Federico Zilio

Tough Decisions in Unclear Situations. Dealing with Epistemic and Ethical Uncertainty in Disorders of Consciousness

1. *The limbo of disorders of consciousness*

Disorders of consciousness (DoCs) such as coma, vegetative state/unresponsive wakefulness syndrome, and minimally conscious state are characterized by the impairment or even complete loss of self-awareness and awareness of the environment. The entire spectrum of disorders of consciousness can be represented as a "grey zone"[1] or a "limbo" characterized by a qualitative continuum (different phenomenal states and dissociations between wakefulness and consciousness) and a quantitative continuum (different state transitions and fluctuations from one degree of consciousness to another). The best known DoC to laypeople is probably coma, represented by the absence of both dimensions (closed eyes, absence of sleep-wake cycle, response to painful stimuli and/or light, and absence of voluntary actions). After a period of generally ten to thirty days, patients who survive the coma can go through different stages of disorder of consciousness. The vegetative state (VS), recently referred to also as unresponsive wakefulness syndrome (UWS), denotes a state of wakefulness (spontaneous opening of the eyes and recovery of the sleep-wake cycle) in the absence of symptoms of awareness (the patient may produce some non-intentional movements and reflexes). The minimally conscious state involves the recovery of some degree of awareness, represented by signs of intention-

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[1] A. Owen, *Into the Gray Zone: A Neuroscientist Explores the Border between Life and Death*, Simon&Schuster, New York 2017.

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al behaviour, execution of simple commands, and non-complex gestural or verbal responses (MCS, MCS+, MCS-, depending on the level of recovery). Finally, patients who recover functional communication and/or functional use of objects are defined as emerging from MCS (EMCS), although in some individuals who remain in a confusional state (CS) there may persist impairment of attention, memory, orientation, perception, etc.

2. *Epistemic and ethical uncertainty*

In recent years, bioengineers and neuroscientists have developed several tools to investigate these pathological conditions; in particular, the recent application of machine learning methods, classification technology, and brain-computer interfaces as complementary approaches to the diagnosis of states of consciousness is indicative of new opportunities and challenges[2]. However, these undefined states of consciousness are raising an increasing number of ethical issues. Although neurotechnologies have certainly improved the differentiation of DoC diagnoses, at the same time, they reveal the complexity of such situations, especially regarding clinical decision-making. In this regard, uncertainty about the concrete state of consciousness of unresponsive patients results in a lack of sufficient information to identify the patient's best interest and make appropriate clinical decisions. Moreover, even in cases where communication can be established with people with disorders of consciousness through simple human-to-human interaction (e.g., blinking) or human-to-machine interaction (e.g., brain-computer interface, BCI), it is not clear whether and to what degree a response (perhaps through a BCI) given by a DoC patient with a degraded or fluctuating level of consciousness can be taken into account for making high-stake decisions.

Taken together, these issues highlight a state of "scientific uncertainty" (or, more generally, epistemic uncertainty), defined as «uncertainty about the diagnosis, prognosis, causal explanation of disease, or treatment rec-

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[2] D. Sinitsyn et al., *Machine Learning in the Diagnosis of Disorders of Consciousness: Opportunities and Challenges*, in B. Velichkovsky, P.M. Balaban, V.L. Ushakov (eds.), «Advances in Cognitive Research, Artificial Intelligence and Neuroinformatics. Intercognsci 2020. Advances in Intelligent Systems and Computing, vol 1358», Springer, Cham 2021, pp. 729-735. D. Larrivee, *Improving Objective Assessment in Disorders of Consciousness: An Option for Classification Technology?*, in «Clinical Sciences Research and Reports», 1 (2017), pp. 1-4.

ommendations»[3], which consequently produces a state of ethical uncertainty[4]. I will now present some of the main issues that characterise the intrinsic uncertainty in neuroscience of disorders of consciousness.

2.1. The problem of misdiagnosis

The assessment of consciousness is a challenging topic that involves ethical and legal implications, as misdiagnosis can have devastating consequences for the lives of people with DoCs. In fact, misdiagnosis can lead to attitudes of underestimation or overestimation of the patient's level of consciousness arise; while overestimation of consciousness (false positives) can lead to ethical problems related to resource allocation and false hope, underestimation (false negatives) can lead to nefarious ethical consequences, such as suspension of treatments for patients whose lives no longer seem worth living without the consent of the conscious patient him/herself.

