

# ETHICAL ISSUES IN THE PERSISTENT VEGETATIVE STATE PATIENT

**James L. Bernat, MD**

Dartmouth-Hitchcock Medical Center  
Lebanon, NH

The persistent vegetative state (PVS), a chronic neurological disorder of consciousness characterized by wakefulness without awareness, is a tragic and ironic artifact of modern medical technology. Patients reach a PVS after suffering a pathological process that has produced widespread damage to cerebral cortical neurons, thalamic neurons, or the white matter connections between the cortex and thalamus, but that largely spares brain stem and hypothalamic neurons. Common etiologies of acute PVS are traumatic brain injury, stroke, and neuronal hypoxia and ischemia suffered during cardiopulmonary arrest.

The ethical issues in managing the PVS patient arise from the meaninglessness of a chronically non-cognitive existence and the desire of families and other surrogates to make medical decisions about continued life support that respect the patient and are consistent with those the patient would have made.

## History

In 1972, Bryan Jennett and Fred Plum coined the name "persistent vegetative state" and defined its essential clinical features (1). Jennett and Plum observed that many patients rendered comatose from head trauma and other brain injuries progressed from a typical eyes-closed comatose state after several weeks to an eyes-open unresponsive and unaware state. Although their sleep-wake cycles returned, these patients appeared to be entirely unaware of themselves and their environment, despite their wakefulness. To the fullest extent determinable, PVS patients appeared incapable of thinking, remembering, feeling, or experiencing. With adequate medical and nursing care, they could remain in this state for many months or years.

The diagnosis and prognosis of PVS have reached public attention through several landmark high court rulings involving termination of life-sustaining treatment, most notably the cases of Karen Ann Quinlan in the 1970s, Nancy Beth Cruzan in the late 1980s, and the current case of Terri Schiavo (2,3). Because of nagging questions about the medical issues of the PVS patient, the Multi-Society Task Force on PVS was impaneled in 1991 and comprised of representatives from the American Academy of Neurology, the American Neurological Association, the American Association of Neurological Surgeons, the American Academy of Pediatrics, and the Child Neurology Society. Their report in a two-part article in the *New England Journal of Medicine* in 1994 contained the most authoritative medical facts on PVS up to that time (4). The American Academy of Neurology drafted a practice parameter on PVS based on this document (5). In 1996, the British Medical Association published guidelines on diagnostic criteria for PVS that were similar to those of the Task Force (6). The entire subject of PVS was reviewed more recently in a journal article (7), book chapter (8), and in a full-length book (9).

## Definition and Criteria

The Multi-Society Task Force on PVS operationally defined the vegetative state as "a condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of brain stem and hypothalamic autonomic functions." A vegetative state may be a transient stage in the recovery from a diffuse brain insult or may be a chronic condition. The Task Force defined the persistent vegetative state as a vegetative state lasting longer than a month (4).

The Task Force stated that the diagnostic criteria for PVS are that patients:

1. exhibit no evidence of awareness of themselves or their environment; they are incapable of interacting with others.
2. exhibit no evidence of sustained, reproducible, purposeful, or voluntary behavioral response to visual, auditory, tactile, or noxious stimuli.
3. exhibit no evidence of language comprehension or expression.
4. exhibit intermittent wakefulness manifested by the presence of sleep-wake cycles.
5. have sufficiently preserved autonomic functions of the hypothalamus and brain stem that enable them to survive given medical and nursing care.

6. exhibit bowel and bladder incontinence.
7. have some preserved cranial nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes.

The repertoire of behaviors of the PVS patient include:

1. intact sleep-wake cycles.
2. blink, move eyes.
3. swallow.
4. vocalize sounds.
5. breathe spontaneously.
6. grimace
7. move limbs.
8. make unsustained visual pursuit for a few seconds.

### **Consciousness**

Patients in PVS are usually classified as unconscious, but the use of the term “consciousness” in this context is potentially misleading. In their famous monograph, Fred Plum and Jerome Posner pointed out that normal consciousness has two necessary components: 1) wakefulness or alertness, served by the ascending reticular activating system of the brain stem and its thalamic projections; and 2) awareness of self and environment served by the cerebral cortex and its connections with itself, the thalami, and subcortical structures (10).

