

# The Song of the Unconscious Brain: Ethical Aspects in Disorders of Consciousness

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In 2012, a woman was admitted to the IRCCS Centro Neurolesi Bonino Pulejo, Italy, with a diagnosis of UWS (Unresponsive Wakefulness Syndrome), wherein patients remain awake but unresponsive, based on behavioural examinations including auditory, verbal, and motor tests(1). However, two years later, she underwent an experimental protocol that assessed brain connectivity. Remarkably, this showed extensive processing within the brain's pain matrix, demonstrating features of Minimally Conscious Syndrome (MCS), wherein patients show some signs of awareness. Over the next 20 months, she regained full consciousness. Her unusual recovery from UWS led doctors to conclude a misdiagnosis in her original state. They attributed her improvement to their intervention that relied on markers found only in MCS patients.

Evidence from functional imaging studies has become crucial in the diagnosis and prognosis of patients suffering from Disorders of Consciousness (DoC)(2). It has also highlighted the need to supplement clinical tests with neuroimaging to improve the accuracy of diagnosis. States of wakefulness (arousal) and awareness (amount of first-person experience) are used to distinguish between DoC such as MCS, UWS, and coma (complete lack of awareness and arousal)(2).

However, DoC by their very nature possess bleeding boundaries and raise several ethical questions, even with the introduction of advanced neuroimaging techniques in their diagnoses. How does such a patient consent to experimental procedures, or their removal from life-support, when we currently do not possess definitive indicators of pain and perception? How do subjective experiences of doctors and caregivers facilitate changes in treatment? Most importantly, how does the spectrum of consciousness manifest between visible behaviour and 'invisible' brain connectivity?

Consider the cases of two patients with Traumatic Brain Injury (TBI) at the Massachusetts General Hospital, studied by Dr. Brian Edlow and Dr. Joseph Fins(3). 'Covert consciousness' refers to the presence of activity in the brain in response to a task, in patients behaviourally diagnosed with DoC(3)(4). For example, a motor-imagery task that asks the patient to imagine squeezing the left hand can elicit activation in specific regions, despite the patient being behaviourally unconscious. Patient I (51y) was behaviourally diagnosed as UWS, but fMRI revealed activation in regions when motor imagery was presented as stimuli, indicating covert consciousness. However, before this analysis was completed, the patient was withdrawn from life support, and he died the next day. Patient II (19y) displayed no signs of covert

consciousness through fMRI but recovered fully after the family decided to sustain her life-support(3).

These findings question many aspects, beginning from the responsible utilization of neurotechnology in the diagnosis of DoC, the presence of false-positive and false-negative results, to effective communication between doctors and caregivers. About 70% of deaths from TBI result due to withdrawal from life-support, an action governed by decisions made by family members and influenced by doctors(5). At this nexus, a doctor's personal beliefs and manner of communication strongly affect care decisions, and decisions to withdraw support. Detecting covert consciousness in a patient also has near-reaching implications. Such patients can perceive pain, discomfort, and auditory stimuli, thereby questioning how caregivers and doctors must conduct themselves around them(4).

Unsurprisingly, opinions on patients' perceptions (particularly that of pain) are influenced by religious beliefs(6). Doctors with strong religious convictions are more likely to refuse to opt for treatment withdrawal, in ICU patients. In a survey conducted by a group at the University of Liège, religion was the highest predictor of caregivers' opinions on pain in patients with UWS(6). These beliefs affect communication between doctors and caregivers, and the manner of care given. In a scenario where personal autonomy and visual indicators are lacking, how does one step around the minefield of possibilities?

Family members interpreting a patient's state on a day-to-day basis, face many concerns in terms of whether the patient is aware of stimuli, or whether they merely process them. As human beings, we respond based on feedback. A caregiver may assume that the person is not in a mental state to experience pleasure or pain, and alter their behavior around them, possibly becoming less interactive and more nihilistic. But in cases where a patient can experience interactions, positive responses can enhance a patient's well-being (2). For instance, familiarity with stimuli (like a voice or touch) can evoke stronger responses than those elicited by unfamiliar sources(7). This calls into question how relevant personal relationships can be to the quality of life of a person diagnosed with DoC, an aspect that one can only navigate in the dark.

When Dylan was hit by a car in 2012, his family was warned that he could require lifetime assistance if he ever woke up(8). But slowly, he began showing signs of improvement, and a year later, returned to school full-time. Doctors predict several factors in his near-impossible recovery, but the one that stands out is plasticity: the brain's ability to make new connections and adapt. This is not only crucial in injury but is also influenced by emotional support. Dylan's mother writes about how his friends stayed by to support him in the early weeks of his recovery, with visitors at the hospital actively interacting with him. Stimulation from social presence could likely have accelerated the process, and Dylan's age could also have improved his chances.

Developing more sensitive tools in neurotechnology is a start to advancing effective neuroimaging indicators. There is an urgent need to address gaps in communication between doctors and caregiver networks, and even then, it is impossible to wholly eliminate clinician bias. The feasibility of maintaining healthy interactions around such patients on a large scale is also an important aspect to contend with. Ultimately, we must ask ourselves, if the brain is indeed capable of singing when we think it's asleep, how much can we hear from outside its theatre,

and how much of what we hear, can we communicate back into a person's life through our actions, as we take the next step towards their future.

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