessment. Quality of life—determined, in part, by functional outcome and disability burden—is an important consideration in making decisions for patients with DoC. But given prevailing negative attitudes about severe brain injury,¹⁸ these biases should be made explicit, acknowledging that future quality of life is often unknown for these patients,¹⁹ and could be subject to value-laden judgments that vary by person, society, and culture.^{20,21}

Approaching discussions of benefits, harms, and uncertainty with transparency allows clinicians to focus on patient and family-centered goals, rather than imposing subjective and potentially value-discordant attitudes about which treatment decisions would be “best.”

Feasibility

Feasibility describes the capacity of individual clinicians (or health systems) to implement the guideline’s recommendations given available resources. Feasibility issues may arise from lack of access to specialized neuroimaging equipment, intensive care unit beds, or health care personnel.

In making feasibility judgments, clinicians should not confuse feasibility with practicality. When a recommendation is impractical, it can be implemented, albeit at a greater cost or effort than what might be expected. Recommendations that are infeasible cannot be implemented due to uncontrollable, limiting factors. For example, the multimodal neuroimaging

assessment described in recommendations 2e, 2f, and 5 (Table 1) cannot be implemented if a hospital does not have the appropriate equipment and the patient is not stable to transfer to a specialized center. By contrast, if this neuroimaging assessment is regarded as impractical, it is because the cost and logistical effort to transfer the patient is deemed too high relative to the will of the family or clinical team. Feasibility is therefore an objective claim about the capacity to perform—or not perform—an intervention, given available resources. Practicality is a value-laden judgment regarding a tradeoff of harms, costs, and benefits.

When clinicians deem a recommendation as infeasible, families need assurance that this is due to uncontrollable factors, not because it is “not worth it.”²² Nihilism about the value of continued therapy could be disguised in the language of feasibility, excusing clinicians who do not want to treat. This erodes trust between families and the clinical team. Clinicians can avoid this by encouraging their institution to adopt prospectively a clear, consensus-based definition of feasibility for the guideline’s recommendations. This would systematize—and localize—decisions and avoid wide variability in the implementation of the guideline. Interpretations of feasibility in particular cases might also be reviewed by an independent, multidisciplinary committee, similar to a “tumor board” for cancer treatment. This might standardize care across cases and assuage worries about prejudicial attitudes toward this population.

Feasibility concerns might also be addressed at the macro level through resource sharing across regional health systems. The Mohonk Report on improving outcomes for patients with DoC stresses the utility of “hub-and-spoke” care delivery.^{23,24} Hospitals and chronic care facilities could cooperate with more advanced specialty hubs to gain access to clinical services that would otherwise be unavailable. These cooperative ventures could mitigate concerns about feasibility and thus realize the beneficent spirit of the guideline.

Costs

Cost considerations for the guideline’s recommendations are fundamentally questions of distributive justice. They force clinicians and families to consider who should receive what when not everyone can receive what they may want or need. Recommended interventions, such as neuroimaging (recommendations 2e, 2f, and 5) or serial neurobehavioral assessment (recommendation 2b), may be scarce in some hospitals (e.g., rural hospital vs urban research hospital), and cost-benefit evaluations may turn on broader allocation considerations or resource tradeoffs between patients.

We have argued previously that, when evaluating the costs of recommended interventions, clinicians and hospital administrators should adopt a principle of prospective benefit.²⁵ This principle asserts that the cost of an intervention should

be discounted by the expected benefit and the likelihood that it will occur. The cost of serial neurobehavioral assessment (recommendation 2b), for instance, should be assessed against the prospective benefit of accurate prognostication and the likelihood that improved diagnostic accuracy will facilitate recovery.

An important consideration in applying this principle in practice, however, is that clinicians need to determine what is beneficial to patients. As highlighted above, the benefit of the interventions enumerated in the guideline can vary across patients, and families might have different attitudes about whether they are worth the cost. This, again, emphasizes the importance of understanding family and patient values (recommendation 11). This can specify how costs and benefits should be balanced for individual cases.