Patients in a typical eyes-closed coma are classified as unconscious because they lack both the wakefulness and awareness components of consciousness. Patients in PVS possess wakefulness but lack awareness; thus they possess only one component of consciousness. But because both components are necessary for normal consciousness, and the absence of awareness is the most relevant characteristic of unconsciousness, PVS patients reasonably may be classified as unconscious. That the PVS patient possesses a relatively intact alerting mechanism is of no functional value in the absence of the capacity for awareness and cognitive life.

### **Limits of Diagnostic Certainty**

How can examiners be certain that PVS patients are utterly unaware and incapable of suffering or of having any other cognitive experience? Is it possible that PVS patients are aware but we simply lack the means to detect evidence of their cognitive life, and thus erroneously deny its presence? (11).

There is a fundamental, irreducible biological limitation in knowing whether another person possesses a conscious life. No person can directly experience the consciousness of another. We can ascertain another's quality and quantity of consciousness only by inference. We interact with others and infer in them a particular level of conscious life on the basis of the quality and quantity of their responses to our stimuli. If the patients' responses to our stimuli are markedly deficient or absent, we may reasonably infer a reduction in the quality and quantity of their consciousness.

Some neurologists have made a false diagnosis of PVS by asserting that their awareness and cognitive life was absent when, in fact, it was present. Two studies of patients purportedly in PVS who then were carefully examined by experienced clinicians showed that 37% and 43% of the patients actually were aware and therefore not in a PVS (12,13). It is probable that some of these patients previously had been in a PVS, but the PVS had improved over time, and evidence for their awareness was not detected until later when they were carefully re-examined. Thus, it is essential for neurologists to carefully examine patients with impaired consciousness for any evidence of awareness before reaching a diagnosis of PVS (8).

Despite the irreducible biological limitation of ever knowing with certainty, it is reasonable to conclude that properly diagnosed PVS patients are incapable of conscious experience, including the experience of pain or suffering, based on three lines of empirical evidence.

First, the motor responses exhibited by PVS patients to verbal, visual, auditory, somasthetic, or noxious stimuli achieve no greater level of complexity or meaning than primitive involuntary subcortical reflexes seen in unequivocally comatose patients. PVS patients respond to verbal and auditory stimuli by opening or moving their eyes. They follow no commands. Their eyes and head can follow a visual stimulus briefly, but they show no signs of purpose, attention, planning, recognition, or sustained optical tracking or visual fixation. In response to noxious

or somasthetic stimuli, they assume stereotyped motor postures and have increased autonomic activity. Thus, the repertoire of PVS patients' motor responses to stimuli, while not conclusively excluding the presence of cognitive life, shows no convincing evidence of it.

Second, PVS patients have markedly diminished rates of cortical glucose consumption suggesting such severe and diffuse impairment of cortical function that awareness is ablated. Measurement of regional cerebral metabolic rate of glucose consumption (rCMRglc) by positron emission tomography (PET) scanning is a reliable indicator of the level of cerebral cortical metabolism. The values of rCMRglc in PVS patients, however, are depressed to less than one-half the normal values, a range seen otherwise only in unequivocally comatose patients and in normal individuals placed in the deepest planes of general anesthesia, both of which states are indicative of a markedly reduced level of cerebral neuronal functioning (14). Thus, the cerebral cortical functioning in PVS patients is analogous to that of normal patients in deep general anesthesia, whom all agree are insensate and utterly incapable of experience.

The demonstration that resting cerebral neuronal metabolism is abnormally depressed in PVS patients does not necessarily mean that it might not be appropriately increased in response to stimulation. In a series of studies of auditory processing in PVS, Steven Laureys and colleagues used PET scanning to test for increases in regional cerebral blood flow and cerebral metabolism in response to auditory stimulation. They found that auditory click stimuli activated bilateral auditory cortices but did not activate the contralateral auditory association cortices, the posterior parietal association area, the anterior cingulate cortex, or the hippocampus of patients in PVS. They concluded that the activation of auditory cortices in isolation, without the multimodal and limbic areas, could not lead to the integrative processes believed to be necessary for awareness. In a subsequent study, they showed evidence for the return of normal thalamocortical conductivity after recovery from PVS (15-17). Some cerebral regions can retain partial functions but the integrated network necessary for awareness is not present in PVS (18,19).

The final line of evidence is based on studies of PVS pathology and on our understanding of the anatomy and physiology of consciousness. Pathological studies have revealed diffuse cortical laminar or pseudolaminar necrosis or widespread bilateral thalamic necrosis in the majority of nontraumatic cases of PVS and diffuse axonal injury in those cases in which PVS was caused by head trauma (20,21) Based on our understanding of the anatomical structures necessary for awareness, we would expect the extent and severity of these lesions in the cerebral cortex to produce a disorder of consciousness so profound that PVS patients could not retain any degree of awareness of themselves or the environment.

