



## Prolonged disorders of consciousness: Damaged brains, damaged minds?

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Prolonged disorders of consciousness (PDOC) are some of the most dramatic sequelae of acquired brain injury. After surviving severe brain damage, in many instances with the help of aggressive neurosurgical interventions, PDOC patients recover their ability to breathe independently and open their eyes spontaneously, but show little or no signs of conscious awareness. Two clinical entities are recognised: the unresponsive wakefulness syndrome (UWS), previously known as the vegetative state (Jennett and Plum, 1972; Laureys et al., 2010), and the minimally conscious state (MCS) (Giacino et al., 2002). While science is steadily unravelling the neurophysiological substrates of these conditions, in daily practice PDOC still confront us with existential themes. These may come in the guise of prognostic uncertainty, or conflicts between professionals and patients' family members. In this paper, we provide some tentative reflections on our struggle with the concept of mind in a damaged brain.

First of all, mind is produced by brain. We may not exactly understand how, but our mental life is anchored in cerebral tissue and our thoughts, emotions and sensations are brought about by events in neurons.

The regrettable sequel is that a damaged brain produces a damaged mind. Each cerebral injury, whether acute or progressive, internal or

external in nature, causes its own particular mind damage.

Some of the worst possible instances of this brain-mind connection are presented by prolonged disorders of consciousness (PDOC). Despite spontaneous eye opening and independent breathing, PDOC patients show but minimal signs of awareness of the self or the environment, or none at all (Jennett and Plum, 1972; Giacino et al., 2002). Afflicted by injuries that would have invariably been lethal up until the 1970's, their brains were long considered to be so severely damaged that even the minutest residue of mind had to have been snuffed out. For a while even, the possibility of harvesting these patients' organs was a serious matter of debate (Hoffenberg et al., 1997). While our scientific understanding of PDOC has greatly increased, treatment options remain scarce. Even the most optimistic clinicians have no time for a Sleeping Beauty scenario of recovery in which a patient opens her eyes after three years of coma, stretches her limbs and hops out of bed with the happy announcement: 'I'm back!' (Wijdicks and Wijdicks, 2006; Giacino et al., 2018).

As soon as the patient's vital functions have been secured, those at the bedside are left with a possibly even more critical assignment: to determine whether the person they were trying to save, is still there.

Relatives' reactions to acute brain injury tend to run a recognizable

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course (Minderhoud, 2003). In the first hours after the incident, death appears imminent. If the patient survives this phase, hope is gradually awakened. The patient becomes the subject of a loving scrutiny with which relatives look for the slightest sign of contact, echoing the way first-time parents study their newborn baby's face for a hint of a smile. And indeed, the patient opens her eyes, flinches to loud noises, coughs, clasps a hand when it grasps hers. She seems to re-emerge.

'It's only a reflex,' says the doctor. 'No', says the husband, 'it's my wife Mary and she is struggling her way back towards me.'

A relative's take on the mental state of their loved one may differ radically from the professional qualification assigned to it, which can be deeply hurtful to the family and paralyse medical decision-making (Span-Sluyter et al., 2018). Uncertainty about the presence of a person, who is at the same time clearly alive, utterly vulnerable and unable to communicate, can be a deeply disturbing experience, probably only distantly comparable to what we encounter when faced with patients with advanced dementia.

'Is she suffering?' 'Can she hear me?' 'Will she come back?' 'What can we do to help her recover, and how long should we try?' 'What would she have wanted?' These questions evolve around a central issue: is anybody there?

In order to arrive at an assessment of what goes on inside hyporesponsive patients Wittgenstein's dictum may be useful: 'An 'inner process' stands in need of outward criteria' (Wittgenstein, 1953). According to this philosopher, we should be parsimonious when it comes to the ascription of mental life to objects or beings in our environment. A chair should not be presumed to be contemplating Brexit or be apprehensive about the smell of burning wood unless it signals to us in some manner that it is occupied by such worries.

For many years PDOC patients were thought to show no outward criteria at all, their reactions regarded as just reflexes not indicative of mental activity. From the definition of MCS (Giacino et al., 2002) in 2002 onwards, it became internationally accepted that in fact a significant proportion of PDOC patients incapable of functional communication or functional object use, exhibit at least some signs of consciousness. These signs correlate to better prognosis (Giacino et al., 2018) and different brain reaction patterns to, for example, painful stimuli (Boly et al., 2005). Next, new techniques such as fMRI showed that a significant proportion of clinically unresponsive patients were capable of functional communication by wilfully modulating their brain activity (Owen et al., 2007; Kondziella et al., 2020; Edlow et al., 2017; Monti et al., 2010).

The latter – even to healthy subjects – very complex task should be considered a clear outward criterion indicative of mind, regardless of the fact that, in 14 years, no actual conversations with patients in this state of 'cognitive motor dissociation' have been published. One would for instance be very interested to hear the patients' views on their own situation and whether they consent to the life-prolonging treatment they are subjected to. With the answers to such questions, the entire problem could well take on a new guise when we wonder to what extent or on what issues we dare to take them seriously.

But what about the finding that some PDOC patients display complexly integrated neural activity in response to their own name (Schiff et al., 1999; Di et al., 2007)? Should we consider this activity proof of mind? And if so, would this indicate Mary's presence, or are we just looking at scattered fragments of mental activity, islands of cognition one might say, which is all the damaged brain can muster? What must her inner landscape look like, in that case?

And what do we conclude when there is no wilful modulation, no higher-order brain activity, no behavioural sign of awareness? Would this mean that the patient is 'truly unconscious', that her mind is absent? Does such a condition even exist, considering absence of proof is not the same as proof of absence?