Although this approach is both theoretically and empirically rigorous,²⁶ it raises questions about how best to ascertain the benefits of the guideline's recommendations with limited resources. Stewardship of available resources is important, but how clinicians ought to deploy the interventions in the guideline to meet this responsibility may be unclear. Diagnostic interventions should be given priority, as clarity of diagnosis is linked to both a patient's prognosis as well as the potential to respond to treatment.^{27,28} Misdiagnosis, by contrast, can lead to medically inappropriate, insufficient, or inefficient use of resources.²⁹ Increasing diagnostic accuracy is valuable to the patient and to the stewardship of available resources. Short-term costs in accurate diagnosis may be high, but the long-term payoff is worth the investment.

In framing costs, it is also important for clinicians to avoid biased assumptions about futility. The concept of futility is important to evidence-based medicine, as it can support withholding medically ineffective treatment and facilitate dialogue with families about end-of-life decisions.³⁰ But the meaning of futility might differ from the vantage point of clinicians and families. Clinicians are often justified in making futility judgments when the requested intervention departs from standards of care,³¹ but this is complicated when standards are evolving. A different interpretation of futility might be consonant with value-laden assumptions about the worth of continued treatment.³² These sorts of judgments may conflate questions of futility with health care rationing.

Clinicians should therefore be exceptionally careful to avoid futility pronouncements when discussing costs. Families might have nonmedical reasons for requesting interventions irrespective of cost or clinical recommendations (e.g., decisional balance skewed toward optimism or cultural preferences). Clinicians do not need to acquiesce to these requests. But unreflective responses may lead families to think that clinicians have negative attitudes toward their loved ones; that their lives are "not worth" the cost of continued care. This can undermine communication with the clinical team and have a lasting negative impact on how families view health systems generally.

Putting Theory Into Practice

The 2018 practice guideline contains the most comprehensive and advanced recommendations on the care of patients with DoC. The document's acknowledgment of benefits, harms, feasibility, and cost highlights its strength, as this allows clinicians the flexibility to grapple with ethical issues when implementing evidence-based recommendations.³³ Yet lack of clarity in how clinicians ought to interpret these terms could allow the specter of clinical nihilism to guide treatment decisions, leading to excessive variation in practice.

The time is ripe for the AAN, ACRM, and NIDILRR to invest in ethical recommendations to complement the guideline. An Ethics Panel on Vegetative State/Minimally Conscious State was originally envisioned as a companion effort when the evidence-based review and practice guideline were contemplated,³⁴ but this effort did not come to pass. Ethicists have called for a comprehensive ethics evaluation of this space as early as 2007³⁵ and more recently in response to the 2018 guideline.^{27,36-42} Broader consensus among experts is needed, incorporating the views of multiple stakeholders, such as families and patient advocates.

Consensus-based ethics recommendations should guide clinicians through each feature of the guideline by highlighting potential hazards and supporting navigation of this complicated terrain. They should also be interdisciplinary and forward-looking, anticipating how clinicians will grapple with the rapidly evolving science of brain injury, and the discoveries of new tools for treatment and rehabilitation (e.g., brain stimulation and pharmacology) that are not yet specified in clinical recommendations, but are well along the translational pipeline.⁴³ The AAN's practice guideline manual outlines a triennial review process for updating substantive scientific recommendations on DoC management.⁴⁴ Yet there is no complementary guidance on how to update the procedural dimensions of putting theory into practice. This could leave physician education, dissemination, and responsible implementation as potential afterthoughts to guideline development.

We have provided preliminary responses to these challenges, but more work needs to be done—soon—for the 2018 Practice Guideline on DoC to reach its full potential. Ultimately, the guideline will realize care for patients that was once thought impossible. To achieve this goal, however, clinicians need direction in how to implement its recommendations faithfully with limited resources and uncertain clinical outcomes. Professional societies have a responsibility to provide clinicians this additional guidance.