### **Prognosis**

Whether a patient rendered vegetative after head trauma or cardiopulmonary arrest is likely to recover awareness is a critical question that the physician must answer before devising a treatment plan in accordance with the patient's and family's wishes and within the standards of good medical care. Any discussion of the ethical and legal issues surrounding decisions to either continue or stop life-sustaining treatment in the PVS patient must be preceded by the physician's clear statement of the patient's probability of recovering awareness.

The Multi-Society Task Force on PVS carefully studied the existing data on the prognosis of acute PVS. From this data, the task force was able to formulate three general rules concerning the prognosis of PVS patients: 1) the probability for recovery of awareness is greater for patients who develop PVS following head trauma than for those who develop PVS following stroke or hypoxic-ischemic brain damage; 2) children recover better than adults after suffering equivalent brain injuries; 3) early prognostic signs are unreliable predictors of recovery of awareness (4).

Reliable probabilities for recovery to a state of awareness are difficult to discern from existing published studies for several reasons. Most studies of prognosis for acute PVS have a retrospective rather than a prospective design, thereby creating a bias. Most studies failed to provide confidence limits for predictive values, thus limiting the positive predictive value of an alleged prognostic sign when the number of patients studied was small. Outcome measures were unclear in many of the studies because PVS was not distinguished from severe disability or nonsurvival.

Finally, and most importantly, in all studies, many patients were provided less than maximal medical treatment when their physicians judged that they had a poor prognosis. Although such decisions may have been correct medically and ethically, they make poor science because the patients' actual pattern of recovery with full

treatment cannot be known. Publishing outcome data that incorporates the prognosis of these patients produces the fallacy of the self-fulfilling prophecy (22).

These facts must be borne in mind when interpreting survival data on patients in PVS collected by the Task Force which found that PVS carried a 70% mortality at 3 years and a 84% mortality at 5 years (4). These data do not necessarily reflect the natural history of maximally-treated PVS but more likely reflect the experiential history of PVS, including the reality that life-sustaining treatment was eventually withheld from many patients.

Despite these categorical limitations, the Multi-Society Task Force on PVS made several general prognostic conclusions. The Task Force found that recovery of awareness from traumatic PVS is rare after one year. Recovery of awareness after nontraumatic (cardiopulmonary arrest, stroke) PVS was rare after three months and exceedingly rare after one year. Although functional recovery in children was better than it was in adults with comparable injuries, the majority of those few PVS patients recovering awareness after six months in traumatic PVS or after three months in nontraumatic PVS, still sustained severe disability with quadriplegia, pseudobulbar palsy, and dementia (4).

### **Treatment**

Determining the appropriate level of medical treatment for the PVS patient requires the consideration of: 1) medical issues of diagnosis and prognosis; 2) ethical issues including discerning the previously expressed wishes of the patient and explaining the basis for the surrogate to reach a decision; and 3) legal issues of state laws governing decision making for incompetent patients.

#### Medical Issues

Treatment of the PVS patient requires the same comprehensive medical and nursing care as in the comatose patient. Nutrition and hydration are provided by gastrostomy tube, with nutritional requirements calibrated according to metabolic demands. Most PVS patients are not ventilator-dependent, but most require tracheostomy tubes for airway protection. Nursing care must be vigilant with excellent skin care and frequent turning to prevent decubitus ulcers, and frequent passive range of motion exercises to prevent contractures. Pulmonary toilet is necessary to prevent pneumonia. Many patients develop recurrent pulmonary and urinary tract infections that require courses of antibiotics. For most medically-stable PVS patients, however, the only ongoing life-sustaining therapy (LST) they require is artificial hydration and nutrition by gastrostomy tube. The Task Force concluded that, as of 1993, there were insufficient controlled data showing efficacy to recommend coma-stimulation therapies for PVS patients (4).

