

Beyond clinical nihilism: personalist bioethics in the care of patients with disorders of consciousness

Más allá del nihilismo clínico: la bioética personalista al cuidado de pacientes con trastornos de la conciencia

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Abstract

Disorders of the nervous system are the leading cause of disability-adjusted life years (DALYs) and the second leading cause of death worldwide. Stroke ranks first in DALYs, while traumatic brain injury ranks

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second in mortality and third in mortality and disability indicators. The resulting disorders of consciousness (DoC) generate complex bioethical dilemmas. Despite interest in preventing, treating, and rehabilitating neurological damage, there is still a systematic lack of attention to the management of patients with DoC. This negligence, reinforced by a clinical nihilism that underestimates suffering, dehumanizes the therapeutic alliance. Faced with this problem, personalist bioethics offers a personalist perspective based on the intrinsic dignity of the human person. This approach promotes comprehensive, personalized, respectful, and anthropologically grounded care for patients in situations of extreme vulnerability, marked by the diagnostic, prognostic, and therapeutic uncertainty inherent in these clinical conditions.

Keywords: severe acquired brain injury (ABI), Clinical Guidelines, Neglect Syndrome, intrinsic dignity.

1. Introduction

DoC constitutes a heterogeneous set of conditions characterized by altered alertness, cognition, and perception of the environment. These conditions mainly result from severe acquired brain damage, such as traumatic brain injury, stroke, and anoxic encephalopathy, posing a considerable challenge to both healthcare systems and affected families. This scenario is part of a larger problem, as neurological disorders are currently the leading cause of Disability-Adjusted Life Years (DALYs)¹ and the second leading cause of death worldwide.

Global statistics for 2021 confirm this reality: stroke tops the list of causes of DALYs, followed by meningitis (6th position), encephalitis (13th), and traumatic brain injury (TBI) (1). TBI deserves special attention as it is the second leading cause of death worldwide and the third when mortality and disability are combined, mainly in

¹ DALYs are a measure that combines years lost due to premature death and years lived with disability. They are used to quantify the total burden of a disease in a population, reflecting both the quantity and quality of life lost.

low-income countries (2). Its incidence and prevalence continue to rise, increasing its impact on DALYs (3).

In response to this reality, the World Health Organization (WHO) has developed the Global Intersectoral Action Plan on Epilepsy and Other Neurological Disorders 2022-2031 (IGAP). Its fundamental objective is to improve access to treatment, optimize care and quality of life for patients and their caregivers. In addition, IGAP addresses key strategic issues: policies and governance, advances in diagnostic methods, treatment, care models, prevention, and priority areas for research (4).

2. Severe acquired brain injury

Within the statistical context of neurological pathologies, severe acquired brain damage is one of the most significant due to its direct link to disability. Brain damage is defined as any structural or functional alteration in the brain that can have a significant impact on the physical, emotional, and cognitive spheres of the affected person. Depending on their etiology, acquired brain injuries are classified as traumatic, such as traumatic brain injury (TBI), and non-traumatic, such as stroke. TBI is usually the result of an external impact, such as a traffic accident, which can cause bleeding or cerebral edema. In contrast, stroke is caused by an interruption in cerebral blood flow, either due to ischemia or hemorrhage, as in the case of arterial occlusion by a thrombus. Although clinical manifestations may overlap, such as hemiparesis or language disorders, differences in the pathophysiological mechanism imply different diagnostic and therapeutic approaches.

Patients with brain damage require a highly specialized approach in intensive care units (ICUs) with continuous real-time assessment of brain function. Advanced digital monitoring allows for early detection of signs of secondary brain damage,² even before obvious

² An injury can cause neurological damage, and neurological damage can cause disability. Disability can be caused by neurological dysfunction without visible structural injury.

clinical manifestations appear. This early diagnostic capability enables timely and more effective interventions, either through surgical or conservative treatments, depending on the clinical context and the patient's evolution (5).

Due to the complex and dynamic nature of these clinical conditions, specialized care protocols are required, integrating multimodal supportive therapies and rigorous monitoring. This comprehensive approach aims to reduce associated morbidity and mortality rates, as well as optimize long-term function and quality of life. ICU care seeks not only physiological stabilization but also the prevention of neurological and systemic complications, which is an essential component of the patient recovery process (5,6).

Advances in emergency medicine and intensive care have contributed to a decrease in mortality associated with these conditions; however, a considerable number of people survive with neurological sequelae —motor, cognitive, and neuropsychological— that significantly compromise their functionality and quality of life (5).

