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Marie-Aurélie Bruno, Steven Laureys, Athena Demertzi

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Patients in coma, vegetative state/unresponsive wakefulness syndrome, and in minimally conscious states pose medical, scientific, and ethical challenges. As patients with disorders of consciousness are by definition unable to communicate, the assessment of pain, quality of life, and end-of-life preferences in these conditions can only be approached by adopting a third-person perspective. Surveys of healthcare workers' attitudes towards pain and end of life in disorders of consciousness shed light on the background of clinical reality, where no standard medical-legal framework is widely accepted. On the other hand, patients with locked-in syndrome, who are severely paralyzed but fully conscious, can inform about subjective quality of life in serious disability and help us to understand better the underlying factors influencing happiness in disease. In the medico-legal arena, such ethical issues may be resolved by previously drafted advance directives and, when absent, by surrogate representation. Lately, functional medical imaging and electrophysiology provide alternative means to communicate with these challenging patients and will potentially mediate to extract responses of medical-ethical content. Eventually, the clinical translation of these advanced technologies in the medical routine is of paramount importance for the promotion of medical management of these challenging patients.

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