The usual assessments based on the clinical consensus of the medical team are not always sufficient to discern different levels of consciousness; indeed, there is still a high rate of diagnostic error based on clinical consensus (~40%, i.e., several patients are considered to be in a vegetative state when instead they preserve some degree of consciousness); consequently, a purely behavioural approach seems insufficient to characterize the conscious state of DoC patients[5]. In this regard, to better interpret the wide spectrum of consciousness in patients with DoCs, recent guidelines suggest advanced neurological investigations (use of mirrors, familiar voices, naturalistic paradigms, etc.) in addition to the standard behavioural scales, supplemented also by repeated neuroimaging examination.

Some neurodiagnostic tools are, for example, positron emission tomography (PET), functional magnetic resonance imaging (fMRI), and electroencephalography (EEG); the latter can also be accompanied by a brain-computer interface (BCI) system to attempt communication with patients. These neurotechnologies are progressively entering neurological diagnostic routines; however, they are not yet homogeneously diffused and / or they are used only in exceptional cases. Neurological data are not easy

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[3] L.S.M Johnson, C. Lazaridis, *The Sources of Uncertainty in Disorders of Consciousness*, in «AJOB Neuroscience», 9 (2018), n. 2, pp. 76-82, p. 79.

[4] L.S.M Johnson, *The Ethics of Uncertainty: Entangled Ethical and Epistemic Risks in Disorders of Consciousness*, Oxford University Press, New York 2022.

[5] M.J. Young et al., *The Neuroethics of Disorders of Consciousness: A Brief History of Evolving Ideas*, in «Brain», 144 (2021), n. 11, pp. 3291-3310.

to analyse and interpret (e.g., a single case of neural-cognitive correlation does not necessarily imply consciousness), and an accurate diagnosis requires several tests applied at different times to avoid false positives (i.e., the subject seems conscious when s/he is not actually conscious) or false negatives (i.e., the subject seems unconscious when s/he actually is)[6]. Furthermore, even the most sophisticated devices should not be considered infallible; current neurodiagnostic tools appear to be accompanied by an intrinsic risk of ambiguity and uncertainty with respect to diagnosis and prognosis[7]. This is probably due to the incomplete development of the technology, which is still in the research and development phase; nevertheless, the neurodiagnostic tool is essentially based on the formulation of indirect and inductive inferences from the neuronal to the conscious activity (when mental state x is engaged, then the neural state y is active; neural state y is active; therefore the mental state x is engaged).

This "reverse inference" is widely used as a good probabilistic tool in cognitive sciences due to its predictive power[8], however it implies a logical fallacy, that is, the so-called "affirming the consequent" (if p then q, q is true; therefore, p is true); therefore, it must be carefully considered, as the presence of a neuronal-cognitive correlation does not necessarily imply a neuronal-phenomenal inference[9]. For this reason, the reverse inference process implied in neurological evaluation is often supported by other tests and should be considered as an ancillary and complementary tool rather than a substitutive one for any clinical and bioethical decision[10].

2.2. The reception of neurodiagnostic information among relatives and caregivers

So far, we have considered some of the problems related to the assessment of disorders of consciousness, not only on the technical and diagnos-

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[6] D. Cruse et al., *Detecting Awareness in the Vegetative State: Electroencephalographic Evidence for Attempted Movements to Command*, in «PLoS ONE», 7 (2021), n. 11.

[7] L.S.M Johnson, C. Lazaridis, *art. cit.*

[8] M. Nathan, G. Del Pinal, *The Future of Cognitive Neuroscience? Reverse Inference in Focus*, in «Philosophy Compass», 12 (2017), n. 7.

[9] G. Northoff, *Does Task-Evoked Activity Entail Consciousness in Vegetative State? 'Neuronal-Phenomenal Inference' versus 'Neuronal-Phenomenal Dissociation'*, in M. Farisco, K. Evers (eds.), *Neurotechnology and Direct Brain Communication*, Routledge, New York 2016, pp. 104-116.