2.1. Care pathways from ICU to rehabilitation

In this context, progressive care pathways have been developed to optimize clinical management from the acute phase to comprehensive rehabilitation. The approach varies depending on the country and available resources (3). In higher-income countries, there are different levels of care: specialized trauma units; intensive care during the hyperacute, acute, and subacute phases; intensive neurological rehabilitation (highly specialized hospitals or specific units); long-term care centers; outpatient and home care (7–9); and palliative care (10).

2.2. Prognostic markers of recovery

As a result of increased survival in IT, early prognostic markers have been developed that allow functional recovery to be anticipated.

However, most of this data has been obtained during the rehabilitation phase in specific units and not in the acute stage of the injury. In addition, studies tend to focus on clinical and biomedical aspects, relegating to the background the long-term repercussions that affect the patient's reintegration into their everyday environment (11).

2.3. Rehabilitation and intervention strategies

Complementarily, the design and implementation of personalized rehabilitation strategies become a fundamental pillar for maximizing functional recovery and quality of life. The WHO Rehabilitation Package for Neurological Conditions establishes strategies for the prevention and treatment of the sequelae of stroke, TBI, and other neurological conditions (12).

2.4. Factors influencing recovery

The effectiveness of rehabilitation interventions is influenced by clinical, individual, and contextual factors that determine the patient's progress. The quality of medical care, access to specialized centers, and availability of trained professionals are decisive factors. In rural areas or areas with limited resources, the shortage of specialists, economic barriers, and limited knowledge about neurological damage hinder access to comprehensive treatment, creating inequalities that affect patient recovery (5).

2.5. Follow-up of patients with TBI

Longitudinal follow-up of patients with TBI is essential for understanding clinical progression and optimizing therapeutic interventions. One of the most important studies is *Transforming Research and Clinical Knowledge in TBI* (TRACK-TBI), which systematically analyzes the natural history of TBI from the acute to the chronic phase. This project conducts systematic functional monitoring beginning in

the first two weeks after injury and continuing at 3, 6, and 12 months, providing essential longitudinal data for understanding recovery (13).

Complementing these findings, various studies have contributed to knowledge about the frequency and extent of recovery in patients with moderate-to-severe TBI, particularly those who develop DoC (14,15). The integration of these studies has been fundamental to the development of more effective treatment strategies and the optimization of care protocols for patients with complex neurological damage.

2.6. Neurological sequelae

Analysis of the sequelae resulting from moderate-to-severe neurological damage reveals a wide spectrum of clinical manifestations, with DoC representing the most severe level of functional impairment and disability. Within this continuum of disorders, the most extreme manifestations include unresponsive wakefulness syndrome and motor-cognitive dissociation, conditions that pose particularly complex diagnostic, prognostic, and ethical challenges.

DoCs not only impact patient functionality but also generate significant clinical uncertainty and raise fundamental ethical dilemmas in therapeutic decision-making. The chronicity of these disorders and their impact on the quality of life of both patients and their families underscores the critical need for comprehensive and ethically grounded care approaches.

This narrative review examines the paradox between the recommendations established in the main American and European clinical guidelines for the care of patients with DoC and the reality of contemporary healthcare practice. Despite the existence of defined clinical standards, there remains a gap between the available scientific evidence and its implementation in everyday clinical practice.

The analysis identifies clinical nihilism and systematic negligence in care as fundamental ethical problems that not only compromise the quality of care but also erode the intrinsic dignity of the patient.

These attitudes perpetuate the disconnect between available scientific evidence and clinical practice, creating a vicious circle that negatively affects the patient and their family.

As a comprehensive response to this complex reality, the paper proposes and outlines a care paradigm based on the principles of personalist bioethics. This approach seeks to coherently articulate the best available scientific evidence with an ethical commitment to the human person, safeguarding their intrinsic dignity, regardless of the communication limitations and diagnostic and prognostic uncertainty inherent in these complex neurological conditions.

3. DoC: clinical characterization

Among the most complex neurological sequelae resulting from severe brain damage, patients who develop DoC represent a significant clinical challenge. This complexity is manifested both in the diagnostic difficulties they present and in the uncertainty that characterizes their long-term evolution.

DoC constitutes a broad spectrum of neurological conditions characterized by the dissociation between the state of wakefulness and consciousness itself. From a pathophysiological perspective, these alterations result from complex dysfunctions in neuronal activity that compromise multiple levels of brain organization, particularly affecting cortico-cortical and subcortical-cortical connectivity and the overall functional integration of specialized neural networks, including prominently the Default Mode Network, among other structures critical for the maintenance of consciousness (16).

