

Title

From awareness to prognosis: Ethical implications of uncovering hidden awareness in behaviourally non-responsive patients

Short Title: From Awareness to Prognosis

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Abstract

Long-term patient outcome after severe brain injury is highly variable, and reliable prognostic indicators are urgently needed to guide treatment decisions. Functional neuroimaging is a highly sensitive method of uncovering covert cognition and awareness in patients with prolonged disorders of consciousness, and there has been increased interest in using it as a research tool in acutely brain injured patients. When covert awareness is detected in a research context, this may impact surrogate decision-making—including decisions about life-sustaining treatment—even though the prognostic value of covert consciousness is currently unknown. This paper provides guidance to clinicians and families in incorporating individual research results of unknown prognostic value into surrogate decision-making, focussing on three potential issues: 1) Surrogate decision makers may misinterpret results; 2) Results may create false hope about the prospects of recovery; 3) There may be disagreement about the meaningfulness or relevance of results, and appropriateness of continued care.

Key Words:

Disorders of consciousness, neuroimaging, surrogate decision-making, ethics, brain injury, prognosis

Introduction

Improvements in intensive care have led to an increased survival rate following coma—the acute state of behavioural non-responsiveness occurring immediately after a brain injury—during which patients exhibit no evidence of awareness of themselves or of the environment. Long-term patient outcome is highly variable. Some will pass away, others will go on to make a good recovery, and a third group will progress into states of behavioural non-responsiveness, such as the vegetative state (characterized by wakefulness with absent awareness, sometimes referred to as ‘unresponsive wakefulness syndrome’) or the minimally conscious state (characterized by wakefulness and minimal awareness). A patient who remains in a vegetative or a minimally conscious state for more than four weeks following severe brain injury is considered to be in a ‘prolonged disorder of consciousness (PDOC).¹ There is currently no clinical tool that can assess whether any individual patient will recover from coma, and, if so, with what degree of cognitive and physical functionality. While several factors have been associated with prognosis after severe brain injury at a population level, including patient age, sex, cause of injury, Glasgow Coma Score, pupil reactivity, and results of computed tomography,^{2,3} these are less informative for the prognosis of individual patients. Therefore, reliable prognostic indicators are urgently needed to guide treatment decisions for individual patients.⁴

As recently recognized by the American Academy of Neurology,⁵ neuroimaging studies have established that a proportion of entirely behaviourally non-responsive patients, who are thought to lack consciousness, are not only consciously aware, but critically, may have highly preserved mental life. Over the last decade, clinical research in this area has established that functional neuroimaging is a highly sensitive method of uncovering covert cognition and awareness in patients with prolonged disorders of consciousness (PDOC).⁶⁻¹⁴ This has led to an increased interest in using functional neuroimaging as a research tool in patients with acute severe brain injury.¹⁵⁻¹⁸ If functional neuroimaging proves useful in predicting recovery after severe brain injury, this could have profound implications for the diagnosis, prognosis, and clinical care of acutely brain injured patients.¹⁹ At the present time, however, the use of functional neuroimaging for the detection of consciousness has not reached routine clinical practice, with only a small number of academic centres in the United States, Europe, and Canada offering it in a research setting.

Given that the assessment of covert consciousness in brain injured patients currently occurs only in a research context, an important consideration is whether researchers should disclose individual results to a patient’s surrogate decision-makers and their clinical team. In prior work, we have argued that the disclosure of individual research results is ethically permissible, provided certain conditions are met.²⁰ However, disclosing this new information about the patient’s condition may complicate surrogate decision-making. For example, if a research intervention reveals that a severely brain injured patient, despite being behaviourally non-responsive at the bedside, remains conscious, this may influence decisions regarding whether to withhold or withdraw life-sustaining treatment, depending upon the legal framework in a particular jurisdiction.

The purpose of this paper is to identify and address ethical implications of incorporating functional neuroimaging research results into surrogate decision-making. First, we briefly review neuroimaging-based assessments of covert consciousness, and then focus on three potential issues: 1) Surrogate decision makers may misinterpret results; 2) Results may create false hope about the prospects of recovery; 3) There may be disagreement about the meaningfulness or relevance of results, and

appropriateness of continued care. By providing recommendations for addressing these issues, we aim to provide guidance to clinicians and families in incorporating individual research results of unknown prognostic value into surrogate decision-making.

