



Revista Latinoamericana de Bioética

ISSN: 1657-4702

ISSN: 2462-859X

Universidad Militar Nueva Granada

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Revista Latinoamericana de Bioética, vol. 21, núm. 1, 2021, Enero-Junio, pp. 7-10
Universidad Militar Nueva Granada

DOI: <https://doi.org/10.18359/rlbi.5594>

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Bioethical Aspects of Patients in a Minimally Conscious State

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How to cite: Garzón Díaz FA. Bioethical Aspects of Patients in a Minimally Conscious State. *Rev. latinoam. bioet* [Internet]. 23 de julio de 2021 [citado 23 de julio de 2021];21(1):9-10. Disponible en: <https://revistas.unimilitar.edu.co/index.php/rlbi/article/view/5594>

The arrival of powerful neuroimaging tools such as functional magnetic resonance imaging (fMRI) or positron emission tomography (PET) has begun to redefine the traditional way in which we have dealt with disorders of consciousness, especially the vegetative state (vs) and minimally conscious states (MCS). However, this same technological advance has sparked the controversy about how these patients should be treated, who are generally almost abandoned waiting for an uncertain “end” and sometimes condemned not to receive any medical treatment. This editorial raises the ethical challenges posed by the new diagnostic and therapeutic neuroimaging applications in patients and families affected by this severe brain injury.

Clinical Case

Terry Wallis (1964-)

An emblematic case of MCS is that of a young man named Terry Wallis, who recovered (2003) from a—so considered until then—permanent vegetative state in which he had been since the mid-1980s, as a result of a severe car accident near Stone County, Arkansas, on July 13, 1984. Terry began to speak spontaneously. His first words were

“mom” and “Pepsi.” As the weeks went by, however, he grew more fluid. Interestingly, Terry Wallis was anchored in time; for him, Ronald Reagan was still the president of the United States (1).

Although recent studies show that 40% of patients are erroneously diagnosed as vs patients in assisted residences, when in fact they are in a MCS, (2,3,4) the truth is that not a single neurologist saw Terry Wallis in 19 years. According to his father, the doctors said it was not necessary as nothing was going to change. The patient developed muscle contractures over the years since he did not receive physiotherapy either. Today, Wallis’s brain continues to recover, but sadly his atrophied body is not keeping up with his brain recovery (1).

Contributions from the group of Dr. Fins and collaborators (6-7,9-10)

Dr. Joseph Fins’ research, published in the most prestigious journals specialized in neurology and bioethics such as *Neurology*, (5-8,11) the *Hastings Center Report*, (4,12-13) or the *American Journal of Bioethics*, (14-16) is the best expression of the need to carry out a critical and ethical analysis on the treatment that clinicians have been providing to MCS patients.

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Fins argues that recent studies have shown that the error rate of patients diagnosed with vs but who are actually MCS patients is up to 40 % (17). An error rate like this would be inconceivable in any other field of medicine (18). The reasons for this misdiagnosis are multifactorial (17). The behaviors that patients manifest in states of unconsciousness are episodic, intermittent, and, in many cases, not captured in a single exam. If the family sees some behavior and only informs the nursing staff, it is likely that this will not be subject to observation, especially when the patient is in the medical center where he/she was definitively diagnosed with vs.

Fins' works attempt to demonstrate through neuroimaging that the vs can turn into an MCS before becoming permanent. The MCS *per se* is never questioned. Fins attempts to contextualize these patients within the range of conditions that constitute disorders of consciousness and refine it against the most recent category MCS. As I have pointed out in several articles, (8,14,17) the MCS is easily confused with the vs, although there are profound biological differences between these two stages. The difference is fundamental; biologically, the brains of patients in an MCS have the capacity for the integrative function, which is the basis of consciousness, unlike patients in a vs who have already lost it.

Fins also describes two crucial works that determine the level of communication in MCS patients. The first work shows, using fMRI, that when receiving a painful stimulus, patients in a vs exhibit limited brain activity in the primary sensory area, that is, in the first station on the way to the brain network, but without activity in the brain network as a whole (19).

On the other hand, Dr. Nicholas Schiff's works, using the same neuroimaging techniques, reveal that when patients in an MCS hear their family members reading short stories to them, all the neural networks of language activate. Schiff concludes that minimally conscious patients are not simply receiving the auditory stimulus, but that the entire neural network of language processes it (20). Strikingly, the research team discovered that when the recording of the same text is played backward (which makes it unintelligible), the

same activation of the language network is not observed, suggesting that MCS patients respond to the syntax and grammar of the language in a way that patients in a vs cannot (21-22).