3.1. Etiology and epidemiology

The causes of DoC are diverse, with the most prevalent being stroke, TBI, metabolic damage, and post-anoxic encephalopathy (16). This etiological variability is reflected in different clinical series: Más-Sesé

et al. (8) identified cerebral hemorrhage as the predominant cause, followed by anoxic encephalopathy, metabolic encephalopathy, and TBI.

Baricich *et al.* (17) prospectively analyzed 49 patients admitted to a specialized vegetative state unit and found that the main etiology was post-anoxic-ischemic encephalopathy, followed in order of frequency by TBI, stroke, aneurysmal subarachnoid hemorrhage, and other acute neurological conditions.

3.2. Clinical classification

The clinical spectrum of DoC encompasses different neurological syndromes with distinctive characteristics, including vegetative state or unresponsive wakefulness syndrome (UWS), minimally conscious state (MCS), and motor-cognitive dissociation (MCD). The global prevalence of UWS/UWSR is estimated to range widely between 0.2-6.1 per 1,000,000 inhabitants, with a clinically significant diagnostic error margin ranging from 37% to 42%, underscoring the difficulties inherent in the differential diagnosis of these conditions (16).

Technological advances in neuroimaging (NI) and neurophysiology (NF) have fundamentally revolutionized our understanding of DoCs (18,19). Particularly relevant has been the identification that some patients clinically diagnosed with EV/SVSR present the phenomenon of *covert consciousness*, characterized by a marked discrepancy between functional brain activity detected by NI and the absence of observable behavioral responses during conventional clinical evaluation.

This phenomenon, formally referred to as DCM (20), has profound clinical and ethical implications, as it suggests that the patient maintains a certain level of consciousness and responsiveness to environmental stimuli through their brain activity, even though these cognitive responses remain imperceptible in clinical examination, posing fundamental challenges for diagnosis, prognosis, and therapeutic decision-making.

3.3. Assessment of progress and prognostic tools

To systematically assess the clinical and functional evolution of patients with moderate or severe brain injury, the *Glasgow Outcome Scale-Extended* (GOSE) (21) is the most widely used tool in the context of clinical research. This scale, conceptually derived from the Glasgow Coma Scale, provides a structured classification of the degree of disability or functional recovery using eight hierarchical levels: death, vegetative state, severe disability (low or higher), moderate disability (low or higher), good recovery (low or higher) (14).

In the field of contemporary translational research, sophisticated multimodal predictive models are being developed and designed to be implemented during the early stages following brain injury, with the aim of predicting long-term functional prognosis in people with DoC. These innovative protocols integrate neurophysiological, advanced neuroimaging, serological, and clinical indicators, providing a holistic and personalized approach to prognostic assessment (11).

4. Clinical issues: clinical attitudes toward pain in DoC

Despite significant advances in the neurobiological understanding and clinical assessment of DoC, the experience of pain in these patients remains a crucial dimension that is insufficiently addressed in clinical practice. This issue takes on relevance when considering that the phenomenon of *covert consciousness*, revealed by NI, raises fundamental ethical and clinical questions about the actual ability to perceive and process aversive sensory experiences, especially in contexts where conventional communication is severely compromised or absent.

The paradox that characterizes the current clinical approach is particularly striking: while scientific and clinical interest in effectively preventing, monitoring, and treating neurological damage has led to specialized and well-established care pathways, and efforts to identify favorable prognostic signs are systematically geared toward opti-

mizing rehabilitation programs, the comprehensive management of patients with SVSR and DCM remains limited and often inadequate.

This fundamental contrast between available knowledge and practical implementation poses a challenge that raises clinical, ethical, and bioethical questions. It is particularly concerning that, despite explicit scientific recognition that these patients retain the capacity to experience pain and suffering, and the availability of international guidelines specifically designed for their management, practical implementation remains deficient and heterogeneous in multiple healthcare settings.

An analysis of this problem reveals that the root of this care gap lies not only in a lack of resources or deficiencies in the technical training of healthcare personnel, but fundamentally in the persistence of clinical nihilism. This professional attitude is characterized by a systematic tendency to underestimate the potential for recovery in these patients and contributes directly to ignoring or minimizing the importance of pain management, leading to premature decisions that are often marked by prejudices about disability and reductionist views of what constitutes quality of life.