[10] A. Peterson et al., *Risk, Diagnostic Error, and the Clinical Science of Consciousness*, in «NeuroImage: Clinical», 7 (2015), pp. 588-597.

tic level, but also on the epistemic and ethical level. Moving now outside the clinical sphere, an additional problem emerges when information from neurological analysis is communicated to laypeople, such as family members and caregivers. Physician-patient-family communication is intrinsically characterized by an epistemic asymmetry, that is, a state of disparity in skills and knowledge; indeed, on the one hand, the physician has much more technical expertise than both the patient and family members, on the other hand, sometimes patients possess privileged subjective knowledge about their illness experience to which the physician cannot access. In this sense, good medical communication must try to prevent this asymmetry from increasing – although it is impossible to remove it – and from producing instances of epistemic injustice, for example, when subjective patient reports or family testimony are underestimated or not considered in formulating diagnosis and prognosis.

In the context of disorders of consciousness, this situation becomes even more complex, as the asymmetry of expertise between clinicians and laypeople increases for two reasons. First, the uncertainty and ambiguity of some neurodiagnostic findings do not help effective communication; second, if the patient seems completely unresponsive (e.g., UWS), no other information about the state of consciousness can be relied upon, making communication with family members even more difficult. Some recent studies have pioneeringly investigated the reception of neurodiagnostic data among family members and caregivers of patients with DoCs. This kind of study can be extremely important to understand the role of neurodiagnostic tools in caregiver attitudes (but also in healthcare professionals) and how they influence end-of-life decisions regarding patients with DoCs.

Schembs and colleagues recently investigated by semi-structured interviews the interpretations, attitudes, and opinions of a group of patients' next of kin (seven) regarding the EEG examination[11]. They found that caregivers tend to adapt neurodiagnostic findings to their belief system, as the preservation of hope is essential to maintaining their ability to care. Therefore, an unfavorable evaluation implied questioning the validity of this type of results, while a positive evaluation allowed us to confirm optimism towards the recovery of their loved one. In particular, they specifically report on some parts of the interviews. Peterson and colleagues also interviewed

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[11] L. Schembs et al., *How Does Functional Neurodiagnostics Inform Surrogate Decision-Making for Patients with Disorders of Consciousness? A Qualitative Interview Study with Patients' Next of Kin*, in «Neuroethics», 14 (2021), n. 3, pp. 327-346.

some caregivers (twenty) of patients with DoCs regarding their reactions to and understanding of the EEG evaluation[12]. The results show an overall understanding of the meaning of these data, but with various reactions (acceptance, rejection, emotional exhaustion, disagreement, etc.). At the same time, the authors highlight the risk of misinterpreting the data and the degree of certainty along with strong expectations about diagnosis or prognostic value, either by overestimation (false positive) or underestimation (false negative).

Overall, these and other studies[13] have shown instances of cognitive dissonance and lack of realization in caregivers and next of kin with respect to patient clinical situations. Less attention (it was not the main point of the studies) has been devoted to investiganting how neurodiagnostic information was provided by healthcare professionals and what epistemic status these data have. For example, it is not explained how neurological information has been provided to family members or whether doctors have followed a specific communication protocol that is identical for all families (adapting the content according to the case). Although it may be true that the next of kin of patients with DoCs does not «share the assumption that an 'objective assessment' of consciousness is possible or valid»[14], but it is also true that the neurodiagnostic assessment of consciousness currently has several problems that prevent it from being defined as "objective". Therefore, it would be a mistake to interpret this dissonance between neurodiagnostic data and the reception of relatives only as a problem of one side of the communication (family and caregivers). In this regard, it would be important to analyze not only the ability of laypeople to understand neuroinformation, but also if and how the diagnostic and prognostic uncertainty of disorders of consciousness is communicated.

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[12] A. Peterson et al., *Caregiver Reactions to Neuroimaging Evidence of Covert Consciousness in Patients with Severe Brain Injury: A Qualitative Interview Study*, in «BMC Medical Ethics», 22 (2021), n. 105.

[13] L.M. Andersen, H.B. Boelsbjerg, M.T. Høybye, *Disorders of Consciousness: An Embedded Ethnographic Approach to Uncovering the Specific Influence of Functional Neurodiagnostics of Consciousness in Surrogate Decision Making*, in «Neuroethics», 14 (2021), n. 3, pp. 351-356. A. Peterson, *How Will Families React to Evidence of Covert Consciousness in Brain-Injured Patients?*, in «Neuroethics», 14 (2021), n. 3, pp. 347-350.

