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Prognostication, Ethical Issues and Palliative Care in Disorders of Consciousness

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Article synopsis

Research advances in recent years have shown that some individuals with vegetative state or minimally consciousness state can emerge to higher states of consciousness even years after injury. A minority of behaviorally unresponsive patients with vegetative state have also been shown to follow commands, or even communicate, using neuroimaging or electrophysiological techniques. These advances raise ethical questions that have important implications for clinical care. In this article, the authors argue that adopting a neuropalliative care approach can help clinicians provide ethical, compassionate care to these patients and their caregivers.

Keywords

Consciousness; Palliative Care; Ethics; Traumatic Brain Injury; Neurocritical Care

Introduction

Advances in the care of severe acute brain injury (SABI) have enabled the survival of patients in states of diminished consciousness. Recent research has offered an increasingly complex picture of the possible inner lives of these patients and their potential for recovery. This shift opens new ethical questions and intensifies the challenges facing patients' surrogate decision-makers, who in the acute period of SABI are tasked with making life-or-death decisions in the face of profound uncertainty. In this article, we define disorders of consciousness (DoC), describe newer findings around DoC diagnosis and prognosis, and discuss ethical questions surrounding the clinical management of patients with DoC. We conclude by illustrating a palliative care approach to some of the more difficult aspects of providing care to these patients and their loved ones.

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Definitions of disorders of consciousness

Consciousness is often separated into two components: wakefulness (or arousal, the so-called “level of consciousness”) and awareness (the contents of consciousness). Disorders of consciousness are currently classified in terms of clinically observed behavior and include coma, vegetative state, minimally conscious and the emergence from minimally conscious state (Table 1)

In coma, the patient is unaware and cannot be aroused; eyes are closed, and noxious stimulation elicits posturing or no response. Progression to vegetative state (VS) is characterized by spontaneous eye opening, giving the appearance of wakefulness, but patients show only reflexive behavior.

Some patients with VS emerge to a minimally conscious state (MCS). In MCS, patients show inconsistent but reproducible behavioral evidence of consciousness, such as command-following, gesturing yes/no to questions, appropriate smiling or crying, reaching for objects, visual pursuit or intelligible speech.¹ Visual pursuit is the most common initial sign of MCS, followed by command following and automatic movements.² Some divide MCS into ‘MCS+’ and ‘MCS-’ according to the presence (+) or absence (-) of behavioral evidence of language comprehension or expression.^{3,4} The transition from VS to MCS has prognostic importance.

DoC syndromes can further be classified according to chronicity. Acute DoC describes the first 28 days after brain injury, while prolonged DoC describes the period after 28 days. The term ‘permanent VS’ is no longer felt to be justified given evidence that some patients can emerge from VS months or years post-injury. Instead, the term ‘chronic VS’ has been suggested to describe patients who have reached stability in the VS state.⁵

Emergence from MCS (eMCS) is characterized by demonstration of functional object use or reliable communication (whether through speech, writing, yes/no signals or communication devices).¹ Patients with eMCS typically are disoriented, cognitively impaired, inattentive, and unaware of their health state.^{6,7} They may have sleep disturbance and restlessness or agitation.⁶

The categories of DoC discussed so far all rely on skilled and repeated neurobehavioral assessment, and misdiagnosis is common.⁸ In addition, this taxonomy has recently been challenged by experiments demonstrating that a minority of patients with VS – showing no detectable behavior at bedside – can follow simple commands detected only by neuroimaging or electrophysiology.^{9,10} This state has been called “cognitive-motor disassociation” (CMD) and is described further below.¹¹

Clinical Examination in DoC

The range of physical and cognitive impairments in DoC, including aphasia, motor, and sensory deficits, make it difficult to distinguish behaviors that indicate awareness from those that are non-purposeful.⁵ Diagnosis is further complicated by fluctuations in arousal and the time required for thorough examination.^{5,12} Overcoming these challenges to establish

an accurate diagnosis in DoC is important in order to educate family members about a patient's current state, inform prognosis, and guide treatment decisions including around the continuation of life-sustaining therapy (LST).

