

VIEWPOINT

The Catch-22 of Neuroimaging, Disorders of Consciousness, and End-of-Life Decisions

Emanuel Cabral, BA
The National Core for Neuroethics, Division of Neurology, Department of Medicine, The University of British Columbia, Vancouver, British Columbia, Canada.

Judy Illes, PhD
The National Core for Neuroethics, Division of Neurology, Department of Medicine, The University of British Columbia, Vancouver, British Columbia, Canada.

Corresponding Author: Judy Illes, PhD, The National Core for Neuroethics, Division of Neurology, Department of Medicine, The University of British Columbia, 2211 Wesbrook Mall, Koerner S124, Vancouver, BC V6T 2B5 Canada (jilles@mail.ubc.ca).

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In 2016, Canada passed legislation to legalize medical assistance in death (MAID) for patients with severe, irremediable conditions. The passage of this law follows those of Switzerland, Belgium, the Netherlands, Luxembourg, and 5 US states that allow patients to choose to die given specific criteria intended to uphold the principles of beneficence, human rights and dignity, and justice.¹ It signals progress in the arena of end-of-life (EOL) decision making and opens new discussions about competence and communication where technology, human intervention, or both are needed as intermediaries. We consider the case where the legitimacy of technology-assisted, medically assisted dying is tested and, however seemingly far-fetched, is already in the public eye. This specific context pertains to patients with brain injuries in whom functional magnetic resonance imaging that relies on blood oxygen levels in particular brain regions, or electrophysiological measurements from the scalp, have been used to reveal signals that are interpreted as consciousness.

Establishing Competence

Vegetative states and minimally conscious states belong to a set of conditions under the umbrella of disorders of consciousness (DOC). Patients in vegetative states have sleep-wake cycles with eyes open for prolonged periods but exhibit no purposeful movements and are unable to follow commands. Patients in minimally conscious states can sometimes follow simple commands and demonstrate purposeful gestures, emotional reactions, object grasping, and eye movements. For health care decision making, responsive competence must be established given measures of understanding and awareness, reasoning, patient appreciation of his or her condition, an ability to express choice, and the possession of appropriate values. In this context, *demonstrated competence* is achieved when a patient communicates directly through verbal, gestural, or written language. We use the term *mediated competence* to describe the situation for patients whose cognition and executive functioning is intact but for whom, as in the case of locked-in syndrome or expressive aphasia, communication must be facilitated through nonverbal codes such as ocular movements, simple gestural movements, language boards, or computer assistance. The term *interpreted competence* then can be used to describe the case of behaviorally non-responsive patients whose communication abilities, and thereby assessment of competence, must be established through complex statistical processing of neurobiological or neurophysiological signals and then further human analysis. Whereas mediated competence provides an indirect measure of decision-making capacity with at most 2 degrees of separation between signal pro-

ducer and signal receiver, interpreted competence has at least 3 degrees of freedom between the production of a signal and a determination of its potential meaning, permitting a proxy measure of competence at best.

Applying Ethics Theories

We look to how clinical, feminist, and disability ethics theories might each provide at least some support for the use of mediated or interpreted signals for enabling EOL decisions. For example, clinical ethics draws attention to beneficence and patient autonomy, including benefits afforded by advances in neurotechnology. Feminist ethics asserts the critical nature of relational autonomy in any health care setting. Disability ethics further highlights human rights and dignity. Through these lenses and others that focus on ethics in medicine and society, mediated or interpreted assessments of competence, in principle, allow health care professionals to obtain more information about the present experience of the patient than would otherwise be possible and empower patients to express preferences and wishes. In the case of EOL decisions, acceding to patient demands for relief from pain is an expression of empathetic care.^{2,3}