Functional Neuroimaging Research

Functional neuroimaging in patients with PDOC has demonstrated that patients may retain ‘covert consciousness’ despite a lack of behavioural response to stimuli. Studies have shown that a proportion of patients diagnosed as PDOC not only remain consciously aware, but may retain numerous cognitive capacities. In rare cases, patients that are diagnosed as PDOC may go on to have significant recovery of function.^{21,22} For example, a 2010 study found that 6 out of 50 patients (12%) recovered consciousness over 12 months post-onset of PDOC.²³

The best-established method of assessing covert consciousness using functional neuroimaging in patients with PDOC is the ‘mental imagery task’.^{24,25} Patients are instructed to imagine preforming tasks, such as playing tennis or navigating their home for 30 second time intervals, while their brain activity is monitored using a functional magnetic resonance imaging (fMRI) scanner. The mental execution of these tasks generates activity in specific brain areas, and provides robust evidence that patients have understood and voluntarily performed the task, thus demonstrating their awareness.

More recently, Lorina Naci and colleagues have developed an alternative paradigm —using movie-watching— to detect covert awareness in patients who lack sufficient attention to understand or comply with task instructions.²⁶ This engages the attention of patients naturally, and allows researchers to track the patient’s executive function —a high level cognitive function, invoked by integrating information over time as they follow the plot, and which requires conscious awareness.²⁷ Naci and colleagues found that activation in frontal and parietal brain regions, areas known to support executive function, was closely synchronized to the plot of the movie across healthy participants, suggesting a common conscious experience of the movie.²⁸ Further, they showed that movie-related activity in these fronto-parietal regions was extinguished when consciousness was abolished with deep anaesthesia, demonstrating that activity in these regions required conscious awareness.²⁹ Using this approach, they demonstrated that a PDOC patient, who was behaviourally non-responsive and thought to lack consciousness for 16 years, demonstrated the same pattern of neural activation as healthy controls, during the same Hitchcock movie. The patient’s brain activity was not only highly synchronized with that of healthy controls, but also responded to the suspense level and executive demands of the movie on a moment-to-moment basis in the same way as individual healthy participants.^{30,31} This showed that the patient was not only consciously aware, but also able to continuously engage in complex thoughts about real-world events unfolding over time.

In the context of acute clinical care, functional neuroimaging research has two aims. The first is to detect covert awareness and cognition in behaviourally non-responsive patients with severe brain injury. A positive result on the mental imagery task or movie watching task provides robust evidence of covert awareness and cognition. This information is available to researchers immediately after scanning the patient and could be disclosed to surrogate decision-makers and the care team shortly thereafter.

The second aim of functional neuroimaging research in the context of acute brain-injured patients is to better inform prognosis by establishing a link, if one exists, between the early detection of covert awareness and patient outcome. If the presence of covert consciousness is a reliable indicator of functional outcome, this could have profound implications for patient prognosis, treatment, and end-of-life decisions.

Research is underway to determine the prognostic utility of detecting covert consciousness in behaviourally non-responsive patients who are in the acute phase, within a few weeks post injury, and who may or may not continue to live. To understand the link between covert awareness and long-term health outcomes, this research will enrol participants who will undergo a functional neuroimaging scan early after their injury, and have their recovery periodically assessed against the initial neuroimaging results. To generate a study of sufficient statistical power, a sizable population of patients is required, and each participant will likely need to be monitored for weeks or months. In order to maintain scientific validity, conditions may also need to be placed on when research results are disclosed.³² However, until a sufficient body of evidence has been generated to demonstrate a connection between early detection of covert awareness and subsequent functional recovery of the patient, the detection of covert awareness will continue to have minimal prognostic value.