4.1. Specific characteristics of pain in DoC

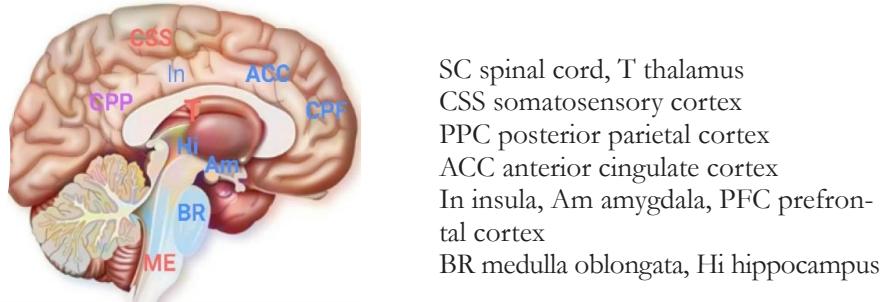
Pain in this neurologically vulnerable population presents unique characteristics and challenges, its distinctive feature being the inability to verbally express the painful experience. This limitation stems not only from the primary alteration of consciousness, but also from multiple secondary neurological factors, including various types of aphasia, fluctuations in alertness levels, spasticity, joint stiffness, and motor and cognitive changes secondary to structural and functional brain damage (22).

4.2. Neurophysiological basis of pain processing

Severe neurological damage causes complex alterations in functional activity between various specialized cortical areas, which might

initially suggest that conscious perception of pain is significantly compromised or absent. However, scientific evidence derived from advanced functional NI and NF studies has shown that, in the presence of nociceptive stimuli, brain structures related to the affective-cognitive processing of pain are activated, even in patients diagnosed with SVSR (23), as shown in Figure 1.

Figure 1. Diagram of the main brain areas involved in pain processing



These areas comprise densely interconnected sensory or discriminative (orange), affective (purple), and associative (blue) regions.

Source: created with Napkin.

This neuroscientific evidence has profound clinical implications, as it suggests that the absence of obvious signs of consciousness does not necessarily exclude the possibility of functionally significant cortical activity. Therefore, it is plausible that a patient may process and even subjectively experience pain without having the ability to express it in a behaviorally observable way or communicate it. This consideration implies that the absence of visible or communicable responses should not be automatically interpreted as evidence of the absence of conscious perception, nor as an indicator of the absence of physiological and neurological responses to potentially noxious stimuli (24).

4.3. Institutional response: development of evidence-based clinical guidelines

In response to these identified clinical and ethical issues, the international neurological community has developed a regulatory framework to improve the care of patients with DoC. The most significant paradigm shift came with the *Practice Guideline update: Recommendations Summary: Disorders of Consciousness* from the American Academy of Neurology (AAN, 2018), developed jointly with the American Congress of Rehabilitation Medicine (ACRM) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). This update is the result of a five-year process of evidence-based review and interdisciplinary consensus that supersedes the 1995 AAN guidelines (25).

The guidelines emphasize the implementation of standardized assessments using multidisciplinary approaches that optimize both diagnostic accuracy and therapeutic effectiveness. They recognize that, although the prognosis is often guarded, scientific documentation of cases with long-term improvement supports the need for periodic longitudinal assessments and individualized treatment plans (25).

For specific pain management, the guideline establishes level B recommendations that include: assessing and treating when there is reasonable cause and informing families about the existing scientific uncertainty (26). These recommendations translate into three fundamental clinical principles: do not assume the absence of painful experience based solely on the inability to communicate; use indirect assessment tools through autonomic or reflex responses; and administer analgesic treatment when pain is suspected, even with uncertainty about its subjective perception (27).

Complementarily, the *European Academy of Neurology guideline on the diagnosis of coma and other disorders of consciousness* (2019) represents a methodological advance by recommending the Revised Nociceptive Coma Scale (NCS-R), a validated tool for the systematic assessment of pain in patients with DoC (28). Functional neuroimaging

studies have demonstrated significant correlations between NCS-R scores and activation of nociceptive cortical processes, particularly in the anterior cingulate cortex (ACC), a key region for conscious pain perception (29–31).

4.4. Persistent limitations and future challenges

Both guidelines are important in counteracting clinical nihilism in the care of patients with DoC. However, despite their scientific rigor, they acknowledge significant shortcomings: difficulties with covert consciousness, lack of specific therapeutic consensus, and a persistent gap between neuroscientific evidence and operational clinical protocols. These limitations require additional research to optimize comprehensive care for this vulnerable population, demonstrating that advances in recommendations, although necessary, are insufficient to completely transform contemporary clinical practice.

4.5. Gap between recommendation and practice

Despite the publication of these evidence-based guidelines, their effective implementation in everyday practice remains a complex challenge. Farisco *et al.* (32) highlighted this problem in an international study conducted in 2023, which revealed significant disparities in the adoption of recommendations, particularly about the diagnosis of consciousness levels and the detection and treatment of pain.