[14] L. Schembs et al., *art. cit.*, p. 339.

2.3. The performativity of clinical language and the concept of vegetative state

The methodological and epistemic uncertainty of the neurodiagnostic data is not the only factor that makes it difficult to understand (before) and communicate (after) the clinical situation and make decisions. Even the use of a certain kind of clinical language can have unintended consequences in medical communication, as well as in the consideration of disorders of consciousness. To address this point, it is necessary to consider the difference between constative utterances and performative utterances[15]. A constative utterance is truth evaluable, for example, a statement that intends to describe the state of some portion of the world (e.g., "this chair is blue"); instead, a performative utterance does not describe or report anything, nor are they true or false; rather, it performs a certain kind of action (e.g., "I promise I will pay for this chair"). Medical language is highly performative as it can alter the reality of the patient[16]. Even the formulation of the diagnosis, that is, the act of identifying a disease or syndrome from signs and symptoms, is not a purely descriptive act, as in specific cases it can change the socio-ontological status of the patient, influencing possible ethical choices towards the patient. Perhaps the clearest example of this performative effect is the diagnosis of death, in which the state of death is defined through a series of clinical criteria (e.g., flat encephalogram), but it is the act of declaration by the physician that makes it real and establishes a concrete spatio-temporal dimension. Or, as argued by Havi Carel, diagnoses of certain degenerative diseases or cancers involve a global transformation of the subject's existence (e.g., loss of opportunities, possibilities, openness to the future, agency and subjectivity, wholeness, certainty and control)[17], even if the disease was already present before the act of communicating the diagnosis.

In the case of disorder of consciousness, the power of performative medical language is particularly relevant. The concept of a vegetative state is a crucial example of this problem, as it highlights a strong indirect performative significance. Initially, Bryan Jennett and Fred Plum proposed the diagnosis of "persistent vegetative state"[18] to indicate a persistent state of

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[15] J.L. Austin, *How to Do Things with Words*. Clarendon Press, Oxford 1962.

[16] E. Lalumera, *Etica della comunicazione sanitaria*, Il Mulino, Bologna 2022.

[17] H. Carel, *Phenomenology of Illness*, Oxford University Press, Oxford 2016.

[18] B. Jennett, F. Plum, *Persistent Vegetative State after Brain Damage. A Syndrome in Search of a Name*, in «Lancet», 1 (1972), n. 7753, pp. 734-737.

wakeful unresponsiveness where the vegetative nervous system (the sleep-wake cycle and autonomic functions) remains intact (something similar to the Aristotelian idea of a vegetative soul[19]). In 1994, the Multi-Society Task Force on PVS declared that a vegetative state can be judged "permanent" (or irreversible) twelve months after a traumatic injury and three months after in patients with non-traumatic aetiology[20].

Now, the truth or falsity of this description of permanence (currently disproved by the number of recoveries even after twelve months) is not the real problem, but the performative consequence of that diagnosis is. First, even though it is not in the original idea of the term, "vegetative state" has acquired a pejorative connotation over time with dehumanizing connotations (referring to a patient as if he or she were a "vegetable")[21]. In 2010, a more neutral terminology, "unresponsive wakefulness syndrome", was proposed[22] as it better recognizes diagnostic uncertanity[23]. Second, the terms "permanent" and "irreversible", unlike the original and more prudent term "persistent", are not just descriptive, as they establish the absence of any recovery capacity. For this reason, recent guidelines suggest that the term "permanent" should be replaced by the term "chronic" to indicate the stability of the condition[24]. In other words, in order to achieve adequate communication and to prevent clinical language

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[19] Z.M. Adams, J.J. Fins, *The Historical Origins of the Vegetative State: Received Wisdom and the Utility of the Text*, in «Journal of the History of the Neurosciences», 26 (2017), n. 2, pp. 140-153.

[20] Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State*, in «New England Journal of Medicine», 330 (1994), n. 22, pp. 1572-1579.

