

Editorial:

The Perilous Vegetative State

Lawrence R. Huntoon, M.D., Ph.D.

In the arena of bioethics, no diagnosis has caused more battles than the persistent vegetative state (PVS).

The term itself made its debut in 1972.¹ It is defined as "...a clinical condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic functions."²

PVS is one of the most devastating diagnoses that patients and their families face. Unfortunately, misdiagnosis is all too common. Various studies report rates of misdiagnosis ranging from 18³ to 43 percent.⁴ One of the most common errors was failure of the physician to take into account that the patient was either blind or had severe visual impairment. Visual tracking is one of the earliest signs that a patient is emerging from a vegetative state. Patients who are blind (often owing to neurological damage), of course, are not capable of visual tracking.

The cognitive abilities of some patients who have been misdiagnosed as having PVS are astounding. A review article on PVS discussed the findings of one study, done in a rehabilitation unit, as follows: "The level of cognitive functioning present in this misdiagnosed group at the time of discharge was considerable: 60 percent were oriented in time, place and person; 75 percent were able to recall a name after 15 minutes delay; 69 percent were able to carry out simple mental arithmetic; 75 percent were able to generate words to communicate their needs; and 86 percent were able to make choices about their daily social activities."⁵

Despite the unacceptable rate of misdiagnosis, a patient once given the diagnosis of PVS enters into the perilous arena where, absent a written directive, others will decide his fate. On one side, the right-to-die and pro-euthanasia forces trumpet "death with dignity" and loss of quality of life as their battle cry. On the other side, right-to-life advocates hold fast to the sanctity of life and protection of the vulnerable and severely disabled. Ultimately, the drama plays out in a courtroom, where the outcome determines whether food and water will be withheld. Taking center stage in this life-and-death struggle is the somewhat nebulous concept of awareness.

Awareness of self and of environment, or lack thereof, is the feature that distinguishes PVS (i.e. lack of awareness) from minimally conscious state (MCS). The minimally conscious state is defined as: "a condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated."⁶ The distinction

between PVS and MCS is important because the MCS is evidence of improvement. MCS patients may respond to and require more aggressive therapy than that provided to PVS patients, and may ultimately have a better outcome.

Awareness, unfortunately, is very difficult to assess. It is highly subjective and highly dependent on the skill and experience of the examining neurologist, the time spent examining the patient at the bedside, the physical capabilities of the patient to provide a response, and a multitude of other factors.

A definition that limits the presence of awareness to only those patients who can demonstrate some type of response that the examining neurologist can see or hear fails to take into account those patients who are aware but unable to respond. Such conditions include, most notably, the locked-in syndrome, which is caused by a brainstem infarct that results in complete paralysis. Often the only movements that locked-in patients can make are slight eye movements or opening and closing of the eyes. Sometimes, locked-in patients are not even capable of making eye movements. Yet, their cerebral cortex is undamaged and patients are fully alert and aware of themselves and their surroundings. Their cognitive abilities remain intact. Using the behavioral definition of awareness, locked-in patients who are not capable of any movement, including eye movements, would be mislabeled as being "unaware" of self and environment.

The technology needed to assess "internal awareness" (awareness without behavioral response) is still in its infancy. A study published in February 2005 revealed activation of cortical networks in MCS patients using functional MRI mapping. The study reported: "These findings of active cortical networks that serve language functions suggest that some MCS patients may retain widely distributed cortical systems with potential for cognitive and sensory function despite their inability to follow simple instructions or communicate reliably." Other studies have reported that certain cognitive evoked potentials are useful in predicting awakening from coma.⁸

Courts, of course, are poorly equipped to understand the complex issues that often center on medical semantics and consensus definitions used to describe a continuum of awareness in neurologically devastated patients.

With respect to the patient's presumed wishes, hearsay is often the deciding factor. Those who talk casually over a few beers would be well advised to watch what they say, as their words may lead to unimagined consequences if they ever are diagnosed as being in a PVS. Was it after the fourth or fifth beer that he said he wanted no tubes and a "DNR" tattooed on his chest?

The process used to make such decisions as whether to withdraw nutrition and hydration from severely disabled PVS patients in countries that have socialized medicine is often entangled in conflicts of interest. In Great Britain, for example, the government argues for both sides in court. All requests to withdraw food and water from PVS patients require the approval of the High Court. The requests typically come from the National Health Service, which is responsible for paying the high cost of caring for such patients. An official solicitor is appointed by the government to represent the interests of the patient. One hundred percent of the cases that go before the court are approved for termination of sustenance.⁹

No one can say exactly how much awareness a patient must display in order to qualify for continued food and water. Is a smile in response to a mother's kind words sufficient? Is visually tracking a balloon over a sustained period enough? What about grimacing and turning one's head away from an unwanted swab around the mouth? What happens if the patient is tired from physical therapy or a bath when the doctor comes by to evaluate?

Maybe it's just too much energy for some to play the game and respond when asked to perform. There ought to be some way to warn such patients: You have the right to remain silent and not respond, but if you choose not to respond or are unable to respond, your food and water may be taken away by a court of law.

Lawrence R. Huntoon, M.D., Ph.D., is a practicing neurologist and editor-in-chief of the *Journal of American Physicians and Surgeons*. Contact: editor@jpands.org.

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