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## Translating the discovery of covert consciousness into clinical practice

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### Abstract

This commentary addresses the clinical implications of the findings in (Claassen et al., 2019, *NEJM*). Our discussion focuses on how families will interpret the discovery of covert consciousness in a patient, and how this might affect their clinical decisions, such as the withdrawal of care.

### Discovering Covert Consciousness in the ICU

In conditions of prognostic uncertainty, neurointensivists and families often struggle to make decisions for unresponsive brain-injured patients. A new study, however, demonstrates that, following brain injury, electrophysiological (EEG) assessment has potential prognostic value. This could have profound implications for clinically and ethically consequential decisions, such as withdrawing life-sustaining treatment or managing potentially life-threatening events, such as sepsis. Here, we outline two interrelated ethical considerations for neurointensivists who use these methods when communicating prognostic information to patients' families.

A recent study of 104 seemingly unconscious brain-injured patients cared for in the Columbia University neuro-ICU demonstrated that 16 responded to the command to open and close their hand [1]. Researchers did not observe this hand movement at the bedside. Instead, they witnessed EEG evidence of motor cortex activation.

A machine-learning algorithm identified latent evidence of brain responsiveness from multiple EEG tests. Six days after injury, half of the 16 patients with responsive brain activity recovered the ability to behaviorally follow commands, and follow-up showed that a majority (n=7) recovered functional independence. Compared to patients who showed no

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evidence of motor cortex activation and recovered (12 of 84, or 14%), patients with brain responsiveness recovered faster and with greater odds of a positive outcome.

These results are similar to those of previous studies reporting brain activity in unresponsive brain-injured patients [2]. Indeed, a significant proportion of unresponsive patients—estimated to be at least 15%—are able to modulate their brain activity to command [3]. These patients are correctly regarded as unconscious according to *clinical criteria*, yet their brain activity shows that they are aware. Such patients are variously described as having “cognitive-motor dissociation” or as being “covertly conscious.” Their consciousness is hidden until we discover it by measuring their brain activity.

These findings have important implications for neurocritical care. The novel combination of machine learning with EEG can improve prognostic accuracy. The feasibility of these methods also suggests that they are likely to be used. In the days following brain injury, EEG is more practical for ICU patients as compared to other costly and complex neuroimaging methods [4].

Despite the promise of these methods, little is known about how families will use test results to make decisions. Will families think that brain responsiveness indicates a rich, inner mental life for their loved one? Or will such information be interpreted like other neuro-ICU measures? The key ethical insight is that families *will* try to find meaning in EEG evidence of brain responsiveness, and clinicians will play an important role in shaping these expectations [5].

## Communicating Evidence of Covert Consciousness to Families

Clinicians have an ethical duty to support patients and families in making autonomous choices. Adherence to this duty is especially important when families make consequential decisions for incapacitated patients. Guidelines for end-of-life care in the ICU emphasize the importance of family-centered decision making [6]. Clinicians play a crucial role in this process so decisions reflect patient values. They provide guidance when families are having trouble reaching a decision and they translate complex medical information in to lay terms.

The U.S. practice guideline on disorders of consciousness also provides direction for disclosing prognostic information [7]. Clinicians should avoid statements of universally poor outcome, use evidence-based language, and become familiar with patient and family values prior to discussing prognosis. These recommendations provide a starting point for disclosing evidence of covert consciousness in the acute care setting. We think at least two interrelated ethical issues should be considered in this process.

First, neurointensivists who use these EEG methods should consider adopting a systematic approach for disclosing results. To date, there are no “best practices” for disclosing information regarding covert consciousness. We have argued previously that guidance might be found in a consensus-based procedure for disclosing “preclinical” neuroimaging results to Alzheimer’s disease patients [5]. This involves step-by-step pre-disclosure education and assessments. Educational interventions are designed to temper expectations, while assessments focus on patient and caregiver wellbeing, their willingness to learn the results,

and the personal implications of positive or negative findings. These assessments inform post-disclosure follow-up and monitoring.

Clinicians should also scrutinize the language used to describe EEG results during disclosure. Clinical guidelines rightly recommend evidence-based language when disclosing prognostic information [7]. However, strict adherence to this recommendation might not be straightforward when discussing EEG findings. It is plausible that evidence-based language could obfuscate, rather than enhance, understanding of the results. To describe a patient's condition, clinicians might use the descriptive term, "cognitive-motor dissociation," as did the authors of the Columbia-ICU study. Yet this language might not be as meaningful to families as more interpretive terms, like "covert consciousness." Some terms are also likely to be complex. Technical details, such as "machine-learning" or "classifier accuracy," will need to be translated into language that is as lay-friendly as possible.

Second, neurointensivists should endeavor to understand how families will use information about covert consciousness to make consequential decisions. This requires not only a familiarity with patient or family values, but also insight into how those values will influence clinical deliberations in light of complex EEG data. Sensitivity to a family's thought process can assist clinicians in counseling them through consequential decisions with dignity.

Clinicians should discuss with families the meaning of key terms and possible test results prior to disclosure of prognostic information. These discussions will help the clinical team and family to understand their respective goals for patient care, and to develop a *shared lexicon* pertaining to value-laden statements like, "quality of life" or a "good death." These discussions will assist the clinical team in anticipating the significance that families will attribute to covert consciousness.

For some families, evidence of covert consciousness might significantly impact medical decisions. Positive results might lead a family to refrain from withdrawing medical care. Other families might find this evidence less significant. These families might think that brain responsiveness (or lack thereof), while important, is ultimately irrelevant to consequential decisions. These families might have deep religious beliefs that supersede considerations of neurological status. Life itself is intrinsically valuable for these families, not the quality of life that their loved one might have.

Our point is that a family's experience of consequential decisions in the ICU is enhanced when they sufficiently understand prognostic information, when they are adequately counseled, and when their values are taken seriously. Anticipating how families will react to the discovery of covert consciousness can assist clinicians in supporting this family-centered decision making.

## Conclusion

Advanced EEG methods that improve prognostication of brain-injured patients have great promise for neurocritical care. Larger, multi-site studies are still needed to assess the clinical utility of these methods. However, we anticipate they will be incorporated in clinical practice in the near future. Clinicians should be cognizant that families will try to find meaning in

EEG evidence of brain responsiveness, and that they will play a critical role in shaping those expectations. Clinical guidelines on disorders of consciousness and end-of-life care are invaluable for addressing these issues [6, 7]. Yet, in some circumstances, clinicians may need to look beyond these guidelines for more nuanced approaches to disclosing evidence of covert consciousness. This will ultimately help families understand, appreciate, and use this information to make decisions that best reflect patient values.

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