The aforementioned dual aim of functional neuroimaging research presents a challenge to clinical and care pathway decision-making. Evidence of consciousness from functional neuroimaging may be relevant to both the clinical team and to surrogate decision-makers, in deliberating about treatment and care goals for each individual patient. However, the prognostic utility of covert consciousness is currently unknown. Consequently, assumptions about the patient's potential for recovery that are based on functional neuroimaging research results would be unfounded. How, then, should the individual results of functional neuroimaging research be incorporated into treatment decisions on behalf of severely brain injured patients?

Distinguishing between what can and cannot be inferred about the patient's current state and their prognosis is critical to ensuring that individual research results facilitate, rather than obfuscate, decision-making on behalf of the patient. In what follows, we examine three potential obstacles to the appropriate interpretation of functional neuroimaging results.

Surrogate Decision Makers May Misinterpret Results

Functional neuroimaging results confound clinical and care pathway decision-making if these results are misinterpreted.³³ First, a negative result might be misinterpreted as evidence that the patient lacks consciousness, rather than as simply a lack of evidence of consciousness, or as evidence that the patient will never recover consciousness. There are a host of reasons why covert awareness may be suppressed in the acute context, including infection, metabolic derangement, biochemical abnormalities, blood loss, other injuries, and the effects of emergency surgeries.^{34,35} Additionally, patients who retain covert consciousness may nevertheless fail to demonstrate this via functional neuroimaging for various reasons, such as lacking the necessary attention or memory to complete the task, misunderstanding instructions, or falling asleep during the task.^{36,37} Therefore, a negative result provides no new information about patient consciousness.

Second, a positive result might lead surrogate decision-makers to make unjustified inferences about the current experiences of the patient. Functional neuroimaging tasks provide robust evidence of consciousness, as well as working memory,^{38,39,40} attention,^{41,42} response selection,^{43,44} language comprehension,^{45,46,47} and executive function.⁴⁸ However, they provide limited evidence of the patient's subjective experience,⁴⁹ and thus, little evidence on which to ground a judgement that the patient is suffering, for example.^{50,51} Surrogate decision-makers must judge whether continued life is in the best interests of the patient, given the patient's prior values, wishes and beliefs. While the presence of consciousness might justifiably influence their decision, it is important that decision-makers not infer more about the patient's cognitive capacity than is warranted by the evidence.

Third, a positive result might lead surrogate decision-makers to make unjustified inferences about the patient's prognosis. Prognosis after brain injury is highly uncertain, and may only become clearer in the weeks or months following injury.^{52,53} While ongoing functional neuroimaging research in acutely brain injured patients may demonstrate a link between early detection of awareness and long-term recovery in the future, no such link has yet been established. However, it is possible that surrogate decision-makers will interpret the detection of consciousness as evidence that the patient will make a good recovery, and incorporate this belief into their decision-making on the patient's behalf. Conversely, they may interpret the lack of evidence of covert awareness as evidence that the patient will not make a good recovery.

Recommendation: Collaborative Communication

In order to mitigate the potential for misinterpretation of functional neuroimaging results, it is important that results be communicated clearly and transparently, but with sensitivity and compassion befitting the difficult emotional state of surrogates.⁵⁴⁻⁵⁶ We suggest that the time prior to scanning, when surrogate decision-makers first provide their informed consent on behalf of patients to participate, is a critical period in which to lay the foundations for understanding the significance of different functional neuroimaging results, and how they may impact patient care. Researchers should discuss potential results with the surrogate decision-makers and physicians in charge of the patient's care, and the range of possible treatment options arising from the results should be conveyed to the surrogates by the care team before scanning takes place, including treatment options that are appropriate independently of the research results.^{57,58} For example, a negative functional neuroimaging result should not prevent a patient from receiving access to appropriate in-patient rehabilitation, because a lack of evidence of consciousness may not reflect a patient's potential for consciousness.⁵⁹ Further, the discussion of potential research outcomes prior to scanning may also help surrogate decision-makers to temper their expectations, including avoiding false hope, as discussed in the next section. It may also help surrogates or the care team to avoid unjustified pessimism about the patient's prospects of recovery, in the case of a negative test result.