The traditional method of diagnosis in DoC is by qualitative bedside examination for reproducible responses to visual, auditory, and/or noxious stimuli, command-following, and communication. However, studies have shown that about 40% of patients with MCS are misclassified as VS using this approach.^{8,13,14} Sources of error in the examination include incomplete, ill-timed or infrequent examinations.^{5,12,15,16}

Diagnosis can be improved through use of standardized neurobehavioral assessments.⁵ The most sensitive is the Coma Recovery Scale-Revised (CRS-R),^{12,17} which is composed of 6 subscales and incorporates the existing diagnostic criteria for VS, MCS and eMCS.¹⁸ Diagnosis in DoC may further be improved by using relevant stimuli, such as a mirror (so patients can follow their own eyes);¹⁹ involving patients' caregivers in the examination;²⁰ reducing sedating medications; and following protocols to enhance arousal (e.g., CRS-R Arousal Facilitation Protocol).¹⁸ If possible, examinations should be conducted in the morning, when behaviors suggestive of MCS are more likely to be detected.¹⁶ Performing an assessment more than once may improve diagnostic accuracy.¹⁵

Multimodal diagnosis in DoC

Even rigorous bedside assessment may fail to detect the presence of covert awareness. Investigational techniques to detect covert awareness have been developed for functional magnetic resonance imaging (fMRI), fluorodeoxyglucose (FDG)-positron emission tomography (PET), single-photon emission computerized tomography (SPECT), and electroencephalography (EEG). These techniques offer more robust evaluation of consciousness than the bedside examination^{12,21} and demonstrate differences between patients with VS and MCS at the group level. However, they have not been rigorously evaluated for diagnosing DoC in individual patients. Practical issues like interrater reliability and technical challenges like motion/muscle artifact may limit their utility, there is no consensus about when to use them or how to interpret them. With that said, these techniques hold promise for advancing diagnosis and prognosis for individuals with DoC.

These techniques can be classified in terms of resting state, passive, and active paradigms. Resting state paradigms measure the presence of intact resting state neuronal networks that are believed to be closely associated with a conscious state. One approach uses FDG-PET to measure differences in metabolic rates in the frontoparietal associative cortices. Using CRS-R as the reference, this technique has high sensitivity and specificity to differentiate between VS and MCS.^{12,21,22} In research settings, visual analysis of standard resting EEG in the post-acute setting (after hospital discharge) for background organization and presence of sleep architecture also has high specificity but low sensitivity for detecting signs of MCS.¹² These resting state paradigms rely on assumptions about the relationship between these networks and awareness; they measure the integrity of what is believed to be the substrate of consciousness.

Passive paradigms examine preserved large-scale functional cortical connectivity following an external stimulus. These techniques detect brain activity that is believed to be closely associated with a conscious state: for example, the activation of “higher order” associative cortical networks for auditory, somatosensory, or visual sensation, in contrast to “lower level” primary sensory cortices. An estimated 55% of MCS and 26% of patients with VS show preserved functional cortical connectivity in passive paradigms.²³ Like resting state paradigms, these approaches have not been rigorously evaluated in the real-world setting and rely on assumptions about the relationship between measurable brain activity and awareness.²¹

Active paradigms measure brain activity as patients are instructed to engage in mental tasks. For example, in a 2006 study by Owen and colleagues, a patient with a clinical diagnosis of VS from traumatic brain injury (TBI) was instructed to imagine playing tennis or imagine moving from room to room in her house while undergoing fMRI; in response, there was reliable activation in her supplementary motor area (SMA) and parahippocampal gyrus (PPA), respectively. These responses were sustained for about 30 seconds, until she was presented with another instruction, a pattern indistinguishable from that observed in healthy volunteers.²⁴ A meta-analysis of six such studies using fMRI or EEG active paradigms suggested that 14.4% of patients with clinically confirmed VS could modulate their brain activity to command.²³ Twice as many patients with MCS could do so. Command following through active paradigms was more common in patients with DoC after TBI than after non-traumatic injury.²³