#### Ethical Issues

Despite the fact that the PVS patient is decisionally incapacitated, respect for the patient's autonomy remains an important goal. The primary factor determining the level of medical treatment for an incompetent patient is the patient's personally expressed wishes for treatment in this situation. The surrogate decision maker should strive to identify and follow the patient's prior treatment directives by following advance directives and other specific instructions to the extent that they clearly apply to the current situation. Without specific expressed wishes, the surrogate should try to reproduce the decision that the patient would have made, were the patient somehow able to decide (the standard of substituted judgment). Such a decision may not necessarily represent the decision that the surrogate decision maker would personally choose if in the patient's situation. In the absence of evidence of the patient's prior wishes, the surrogate should balance the burdens resulting from continued treatment against the benefits accrued from continued treatment, and follow a best interest standard

In the absence of specific advance directives, family members may explain to the physician the informal previous statements made by a patient. For example, patients may have told a family member that they never wanted to be kept alive as "a vegetable" and insisted on being allowed to die rather than to sustain a hopeless and meaningless existence maintained "on machines." More uncommonly, patients may have expressed wishes for continued aggressive treatment in this state. Physicians and surrogate decision makers should explore the exact circumstances of these discussions to determine whether or not this information is relevant and reliable.

The best interest standard must be used when there is no knowledge of how the patient would have decided but at best it is problematic. The benefit of continued treatment is extending the patient's life. The burdens of treatment in PVS are a matter of debate. Some scholars have argued that PVS patients cannot have burdens caused by continued treatment because they are permanently noncognitive and thus are incapable of any experiencing anything (2). Although it is certainly true that PVS patients have no awareness of their plight, their

continued vegetative life represents a clear emotional and financial burden on their family and loved ones. This burden of dependency is precisely what the majority of older and chronically ill patients strive to avoid. Because patients almost universally do not wish to be a burden to their loved ones without the countervailing benefits of conscious experience, I believe it is most reasonable to conclude that PVS patients incur a burden of treatment despite being unaware of it.

Physicians and surrogates should remain cognizant of the limitations and risks in employing a best interest standard in deciding about the level of treatment in PVS patients. When a healthy surrogate employs a quality-of-life assessment on a severely disabled patient, there is always a risk of choosing under-treatment. Surrogates may undervalue the continuation of a vegetative existence that, for religious or other personal reasons, some patients may believe to be beneficial (23). Physicians should proceed with caution whenever surrogates employ a best interest standard.

### Medicolegal Issues

High court judicial decisions in the famous cases of Karen Quinlan and Nancy Cruzan provided important legal precedents for surrogates to withhold life-sustaining treatment (LST) in PVS patients. Both Quinlan and Cruzan were young women who developed PVS following diffuse hypoxic-ischemic neuronal injuries and in both cases, their parents wished to discontinue their life-sustaining therapy to allow them to die because they believed refusing treatment was what the young women would have wanted for themselves. The LST in question was the ventilator for Quinlan and the feeding gastrostomy tube for Cruzan. Their brief and tragic lives were memorialized in precedent-setting medicolegal decisions permitting surrogates acting on their behalf to discontinue LST.

*Quinlan* was a landmark ruling in the 1970s because it first permitted a legally-authorized surrogate to refuse LST on behalf of an incompetent patient even if the patient would die as a result. *Quinlan* initiated a sea change in medical practice by asserting that physicians were permitted to withdraw LST from a PVS patient once it was refused by a legally authorized surrogate. *Quinlan* clarified that if the patient died as a result of stopping LST, there could be no enforceable charge of homicide because the patient would have died of her pre-existing disease (24).

*Cruzan* was important in 1990 because the United States Supreme Court for the first time found a constitutional basis for all citizens unconditionally to refuse LST or any other therapy they did not want, including artificial hydration and nutrition, even if the patient died as a result. They asserted that this right is not extinguished by patient incompetence but is transferred to a legally authorized surrogate decision maker to exercise on behalf of the incompetent patient. They specifically stipulated that life-prolonging artificial hydration and nutrition was a type of therapy that a patient could refuse via a surrogate (25).

The recent Florida case of Terri Schiavo has received widespread public attention largely because of the poignancy of the dispute between her husband and her parents over whether she would wish to continue to receive artificial hydration and nutrition by gastrostomy tube after being in PVS for 14 years without hope for recovery. Trial and appellate courts, after weighing the evidence, have ruled that her husband can best represent her wishes in this regard. He claims that she would not wish to continue to receive artificial hydration and nutrition with no realistic hope for recovery. The courts relied on the constitutional precedent set in *Cruzan*. Once her husband, acting on her behalf, refused further continuation of her feeding tube, a political process was unleashed by the "right to life" lobby that led the Florida legislature and the governor to enact and sign a special law ("Terri's law") requiring the provision of her artificial hydration and nutrition to continue. The Florida Supreme Court recently struck down this law as an unconstitutional intrusion of the legislature on judicial prerogative, a decision that as of December 2004 is under appeal (26).

