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Peterson and Naci: Confronting ethical implications of detecting awareness in the vegetative state

By Andrew Peterson and Lorina Naci
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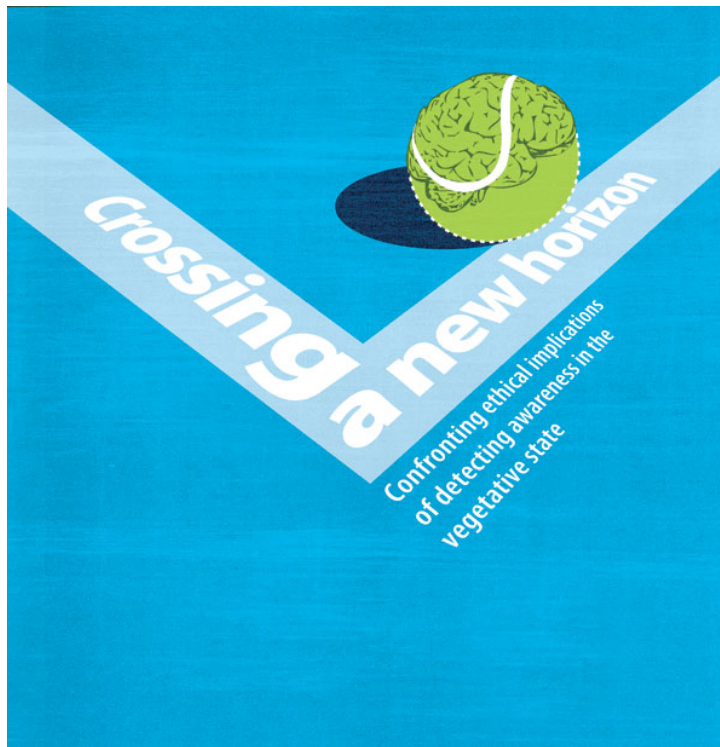


Illustration by Scott Woods

Imagine that a close family member of yours was involved in a terrible car accident.

The accident caused a traumatic brain injury that, despite the best efforts of physicians, has left your family member with a nebulous prognosis and severely diminished levels of consciousness. The attending neurologist explains to you that your family member has received a diagnosis of vegetative state — a disorder of consciousness characterized by cycles of wakefulness without concomitant awareness.

"Only time will tell," the neurologist explains, as you and your family struggle to cope with the consequences of this life-altering event.

Consider, now, the possibility of utilizing novel neuroimaging techniques to reveal further information about your family member's condition.

What if you could uncover your loved one is indeed aware, despite the negative results of previous diagnostic procedures? Moreover, what if these techniques could lead to meaningful communication? How might this change their condition? Could

this improve quality of life?

In light of recent breakthroughs in neuroscience, questions like these increasingly represent real clinical options for patients, families and physicians. Investigators at Western's Brain and Mind Institute, for example, have shown innovative uses of neuroimaging techniques can reveal hidden awareness in patients with severe disorders of consciousness.

By placing vegetative-state patients in a functional magnetic resonance imaging (fMRI) scanner, and instructing them to imagine playing tennis or walking from room to room in their house, Western researchers have been able to detect and reliably track neural activation in distinct areas of the brain. This data has then been used as a behavioral proxy for patients who are unable to display overt (e.g., behavioral) signs of conscious awareness, such as command following.

In this way, some disorder of consciousness patients, who were previously identified as behaviorally non-responsive, have shown that they can, in fact, respond to instructions by modulating their brain activity. In the most extensive study to date, four of 23 diagnosed vegetative state patients (17 per cent) willfully modulated their brain activity to verbal commands, thereby indicating that they were consciously aware.

Critically, this technique may also permit patients to meaningfully communicate with family members and physicians. Two reported vegetative-state patients, for example, have been able to successfully answer a series of autobiographical questions over repeated fMRI scanning sessions. To accomplish this, investigators coded the two imagined events — tennis imagery and spatial navigation — with the respective answers 'yes' or 'no.' Patients were then asked yes/no questions and instructed to respond by simply imagining the corresponding activity for 'yes,' and the alternative corresponding activity for 'no.'

One of these patients, London, Ont., resident Scott Routley, who has been diagnosed as vegetative state for approximately 12 years, successfully answered 'no' to the question, "Are you in pain?"

Given Rouley's success, as well as the existence of other patients, who retain similar cognitive abilities, a natural step forward in this research program may be to permit disorder of consciousness patients to communicate medical preferences in the clinical setting. Indeed, this practical application may improve quality of life for this population, by availing patients of a sense of agency and well being lost to the initial injury.

Although the clinical application of this research is highly promising, several philosophical questions — particularly, ethical and epistemological issues — stand in the way. These questions include:

- Should information acquired from these techniques be disclosed to patients' families?
- Will the use of neuroimaging techniques cost too much to be sustainable?
- Is it possible for any individual disorder of consciousness patient to show decision-making capacity?
- What clinically relevant questions are ethically permissible to ask?

In January 2012, members from Western's Rotman Institute of Philosophy and the Brain and Mind Institute came together to form a collaborative research team, with the sole aim of tackling these pressing ethical and epistemological questions. The broad goal of this research project is to develop a conceptual framework that facilitates the seamless integration of brain-computer interfaces into medical practice.

Supervised by Charles Weijer, Tier 1 Canada Research Chair in Bioethics, and Adrian Owen, Canada Excellence Research Chair in Cognitive Neuroscience, this group meets regularly to find solutions to the forgoing questions, and to develop novel contributions to the burgeoning field of *Neuroethics*.

Of the issues identified as ethical obstacles to utilizing these neuroimaging methods in clinical practice, the assessment of decisional capacity has become a central area of research focus.

For any given patient to make medically relevant decisions, such as consenting to treatment or refusing medical intervention, it must be evident the patient can understand and reason carefully amongst the various treatment options. In doing so, the patient shows he/she sufficiently grasps the complex medical information, is able to relate it to the consequences of choosing one treatment as opposed to another, and is able to exercise his/her own, unique rationale while making a final decision.

If patients successfully exhibit these reasoning faculties, it is said they have decision-making capacity.

If, on the other hand, a patient is shown to have a neurological condition or an insufficient understanding of the medical information, it is presumed the patient's rational faculties constitutive of decisional capacity are limited. In these cases, medical decision-making privileges may not be granted to the patient, and will likely remain in the hands of the family, or other legally authorized proxy decision makers. This ensures the best interests of the patient will be represented in the decision-making process.

Importantly, the simple limitation of communicating through 'yes' or 'no' questions poses great difficulty for unequivocal evidence of decisional capacity. This, however, is not an ethical problem that can be avoided since most medical decisions relevant to disorders of consciousness patients will require some decisional capacity, albeit in different degrees.

Herein lies one of the central philosophical obstacles for integrating these innovative neuroimaging techniques into medical practice: How can we possibly know that a medical decision provided by a disorders of consciousness patient, through neuroimaging techniques, represents a well-reasoned and well-informed choice?

Answers to philosophical questions like these are exceedingly difficult.

Yet, we remain optimistic that, through ingenuity and technical progress, solutions to these problems can be worked out in the near future. For now, however, we can be certain the use of these neuroimaging techniques will compliment the clinical measures used at the bedside, thereby enhancing the diagnostic accuracy in this patient group.

By developing a conceptual framework that addresses the ethical and epistemological issues raised by this research, we hope to broaden this application in ways that stand to benefit this patient group, their families, and the physicians that care for them.

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