Research suggests that participants prefer face-to-face communication for receiving feedback on research results, especially when findings relate to severe or untreatable conditions,⁶⁰ suggesting they would benefit from a detailed discussion with researchers. In addition to face-to-face communication, surrogate decision-makers should be provided with a written letter detailing the participant's results, which they can refer back to at a later time. Results should be communicated in

simple and accessible language, bearing in mind that most surrogate decision-makers may have little experience with research of this kind.

Feedback of results to surrogate decision-makers must be a collaborative process and should be carried out by the patient's ICU physician and nurse, in conjunction with a member of the research team, and possibly a neurologist or neurorehabilitation specialist.⁶¹ Research has shown that participants prefer to receive research results from an individual with whom they have an existing relationship, and who is perceived as trustworthy, knowledgeable, and familiar.⁶² For patients with severe brain injury, this individual will likely be the attending neurologist. If this is the case, surrogate decision-makers must give their consent to have research results disclosed to the neurologist. This should occur when they provide informed consent to participation in the research, and ought to be confirmed again prior to disclosure. A member of the research team must ensure that the person providing the results to the surrogate understands the nature of the results and can accurately explain them to the surrogate. This should include the cognitive capacities that can be inferred from a positive result, and the limited inferences in cases of a negative result, i.e., that a lack of response does not entail a lack of awareness.⁶³

In addition to ensuring that surrogates understand the nature of the research results, it is critical that the neurologist contextualize the results with respect to other diagnostic and prognostic tests. A lack of appropriate context can lead to misinterpretation and mistaken conclusions about the patient's current and future state. Surrogate decision-makers report frustration when they are not provided with the information they need to make decisions, or are excluded from conversations about patient care.⁶⁴ For example, a positive result on a functional neuroimaging task must be balanced against other potential indicators of recovery, such as the patient's Glasgow Coma Score, CT scan, or diffusion tensor imaging. No currently available prognostic test can infallibly predict individual patient recovery, and none should be used in isolation. Further, because the relationship between preserved covert consciousness and future recovery is presently unclear, it is critical that researchers work with the clinical team to clearly communicate to surrogate-decision makers this gap during the consent process, as well as prior to the disclosure of research results.

Results May Create False Hope

Hope shapes how severe brain injury to a family member affects surrogate decision-makers, and can influence how they manage treatment decisions.^{65,66} Surrogates and families usually hope for a concrete outcome, e.g., that the patient will regain consciousness or recover the ability to speak or walk. Their level of hope generally remains stable, but can fluctuate significantly depending on new events or information. Thus, it is reasonable to expect that a positive functional neuroimaging research result could influence the hope and expectations of surrogate decision-makers.

Feelings of hope can be influenced by the information that surrogates receive. Research shows that what and how information is conveyed are key factors in promoting grounded hope, which can be beneficial to families in dealing with the burdens of an uncertain outcome and avoiding false hope. William Ruddick argues that different kinds of hope in a clinical setting can be distinguished by their epistemic warrant.⁶⁷ A 'probability hope' is grounded in the specific probability of an event occurring, i.e., my confidence in the hope being realized increases or decreases in response to the

available evidence. A ‘possibility hope’ is a hope for an outcome for which there is insufficient evidence for an estimate of probability, but where the outcome is at least possible. For example, there is an uncertain probability that an athlete will win an Olympic gold medal, but this is at least possible if they qualify. Conversely, ‘false hope’ is hope for an outcome that cannot happen, such as winning the lottery without buying a ticket.

Douglas White and colleagues found that a large proportion of the discord regarding prognosis between physicians and surrogate decision makers of critically ill patients, where the latter hold more optimistic beliefs about prognosis, can be attributed to the surrogate’s stated need to maintain hope.⁶⁸ Of the surrogate decision-makers who held a more optimistic view of patient prognosis than physicians, 47% believed that maintaining optimism would improve the patient’s outcome, while 33% believed the patient possessed unique strengths unknown to physicians, and 20% grounded their hope in religious beliefs.