At this point we should mention that to many religious people the very inclination to wonder about the nature of PDOC patients (questioning whether they are still there, and to what extent, and how we should deal with them), is the result of a mistaken conception of what a

human being is. Regardless of the apparent unresponsiveness and the bleak pictures on scans, the fact that these patients are alive means that their lives must be sustained. Interestingly, a 1999 study showed that especially highly religious people may consider a PDOC patient to be devoid of a soul and attribute to them less mind than to a dead person, living on in the afterlife (Gray et al., 2011).

We do not intend to refute or defend these views. They should be acknowledged, as well as the fact that even considering the sanctity of life, we may find ourselves looking at inscrutable fellow humans of whom it is unclear to what extent they are still in our midst.

In a 2018 publication (Playford and Playford, 2018) Aristotle was called to the rescue. The premise from which the authors argue is that a living being becomes a person when it is capable of rational thought.

To have rationality under an Aristotelian schema is to have the intrinsic potential to engage in rational thought. This potential does not then need to be exercised in order for the subject to have rationality. It simply needs to be a potential. (...) a subject who has had his or her ability to engage in rational thought destroyed by a brain injury has not lost their rationality. Instead, their rationality (a potential to engage in rational thought) is still there. It is simply being blocked by the brain injury. They cannot manifest their ability to think because of their brain injury, but it is still there as an intrinsic, albeit blocked, potential.

The authors add to this argument that: *This may at first seem strange*. It does, and after giving it some thought the strangeness only increases. We are, after all, searching for an assessment of the mental content of people hitherto considered unresponsive. Jostling with no doubt impeccable concepts does not exactly shine a light on the situation. Imagine a doctor saying to a desperate wife who stands by her husband who has been unresponsive for 3 years: 'But there is always the consoling thought that his intrinsic potential to engage in rational thought remains unhampered.'

Moving on a few centuries, when we try to assess the notion of personhood, John Locke is often quoted on his idea of what a person is (Locke, 1690):

*... we must consider what person stands for; which I think, is a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking, and, as it seems to me, essential to it. ... When we see, hear, smell, taste, feel, meditate or will anything, we know that we do so. Thus it is always as to our present sensations and perceptions; and by this everyone is to himself that which he calls self.*

We might think that the responses in the scanner show that the patients do experience themselves as *the same thinking thing, in different times and places* because they are capable, mentally, of returning to the house where they once lived. But from this finding it does not automatically follow that they meditate, reason and reflect. This modulated response is like the smile on the sphinx: one doesn't know what to think of it.

David Hume denied the very idea of personhood (Hume, 1739):

There are some philosophers who imagine we are every moment intimately conscious of what we call our self; that we feel its existence and its continuance in existence; and are certain, beyond the evidence of a demonstration, both of its perfect identity and simplicity ... For my part, when I enter most intimately into what I call myself, I always stumble on some particular perception or other, of heat or cold, light or shade, love or hatred, pain or pleasure. I never can catch myself at any time without a perception, and never can observe any thing but the perception.

and a bit further on he states that people:

*... are nothing but a bundle or collection of different perceptions which succeed each other with an inconceivable rapidity, and are in a perpetual flux and movement.*

Applying this to PDOC patients doesn't get us very far. As Hume never allows for any personhood or 'I' to be in existence anywhere, he would naturally not expect to chance on it in unresponsive patients. We may add that the very existence of the Human bundle is questionable in our patient group. Are the fMRI-activities we noticed part of a bundle or are

these just random, singular strands?

A more recent effort stems from Galen Strawson, who mentions seven elements of the sense of self (Strawson, 1996).

- it is a thing
- it is mental
- it is the subject of experience
- it is single
- it is distinct
- it is an agent, it does things
- it has a certain character or personality

Strawson enters into a subtle analysis of these aspects, and the more subtle he gets, the more pressing the question becomes how a web of such intricate ramifications can arise out of our brain. As stated before: although we don't know how this happens, we do know that it happens. But at this point we may well ask: what are the chances that something like 'the sense of self' is brought forth by a severely damaged brain?

We could look at other people who sustained considerable brain injury but didn't lose consciousness. Correlating the nature of their mental functioning with their post-traumatic brain anatomy might allow an extrapolation to the post-traumatic mental functioning of 'our' group of patients.

But we do not expect to reach so sophisticated a brain map in the foreseeable future. Each individual brain has its own map, especially when it comes to the finer grades of perceiving, thinking, feeling and moving. 'The same' injury would mean for person A that she can no longer play the piano while for B it means he cannot go out fishing anymore. We put 'the same' between inverted comma's, because the termination of a capacity like piano playing or fishing may be caused by a whole host of different anatomical lesions. What anatomical lesion would remove 'personhood' or 'the feeling of a persistent "I"' from a human brain?

In conclusion, we can never be sure that a live but damaged brain is, or isn't, producing a mind. Neurophysiological techniques allow us, with more sensitivity than ever, to detect outward criteria possibly indicative of at least part of the patient's complex and unique self. But as long as there are no unambiguous signs allowing that self to be heard or seen, those criteria may as well point only at fragments of what made up the patient's personhood before the injury.

As much as we would like it to, philosophy does not resolve the fundamental and emotionally charged dilemmas we face when caring for PDOC patients. We already surmised, standing at the bedside of a PDOC patient, that the person is not wholly present. Philosophy only deepens our embarrassment around the mental status of these patients.

Caring for people who may not really be there anymore, who can only undergo things, and are unable to act or speak up for themselves, places a tremendous responsibility on the shoulders of those professionally and personally involved.

When trying to determine what the right treatment is for an individual patient, we must gather all the medical facts we can, according to the latest neuroscientific insights, and use our own minds and hearts to determine what he or she would want us to do.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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