Alongside imaginative new possibilities for engaging with persons in DOC, ethical arguments opposing the coupling of interpreted signals and EOL decisions, let alone MAID, weigh heavily. The greatest concerns turn on the reliability and reproducibility of the signals, and the interacting forces of cognitive impairment naturally associated with any brain injury that leads to a persistent DOC, even if not a vegetative state. Each benefit is predicated on the requirement for informed consent, which may be present with mediated communication but elusive in the interpreted case. Specifically, each layer of interpretation introduces an additional level of uncertainty that is a function of the cognitive impairments and the delayed or undetectable signals they produce, the irreproducibility of signals owing to the daily or hourly fluctuations in the patient's cognitive reserve, and the sensitivity of the statistical model used to interpret the signals.^{4,5} This progressive uncertainty casts significant doubt on the fidelity of the proxy interpretation to the source response and obfuscates attempts to clearly assess competence.

Following this argument, robust challenges exist in the application of interpreted competence to the EOL scenario, although possibly less so for quality of life and other medical management decisions. Clinical, feminist, and disability ethics reaffirm that the degree of competence must be proportional to the risks of potential treatment outcomes, and that the highest level of competence is required for MAID owing to its finality.

Following the principle of nonmaleficence, clinical ethics would not permit interpreted competence for EOL decisions because signal fluctuations and response ambiguity impede the establishment of adequate levels of competence. Feminist ethics would bolster this position from a perspective of care: while wishes may be expressed in a potentially reproducible albeit stochastic manner,⁵ establishing informed consent is likely an elusive goal. Disability ethics would reject interpreted competence in the EOL setting from a position of respect for persons, in that such high-risk decisions disavow the patient's dignity as a person and potentially enable harmful ideas linked to marginalized DOC patients to bias interpretation of responses.⁵

Justice and Other Considerations

Although we argue that interpreted competence is impermissible for high-risk decisions, such as MAID, it may become permissible in low/moderate-risk quality-of-life decisions (eg, movement of bed and personal preferences) and low/moderate-risk medical management decisions (eg, administration of medication for pain and some types of surgery). However, permissibility is counterbalanced by feasibility, where the allocation of the resource and cost make such applications prohibitive. Electroencephalography may solve some of these challenges in the future⁶ and, arguably, high costs associated with magnetic resonance imaging could potentially be regained if

undesired and unnecessary treatments are avoided by following patient-expressed wishes.

In Pursuit of Balance

While the potential to enhance patient autonomy and alleviate irremediable distress is enticing, the limitations in using interpreted competence for the EOL case, however construed, are presently insurmountable. Indeed, applications of neurological science can be at once intriguing while seemingly futuristic. Consider the use of brain-computer interfaces to restore mobility in paralyzed individuals or the application of deep brain stimulation to restore consciousness in previously vegetative patients: these emerging capabilities attract the interest of the public and patient communities, which demand new information and transparency about them. Of these capabilities, neuroimaging in the context of EOL decision making represents a classic catch-22. It is neither feasible nor reasonable in the most critical life decision—EOL—but is too expensive and too limited to be applied to decisions of a lesser gravity. Regardless, these discussions must not be left to currents of thought in news and social media. Difficult questions remain for MAID both in DOC and in seemingly more straightforward cases.⁷ Public trust and understanding, especially for those who face traumatic and irreversible decisions, will only come with our anticipatory, open engagement with the issues.

ARTICLE INFORMATION

Published Online: March 6, 2017.
doi:10.1001/jamaneurol.2016.5994

Conflict of Interest Disclosures: None reported.

Funding/Support: Preparation of this article was supported by grant EOG120257 from the Canadian Institutes for Health Research (Dr Illes) and the Vancouver Coastal Health Research Institute (Dr Illes).

Role of the Funder/Sponsor: The funders had no role in the preparation, review, or approval of the manuscript, or the decision to submit the manuscript for publication.

Additional Contributions: We acknowledge John Stoessel, MD, and Peter Reiner, VMD, PhD, and

members of the National Core for Neuroethics for thoughtful engagement on the topic of this Viewpoint. They did not receive compensation.

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