The principal legal precedent for withholding artificial hydration and nutrition from a PVS patient in the United Kingdom was *Airedale N.H.S. Trust v. Bland*. The House of Lords ruled that it was lawful for a physician to cease tube feedings for a PVS patient even though this act would lead invariably to the patient's death and (most remarkably) that the physician's intent in doing so was to kill the patient. The *Bland* ruling created a firestorm of controversy that persists to the present time (27).

As a procedural matter, it is often desirable to request an oversight consultation from the hospital ethics committee in cases in which the physician is considering ordering a level of treatment that will predictably shorten the life of a non-terminally ill patient. The hospital ethics committee should ascertain: 1) that physicians have

reached a clear diagnosis and prognosis, 2) that advance directives, if available, are followed, and 3) that the previous wishes of the patient and the present wishes of the family or other surrogate are recognized and followed.

In 2004, Pope John Paul II, in an allocution that some commentators claimed was in reaction to the publicity surrounding the *Schiavo* case, stated that feeding tubes in PVS patients were “not a medical act” and that their routine use “always represents a natural means of preserving life.” Therefore, the use of feeding tubes in PVS patients constitutes “normal care” and therefore the removal of feeding tubes comprises “euthanasia by omission.” (28). The reaction to this allocution by American Roman Catholic bioethicists was one of puzzlement because they had clearly understood Catholic teaching to classify tube feeding of PVS patients as “extraordinary” care that could be withheld. But now the Pope has explicitly classified such treatment as “ordinary” and therefore obligatory (29,30). It remains to be seen how this matter will be sorted out in Catholic hospitals where American citizens have a constitutional right to refuse feeding tubes.

### **The “Minimally Conscious State”**

Disorders causing diffuse and widespread cortical, subcortical, or thalamic damage comprise a clinical spectrum of severity from a mild encephalopathy to brain death. A PVS is created when the ascending reticular activating system is spared but the damage diffusely disconnects or destroys the cerebral cortex or thalami. Just as patients often evolve from coma to PVS several weeks following the brain insult, some patients may recover from PVS weeks or months later to enter a state of profound neurological dysfunction but in which awareness is present, at least to some extent, and at some times. Such a state recently has been called the minimally conscious state (MCS).

Although patients in this condition have been described for years, classifying them as in a MCS is a product only of the past several years, primarily in the head trauma rehabilitation literature. The Aspen Neurobehavioral Conference recently impaneled a task force to study the available literature and seek consensus-based recommendations regarding the diagnosis, prognosis, and management of the MCS (31). The report of the Aspen Neurobehavioral Conference defines the MCS as “a condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated.” They require that patients in MCS show “limited but clearly discernible self or environmental awareness on a reproducible or sustained basis” by demonstrating one or more behavior, including, following simple commands, gesturing yes/no answers to questions, intelligible verbalizations, purposeful behavior, appropriate smiling or crying, reaching for and touching objects, and pursuit eye movements (31,32).

Like the PVS, the MCS may be seen as a transient stage in the recovery after severe head injury or other brain insult or it may be a permanent condition. With continued recovery, patients may emerge from MCS to a higher state of consciousness. Evidence for this improvement is present if the patient can engage in functional interactive communication or use two different objects functionally. The prognosis of the MCS has not been studied sufficiently to make recommendations, other than to say it is better than the PVS (31,32). It is obviously critical for clinicians to distinguish the PVS from the MCS.

Some scholars have feared that carving out a category called MCS from the continuum of global neuronal damage has been motivated by an ideological desire to devalue the lives of MCS patients and to facilitate withdrawal of their life-sustaining treatment. Defenders claim this is untrue and they just wish to describe and classify neurological conditions. Time will determine whether the critics’ fears are realistic or an overreaction. In the interim, neurologists should follow ideal practice behaviors by assuring the following: 1) they examine patients with diffuse brain damage carefully; 2) they state only what they observe and can know of the conscious lives of such patients; and 3) that they follow accepted guidelines governing decisions about their treatment (33).

Recent studies of cerebral processing in MCS with PET and cognitive evoked potentials show diminished cerebral metabolism to below half of normal values but widespread cortical activation after hearing the patient’s name and preservation of the P300 cognitive potential (34,35).