The absence of a gold standard for detecting consciousness complicates our ability to calculate sensitivity and specificity for active paradigms. The fact that most patients with MCS are unable to follow commands using these protocols – despite, by definition, being able to demonstrate intentional behavior at the bedside²⁵ – suggests low sensitivity. In fact, a substantial number of healthy controls cannot cooperate with active paradigms.^{23,26} Recent guidelines from the European Academy of Neurology concluded that active paradigms have high specificity but low sensitivity in identifying patients with VS who can follow commands despite appearing unresponsive.¹²

The problem of other minds

In active paradigm studies, the ability to follow commands is interpreted as agency – a marker of consciousness. Some have argued, however, that a person in possession of motivational and cognitive states and capacities, such as the ability to visualize playing tennis, is not necessarily “conscious” in the sense that we typically think of the term – that is, that person does not necessarily have a qualitative, inner experience of being aware.²⁷ This latter concept is known as *phenomenal consciousness*: there is something “it is like” to be that person.²⁸ The philosophical barrier here is known as the “problem of other minds.” It is impossible for one person to directly assess the conscious experience of another person;²⁹ we can only infer it by assessing their behaviors and responses to stimuli.¹⁰ We are particularly reassured that another person is having a conscious experience when they can tell us about it.

A small handful of studies have attempted to teach behaviorally unresponsive individuals to use mental imagery to communicate. In 2010, Monti and colleagues again asked patients with VS and MCS to imagine hitting a tennis ball back and forth with an instructor (SMA) or imagine navigating a familiar place (PPA). Five of 54 patients had measurable brain activity in the SMA or PPA to these commands. One patient with VS five years after TBI, with no behavioral evidence of awareness on repeated examinations, was then asked to use one type of imagery (either tennis or spatial imagery) for yes, and the other for no. He answered five out of six biographical questions correctly.³⁰ This finding was replicated in 2013 in a man with VS due to TBI 12 years prior, who over many sessions in the fMRI scanner demonstrated accurate answers to biographical questions, although he did not respond on every occasion he was scanned.³¹ Several other studies attempting to replicate communication using mental imagery with patients with DoC have had negative results. In one, six patients with MCS were unable to use mental imagery to communicate, two of whom demonstrated ability to communicate at the bedside.²⁵ It may be that the cognitive demand of communication tasks is too high for most patients with VS/MCS.¹¹

There are several important limitations to these data. Most of these studies were single-center convenience samples, often lacking a clear statement about the number of excluded patients and why they were excluded. Patient numbers were generally low.²³ The reference standard of clinical examination is subject to error; in the study by Monti and colleagues discussed above, two patients with “VS” who performed the command-following task were reexamined and found to have behavior consistent with MCS.³⁰ Further, the low sensitivity of these tests and lack of a gold standard for consciousness creates ambiguity around the meaning of a negative result.

Prognosis in DoC

Estimating prognosis for individual patients with DoC remains challenging, in part due to methodological issues with the longitudinal studies of these patients. Most available long-term studies have examined patients after admission to inpatient rehabilitation centers^{32,33} and are therefore likely to overestimate the proportion of patients with good outcome, since patients are typically pre-selected for a rehabilitation stay if they are considered to have a good chance of recovery.³⁴ Studies also often pool patients with VS and MCS.^{33,35,36} Separating these groups is important because patients admitted to acute rehab with MCS have significantly better survival and functional prognosis than those with VS,^{5,37,38} particularly patients with preserved language function (MCS+).^{38,39} Studies that have pooled patients with VS/MCS have suggested that approximately 20% recover to a level where they are judged to be eventually capable of returning to employment.^{32,33} The available data for patients with VS are less optimistic. Among those admitted to acute rehab with VS, about 17% will reach MCS by six months post-injury.⁵ In one French study that tracked 33 patients with VS for up to 2.5 years, 28 (84.8%) had died by the end of the study period, three (9.1%) were in a state of severe disability [Glasgow Coma Outcome - Extended (GOSE) score of 3], and only one (3.0%), a 24-year-old man with VS due to intoxication, reached moderate disability (GOSE 5). This study was limited in that most patients had non-traumatic etiologies of VS, such as anoxic injury and intracerebral hemorrhage,³⁷ which are associated with worse outcomes.³³