[21] C. Lazaridis, *Withdrawal of Life-Sustaining Treatments in Perceived Devastating Brain Injury: The Key Role of Uncertainty*, in «Neurocritical Care», 30 (2019), n. 1, pp. 33-41. There is a long series of other terminologies that indicate – more or less voluntary – processes of dehumanisation of the patient with a disorder of consciousness: "s/he is a corpse with a beating heart", "s/he is a piece of meat or an empty shell", "pulling the plug", "it is a fate worse than death", etc. All this highlights that the treatment of patients with DoCs does not depend exclusively on technical-methodological issues concerning diagnosis, prognosis, and rehabilitation, but also depends on the ethical-ontological background that underpins the clinical attitude towards patients. Cfr. F. Zilio, *Personhood and Care in Disorders of Consciousness. An Ontological, Patient-Centred Perspective*, in «Medicina e Morale», 69 (2020), n. 3, pp. 327-346.

[22] S. Laureys et al., *Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome*, in «BMC Medicine», 8 (2010), n. 68.

[23] However, being limited only to behavioural description, this terminology remains "agnostic" regarding consciousness and, therefore, although it avoids diagnostic error about consciousness, it is not concretely informative alone for clinical decision-making. Cfr. L.S.M Johnson, *op. cit.*, pp. 21-23.

[24] J.T. Giacino et al., *Practice Guideline Update Recommendations Summary: Disorders of Consciousness*, in «Neurology», 91 (2018), n. 10, pp. 450-460.

itself from negatively influencing attitudes towards treatment, greater nosological humility would be required, i.e., recognising the current lack of knowledge about disorders of consciousness[25], the fluidity and variability of such clinical conditions, and consequently the need for conceptual and temporal prudence regarding diagnosis and prognosis (e.g., "persistent" instead of "permanent").

Additionally, the way clinical information is presented can influence decision-making processes toward a specific choice (e.g., withdrawing, withholding, or continuing life-support treatments) without actually denying any option. In this sense, the above-mentioned epistemic asymmetry could turn into 'epistemic manipulation' where information is presented (or intentionally left out) for socioeconomic factors or to promote something useful to the hospital (e.g., allocation of healthcare resources), rather than to the person with DoCs *per se*[26]. For example, some may focus the communication on the severity of brain injury and the low probability of recovery during the acute phase, when it is still very difficult to make an accurate diagnosis and prognosis, in order to (more or less consciously) suggest hasty end-of-life decisions, such as withdrawing life-supporting treatments, which could particularly influence the decisions of families in economic poverty and lack of health insurance.

Together, the misconception of the vegetative state, along with the clinical language of performative use and the risk of epistemic manipulation, has major implications for family counseling, decision-making, and ethics of the field. Although they may appear as a mere exposition of descriptive contents, diagnoses and prognoses regarding disorders of consciousness can lead to biased clinical attitudes and decisions that limit the possibility of patient recovery. Indeed, what Joseph Fins has called "therapeutic nihilism" and "prognostic pessimism"[27] can also depend on conceptual ambiguities and the underlying prescriptive values of certain clinical categorizations. In this sense, patients with a bad diagnosis may have a lower chance of recovery, not just due to the bad outcome of the clinical analysis *per se*, but because the prediction of mortality and the lack of neurorehabilitation programs could prompt premature practices of withdrawing or

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[25] J.J. Fins, *Syndromes in Search of a Name: Disorders of Consciousness, Neuroethics, and Nosological Humility*, in M.D. Lockshin, M.K. Crow, M. Barbhaiya (eds.), *Diagnoses Without Names: Challenges for Medical Care, Research, and Policy*, Springer, Cham 2022, pp. 163-175.

[26] L.S.M Johnson, *op. cit.*

[27] J.J. Fins, *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*, Cambridge University Press, New York 2015.

withholding treatments. Therefore, we could speak of “self-fulfilling negative prognoses” (from the self-fulfilling prophecy bias[28]), that is, a vicious circle in which these negative expectations influence clinical choices and outcomes[29].

