

Questioning the Persistent Vegetative State

Kim J. Medis

University of Kansas School of Nursing

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This paper concerns the topic of the Persistent Vegetative State (PVS) and some of the ethical dilemmas surrounding it. PVS is defined as a “condition in which the patient is wakeful but devoid of conscious content, without cognitive or affective mental function” (Smeltzer, Bare, Hinkle, & Cheever, 2010, p. 1857). This is an important subject to nurses as they are called to be advocates for patients and endeavor to “do no harm.”

Review of Literature

The PVS term was developed in 1972 by two doctors, Jennett and Plum, because of the increasing number of brain damaged patients surviving trauma in a state that was not comatose and appeared irrecoverable (Jennett, & Plum, 1972). Most recently PVS has been amended by the Multi-Society Task Force and the Royal College of Physicians in 2003 to include characteristics of a patient with a sleep-awake pattern, responding to stimulation only in a reflex manner, and showing no meaningful response to the environment; considered awake but not aware (Royal College of Physicians Working Group, 2003).

Although diagnostic criteria can be somewhat universal, as seen by the two previous definitions, professional organizations differ in specifics. Some may use bowel or bladder incontinence as part of their criteria while others completely omit it (Borthwick, & Crossley, 2004). Differentiation in criteria can be problematic with regards to diagnosis and misdiagnosis. Although Jennett goes on to state that recovery from PVS is rare and exceptional, studies show that misdiagnoses is notable, varying from 17% to 75% (as cited in Borthwick et al., 2004).

The prevalence of PVS in the United States is 46-100 per million people (Jennett, 2002). Because of low incident rates, physician exposure to clients with PVS is disproportionate indicating a lack of expertise particularly in diagnosis (Borthwick et al., 2004). “Even those

clinicians who see a number of such patients are rarely responsible for, or trained in, the longer term management of brain damaged people” (Andrews, Murphy, Munday, Littlewood, 1996, p.4). This brings into question who *is* qualified to determine a diagnosis of a vegetative state.

Diagnosis of a vegetative state takes substantial skill, should be regularly assessment over a considerable length of time, and must never independently determined by a physician from the bedside. The rationale is that a multidisciplinary approach must be used including those with expertise in the care and management of clients with complex disabilities (Andrews et al., 1996). Family accounts must also be sincerely considered. It is usually other members of the multidisciplinary team such as occupational therapists and psychologists that determine “awareness” in clients and ultimately communicate this with the physician (Royal College of Physicians Working Group, 2003). It is critical to understand, though, that the physician is the final determinant of the diagnosis and ultimately, of referral to courts for removal of nutrition or hydration (Andrews et al., 1996).

Cognition or awareness can be determined by eliciting responses to simple commands through pressing buzzers, eye pointing, or motor responses such as finger, arm, shoulder, or head movements (Andrews et al., 1996). Therapists are aware, though, that clients are affected by a multitude of factors including fatigue, general health, contractures, medications, and underlying conditions, which can alter responses making them inconsistent (Borthwick et al., 2004). In a study conducted by Andrews et al. (1996), all of the misdiagnosed patients were actually severely disabled, 65% being either blind or severely visually impaired, making motor and visual responses difficult to impossible (Andrews et al., 1996). Positioning is imperative for appropriate motor responses and clients may need rehabilitation to achieve an optimal state to even elicit a response. Stress is a factor to consider as the patient is mandated to respond to stimuli in order to

prove his awareness (Borthwick et al., 2004). Depression, as well, could substantially inhibit a patient's motivation to interact due to his perception that he is being treated like a "vegetable" (Shewmom, 2004).

The terminal patient may be someone dying from renal failure or cancer. As he nears death, he often refuses nutrition and hydration. This is believed to be a normal, natural, and painless progression towards death as the patient submits to his underlying medical condition (Smith, 2003). The question lies, though, in the nature of the person diagnosed with PVS. Is this patient terminal? Is this patient dying? The PVS patient suffers from a failing brain which inhibits the ability to eat. The digestive tract is intact and functional, able to absorb and use nutrients (Truog, 2005). The lack of food and water for this patient could be the cause of death, a death by dehydration and starvation.