This research included 216 professionals from 40 countries (54% women, 44% men) with an average age of 50, offering a revealing overview of the clinical reality. Of the total number of participants, 87% were professionals in active clinical practice and 48% worked in specialized intensive rehabilitation units, with 63% of physicians having more than a decade of experience. The distribution (38% Europe, 34% USA, 21% Asia-Pacific, and 7% Africa (APA)) identified significant regional variations in the application of the recommendations (32).

The study revealed that, despite advances in neuroscience and guidelines, there remains marked heterogeneity in diagnostic practices for level of consciousness. While 79% of professionals relied primarily on behavioral assessments, only 54% used neurophysiological studies and 52% used structural neuroimaging. These disparities are accentuated when examining regional differences: in Europe, 89% used behavioral assessment and 66% used neurophysiological studies, while in the US, the latter percentage drops to 38%. In addition, the repetition of behavioral assessments showed notable variations: 76% in APA, 71% in the US, and only 44% in Europe (32).

4.6. Critical differences in the assessment and treatment of pain

The inconsistency in the implementation of recommendations on pain assessment and treatment is concerning. Although 76% of clinicians reported systematically assessing pain, there are substantial methodological differences: 59% use nonspecific clinical assessment and only 47% use the NCS-R. The disparities are more pronounced at the regional level: in the US, unstructured clinical assessment predominates (80% compared to 39% in Europe), while Europe more frequently adopts the NCS-R (60% compared to 24% in the US). This data reveals a significant gap between the recommendations in the guidelines and clinical reality, where heterogeneous and less structured approaches prevail.

About pharmacological treatment, although the overall percentages seem encouraging (96% in Europe, 82% in the US), there are differences depending on the care setting: 84% in IT, 87% in specialized rehabilitation units, and only 55% in centers for chronic patients. In addition, only 81% of professionals inform families about the difficulties in detecting pain in patients with DoC (32). This diversity suggests that patients with prolonged DoC receive suboptimal pain care, precisely when its assessment and treatment are most complex and crucial.

The findings of Kuehlmeyer *et al.* (33) complement this picture by investigating German and Canadian medical attitudes toward

pain detection in DoC. Using a clinical case, 70% considered that patients could perceive pain and 51% could perceive tactile sensations, with a higher prevalence among German physicians. These attitudinal differences, possibly influenced by cultural factors or by the German model of rehabilitation for non-hospitalized chronic patients, have a direct impact on clinical decisions, including the approach to pain.

The research by Bonin *et al.* cited by Bonin (24) reveals a disturbing reality: although most patients with DoC show clinical signs of pain during procedures such as mobilization, only a third receive adequate treatment. This discrepancy reflects a systemic failure to translate theoretical knowledge into effective practices, compromising the quality of care and dignity of these patients.

These studies reveal inconsistent implementation of clinical guidelines, raising serious questions about the equity and quality of care received by patients with DoC. The disparities observed are not mere methodological variations, but substantial differences in the conceptualization of pain and the commitment to adequate assessment and treatment in this vulnerable population.

5. Ethical and bioethical considerations

5.1. Clinical nihilism as a therapeutic barrier

The assessment and management of patients with DoC represent a complex clinical challenge, exacerbated by the persistence of clinical nihilism in contemporary medical practice. This systematic skepticism misinterprets the absence of verbal or motor communication as evidence of the absence of conscious experience, despite neuroscientific evidence demonstrating brain activity consistent with pain perception in some patients, even without observable behavioral manifestations.

This stance denies the value of medical intervention in conditions considered “irreversible,” based on the absence of visible responses

rather than on available scientific evidence. Ontologically, it is dangerous because it reduces the patient to a body without a voice, without intrinsic value, and ultimately without fundamental rights.

The gap between theoretical recognition and effective pain management is concerning, although 76% of physicians assess pain and 82% claim to treat it, less than half use specific instruments such as the NCS-R. Consequently, only between 33% and 55% of chronic patients receive adequate analgesic care, highlighting the distance between theoretical knowledge and practical implementation.

This nihilism in intensive care can lead to the premature withdrawal of life support, and in chronic patients, to inappropriate transfer to custodial care centers in suboptimal conditions, depriving patients of specialized rehabilitation. These scenarios constitute errors of omission and commission that are not in line with the fundamental objectives of the guidelines and other international documents mentioned above, aimed at optimizing care for this vulnerable population (26).

This nihilism/skepticism, which the guidelines themselves attempt to counteract, has prevailed for decades, influencing perceptions of recovery and fostering a disturbing insensitivity to pain and care for these patients.

