Ethics and the 2018 Practice Guideline on Disorders of Consciousness

A Framework for Responsible Implementation

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

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, 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.

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. The product of a 5-year evidence-base review, 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.

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.
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.” 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. 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

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### Table 1 Selected Recommendations Containing Flexibility for Clinical Judgment

| 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 2c: 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 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 1–6 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.

Language directly represents the recommendation tables included in the practice guideline. 1
Acknowledging that feasibility is different from practicality.

The coast of Africa in the Atlantic; the trajectory and

Level B recommendations represent a lower priority than Level A recommendations but are still supported by strong evidence and

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 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.” 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 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.” These recommendations are supported by sparse evidence and contain the verb “may.” Fourteen 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.

Table 2 Priority Levels of Practice Guideline Recommendations

| 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.” 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.” These recommendations are supported by sparse evidence and contain the verb “may.” Fourteen 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.

Priority levels are representative of the language in the practice guideline.

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 consultations through body language, tone, and terminology, or in failing to acknowledge a family’s values or concerns. 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. 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. 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. | • 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. | • 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. | • 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 offshore 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, 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.

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, these biases should be made explicit, acknowledging that future quality of life is often unknown for these patients, and could be subject to value-laden judgments that vary by person, society, and culture.

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 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 due to uncontrollable factors, not because it is “not worth it.” 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. 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. 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, 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. Misdiagnosis, by contrast, can lead to medically inappropriate, insufficient, or inefficient use of resources. 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. 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, 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. 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. 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, but this effort did not come to pass. Ethicists have called for a comprehensive ethics evaluation of this space as early as 2007 and more recently in response to the 2018 guideline. 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. The AAN’s practice guideline manual outlines a triennial review process for updating substantive scientific recommendations on DoC management. 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
JJ. Fins receives royalties from Oxford University Press and Cambridge University Press. A. Peterson and MJ. 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

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• 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

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