One important realization in recent years is that late emergence from VS to MCS is possible. In 1994, the AAN Multi-Society Task Force defined VS as “persistent” three months after nontraumatic brain injury and 12 months after TBI, concluding that unexpected “recovery of consciousness” (i.e. evidence of voluntary behavior or awareness of self/environment, both now considered criteria for MCS) after 3 months occurred in 2.4% of patients with non-traumatic injury and after 12 months in only 1.6% of patients with TBI.⁴⁰ However, a 1996 reanalysis of the Task Force data found that the study had suffered from inconsistent follow-up; of 434 patients with VS due to TBI, only 25 were followed after 12 months and six had “recovery of consciousness” by three years post-injury, putting the rate of late recovery at 14% or higher.⁴¹ More recent studies suggest that late transition from VS to MCS may occur in as many as 20% of patients who met “permanent VS” criteria,⁵ albeit with continued severe disability.⁴² This realization has led to replacing the term “permanent VS” with the term “chronic VS.”⁵

Newer multimodal strategies incorporating specialized functional imaging or electrophysiologic studies may improve prognostication. In VS due to TBI, several techniques have been proposed to improve estimates of the likelihood of reaching MCS at 12 months, including MRI at 6-8 weeks post-injury, SPECT at 1-2 months post-injury, and the presence of P300 or EEG reactivity at 2-3 months post-injury. In VS due to non-traumatic etiologies, the CRS-R and somatosensory evoked potentials may assist in prognostication regarding reaching MCS at 24 months.⁵

Acute DoC

Research into covert awareness in DoC has focused on the post-acute stage (after hospital discharge). The great majority of patients who have shown covert awareness on functional neuroimaging or electrophysiology have been months or years post-injury. At this stage, end-of-life decisions tend not to be pressing. The highest-stakes time for patients with DoC is much earlier, in the first hours to weeks, when uncertainty is greatest and treatment decisions are first made around respiratory support, artificial nutrition and hydration.

In the acute setting, prognostication relies on clinical, electrodiagnostic and imaging findings seen within the first week as well as age and presence of other comorbidities. Different criteria are used for different etiologies of SABI, including stroke, TBI and cardiac arrest.⁴³⁻⁴⁵ Recent studies are looking at using multimodal imaging or artificial intelligence⁴⁶ to improve prognostication in the acute phase of SABI.

Despite these tools, uncertainty characterizes the early period of SABI. This uncertainty may lead providers to offer vague, inaccurate and/or falsely confident prognoses to surrogate decision-makers.⁴⁷ Overly optimistic prognoses may lead to overtreatment, while overly pessimistic prognoses may lead to self-fulfilling prophecies through withdrawal of LST.⁴⁷⁻⁴⁹ In one multicenter retrospective cohort study of 720 patients with TBI in Canada, withdrawal of LST accounted for 70% of in-hospital deaths and was more closely associated with the facility where care was provided than with patient characteristics. About half of withdrawal of LST decisions occurred during the first 72 hours of injury.⁵⁰

Ethical considerations in the care of patients with DoC

The discovery 15 years ago of covert command following among a minority of patients with VS raised important ethical issues. Some are unique to DoC, while others reflect ethical challenges in the care of many patients with SABI.