The importance of distinguishing the MCS from the PVS was illustrated in the tragic medicolegal case of Nancy Jobes. Mrs. Jobes suffered pelvic fractures in an automobile accident killing her four-month-gestation fetus. She then suffered a cardiopulmonary arrest and consequent diffuse hypoxic-ischemic brain damage during surgery to remove the dead fetus. Thereafter she was in what was diagnosed as a PVS. After surviving five years in this state, her husband asked her physicians to remove her feeding tube to permit her to die, an act he claimed was in

accordance with her prior stated wishes. In the ensuing litigation, she was examined by four prominent neurologists with recognized expertise in disorders of consciousness to determine if indeed she was in a PVS (36).

Following their neurological examinations, two of the expert neurologists concluded that she was in a PVS and the other two that she was essentially in a MCS (although they did not use that term). Ironically, to resolve the conflicting opinion, the judge examined Mrs. Jobses himself and pronounced her to be in a PVS and approved the petition to remove her feeding tube. I have critiqued several aspects of this case (37). The Jobses case underscored the clinical difficulty in performing and interpreting neurological examinations in severely brain damaged patients, and the ambiguity arising when even a skilled examiner tries to perceive minimal evidence of awareness in a severely brain-damaged patient.

The judge concluded that the two neurologists who found Mrs. Jobses to be aware had lost their objectivity in the matter because of their strong moral beliefs that it was wrong for such patients to have feeding tubes removed, a factor he said caused them to see evidence of awareness where none existed. However, I believe a more plausible explanation is that she was in a MCS on good days and in a PVS on bad days. Such a so-called remitting vegetative state (38) may constitute a baseline MCS with minimal awareness that, when complicated by metabolic or toxic factors such as the effect of medications, fever, infection, or electrolyte imbalance, descends temporarily to a PVS.

The most recent nationally publicized MCS case is that of Robert Wendland. This middle-aged man developed a chronic MCS from head trauma suffered during a motor vehicle accident seven years earlier. He had completed no advance directives. At dispute over his level of treatment are his wife and his mother. His wife claims he would want his gastrostomy feeding tube removed to allow him to die, because of her belief that he never wished to live in such a state. By contrast, Wendland's mother wishes to maintain his gastrostomy tube feedings to keep him alive, claiming that he would wish to live under these circumstances. In its national publicity, the case also has become politicized. "Right-to-die" advocates including some medical ethicists and the American Civil Liberties Union supported his wife's position and disability-rights advocates including other medical ethicists supported his mother's position. California's highest court mandated continued treatment (39,40). The dispute most likely could have been prevented if Wendland had executed advance directives prior to his injury.

### **Acknowledgement**

Portions of this article were adapted, with permission of the publisher, from Bernat JL. Ethical Issues in Neurology, 2<sup>nd</sup> ed. Boston: Butterworth-Heinemann, 2002:283-305.

### **References**

1. Jennett B, Plum F. Persistent vegetative state after brain damage: a syndrome in search of a name. *Lancet* 1972;1:734-737.
2. Beresford HR. Legal aspects of termination of treatment decisions. *Neurol Clin* 1989;7:775-788.
3. Weir RF, Gostin L. Decisions to abate life-sustaining treatment for nonautonomous patients: ethical standards and legal liability for physicians after *Cruzan*. *JAMA* 1990;264:1846-1853.
4. Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state. Parts I and II. *N Engl J Med* 1994;330:1499-1508, 1572-1579.
5. American Academy of Neurology Quality Standards Subcommittee. Practice parameters: assessment and management of patients in the persistent vegetative state (summary statement). *Neurology* 1995;45:1015-1018.
6. British Medical Association. BMA Guidelines on Treatment Decisions for Patients in Persistent Vegetative States. London: British Medical Association, 1996.
7. Zeman A. Persistent vegetative state. *Lancet* 1997;350:795-799.
8. Bernat JL. Ethical Issues in Neurology, 2<sup>nd</sup> ed. Boston: Butterworth-Heinemann, 2002:283-305.

