

## **Does consciousness fluctuate in complete locked-in syndrome? A neuroethical analysis through an empirical and conceptual approach**

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease that results in the loss of motor neurons and the ability to move, talk, swallow, and breathe autonomously. Some of these patients eventually convert to complete locked-in syndrome (CLIS), characterized by loss of all motor body functions, including eye movements<sup>1,2</sup>. In this state, communication through eye movements and/or brain-computer interface (BCI) is no longer reliable. In fact, it appears that vigilance and alertness may fluctuate and worsen in the long run<sup>3–5</sup>, suggesting that people with CLIS-ALS may be subject to fluctuations or ‘windows’<sup>6</sup> of consciousness. Thus, the search for markers of consciousness in CLIS is rather urgent, and the dissemination of innovative BCIs a moral imperative. This paper proposes a neuroethical analysis of the issue both empirically and conceptually.

On the empirical level, I will briefly present the results of a study currently under review, where we found significant fluctuations in brain dynamics in CLIS-ALS subjects, locating them in degrees of proximity to the brain dynamic values of altered states of consciousness (ketamine, sevoflurane, and sleep stages)<sup>7</sup>. Deciphering these fluctuations in brain dynamics could have several implications (e.g., consciousness assessment and communication through BCI), but it also raises epistemological and ethical issues.

On the conceptual level, I will propose:

- Three epistemological issues (reverse inference, dissociation between dimensions of consciousness, inverse error) that put a brake on the direct inference between neuronal dynamics and states of consciousness.
- Three ethical considerations (transfer of ethical imperatives for neurotechnological assessment of consciousness<sup>8</sup>, epistemic and ethical prudence, advance care planning<sup>9,10</sup>) that could help interpret and manage difficult clinical situations with patients with CLIS-ALS.

There is still much to do for patients with ALS locked inside their bodies. These empirical research and conceptual analysis are intended to move a step toward new opportunities for these people.

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