Quality of Life

The presence of CMD among some patients with VS has led to concern about the quality of life (QoL) of these individuals. In traditional conceptions of VS, the absence of behavior was assumed to mean the absence of consciousness, and therefore the absence of suffering. With knowledge of CMD comes concern that some behaviorally unresponsive patients may experience suffering but may be unable to communicate their wishes or needs at the bedside. Savulescu and Kahane have characterized the situation as “far worse than someone in the worst form of solitary confinement” and have argued that “terminating these patients’ lives might be morally required, not merely permissible.”²⁷

Many clinicians and members of the general public share this attitude. A study of European physicians found that even after education about the rate of diagnostic error in VS and evidence of residual cognition in VS, 82% would prefer not to be kept alive in a chronic VS.⁵¹ Avoidance of suffering is a common justification for LST withdrawal in many patients with VS.⁵² Yet the concepts of suffering and QoL are speculative in noncommunicating patients⁵³ and needs to be regarded in the context of the disability paradox, wherein people with a disability rate their QoL higher than non-disabled people imagining life with disability.⁵⁴

In individuals with DoC who cannot self-report, there have been attempts to consider objective factors thought to be important to QoL. Three generally accepted domains of QoL include having pleasant experiences; personal achievements; and desirability of a health status according to the values of a population.^{53,55} It has been argued that aware patients with DoC can enjoy well-being in the first domain only, and that this results in a low QoL.²⁷ Yet this argument does not account for response shifts, in which individuals with severe chronic illness or disability experience a reprioritization of the factors that contribute to QoL.^{21,56-58} In DoC, QoL may depend more on perceived social support and “hedonic experiences” both negative (pain; depression; boredom) and positive (physical contact, companionship, mental stimulation).^{55,57,59}

More research is needed to attempt to assess the subjective well-being of aware patients with DoC. Without such tools, medical decision-making is subject to the inference, suppositions and preconceptions of medical providers and surrogate decision-makers, an issue discussed further below.^{53,55}

Medical Decision-Making

Patients with VS or MCS need various degrees of support to remain alive, most commonly artificial nutrition and hydration provided through a gastrostomy tube and ventilatory support using a tracheostomy. They also lack the capacity to make and communicate treatment decisions. How treatment decisions are made in such scenarios varies by nation.

In the United States, patients enjoy a constitutionally protected right to refuse both the initiation and the continuation of LST. When a brain-injured patient cannot make treatment decisions, that right is transferred to a lawful surrogate decision-maker. The legality of discontinuing artificial nutrition and hydration in accordance with a patient's previously stated wishes was upheld in 1990 surrounding the case of Nancy Beth Cruzan, a young woman with VS.⁶⁰ All subsequent legal decisions on withdrawing of LST have cited Cruzan as the precedent, including the heavily publicized 2005 case of Theresa Schiavo.^{61,62}

Surrogate decision-making is founded in patient autonomy. Surrogates make decisions for patients using established standards. If a patient has relevant, previously expressed wishes, they should be followed. If not, the surrogate should use substituted judgment and attempt to reproduce the decision the patient would have made by applying the patient's values and preferences to the clinical circumstance. When that is not possible, surrogates should attempt to determine what is in the best interest of the patient.⁶¹⁻⁶⁴

There are real-life limitations to this established system of surrogate decision-making. First, there is only moderate concordance between surrogates and patients around treatment preferences; one meta-analysis of 16 studies showed that surrogates predicted patients' treatment preferences (including around a VS scenario) with 68% accuracy, a rate that did not improve among patients who had previously discussed treatment preferences with their surrogates.⁶⁵ Moreover, some surrogates for patients with DoC choose to continue LST despite the patient's clearly-stated wishes not to receive it. In one qualitative study, caregivers for patients with chronic VS described overruling the patient's wishes for several reasons, including expectation of recovery and a perception that artificial nutrition and hydration do not constitute LST. Other surrogate decision-makers may make decisions incrementally in the acute setting, not realizing that there is often a "window of opportunity" for death in SABI, after which the dependence on LST decreases, with the last LST usually being artificial nutrition and hydration.⁶⁶ Surrogate decision-makers develop their understanding of diagnosis and prognosis using personal observations and beliefs, not just the information communicated by clinicians.⁶⁷ One study found that 90% of caregivers of patients in VS regarded the patient as conscious.⁶⁸ These observations highlight the importance of sensitive, empathetic communication with surrogate decision-makers.