Research involving families of critically ill patients demonstrates that families want information in order to understand what is happening to their family member, and on which to base hope.^{69,70} Surrogates and physicians agree that false hope is unhelpful and should be avoided. Yet, there is disagreement about how information should be provided to avoid false hope. For example, in one study, the majority of surrogate decision-makers (82%) prefer numeric estimates of the patient’s prognosis, as this limits uncertainty, which they find frustrating. Conversely, the same study found that 75% of physicians intentionally avoid providing numeric estimates of prognosis, due to worries about families’ ability to interpret probabilities and the resulting risk of creating false hope.⁷¹

At the same time, research suggests that as many as 88% of surrogate decision-makers have doubts about the ability of physicians to accurately prognosticate for critically ill patients.⁷² Surrogates cite belief in God altering the course of an illness, as well as a scepticism about predicting the future, and prior experience with inaccurate prognostication by physicians, as reasons for doubting physician prognosis.

Given the uncertainty of prognosis after severe brain injury, it is reasonable for physicians to avoid giving precise numeric estimates of prognosis. However, vague qualitative estimates are perceived by surrogate decision-makers as unhelpful, and can lead to frustration or distrust.⁷³ Research suggests that, despite their problems in coping with uncertainty, surrogate decision-makers understand that, in some cases, a precise prognosis cannot be given. If physicians are clear and forthcoming about the uncertain nature of the patient’s prognosis, surrogates tend to accept this.

Recommendation: Contextualize Results, While Acknowledging Surrogate’s Need for Hopefulness

Accordingly, when a surrogate decision-maker is provided with the results of a patient’s functional neuroimaging scan, they should be clearly informed of the lack of prognostic utility of the results. Nevertheless, it is important for physicians to acknowledge that surrogate decision-makers may have a different conception of when hope should be abandoned. Surrogate decision-makers often do not connect the intensity of their hope with the likelihood of a particular outcome, i.e., their hopes for patient recovery are ‘possibility hopes’ rather than ‘probability hopes’.⁷⁴ Thus, surrogate decision-

makers may maintain hope for an unlikely outcome, while fully appreciating the information provided and recognizing that the outcome is unlikely.

How should research results be disclosed to patients' families and medical teams, in order to minimize the potential for false hope? Simply presenting the results in as neutral a fashion as possible, without endorsing or encouraging the surrogate decision-makers' hope, is not enough. Surrogate decision-makers often look to the care team for guidance or reassurance about their decisions, and strict neutrality could be interpreted as indifference or a lack of concern for the patient.^{75,76} Conversely, it would be inappropriate for a member of the care team to attempt to convince surrogate decision-makers that their hopes are false, when they are at odds with the physician's beliefs.⁷⁷

A good relationship between physician and surrogate is one of partnership, which acknowledges the autonomy of the surrogate decision-maker to make their own decisions on behalf of the patient, while recognizing that the surrogate is in a difficult and vulnerable position. The physician should acknowledge that a hopeful orientation may be necessary for surrogates to make decisions, and moderate their disclosure of information in a way that either presses certain evidence, or maintains hopefulness, as the surrogate requires. For example, if a surrogate decision-maker remains hopeful of recovery, and is not prepared to consider the possibility of withdrawing care, it may not be helpful to insist that this be discussed. Therefore, discussing the possible outcomes of the research with surrogate decision-makers prior to scanning taking place is critical. It can inform members of the care team on how surrogate decision-makers might react to future results, to helpfully frame them, and give family members a chance to temper expectations.

A caveat here concerns the timing of decisions to withhold or withdraw treatment in acutely brain injured patients. The unpredictable time-course of patient recovery would seem to be a *prima facie* justification for delaying decisions to withhold or withdraw life-sustaining treatment as long as possible, regardless of the outcome of functional neuroimaging research. Even if physicians are concerned that a surrogate's hope for the patient's recovery is highly unlikely, the patient should be provided with the opportunity to recover. The fact that the decision to maintain care is reversible, while the decision to withhold or withdraw care is not, provides a compelling reason against withholding or withdrawing care prematurely, thus eliminating the chance of a favourable recovery.