9. Jennett B. *The Vegetative State: Medical Facts, Ethical and Legal Dilemmas*. Cambridge: Cambridge University Press, 2002.
10. Plum F, Posner JB. *The Diagnosis of Stupor and Coma*, 3<sup>rd</sup> ed. Philadelphia: F.A. Davis Co, 1980.
11. McQuillen MP. Can people who are unconscious or who are in the persistent vegetative state feel pain? *Issues Law Med* 1991;6:373-383.
12. Childs NL, Mercer WN, Childs HW. Accuracy of diagnosis of persistent vegetative state. *Neurology* 1993;43:1465-1467.
13. Andrews K, Murphy L, Munday C, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *Brit Med J* 1996;313:13-16.
14. Levy DE, Sidtis JJ, Rottenberg DA, et al. Difference in cerebral blood flow and glucose utilization in vegetative versus locked-in patients. *Ann Neurol* 1987;22:673-682.
15. Laureys S, Faymonville M-E, Degueldre C, et al. Auditory processing in the vegetative state. *Brain* 2000;123:1589-1601.
16. Laureys S, Faymonville ME, Luxen A, et al. Restoration of thalamocortical conductivity after recovery from persistent vegetative state. *Lancet* 2000;355:1790-1791.
17. Laureys S, Faymonville ME, Peigneux P, et al. Cortical processing of noxious somatosensory stimuli in the persistent vegetative state. *NeuroImage* 2002;17:732-741.
18. Schiff ND, Ribary U, Moreno DR, et al. Residual cerebral activity and behavioural fragments can remain in persistently vegetative brain. *Brain* 2002;125:1210-1234.
19. Kobylarz EJ, Schiff ND. Functional imaging of severely brain-injured patients. *Arch Neurol* 2004;61:1357-1360.
20. Kinney HC, Samuels MA. Neuropathology of the persistent vegetative state: a review. *J Neuropathol Exp Neurol* 1994;53:548-558.
21. Adams JH, Graham DI, Jennett B. The neuropathology of the vegetative state after an acute brain insult. *Brain* 2000;123:1327-1338.
22. Becker KJ, Baxter AB, Cohen WA, et al. Withdrawal of support in intracerebral hemorrhage may lead to self-fulfilling prophecies. *Neurology* 2001; 56:766-772.
23. Dresser RS, Robertson JA. Quality of life and non-treatment decisions for incompetent patients: a critique of the orthodox approach. *Law Med Health Care* 1989;17:234-244.
24. Beresford HR. The *Quinlan* decision: problems and legislative alternatives. *Ann Neurol* 1977;2:74-81.
25. White BD, Siegler M, Singer PA, et al. What does *Cruzan* mean to the practicing physician? *Arch Intern Med* 1991;151:925-928.
26. Dresser R. *Schiavo*: a hard case makes questionable law. *Hastings Cent Rep* 2004;24(3):8-9.
27. Keown J. Restoring moral and intellectual shape to the law after *Bland*. *Law Quart Rev* 1997;113:481-503.
28. Shannon TA, Walter JJ. Implications of the papal allocution on feeding tubes. *Hastings Cent Rep* 2004;34:18-20.
29. Editorial. Allowing to die II. *Commonweal*. April 23, 2004:5-6.

30. Hamel R, Panicola M. Must we preserve life? *America* 2004;190:6-13.
31. Giacino JT, Ashwal S, Childs N, et al. The minimally conscious state: definition and diagnostic criteria. *Neurology* 2002;58:349-353.
32. Ashwal S, Cranford R. The minimally conscious state in children. *Semin Pediatr Neurol* 2002; 9:19-34.
33. Bernat JL. Questions remaining about the minimally conscious state. *Neurology* 2002;58:338-339.
34. Laureys S, Perrin F, Faymonville M-E, et al. Cerebral processing in the minimally conscious state. *Neurology* 2004;63:916-918.
35. Boly M, Faymonville M-E, Peigneux P, et al. Auditory processing in severely brain injured patients: differences between the minimally conscious state and the persistent vegetative state. *Arch Neurol* 2004;61:233-238.
36. *In re Jobes*, 108 NJ 394, 529 A2d 424 (1987).
37. Bernat JL. The boundaries of the persistent vegetative state. *J Clin Ethics* 1992;3:176-180.
38. Thomasma DC, Brumlik J. Ethical issues in the treatment of patients with a remitting vegetative state. *Am J Med* 1984;77:373-377.
39. Lo B, Dornbrand L, Wolf LE, Groman M. The *Wendland* case – withdrawing life support from incompetent patients who are not terminally ill. *N Engl J Med* 2002;346:1489-1493.
40. Dresser R. The conscious incompetent patient. *Hasting Center Rep* 2002;32:9-10.

# Ethical Issues in the Persistent Vegetative State Patient

## Key Points

### Definition:

The persistent vegetative state (PVS) is a chronic neurological disorder of consciousness characterized by wakefulness without awareness.