There has been recent debate around whether clinicians are obligated to disclose to families of patients with VS the fact that some patients with VS may demonstrate covert awareness by investigational neuroimaging.²¹ On the one hand, the withholding of medical information from patients/surrogates without their consent represents a violation of the principle of autonomy. On the other, at present, few patients can access testing to detect covert awareness, and disclosing the presence of CMD in some patients without being able to test for it in an individual patient could lead to false hope and overtreatment. Disclosures ought to include caveats that multimodal evaluations return negative findings in the majority of patients with VS/MCS, and that the link between positive findings and phenomenal consciousness remains unclear.²¹

Therapeutic nihilism

The traditional understanding of VS as a permanent state of unresponsiveness may lead to perceptions that prolonging life for such patients is potentially inappropriate or medically futile.⁶⁹ Medical futility is invoked when a therapy that is hoped to benefit a patient's medical condition is expected not to do so on the basis of the best available evidence.⁷⁰ Declarations of medical futility in DoC need to take into account evolving understanding of diagnosis and prognosis in DoC. The AAN now recommends that clinicians discussing prognosis with caregivers of patients with acute DoC (during the first 28 days post-injury) should avoid statements that suggest these patients have a universally poor prognosis,⁵ in order to avoid self-fulfilling prophecies.⁷¹

Systems of Care

Evidence of covert awareness among patients with VS, frequent misdiagnosis of VS/MCS, and the possibility of late recovery from both conditions raise ethical concerns about the systems of care in place for these patients. Erp and colleagues have described a "vicious circle" of epidemiology, organization of care, and end-of-life decisions for patients with VS: this group of patients is small and recovery is rarely witnessed by those providing acute care; because of this, care is organized ad-hoc, resulting in misdiagnosis and lack of specialized rehabilitation; and decisions about whether to continue life-supporting treatment are made without an accurate diagnosis or evidence-based prognostication.⁷² At the same time, the aggressive care of patients with limited or no awareness raises questions of distributive justice and allocation of resources.⁷³ Research is needed to develop evidence-based systems of care for patients with VS/MCS and better identify those who are likely to benefit from early intensive neurorehabilitation.

Inpatient care for patients with DoC: A Neuropalliative Care Approach

The changing medical and scientific understanding of DoC and the ethical issues described above add to the complexity of caring for patients with DoC and supporting their loved ones, surrogate decision-makers and/or family members. We recommend a palliative care approach to dealing with these complex issues. Palliative care aims at preventing and relieving physical, social, psychological and spiritual suffering; it encompasses symptom management as well as communication around diagnosis, prognosis, treatment options, goals of care, shared decision-making, and advance care planning.⁷⁴ "Primary" palliative care is provided by a patient's primary team and is based in the idea that all healthcare providers should possess certain palliative care skills, with the support of specialists as needed. Table 2 summarizes a list of proposed palliative care skills for the neurohospitalist caring for patients with DoC.

Symptom management

Symptom management in DoC remains difficult because of patients' limited ability or inability to communicate. The very concept of a "symptom" is ambiguous in this population because it implies phenomenal consciousness, the presence of which is uncertain. Experiencing pain requires nociception, sensory/discriminative dimensions of pain (which

may produce autonomic responses and patterned behavior like grimacing) and the affective/motivational dimensions of pain (which are thought to generate the feeling of pain and may produce an urge to avoid the stimulus).^{53,55,75} In PET studies, patients with VS exposed to pain consistently show activation of the midbrain, contralateral thalamus, and S1 areas,^{76,77} suggesting relatively preserved nociception and at least partial sensory-discriminative pain processing.⁵⁵ Higher order associative areas such as S2, insula, and anterior cingulate cortexes also tend to activate in response to pain in patients with VS, but appear functionally disconnected from each other.^{76,78,79} These connections are typically preserved in patients with MCS,⁷⁸ which may suggest that patients with MCS can experience pain as noxious, while patients with VS cannot. However, there is no way to confirm this hypothesis in patients who are unable to self-report.