The difference between these two types of patients is that in an MCS, we could advance in re-establishing functional communication, while in the irreversible permanent vs, any type of communication is impossible.

Bioethical implications

- *Challenges in the face of non-maleficence*: Every patient has the right to an adequate clinical diagnosis. We are aware that it is not easy to make a good diagnosis in MCS patients. However, clinicians must make every effort and use all available means and knowledge to reduce uncertainty concerning the diagnosis, prognosis, and rehabilitation of patients with disorders of consciousness. From bioethical principlism, we would be violating the highest principle that governs health workers: non-maleficence (1).

- *Do not abandon patients*: When a patient is misdiagnosed as vegetative, it seems like the medical team loses interest in him/her. It is almost like calling him/her a "non-recoverable patient," which means that acute treatment centers do not start or stop treatment or even make these patients organ donors before they are allowed to demonstrate their potential to recover (1).

- *Right to treatment*: Fins published in Nature how the rehabilitation of patients in a MCS could be:

bilateral deep brain stimulation in the intralaminar nucleus of the thalamus could produce an improvement in cognitively mediated functions, such as language and control of the limbs, and that the ability to feed orally was recovered in a minimally conscious patient who, before stimulation, was unable to communicate and who relied on a tube for feeding (23 p601).

- *Futile or unnecessary treatments*: Futile comes from the Latin *futillis*, which means pointless and is a synonym of vain, useless, and sterile (24). Ultimately, it means that treatment is irrelevant to the consequences. Futility is twofold since, on the one hand, it implies the implementation of therapeutic measures that would be useless and their repercussions (giving

false hope to the family, increasing institutional costs, among others), and on the other, the dreaded prolongation of the agony, which is undoubtedly much more severe. Are we providing ineffective treatments to minimally conscious patients? What Fins maintains is that the distinction between the vs and the MCS is that the objectives must be different because the conditions are different. For example, we can advance in the restoration of functional communication as a goal in an MCS, which is not achievable in the irreversible permanent vs, assuming the diagnosis is correct. Therefore, there is a probability that we give unnecessary treatments to patients in a vs and not to patients in a MCS, for whom I consider all possible means to restore their condition should be increased.

- *Quality vs. quantity*: Could we affirm that patients in an MCS state have a poor quality of life? How do we measure it? Who or who determines it? Is the quality of life of a patient in a MCS so poor that dying is preferable to continuing to live? The problem with the concept of quality of life is that it is tough to define since it is not an intellectual or objective concept. Instead, it is an aspiration or ideal that can only be realized in a specific historical, social, and personal context. It is necessary to develop a concept of quality of life that does not relativize the value of people based on merit, rank, or social utility (25).

- *Communication*: One way to abandon a patient is by limiting communication with him/her or with his/her close relatives or representatives. For Dr. Ara, communication between the doctor and the patient or whoever is representing him/her must be truthful, understandable, progressive, and sensitive, providing the necessary information so that the latter can decide. When communicating, the doctor should try to avoid prejudices about the treatment and the quality of life in these situations of disability (26-27).

- *Returning to Terry*: The fundamental difference between patients like Terry Schiavo (as well as Karen Quindlan) and Terry Wallis is that Schiavo suffered anoxic brain damage in 1990, while Terry Wallis suffered traumatic brain damage in 1984. Several studies confirm that damage from anoxia has a much worse prognosis than

traumatic brain damage and that those who spend more than three months in a vs due to anoxia will remain vegetative forever. Fins says that

Terry Wallis, on the other hand, spent years without being evaluated by anyone. Schiavo received deep brain stimulation as part of a Medtronic company clinical trial in the early 1990s, without regaining any level of consciousness. Wallis, on the other hand, spontaneously developed signals that he connected with the environment. Terry Schiavo was in a vegetative state. The motor responses were reflexes. There was no change or progress in his brain state, and it can be said that his brain was disintegrated, that it did not function as an integrated whole (1 p42).

However, the ethical treatment that was given to the two cases was different: both Quindlan's and Schiavo's (due to their permanent vs) representatives resort to the courts to obtain a dignified death for their loved ones arguing that "They would let them die with dignity and in peace." Meanwhile, Fins thinks that cases like Terry Wallis and thousands of others that are diagnosed with MCS must be brought to the courts to ensure that all efforts are made for these patients to recover their life in society in the best possible way:

But Wallis, unlike Schiavo, emerged in 2003 gaining coherent communicative functionality, and continues to improve to this day, accumulating new layers of memories in his memory, gaining capacity and recovering the sense of time. Your brain is being functionally reintegrated, in the sense that it can now reassemble neural networks. This dynamic, this brain plasticity constitutes the most notable difference between the vegetative state and the state of minimal consciousness (1 p43).

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