5.2. Medical negligence in the treatment of patients with DoC

Fins (34) has coined the term “Neglect Syndrome” to describe the set of factors that lead to the systematic abandonment of patients with DoC. This phenomenon is characterized by the dissemination of inaccurate information in the media, political influences, limited social understanding of DoC, lack of detailed clinical records, and difficulties in identifying significant diagnostic transitions, particularly the progression from SVSR to EMC. This neglect syndrome reinforces the nihilistic mindset that culminates in therapeutic inaction, consolidating the erroneous belief that recovery is unattainable. The direct consequence is a worrying indifference and lack of intellectual curiosity in the medical community, an attitude that contrasts sharply with emerging scientific evidence.

Fins (35) emphasizes the need to consider patients with DoC not as static entities, but as subjects immersed in dynamic recovery processes, where time and biology play fundamental roles. This perspective would allow for an objective assessment of scientific findings on pain perception and the potential efficacy of therapeutic interventions in this population.

Empirical evidence contradicts widespread skepticism. Several studies show that a significant percentage of patients with severe neurological damage achieve favorable outcomes months or even years after injury. Más-Sesé *et al.* (8) documented that 43.4% of patients with DoC showed improvement from their initial condition, reaching 35.3% in the group with SVSR and 66.6% in those with EMC, with the improvement being most significant during the first three months after the injury.

McCrea *et al.* (14), analyzing 484 patients from the TRACK-TBI study, observed that two weeks after injury, 36 of 290 individuals with severe TBI and 38 of 93 with moderate TBI had a positive clinical outcome. At 12 months, 52.4% of severe cases and 75% of moderate cases achieved favorable outcomes. In the SVSR group, 78% regained consciousness within the first two weeks, and 25% achieved orientation within a year.

These findings contrast sharply with the widespread practice of withdrawing life support after 72 hours, a period in which one-third of deaths occur in patients hospitalized for severe TBI, half in the first week, and three-quarters within two weeks of injury (14). This data reveals that, frequently, the main cause of death is not the severity of the neurological damage *per se*, but rather the medical decision to prematurely withdraw life support, based on a clinical nihilism that systematically underestimates the chances of recovery (36).

5.3. Quality of life and suffering: fundamental ethical dimensions

The central issue in the ethical approach to patients with DoC lies not only in determining whether they can experience pain, but also

in how we interpret their suffering from an ethical perspective and how we respond to it in medical practice. This approach requires transcending the reductionist biomedical paradigm that associates disability with an “undignified life” (34) in order to adopt a comprehensive approach that recognizes the intrinsic dignity of the patient in all circumstances.

The bioethical debate surrounding quality of life and suffering remains complex, mainly due to their inability to express themselves verbally, which has led to interpretations based on often biased medical and social assumptions.

A recurring prejudice is the so-called “disability paradox,” which shows how people with severe disabilities often report a satisfactory or even higher quality of life than people without disabilities (37), while public opinion and part of the medical community tend to systematically underestimate it. This phenomenon reveals an inability to understand the patient’s subjective experience and creates ethical and clinical dilemmas in decision-making (36).

For a comprehensive assessment of quality of life, three fundamental dimensions are recognized: the experience of pleasurable experiences, personal fulfillment, and the perception of a desirable state of health according to prevailing social values. In the specific case of patients with DoC, quality of life may depend to a greater extent on perceived social support and positive sensory experiences such as physical contact, companionship, and appropriate multisensory stimulation (37).

Given the uncertainty of prognosis and the ability to perceive pain, Graham³ (38) emphasizes the ethical and moral obligation to treat patients with DCM as sentient beings and to act with caution.

³ Mackenzie Graham, a neuroethicist, reflects a position within medical ethics based on the precautionary principle and bioethical humanism, seeking to ensure respect and dignity for patients, even in situations of uncertainty about their capacity for perception and suffering. Her work focuses on ethical issues related to neuroimaging, especially in patients with severe brain injuries. She has researched the concept of covert consciousness in people with SVSR and the ethical challenges of communicating these findings to family members.

A comprehensive approach, including sensory stimulation (music, social interaction, and recreation) and clear communication to reduce anxiety, could significantly improve their well-being. This approach, which is accessible and undemanding in terms of resources, could have a significant impact on the care of these patients.

A particularly controversial ethical dilemma arises in the end-of-life context, specifically regarding the decision to withdraw food and hydration from patients with DoC. Some clinical practices opt for this procedure with the intention of causing death without the concomitant administration of prophylactic analgesics. The ethical relevance of this behavior requires further investigation to differentiate between the perception of pain and suffering, not only to protect patients, but also to guarantee family members the ethical responsibility of the medical team (39).