Given ongoing ambiguity on the extent to which patients with DoC can experience discomfort, attempts should be made to try to minimize it⁵⁵ and offer pleasurable experiences when possible, like pleasant tastes, smells, and music. Sources of discomfort may include immobility, spasticity, pressure ulcers, infections, paroxysmal sympathetic hyperactivity, and invasive procedures, and confusion or agitation. Providers should attempt to minimize discomfort and generally keep in mind the possibility of covert awareness while examining and speaking to these patients.⁸⁰

Communicating uncertainty

Outcomes from SABI can range from lifelong unresponsiveness to functional independence. Markers for very poor prognosis have been identified in certain types of SABI, but we are only beginning to develop tools to estimate prognosis for the majority of individual patients. One of the central challenges in caring for patients with DoC is communicating this uncertainty.

Two principles of managing uncertainty in SABI are to remove uncertainty when possible, and to be transparent about the uncertainty that remains. Clinicians should minimize misdiagnosis by using evidence-based behavioral assessments, strategies to enhance arousal, and multimodal evaluation where applicable and available.

Most surrogates appreciate receiving prognostic information early in the course of critical illness, even if that prognosis is uncertain.^{81,82} Several strategies exist to help clinicians communicate uncertainty.⁸³ First, clinicians need to be able to acknowledge their own uncertainty, since suppressing this knowledge can lead to premature closure, the single most common phenomenon in misdiagnosis.^{83,84} Clinicians should disclose prognostic uncertainty to surrogate decision-makers while bracketing estimates with ranges where possible (e.g., sharing the best-case and worst-case scenario).⁸⁵ Misleading language (“no hope”) or ambiguous language (“meaningful recovery”)⁸⁶ should be avoided. Clinicians should acknowledge the difficult emotions evoked by uncertainty and show their commitment to ongoing engagement with the patient and family going forward (“I don’t know right now, but I will continue to be honest with you as we learn more”).⁸³ Finally, anticipatory guidance can help families know what to expect in terms of a time course of treatment and possible future complications.⁵ If a decision is made to pursue life-sustaining

therapy including artificial nutrition and hydration, clinicians might suggest a time-limited trial, with a plan to revisit goals of care in a predetermined number of weeks or months pending the patient's clinical course.^{87,88}

Caregiver support

In SABI, patients' loved ones assume the role of caregiver suddenly. From the first moment in the emergency department or ICU, they must simultaneously learn new medical information, navigate new systems of care, and confront financial and logistical barriers, all while grieving.

Caregivers for patients with chronic DoC have been shown to experience a prolonged grief reaction.^{89,90} The patient's ongoing physical presence but absent or limited behavioral presence creates ambiguity around the nature of the loss. Whereas grieving for death typically recedes over time, caregivers for patients with DoC may find the patient's "concurrent presence-absence" challenging and may struggle to find a strategy for mourning.^{90,91} Meanwhile, they may serve simultaneously as the patient's caregiver, care coordinator, advocate, and financial provider. The responsibility of caregiving affects how they can contribute to other relationships and roles in their lives.⁹⁰

Greater access to resources and stronger social networks may decrease caregiver burden.^{90,92} Inpatient providers can begin this process by connecting caregivers to existing services and establishing a robust follow-up plan.

Summary

Advances in the understanding of diagnosis and prognosis in DoC raise important ethical questions and underline the need to provide a palliative care approach to these patients and their caregivers. As described above, many gaps in knowledge remain. There is an urgent need for improved prognostic tools in the acute setting, when stakes are high and uncertainty is greatest. More research is needed to facilitate communication with capable individuals with DoC, both for therapeutic purposes and to directly involve these individuals in medical decision-making. Despite ongoing advances in DoC research, uncertainty continues to characterize these patients' diagnosis, prognosis, and QoL. Clinicians should clearly communicate this uncertainty, provide support to patients' loved ones, and facilitate difficult decision-making in the face of the unknown.