### Pathology:

Widespread damage to cerebral cortical neurons, thalamic neurons, or the white matter connections between the cortex and thalamus, that largely spares brain stem and hypothalamic neurons.

### Etiology:

Traumatic brain injury, stroke, or neuronal hypoxia and ischemia during cardiopulmonary arrest.

### Diagnostic Criteria:

1. no awareness of themselves or their environment; they are incapable of interacting with others.
2. no sustained, reproducible, purposeful, or voluntary behavioral response to visual, auditory, or tactile stimuli.
3. no evidence of language comprehension or expression.
4. intermittent wakefulness manifested by the presence of sleep-wake cycles.
5. sufficiently preserved autonomic functions of the hypothalamus and brain stem that enable them to survive given medical and nursing care.
6. bowel and bladder incontinence.
7. preserved cranial nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes.

### Investigations:

CT and MRI show atrophy later; EEG diffusely but variably slow; evoked potentials not helpful diagnostically; PET shows dramatic decrease in regional cortical glucose metabolism

### Prognosis:

If nontraumatic PVS, very poor chance of regaining awareness after 3 months. If traumatic PVS, very poor chance of regaining awareness after 12 months.

### Treatment:

Gastrostomy tube for nutrition and hydration; tracheostomy tube for airway protection; vigilant nursing care to skin, frequent turning, passive range of motion exercises, pulmonary toilet; insufficient controlled data to recommend coma-stimulation therapies.

### Ethical Issues:

Surrogate decision making is required to determine level of treatment. Surrogates first use the standard of expressed wishes using advance directives. If not possible, use substituted judgment to reproduce decision patient would have made. If not possible, use best interest judgment to balance benefits and burdens of treatment. Ask assistance of hospital ethics committee.

### Medicolegal Issues:

*Quinlan* court (1975) found right to refuse life-sustaining therapy that could be exercised by surrogate. *Cruzan* court (1990) found constitutional basis for surrogate to refuse all forms of therapy including artificial hydration and nutrition. Recent *Schiavo* case (2004) breaks no new legal ground but has been highly publicized with much public misinformation. Pope John Paul II made 2004 allocution stating artificial hydration and nutrition are required in PVS. Impact remains to be seen in American Catholic hospitals.

### Minimally Conscious State:

Definition: a condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated. Diagnosis: limited but clearly discernible self or environmental awareness on a reproducible or sustained basis by demonstrating one or more behaviors, including, following simple commands, gesturing yes/no answers to questions, intelligible verbalizations, purposeful behavior, appropriate smiling or crying, reaching for and touching objects, and pursuit eye movements. Course: may be a transient stage in the recovery after severe head injury or other brain insult or a permanent condition. Medicolegal cases of *Jobes* (1987) and *Wendland* (2002).

Hence, any attempt to discuss ethical issues that surround treatment of people in such states, will have to be an exercise in possibilities, based on the weighing of scientific evidence, where every finding has multiple interpretations. A short description of the persistent vegetative state. It was not until 1972 that Jennett and Plum attempted to describe the clinical features of what is now known as the vegetative state (VS). Consequently, the same authors proposed the concept of a Persistent Vegetative State (PVS) to distinguish patients who remain in a PVS from. When Kampfl and colleagues [9] conducted a magnetic-resonance imaging (MRI) study on 80 patients in a vegetative state they found damage in the corpus. Previously, the term persistent vegetative state (PVS) was used to describe all patients with prolonged disorders of consciousness. PVS has become marked by ethical and medical dilemmas, often, if not always, requiring legal assistance. There are now several cases where patients diagnosed as being in PVS have subsequently regained consciousness. It has, however, become increasingly clear that patients with altered levels of consciousness can exhibit varying levels of awareness. As such, an umbrella term called 'prolonged disorders of consciousness' (PDOC) has been defined by the Royal College of Physicians (RCP) and encompasses patients who have had impaired consciousness of over four weeks in duration. The vegetative state: medical facts, ethical and legal dilemmas / Bryan Jennett. p. cm. Includes bibliographical references and index. Of course many patients in a vegetative state following an acute insult will have been in coma for some time before regaining wakefulness, although some nontraumatic cases may become vegetative after only a day or so in coma. Persistent vegetative state (PVS) was recommended as the term of choice in the 1993 report of the American Neurological Association (20) and in the 1994 statement of the Multi-Society Task Force (21), and it has been widely adopted also by philosophers, lawyers and others outside medicine. As Jennett and Plum (1) stated, the word vegetative itself is not obscure.