However, the process of withdrawing treatment outside the intensive care unit (ICU) setting may be experienced quite differently by surrogate decision-makers than withdrawing care in the ICU.⁷⁸ The period of time during which a severely brain injured patient is dependent on interventions like surgery, mechanical ventilation, or tracheostomy, has been referred to as 'the window of opportunity', where withholding or withdrawing these interventions will allow the patient to die. Once the patient becomes physiologically stable and moves out of the ICU, however, it can be more difficult to allow a patient to die. For example, prior to a UK Supreme Court decision in 2018, surrogate decision-makers were required to gain permission from the courts—in a lengthy and difficult process—to withdraw artificial nutrition and hydration.⁷⁹ Even in jurisdictions where artificial nutrition and hydration can be removed from a patient in a PDOC, this decision is agonizing for surrogates.⁸⁰ Whereas patients may pass away within hours or days in the ICU, a patient in the sub-acute or chronic stages of severe brain injury may spend weeks or months in long-term hospice care prior to death. Surrogates and other family members may feel guilty or distressed at the idea of

having caused the patient to suffer unnecessarily.⁸¹ The possibility of this additional emotional burden merits consideration when disclosing research results to surrogate decision-makers, but is not sufficient grounds to fail to disclose research results. Surrogates may require emotional and institutional support, e.g., through chaplains and/or social workers, in incorporating functional neuroimaging results into their decision-making. They may also benefit from having a dedicated staff, such as a critical care nurse, who can address questions about the patient's condition when clinicians are not available, and to provide emotional and psychosocial support as surrogates make care decisions.⁸²

There may be disagreement about meaningfulness or relevance of results, and appropriateness of continued care

When surrogate decision-makers receive the results of the patient's functional neuroimaging scan, they are likely to look to the care team (i.e., physicians, nurses) for guidance on what the results mean, and how they should inform treatment decisions. However, there may not be agreement amongst the care team on the significance of the results, or on how they should affect treatment.^{83,84} For example, there may be disagreement on whether the discovery of covert consciousness should be taken as reason to continue to provide life-sustaining treatment, or remove it. Treatment recommendations from the care team are unavoidably value-laden. Numerous studies have demonstrated that physicians differ widely in the values they appeal to when making treatment decisions regarding end-of-life care, resulting in a range of treatment practices.⁸⁵⁻⁸⁸ Physician age, gender, religion, and personal, cultural, or religious views have all been found to influence their treatment recommendations.^{89,90} Individual care team members might disagree about whether providing life-sustaining treatment to patients who are unlikely to recover functional independence—even if they are covertly, or minimally aware—is in the patient's best interest. This judgement might be based on the belief that a life of complete dependence is not worth living, or that the cost of sustaining such a life is not justified by the potential benefit to the patient. Other members of the care team might judge that even a life with severe disability can be worth living, and treatment should be continued if this is consistent with the patient's prior wishes and values.

Cultural and legal factors also influence the relevance of the presence or absence of covert awareness. In countries like Ireland, where many hospitals are owned by the Catholic Church, treatment may be influenced by religious ethos.⁹¹ For example, in 2004 the Catholic Church issued a statement declaring a moral obligation to provide artificial nutrition and hydration to patients in a PDOC, as an instance of 'basic care.'⁹² While Irish law permits the refusal of treatment—including life-sustaining treatment—through an Advance Healthcare Directive, this directive may not be applicable in cases where circumstances differ from those specified in the directive.⁹³ It is likely that many Advance Healthcare Directives will not anticipate covert consciousness. Subsequently, the religious ethos of a hospital may influence the type of care patients with PDOC receive.

In the UK, the decision to provide or withdraw life-sustaining treatment to a patient who lacks decision-making capacity is governed by the Mental Capacity Act, and must be based on the best interests of the patient.⁹⁴ According to the Act, a determination of a patient's best interests must take into account "all the relevant circumstances", including the patient's past and present wishes

and feelings, values, beliefs, and other factors that they would consider relevant to their decision, were they able to decide for themselves, as interpreted by surrogate decision makers.⁹⁵