3. *Clinical decision-making for people with DoCs*

As presented above, disorders of consciousness present several epistemic and methodological issues, which, in turn, generate a number of issues on the ethical and clinical levels. I have discussed some of the problems related to the intrinsic uncertainty of disorders of consciousness: diagnostic error, prognostic uncertainty, communication with family and caregivers, and the performative value of clinical language. All this particularly affects clinical decision-making processes, as it prevents the formulation of a proper balance between scientific evidence, known best practices, knowledge of the clinical situation of the individual case, and physician-patient-family communication. In fact, scientific knowledge on disorders of consciousness and neurodiagnostic technologies, despite important recent steps, is still not as developed and spread as in other clinical areas, and clinical guidelines often suggest a cautious attitude (in both clinical practice and communication) due to the above-mentioned state of uncertainty[30].

Additionally, uncertainty about the patient’s state of consciousness also complicates the surrogate decision-making process. The surrogate decision-making process is initiated when a person is unable to make decisions about personal health care (i.e., incompetence); in that case, other legal instruments or persons provide in decision making: first of all, any written advance healthcare directives or any trustees/surrogates/attorneys who should interpret the patient’s current wishes according to his past actions and decisions are taken into account. In the absence of these (advanced directives, surrogates, knowledge about past wishes), it becomes necessary to determine the best interest for the patient.

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[28] M. Mertens et al., *Can We Learn from Hidden Mistakes? Self-Fulfilling Prophecy and Responsible Neuroprognostic Innovation*, in «Journal of Medical Ethics», (2021), pp. 1-7.

[29] F. Zilio, *art. cit.*

[30] D. Kondziella et al., *European Academy of Neurology Guideline on the Diagnosis of Coma and Other Disorders of Consciousness*, in «European Journal of Neurology», 27 (2020), n. 5, pp. 741-756. J.T. Giacino et al., *art. cit.*

Two problems can be highlighted here with respect to DoCs. First, there is often no certainty about the degree of consciousness of the patient, and this compromises the effectiveness of advanced directives or surrogates because, if there is a possibility that the patient is conscious, it is important to respect her/his autonomy first. Second, even if one recognises that the patient has a certain level of consciousness (e.g., MCS or CMD), the criteria are not clear to include such a patient in supported decision making for important medical decisions[31]. Furthermore, even if one could communicate with a patient with covert consciousness through the use of BCI, it is first to understand whether and what ethical and legal value a response or message displayed through a computer that decodes and classifies brain states has, particularly when limited to closed questions with "yes / no" answers[32].

In general, several issues hinder the formulation of a classic clinical decision-making process in the field of disorders of consciousness, not because the person is unconscious or incompetent (this is already the case in several other pathologies), but because of the epistemic uncertainty about consciousness that consequently implies ethical uncertainty. How do we overcome this impasse? L. Syd M Johnson proposes an inductive balance (instead of deductive, given the intrinsic uncertainty) between two types of risk: epistemic risk, i.e., the risk of being wrong in accepting an incorrect hypothesis, and ethical risk, i.e., the ethical consequences of being wrong. These two types of risk should mutually constrain each other through two principles of inductive risk. The first principle of inductive risk (taken from Richard Rudner) says that «the tolerable level of epistemic risk […] should be limited by the ethical risk of being wrong»[33]. Applying this principle to DoCs, given the high level of ethical risk (e.g., risk of undertreatment, self-fulfilling prognosis, unwanted death), a low level of epistemic risk should be allowed, which unfortunately cannot yet be guaranteed.

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[31] A. Peterson, K. Mintz, A.M. Owen, *Unlocking the Voices of Patients with Severe Brain Injury*, in «Neuroethics», 15 (2022), n. 9.

[32] M.N. Abbott, S.L. Peck, *Emerging Ethical Issues Related to the Use of Brain-Computer Interfaces for Patients with Total Locked-in Syndrome*, in «Neuroethics», 10 (2017), n. 2, pp. 235-242. W. Glannon, *Communication with Brain–Computer Interfaces in Medical Decision-Making*, in I. Opris, M.A. Lebedev, M.F. Casanova (eds.), *Modern Approaches to Augmentation of Brain Function*, Springer, Cham 2021, pp. 141-161.

[33] L.S.M Johnson, *op. cit.*, p. 87.