St. Louis neurologist, William Burke, states that the cognitively disabled person removed from nutrition and hydration suffers from dehydration. As his mucous membranes dry out, his skin, tongue, and lips crack. He suffers from nose bleeds. His stomach lining dries out and he suffers in agony from the pangs of hunger and thirst (as cited in Smith, 2003).

Kate Adamson suffered from an incapacitating and debilitating stroke at the age of 33. She was misdiagnosed with PVS and eventually her feeding tube was removed per court order. She suffered eight days without nutrition or hydration before her feeding tube was reinserted. She described those eight days as, "sheer torture" ("She recovered from," 2003, p. 1).

Jennett refers to disabled patients as a burden to the health care system, a waste of care better spent on those who are more deserving (Jennett, 1976). Ronald Cranford's editorial in the British Medical Journal states that the severely handicapped state is of more abhorrence to most

people than the possibility of being in a state of persistent vegetation and might even be considered a greater impetus behind ceasing nutrition than PVS itself (Cranford, 1996)!

From this utilitarian perspective, the human person is defined by strictly functional criteria: consciousness, for example, with the rational and motor capacities necessary to make decisions and take action. These are criteria of social utility, derived from a philosophical position that places function above being. The simple fact that one exists is no longer sufficient for that individual to qualify as a person, worthy of respect and legal protection. That individual must be able to think and act rationally and be endowed with the capacity to contribute actively and positively to social life. Otherwise, the argument goes, society has no obligation whatsoever to assume the financial and psychological burdens that a profoundly handicapped person imposes on it. (Breck, & Breck, 2005, pp. 136)

These views, which may be prevalent, are not universal. Many believe that the human person is to be valued because he is inherently sacred and valuable regardless of his physical or mental health.

Even the most severely disabled and helpless patients retain the full dignity of human personhood, justifying the provision of nutrition and hydration which, “should be considered ordinary, proportionate, and morally obligatory” (Baumgartner, 2006, para. 3). It is essential that patients unable to orally consume food should receive nutrition and hydration including those in persistent vegetative states. This moral obligation may at times become devoid as in cases where the patient approaches inevitable death and prolonging life would be exceedingly burdensome causing discomfort (United States Conference of Catholic Bishops, 1996).

Conclusion

The patient in a vegetative state is at risk for being misdiagnosed or treated by a doctor with little expertise in dealing with brain damaged people. Vegetative states are difficult to diagnose and take the teamwork of all disciplines. Even with a correct diagnosis, PVS patients with severe physical disabilities are worthy of treatment including nutrition and hydration.

The primary loyalty of the nurse is to the patient. We are expected to be advocates especially to vulnerable populations. Patients have the right to self determination but those in persistent vegetative states may be vulnerable to the wishes of their surrogates or medical providers in the case of misdiagnosis. Nurses, being the closest healthcare provider to the patient, can offer enlightenment and information that other members of a multidisciplinary team cannot. It is pertinent for nurses to become more informed about these issues and to educate others. They can participate in ethics committees at their institutions of employment or within the community. Ultimately, it may be impossible for nurses to intervene in situations where surrogates or providers are making decisions with which they do not agree. In these situations, they are not obligated to participate in practices that encourage compromise of personal beliefs. They can be true to their moral and legal convictions and if needed, refuse to engage in unethical situations.

As a future nurse, I approached this topic with some preconceived ideas about PVS and the ethical issues surrounding it. Through research, my view became further solidified. I found information that was much more varied than I anticipated including the topic of inadequate care to the disabled, which I find alarming yet fascinating. I definitely feel that my knowledge of PVS has been expanded and that I can speak on this subject with increased confidence.