5.4. From evidence to encounter: the personalist paradigm as the horizon of clinical practice

The lack of clear consensus on pain management in patients with DoC has contributed to a notable disparity in the quality of care, leading to clinical decisions based on inferences, prejudices, or unverified assumptions (37). The ethical imperative lies not only in perfecting diagnostic tools, but also in recognizing that untreated pain profoundly affects well-being (22), demanding an approach guided by caution and based on the inherent dignity of every person (40).

Medicine must adopt a comprehensive paradigm in which suffering, although not always observable, is recognized as a sign that calls for professional responsibility (36). This commitment requires constant scientific updating and the development of empathic skills that allow for the humanization of care (20,26,41). The subjective experience of pain can be translated, through advanced clinical and neuroscientific tools, into objective and clinically relevant information for designing comprehensive therapeutic interventions (42).

6. Personalist bioethics as a comprehensive response to care

Despite the development of specific guidelines by the American Academy of Neurology and the European Federation of Neurological Societies, there remains a significant gap between these recommendations and their actual clinical application, reflecting a dominant therapeutic nihilism that tends to systematically minimize the suffering of these patients.

The convergence between the epidemiological magnitude of the problem, the commitment to evidence-based medicine, and the persistence of nihilistic attitudes demands a comprehensive bioethical response. In this context, the personalist bioethics (PB) model maintains that the ontological dignity of the human person remains intact, regardless of their state of consciousness or capacity for interaction (43–45).

Inherent dignity has fundamental characteristics: it is innate, inalienable, equal, universal, and inviolable. It is not based on cognitive or productive capacities but rather constitutes the guiding principle that excludes any form of conditionality. In this sense, it cannot be accepted that, in the face of the need to protect certain instrumental values, the violation of fundamental human dignity can be justified (46).

6.1. Personalist bioethics (PB) and triangular methodology.

PB requires an interdisciplinary approach that articulates three fundamental dimensions systematized in the triangular method (47), which allows for a comprehensive reading of bioethical dilemmas, especially in complex contexts such as DoCs, including SVSR and DCM.

a) Biomedical level

Contemporary neuroscience has highlighted the fragility of traditional clinical assumptions. Research using *fMRI* and neuroimaging

(39) has demonstrated responses to pain and preserved patterns of brain connectivity in patients diagnosed with SVSR, challenging clinical nihilism and justifying the systematic use of pain scales, physiological monitoring, and preventive analgesia.

Furthermore, in contexts of diagnostic and prognostic uncertainty, the precautionary principle requires that the absence of consciousness not be assumed without conclusive evidence (37). Multiple studies support the relevance of implementing intensive neurorehabilitation programs, especially in the subacute phase (48), confirming the duty to act therapeutically even when recovery seems uncertain.

b) *Anthropological level*

From a personalist anthropological perspective, the human person retains their identity and dignity regardless of their expressive or functional capacity. In this framework, patients with SVSR or DCM do not lose their personal status, as the person remains psychosomatically whole and essentially relational (47).

The existence of a human body necessarily implies the presence of a person (49), forcing us to understand these states not as mere biological conditions, but as extreme human situations where the characteristics of the human condition are manifested with intensity: finitude, vulnerability, dependence, and need for others. The person is not defined by their cognitive manifestations, but by their ontological being, rejecting any functionalist reduction (50).

c) *Ethical level. Analysis of the problem*

PB addresses processes of dehumanization by reversing the functionalist paradigm, which considers that people emerge from specific human qualities. PB maintains that people are human beings on whom specific human qualities (e.g., cognitive abilities) can be developed.

This reorientation has transformative practical implications: more respectful professional attitudes, holistic approaches centered

on the triad “human being-person-patient,” and overcoming therapeutic nihilism. It maintains an ethical balance that avoids both therapeutic adventurism and disproportionate medical obstinacy (50).

7. Paradigms in tension: clinical nihilism versus personalist bioethics

7.1 Conflicting conceptual foundations

Clinical nihilism. It adopts functionalist assumptions that define the person by specific cognitive abilities (consciousness, communication, autonomy). When these are affected, it is considered that the condition of personhood is proportionally eroded, justifying decisions based on “quality of life” and a “life not worth living”

Personalist bioethics. It is based on an ontology where human capacities emerge from personal beings. The person ontologically precedes their functional manifestations, maintaining their dignity intact regardless of cognitive functions.

Criteria for clinical decision-making:

Nihilism. This perspective prioritizes cost-benefit analysis and considers not only the withdrawal of life support but also feeding and hydration as an expression of “clinical realism” in the face of “therapeutic futility.” Decisions are based on functional prognoses and estimates of the patient’s future social productivity.