Johnson thus proposes to couple this principle with a "second principle of inductive risk" that determines the level of ethical risk by the level of epistemic risk[34]. There are different levels of ethical risks in the medical field that are related to the potential consequences of continuing, limiting, withdrawing or withholding therapeutic treatments, such as minor discomfort, considerable side effects, or even death. Applying this principle to DoCs, given the current high diagnostic error and prognostic uncertainty, the ethical risk should be limited; in other words, in situations where there is diagnostic uncertainty about the state of consciousness and prognostic uncertainty about the chances of survival and recovery, high-stakes decisions (i.e., decisions where the risk-to-benefit ratio is substantially worse than alternatives)[35], should be avoided. To give an example, prompt decisions to withhold or withdraw treatments, donate organs, and recommend deep palliation or "do not resuscitate" orders in acute brain injury should be considered premature and extremely risky from an ethical point of view, given the high epistemic uncertainty regarding acute coma (see also the therapeutic nihilism and prognostic pessimism mentioned above)[36].

Another example can be used with respect to the evaluation of DoC patients (e.g., MCS) based on their ability to use a brain-computer interface. Given the experimental stage of many BCIs, while a high BCI performance indicates a good level of consciousness, a low or absent BCI performance does not necessarily imply low or absent consciousness (denying the antecedent fallacy/inverse error); indeed, the subject may not want to answer, questions may be misunderstood, or the BCI device might have low precision. Therefore, BCI *per se* does not provide a reliable marker for assessing consciousness and, consequently, influencing clinical decision-making.

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[34] L.S.M Johnson, *op. cit.*, p. 91.

[35] A. Peterson, K. Mintz, A.M. Owen, *art. cit.*, p. 9.

[36] J.J. Fins, *op. cit.* In this respect, many authors criticise the high number of hospitality deaths (~70%) due to hasty withdrawals (within very few days of brain injury) of treatments in neurointensive care (acute coma). Cfr. B. Edlow, J.J. Fins, *Assessment of Covert Consciousness in the Intensive Care Unit: Clinical and Ethical Considerations*, in «The Journal of Head Trauma Rehabilitation», 33 (2018), n. 6, pp. 424-434. L.S.M. Johnson, *op. cit.*, pp. 98-99.

4. *Conclusions*

The limbo of disorders of consciousness is characterised by an inherent uncertainty involving both technological-methodological factors (neuroimaging), conceptual and linguistic factors (clinical communication and terminology), and ethical factors (nihilistic and pessimistic attitudes on diagnosis and prognosis). This epistemic and ethical uncertainty significantly affects clinical decisions for patients with DoCs. Consequently, greater epistemic humility and recognition of such uncertainty could improve clinical and ethical attitudes, avoiding hasty end-of-life decisions and cases of misinterpretation and manipulation in physician-family communication[37].

Abstract

Disorders of consciousness (DoC) are characterized by impaired or complete loss of self-awareness and awareness of the environment. It is not easy to assess the level of consciousness of people with DoCs; indeed, there may be cases of covert awareness, that is, people who manifest complete behavioural unresponsiveness but preserve some degree of consciousness. This makes the search for neuronal markers of consciousness in subjects with DoC quite urgent, and the improvement and dissemination of innovative neuroimaging technologies a moral imperative. Neuroethics, considered here as a special branch of clinical ethics, should deal with the ethical implications of these neurotechnologies and the intrinsic uncertainty of diagnosis and prognosis about disorders of consciousness, with a focus on how these issues affect clinical decision-making. First, I will present some epistemic and methodological issues that characterise the disorders of consciousness: diagnostic error, prognostic uncertainty, communication with family and caregivers, and the performative value of clinical language. The epistemic uncertainty emerging from these problems is deeply intertwined with ethical uncertainty, especially when dealing with clinical decisions that may lead to the death of persons whose states of consciousness (and wishes) are not entirely clear. I will suggest the need for epistemic and ethical prudence, through the formulation of a balance between the two principles of inductive risk as proposed by L. Syd M Johnson. Consequently, recognition of intrinsic uncertainty in the field

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of disorders of consciousness could improve clinical and ethical attitudes, avoiding hasty end-of-life decisions and cases of misinterpretation and manipulation in physician-family communication.

Keywords: epistemic uncertainty; ethical uncertainty; disorders of consciousness; consciousness; clinical decision-making.

Federico Zilio
Università di Padova
federico.zilio@unipd.it