Study Funding

A.P. is funded by R21AG069805 and the Greenwall Faculty Scholars Program. M.J.Y. is funded by NIH BRAIN Initiative F32MH123001, the American Academy of Neurology (AAN) Palatucci Advocacy Leadership Award, and the Tiny Blue Dot Foundation. J.J.F. is funded by the E. William Davis, Jr., MD,

Chair in Medical Ethics and NIH BRAIN Initiative 1RF1MH12378-01. The content of this article does not necessarily represent the official views of the NIH or private foundations. The funders played no role in the preparation, review, approval, or decision to submit this manuscript for publication.

Disclosure

J.J. Fins receives royalties from Oxford University Press and Cambridge University Press. A. Peterson and M.J. Young have no interests to disclose. Go to Neurology.org/N for full disclosures.

Publication History

Received by *Neurology* October 1, 2021. Accepted in final form February 16, 2022. Submitted and externally peer reviewed. The handling editor was Linda Hershey, MD, PhD, FAAN.

Appendix Authors

Name	Location	Contribution
Andrew Peterson, MA, PhD	Institute for Philosophy and Public Policy, George Mason University, Fairfax, VA; Penn Program on Precision Medicine for the Brain, University of Pennsylvania, PA	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design
Michael J. Young, MD, MPhil	Department of Neurology and Edmond J. Safra Center for Ethics, Harvard University, Cambridge, MA	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design
Joseph J. Fins, MD, MACP, FRCP	Division of Medical Ethics, Weill Cornell Medical College, Cornell University, New York, NY; Solomon Center for Health Law & Policy, Yale Law School, New Haven, CT	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design

References

- Giacino JT, Katz DI, Schiff ND, et al; for the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. Practice guideline update recommendations summary: disorders of consciousness: report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research. *Neurology*. 2018;91(10):450-460.
- Giacino JT, Katz DI, Schiff ND, et al; For the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. Comprehensive systematic review update summary: disorders of consciousness: report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research. *Neurology*. 2018;91(10):461-470.
- Fins JJ. *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*. Cambridge University Press; 2015.
- Wijdicks EF, Rabinstein AA. The family conference: end-of-life guidelines at work for comatose patients. *Neurology*. 2007;68(14):1092-1094.
- Jones K, Quinn T, Mazor KM, Muehlschlegel S. Prognostic uncertainty in critically ill patients with traumatic brain injury: a multicenter qualitative study. *Neurocrit Care*. 2021;35(2):311-321.
- Anderson WG, Cimino JW, Ernecoff NC, et al. A multicenter study of key stakeholders' perspectives on communicating with surrogates about prognosis in intensive care units. *Ann Am Thorac Soc*. 2015;12(2):142-152.
- Davidson JE, Powers K, Hedayat KM, et al, for the American College of Critical Care Medicine Task Force 2004-2005, Society of Critical Care Medicine. Clinical practice

- guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med*. 2007;35(2):605-622.
- Turgeon AF, Dorrance K, Archambault P, et al, for the Canadian Traumatic Brain Injury Research Consortium and the Canadian Critical Care Trials Group. Factors influencing decisions by critical care physicians to withdraw life-sustaining treatments in critically ill adult patients with severe traumatic brain injury. *CMAJ*. 2019;191(24):E652-E663.
- Turgeon AF, Lauzier F, Simard JF, et al, for the Canadian Critical Care Trials Group. Mortality associated with withdrawal of life-sustaining therapy for patients with severe traumatic brain injury: a Canadian multicenter cohort study. *CMAJ*. 2011;183(14):1581-1588.
- White DB, Ernecoff N, Buddadhumaruk P, et al. Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. *JAMA*. 2016;315(19):2086-2094.
- Wartenberg KE, Hwang DY, Haeusler KG, et al. Gap analysis regarding prognostication in neurocritical care: a joint statement from the German Neurocritical Care Society and the Neurocritical Care Society. *Neurocrit Care*. 2019;31(2):231-244.
- Malenka DJ, Baron JA, Johansen S, et al. The framing effect of relative and absolute risk. *J Gen Intern Med*. 1993;8(10):543-548.
- Fox CR, Tversky A. Ambiguity aversion and comparative ignorance. *Q J Econ*. 1995;110(3):585-603.
- Blumenthal-Barby JS, Krieger H. Cognitive biases and heuristics in medical decision-making: a critical review using a systematic search strategy. *Med Decis Making*. 2015;35(4):539-557.
- Fins JJ. Disorders of consciousness in clinical practice: ethical, legal and policy considerations. In: Posner JB, Saper CB, Schiff ND, Claassen J, eds. *Plum and Posner's Diagnosis and Treatment of Stupor and Coma*, 5th ed. Oxford University Press; 2019:449-478.
- Almashat S, Ayotte B, Edelstein B, Margrett J. Framing effect debiasing in medical decision-making. *Patient Educ Couns*. 2008;71(1):102-107.
- Garcia-Retamero R, Galesic M. How to reduce the effect of framing on messages about health. *J Gen Intern Med*. 2010;25(12):1323-1329.
- Wilson JE, Shinall MC, Leath TC, et al. Worse than death: survey of public perceptions of disability outcomes after hypothetical traumatic brain injury. *Ann Surg*. 2021;273(3):500-506.
- Graham M. Domains of well-being in minimally conscious patients: illuminating a persistent problem. *AJOB Neurosci*. 2018;9(2):128-130.
- Zulato E, Montali L, Bauer MW. Understanding a liminal condition: comparing emerging representations of the "vegetative state." *Eur J Soc Psych*. 2021;51(6):936-950.
- Weisman K, Legare CH, Smith RE, et al. Similarities and differences in concepts of mental life among adults and children in five cultures. *Nat Hum Behav*. 2021;5(10):1358-1368.
- Carey B. *Mute 19 Years, He Helps Reveal Brain's Mysteries*. *The New York Times*; 2006. Accessed September 13, 2021. [nytimes.com/2006/07/04/health/psychology/mute-19-years-he-helps-reveal-brains-mysteries.html?searchResultPosition=1](https://www.nytimes.com/2006/07/04/health/psychology/mute-19-years-he-helps-reveal-brains-mysteries.html?searchResultPosition=1).
- Berube J, Fins J, Giacino J, et al. *The Mohonk Report: A Report to Congress on Improving Outcomes for Individuals with Disorders of Consciousness*. National Brain Injury Research, Treatment & Training Foundation; 2006.
- Young MJ, Edlow BL. Emerging consciousness at a clinical crossroads. *AJOB Neurosci*. 2021;12(2-3):148-150.
- Peterson A, Aas S, Wasserman D. What justifies the allocation of health care resources to patients with disorders of consciousness? *AJOB Neurosci*. 2021;12(2-3):127-139.
- Giacino JT, Bodien YG, Zuckerman D, et al. Empiricism and rights justify the allocation of health care resources to persons with disorders of consciousness. *AJOB Neurosci*. 2021;12(2-3):169-171.
- Fins JJ, Bernat JL. Ethical, palliative, and policy considerations in disorders of consciousness. *Neurology*. 2018;91(10):471-475.
- Edlow BL, Claassen J, Schiff ND, Greer DM. Recovery from disorders of consciousness: mechanisms, prognosis and emerging therapies. *Nat Rev Neurol*. 2021;17(3):135-156.
- Hammond FM, Katta-Charles S, Russell MB, et al, for the Curing Coma Campaign and its contributing members. Research needs for prognostic modeling and trajectory analysis in patients with disorders of consciousness. *Neurocrit Care*. 2021;35(suppl 1):55-67.
- Knowlton SF, Fins JJ. Mediative fluency and futility disputes. *Perspect Biol Med*. 2018;60(3):373-382.
- Weijer C, Singer PA, Dickens BM, Workman S. Dealing with demands for inappropriate treatment. *CMAJ*. 1998;159(7):817-821.
- Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med*. 1990;112(12):949-954.
- Armstrong MJ, Gronseth GS. Approach to assessing and using clinical practice guidelines. *Neurol Clin Pract*. 2018;8(1):58-61.
- Emails in possession of Dr. Fins (March 8, 2007) re: "AAN Ethics Panel on VS/MCS."
- Fins JJ, Schiff ND, Foley KM. Late recovery from the minimally conscious state: ethical and policy implications. *Neurology*. 2007;68:304-307.
- Sethi NK. Reader response: ethical, palliative, and policy considerations in disorders of consciousness. *Neurology*. 2019;92(20):973-974.
- Fins JJ, Bernat JL. Author response: Ethical, palliative, and policy considerations in disorders of consciousness. *Neurology*. 2019;92(20):974.
- Young MJ, Bodien YG, Giacino JT, et al. The neuroethics of disorders of consciousness: a brief history of evolving ideas. *Brain*. 2021;144(11):3291-3310.
- Young MJ, Edlow BL. The quest for covert consciousness: bringing neuroethics to the bedside. *Neurology*. 2021;96(19):893-896.