The Mental Capacity Act does not specify the weight to be given to these various factors. In practice, a judgement of best interests tends to give weight to the patient's diagnosis, prognosis, as well as a general (though not determinative) presumption in favour of preserving life. Consider two legal cases in the UK in the last decade, which have informed the interpretation of the Act. In the 2011 case [*W v M and other (Re M)*],⁹⁶ the court rejected an application to withdraw life-sustaining treatment from a woman with a PDOC, on the grounds that her condition was not so burdensome as to override the presumption in favour of preserving life. This decision was made despite the vigorous claims of M's family that withdrawal of life-sustaining treatment was consistent with M's best interests, and what she would have decided for herself. Conversely, in the 2016 case [*Briggs v Briggs*],⁹⁷ the court agreed with Mr. Briggs' family that continuing to receive life-sustaining treatment while in a PDOC with little chance of recovery was inconsistent with his wishes and values, and, thus, not in his best interests. The withdrawal of life-sustaining treatment was permitted in this case. These cases illustrate the potential divergence between the courts in their interpretation of what constitutes the best interests of a patient in a PDOC, even in highly similar circumstances. We suggest that this divergence likely reflects similarly diverging views of clinical team members —and society in general— about the importance of preserving a patient's life and whether withdrawal of care is in the patient's best interest.

Critically, disagreement amongst members of the care team can impact how the discovery of covert consciousness, or lack of evidence of consciousness, is interpreted by surrogate decision-makers. Even if physicians are committed to respecting the judgement of surrogate decision-makers, and thereby respecting the autonomy of the patient, their own values may subtly influence the treatment options they present, or even the way they present clinical information, including body language, word choice, or tone of voice.^{98,99} Surrogates may be confused or frustrated by the variability of opinion between different members of the care team, and this can lead to significant alterations to the care pathway, including on whether to withdraw life-sustaining treatment.¹⁰⁰

Even when consensus exists between members of the care team about the relevance of functional neuroimaging research results, there may be disagreement with surrogate decision-makers. Just as physician beliefs about patient prognosis —and their resulting treatment recommendations— can be influenced by a number of factors, surrogates' beliefs about patient prognosis are shaped by values and biases. Elizabeth Boyd and colleagues found that most surrogate decision-makers' beliefs about patient prognosis incorporated a variety of factors, including perceptions about the patient's 'will to live', their history of survival through illness, the surrogate's own observations of the patient's appearance, and the surrogate's own optimism and faith.¹⁰¹ In fact, less than 2% (3 of 179) of surrogates based their beliefs solely on the prognostic information conveyed by physicians, with many stating that this information was less important to their beliefs than other factors.¹⁰²

Recommendation: Clinicians must justify and communicate their values to surrogates and each other

Given this plurality of values, how should the discovery of covert consciousness shape the interpretation of a patient's best interests, as it concerns the appropriateness of continued care? We argue that the discovery of covert consciousness cannot, in and of itself, determine whether continued provision of life-sustaining treatment is in a patient's best interests. Rather, it requires that the care team and surrogate decision-makers think about the well-being of the patient more deeply, and consider how their own values and biases may influence their judgement of the patient's best interests.

First, the discovery of covert consciousness may provide an impetus for further therapy. Research has shown that preserved consciousness in severely brain injured patients may be supported by therapeutic interventions like deep-brain stimulation,¹⁰³ non-invasive neuromodulatory therapies,^{104,105} and pharmacologic interventions.^{106,107}

Second, the discovery of covert consciousness provides a fuller picture of the residual cognitive capacities of the patient, which, in turn, allows for a more informed judgment of the best interests of the patient. Covert consciousness allows for the possibility that the patient may be capable of painful or pleasant sensory experiences, for example, as well as other experiences that might contribute to or detract from their overall well-being.¹⁰⁸ They may also be capable of forming preferences or desires, which could be expressed through neuroimaging-based communication.¹⁰⁹⁻¹¹²

While research suggests that many healthy individuals would not want to be provided life-sustaining treatment if they were in a PDOC, or other severely disabled state, it is possible that, once in this state, patients might have a different perspective. For example, research has found that many patients with locked-in syndrome (complete paralysis, except for wilful eye-movement and blinking) report being happy, despite their condition.^{113,114} Moreover, healthy individuals tend to underestimate the subjective well-being of these patients.¹¹⁵ If an acutely brain-injured patient with covert awareness could adequately adapt to life with severe disability, the continued provision of life-sustaining treatment could be in their best interests. Conversely, some patients may suffer tremendously living in a severely disabled state.¹¹⁶ The presence of consciousness would not provide sufficient reason to continue providing life-sustaining treatment in these patients.