Personalism. This approach bases decisions on the ontological dignity of the person, favoring longitudinal assessments and comprehensive care. Clinical decisions respect the intrinsic value of the human being, regardless of functional prognosis.

Implications for healthcare practice (acute and chronic phases):

Clinical nihilism is characterized by a tendency to systematically minimize suffering, resist the implementation of palliative care, and prematurely withdraw medical interventions, both in the acute and

chronic phases. This approach can lead to decisions that prioritize technical efficiency over comprehensive care, reducing the complexity of care to functional and utility criteria.

Personalism, on the other hand, recognizes suffering as a reality that challenges medical responsibility in all phases of the care process. It integrates palliative care from the acute phase, not only as a strategy for pain management and comfort, but as a tool that affirms the dignity of the person throughout the entire process, until natural death.

8. Principles of personalism in the context of DoC

The application of PB principles to international guidelines on DoC provides an anthropological framework that goes beyond purely technical limitations, constituting a more solid ethical and humanistic basis for clinical decision-making in contexts marked by diagnostic and prognostic uncertainty.

Principle of the inviolability of human life. This principle, which precedes all others, recognizes bodily life as an essential dimension of the person. It implies negative (non-suppression) and positive duties: active defense and promotion of life and health according to individual needs (47). It opposes nihilism by affirming personal dignity regardless of the level of consciousness, demanding personalized care. International guidelines, by recommending systematic assessments and analgesic treatment when pain is suspected, implicitly recognize this fundamental principle.

Principle of totality (therapeutic). It considers the existential totality of the person, including the physical, psychological, social, and spiritual dimensions. Linked to the criterion of proportionality, it guides interventions that avoid both neglect and excessive or futile treatments (47). Proportionality is not assessed solely in terms of survival or functionality, but in terms of the overall well-being that includes pain and suffering. Therefore, measures such as nutrition, pain relief, and comfort remain proportionate, regardless of prog-

nosis. The guidelines recommend multidisciplinary approaches that address not only clinical aspects but also human dimensions.

Principle of freedom and responsibility. Although DoC patients have obvious limitations in exercising their autonomy, this principle remains relevant through the therapeutic alliance with family members, in a relational and medical responsibility dimension, recognizing cultural, religious, and social preferences to achieve shared decision-making (SDM) (51). The guidelines implicitly recognize this principle by promoting family participation and the development of individualized care plans.

Principle of sociability and subsidiarity. This principle applies to healthcare and the social dimension of health (47). The former recognizes that severe neurological damage involves the entire care community, including family, healthcare professionals and society. The common good is promoted when the well-being of every citizen is favored; therefore, the community has a responsibility to ensure that everyone has access to the necessary medical care. For its part, subsidiarity establishes that the community must allocate greater resources where needs are most urgent, which means that utilitarian economic criteria should not be the only ones considered. Specifically, medical care cannot be denied to those who need it most, since access to it is a concrete expression of justice and solidarity (52).

9. Conclusions

Despite clinical and regulatory advances in the treatment of neurological damage and disorders of consciousness, there remains a worrying gap between international recommendations and their effective implementation, caused not so much by technical limitations as by a reductionist and functionalist view of patients with neurological damage. This clinical nihilism minimizes the possibility of recovery and the experience of pain, revealing an underlying anthropological and ethical crisis.

In this context, personalist bioethics offers an alternative and necessary framework: it recognizes the ontological dignity of the person beyond their functions and maintains that all clinical intervention should be oriented toward proportional and comprehensive patient care. From this perspective, the patient's vulnerability directly challenges the medical responsibility to recognize and validate their unconditional dignity. Integrating this approach allows for the reconfiguration of clinical practice towards an authentically human model, in which each patient, even in silence and immobility, is recognized as a person deserving of respect and protection.

The triangular methodology, which articulates biomedical evidence, anthropological foundations, and ethical reflection, provides conceptual and practical tools that overcome the dominant functionalist reductionism. This integration not only transcends the limitations of therapeutic nihilism but also provides solid and well-founded decision-making criteria. In this sense, personalist bioethics is not only presented as a theoretical alternative, but as a proposal for practical transformation capable of guiding health policies, care protocols, and training processes toward truly person-centered medicine.

The future challenge is to systematically implement this paradigm in healthcare institutions, develop quality indicators that reflect their fundamental principles, and design training programs that enable professionals to recognize and respond appropriately to the specific vulnerability of these patients. This will make it possible to close the gap between ethical commitment and clinical practice, ensuring that no patient with disorders of consciousness is abandoned to the inaction that characterizes therapeutic nihilism.

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