40. Peterson A, Owen AM, Karlawish J. Translating the discovery of covert consciousness into clinical practice. *JAMA Neurol.* 2020;77(5):541-542.
41. Peterson A, Webster F, Gonzalez-Lara LE, et al. Caregiver reactions to neuroimaging evidence of covert consciousness in patients with severe brain injury: a qualitative interview study. *BMC Med Ethics.* 2021;22(1):105.
42. Peterson A, Owen AM, Karlawish J. Alive inside. *Bioethics.* 2020;34(3):295-305.
43. Edlow BL, Sanz LR, Polizzotto L, et al. Therapies to restore consciousness in patients with severe brain injuries: a gap analysis and future directions. *Neurocrit Care.* 2021; 35(1):68-85.
44. Gronseth GS, Cox J, Gloss D, et al; on behalf of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. *Clinical Practice Guideline Process Manual.* American Academy of Neurology; 2017.

NPub.org/patient Offers Important Information to Patients and Caregivers

The *Neurology*[®] Patient Page provides:

- A critical review of ground-breaking discoveries in neurologic research that are written especially for patients and caregivers
- Up-to-date patient information about many neurologic diseases
- Links to additional information resources for neurologic patients

All *Neurology* Patient Page articles can be easily downloaded and printed, and may be reproduced to distribute for educational purposes. Access NPub.org/patient for a complete index of Patient Pages.

Call for Voices: Lived Experiences


The Editor of the *Neurology* specialty section Inclusion, Diversity, Equity, Anti-racism, & Social Justice (IDEAS) encourages you to submit short first-person accounts (1,000 words or less) of experiences lived within the realm of IDEAS with the goal of informing and enlightening our community on these critical issues. Some topics to consider include, but are not limited to:


- Descriptions of personal experiences that shaped your views of IDEAS.
- Reflections on the intersection between personal identity and career.
- Discussions at the intersection of IDEAS and neurology patient care, research, education, advocacy, or policy.

Submit your contributions to journal@neurology.org and include “Voices Submission” in the subject line.

Visit the *Neurology*[®] Website at Neurology.org/N

- More article-based content on home pages
- Streamlined menus and navigation
- Enhanced blog sections for specialty areas
- Same experience on desktop, tablet, and mobile devices
- Improved article reading experience; links more evident (pdf, analytics, social media)
- *Neurology*[®] Clinical Practice initiative “Practice Current” global surveys will be accessible across sites

 Find *Neurology*[®] on Facebook: <http://tinyurl.com/neurologyfan>

 Follow *Neurology*[®] on Twitter: <https://twitter.com/GreenJournal>