A broad range of values may be relevant to treatment decisions, and these may not be shared amongst the care team and surrogate decision-makers. As a result, there may not be a single correct decision to be made about the patient's course of treatment and care, but a range of reasonable decisions. Surrogate decision-makers should be presented with this range of options, and those communicating with them should acknowledge that there may not be a single 'correct' decision. Indeed, discussions about the best interests of the patient and available treatment options, including palliative care, should occur prior to any consent to participate in research.

Discussion amongst the care team about their reasons for a particular treatment recommendation, and how their values inform this recommendation, can help to illuminate the nature of potential disagreements. When there are value-based disagreements amongst the care team, discussion and

reflection can help to illuminate these values, and oblige those who hold them to justify them to others. Indeed, a physician may not even be aware of the ways in which their personal biases or values influence their decisions, until they are required to justify them. For example, decompressive craniectomy is often performed after severe brain injury to relieve brain swelling. Failure to perform such a procedure may allow the patient to die, but could also result in their survival with more severe brain injury and subsequent disability. Physicians with a more pessimistic view of life with severe disability may be less supportive of this treatment option, while physicians with a more optimistic view may be more likely to recommend this to surrogate decision-makers. Similarly, recommendations to pursue aggressive treatment like tracheostomy, or provide antibiotics if patients develop pneumonia, may be presented to surrogates as obligatory by clinicians with a presumption towards preserving life, even where surrogate decision-makers do not believe this would be in the best interests of the patient.¹¹⁷ Acknowledging one's reasons for a particular treatment recommendation allows others to determine for themselves whether they consider these reasons legitimate.

In some cases, physicians may have an obvious bias which influences their beliefs about the patient's prognosis, or the appropriateness of continued treatment, such as a religious belief in the sanctity of life.^{118,119} In other cases, however, it may be difficult to separate a physician's personal values and biases from their expert medical opinion. For example, a physician may be pessimistic about the prognosis of a particular patient because of their past experience with similar patients, and more likely to downplay the significance of covert consciousness. It is unrealistic to expect clinicians to fully account for every possible value or bias that might influence their recommendations to surrogates, or other members of the care team. Nevertheless, we argue that clinicians have an obligation to surrogate decision-makers to justify their beliefs about appropriate treatment. While this may not ultimately lead to agreement, it may facilitate the curation of a range of options to present to the surrogate decision-maker, and allow treatment decisions to be considered in light of a range of possible outcomes.

The role of the care team is to help surrogate decision-makers to develop the values that they will draw on to decide on behalf of the patient, by engaging with them in an open and honest discussion. This will help surrogate decision-makers to develop their own conception of what is in the best interests of the patient, and support their decision-making, even if surrogate decision-makers and the care team have a different conception of a 'life worth living'. In some cases, there will be disagreement between the care team and the surrogate decision-maker, which may require further mediation or appeal to a neutral authority, such as an arbitrator or court. The aim of the care team should not be to impose values on the surrogate decision-maker, but to support surrogate decision-making that is responsive to empirical evidence, and takes seriously the values and prior wishes of the patient.

Conclusion

Prognosis after severe brain injury is highly uncertain, and reliable prognostic markers are urgently needed to aid treatment decisions. Functional neuroimaging has proven to be a reliable means of detecting covert awareness in patients with chronic disorders of consciousness, and could prove

highly valuable in the acute care context. However, further study is required to determine the relationship between detection of covert consciousness in acutely brain injured patients, and subsequent recovery. This creates challenges for surrogate decision-makers and the care team in interpreting the results of functional neuroimaging research. We argue that clear and accessible communication, which acknowledges prognostic uncertainty and embraces the potential for disagreement about the values that inform treatment decisions, are critical to ensuring that surrogate decision-makers understand functional neuroimaging research results and make treatment decisions in the best interests of the patient.

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