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Clinical Care Points

- About 40% of patients with minimally conscious state are erroneously classified with vegetative state using bedside examination.
- Bedside diagnosis of disorders of consciousness (DoC) can be improved through the use of standardized neurobehavioral assessments and through simple practices like evaluating visual pursuit using a mirror, involving caregivers in the examination, and performing serial exams.
- About 14% of patients diagnosed with vegetative state on neurobehavioral assessments can follow commands as detected by neuroimaging and electrophysiology techniques. A handful of these patients have used these technologies to communicate.
- The discovery of covert awareness among some patients with VS raises ethical questions around quality of life and medical decision-making.

Key Points:

- A subset of patients with disorders of consciousness who are behaviorally unresponsive may have awareness detected only by neuroimaging or electrophysiology.
- These and other recent research advances in disorders of consciousness raise ethical questions that have important implications for acute and post-acute care of these patients.
- A palliative care framework can help providers deliver ethical, compassionate care to these patients and their loved ones.

Table 1:

Clinical Features of Disorders of Consciousness

	Coma	VS	MCS	eMCS	CMD
Eye opening	None	Spontaneous	Spontaneous	Spontaneous	Spontaneous
Movement	None	Reflexive; non-purposeful	Automatic; object manipulation	Functional object use	Reflexive; patterned
Response to noxious stimuli	Reflexive; posturing; none	Posturing; withdrawal	Localization	N/A	Posturing; withdrawal
Visual response	None	Startle; none	Sustained pursuit and/or fixation, may reach for objects (MCS-) or recognize objects (MCS+)	Recognizes objects	Startle or none
Affective response	None	Random	Congruent with stimulus	Congruent with stimulus	Random
Response to command	None	None	Inconsistent, reproducible	Consistent, reproducible	Consistent, reproducible (as detected by neuroimaging or electrophysiology)
Vocalization	None	None	Inconsistent, random vocalization or none(MCS-); inconsistent, intelligible words (MCS+)	Intelligible words	None
Communication	None	None	Unreliable	Reliable	In rare individuals, detected by neuroimaging or electrophysiology

VS: vegetative state; MCS: minimally conscious state; eMCS: emergence from minimally conscious state; CMD: cognitive-motor dissociation.

Table 2:
Primary Palliative Care Skills for Patients with Disorders of Consciousness.

Adapted from Creutzfeldt CJ, Holloway RG, Curtis JR. Palliative Care: A Core Competency for Stroke Neurologists. Stroke. 2015;46(9):2714-2719; with permission

	Primary palliative care skills
Symptom management	Recognize subtle signs of awareness and address all patients as if they are aware Recognize and treat reproducible signs of pain, agitation, delirium Offer pleasant experiences and minimize uncomfortable experiences for all patients, including those whose subjective experience is unknown
Communication skills and goals of care	Communicate with patients and surrogates with empathy and compassion Effectively elicit the patient's goals, values, and treatment preferences Effectively communicate information to surrogate decision-makers in language they understand Offer evidence-based prognostic estimates and avoid overly negative or positive prognostication Effectively communicate about uncertainty Avoid making assumptions about the quality of life for noncommunicative patients Provide anticipatory guidance regarding treatment trajectories Help decision-makers establish goals of care based on the patient's values, goals, and treatment preferences Incorporate ethical principles into communication and decision-making Develop consensus for difficult decisions Identify and manage moral distress among interdisciplinary team members
Psychosocial and spiritual support	Identify psychosocial and emotional needs among the patient's loved ones / caregivers Identify needs for spiritual or religious support and provide referrals Access resources to support the patient's loved ones / caregivers Practice cultural humility
Systems of care	Establish a follow-up plan in which the patient's / caregivers' palliative care needs will continue to be addressed
End of life care	Emphasize non-abandonment and provide continued emotional support through the dying process Provide anticipatory guidance regarding the dying process Facilitate bereavement support