References

- Andrews, K., Murphy, L., Munday, R., & Littlewood, C. (1996). Misdiagnosis of the vegetative state: Retrospective study in a rehabilitation unit. *British Medical Journal*, 313(7048), Retrieved from: <http://proquest.umi.com.proxy.kumc.edu:2048/pqdlink?Ver=1&Exp=11-13-2015&FMT=7&DID=9892024&RQT=309>
- Baumgartner, F. (2006). The ethical requirement to provide hydration and nutrition. *Archives of Internal Medicine*, 166. Retrieved from <http://archinte.ama-assn.org.proxy.kumc.edu:2048/cgi/content/full/166/12/1324>
- Borthwick, C.J., & Crossley, R. (2004). Permanent vegetative state: Usefulness and limits of a prognostic definition. *NeuroRehabilitation*, 19. Retrieved from <http://web.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=5&hid=113&sid=3eaf9cf7-7ffb-4e53-8a6f-4792da9f136a%40sessionmgr112>
- Breck, J., & Breck, L. (2005). *Stage's on life's way: Orthodox thinking on bioethics*. New York: St. Vladimir's Seminary Press.
- Cranford, R. (1996). Misdiagnosing the persistent vegetative state. *British Medical Journal*, 313. Retrieved from <http://www.jstor.org.proxy.kumc.edu:2048/sici?sici=0959-8138%281996%29313%3A7048%3C5%3AMTPVS%3E2.0.CO%3B2>
M&origin=serialsolutions
- Jennett, B.J. (1976). Resource allocation for the severely brain damaged. *Archives of Neurology*, 33. Retrieved from <http://archneur.ama-assn.org.proxy.kumc.edu:2048/cgi/reprint/33/9/595>

- Jennett, B. J. (2002). The vegetative state. *Journal of Neurology, Neurosurgery & Psychiatry*, 73(4), Retrieved from <http://jnnp.bmj.com/content/73/4/355>. Full doi: 10.1136/jnnp.73.4.355
- Jennett, B.J., & Plum, F.B. (1972). Persistent vegetative state after brain damage. *Lancet*, 35. Retrieved from <http://web.ebscohost.com.proxy.kumc.edu:2048/ehost/detail?vid=5&hid=104&sid=1d3abce8-83cd-4126afa9c78992389ad7%40sessionmgr104&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=4000063139>
- Royal College of Physicians Working Group. (2003). *The vegetative state: Guidance on diagnosis and management*. Retrieved from <http://www.rcplondon.ac.uk/pubs/contents/47a262a7-350a-490a-b88d-6f58bbf076a3.pdf>
- She recovered from a persistent vegetative state*. (2003, November 5). Retrieved from <http://www.rense.com/general44/vege.htm>
- Shewmom, A.D. (2004). A critical analysis of conceptual domains of the vegetative state: Sorting fact from fancy. *NeuroRehabilitation*, 19. Retrieved from <http://web.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=5&hid=113&sid=74e4b806-29f8-454b-b000-6fbbb5b62116%40sessionmgr112>
- Smeltzer, S.C., Bare, B.G., Hinkle, J.L., & Cheever, K.H. (2010). *Textbook of medical-surgical nursing*. Philadelphia: Wolters Kluwer Health / Lippincott Williams and Wilkins.
- Smith, W.J. (2003, November 11). A "painless" death? [Web log message]. Retrieved from <http://www.weeklystandard.com/Content/Public/Articles/000/000/003/370oqiwy.asp?page=2>

Truog, R.D. (2005). Refusal of hydration and nutrition. *Archives of Internal Medicine*, 165.

Retrieved from <http://archinte.ama->

[assn.org.proxy.kumc.edu:2048/cgi/content/extract/165/22/2574](http://archinte.ama-assn.org.proxy.kumc.edu:2048/cgi/content/extract/165/22/2574)

United States Conference of Catholic Bishops. (1996). *Ethical and religious directives for catholic health care services* (5th ed.) [Brochure]. Washington, D.C.