

Ethics, Personhood and the Persistent Vegetative State: New Evidence, New Obligations?

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A vegetative state is diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes. (Medical Aspects of the Persistent Vegetative State, The Multi-Society Task Force on PVS, *N Engl J Med* 1994; 330:1499-1508 May 26, 1994 DOI: 10.1056/NEJM199405263302107)

The diagnosis is not normally made until the patient has been in that state for at least three months. Hence: “persistent.” In what follows I will try to lay out the arguments and the issues as clearly as I can. This may be bluntly put but we have to remember that the patients under discussion are real people with families who love and care for, and about, them.

The key ethical elements of this definition are lack of awareness of self or environment (we will return later to the relevance of “evidence.”) Many would argue that the key and essential element of what it is to be a “person” is that one has an awareness of one’s self as a self and an awareness of one’s self in distinction to one’s environment. That is, one knows or is aware of oneself as a thinking thing, an agent of consciousness that can imagine, hope, wish, fear, choose and so on. (This goes back at least to Descartes’s “cogito ergo sum”, I think therefore I am.) In the context of a patient in a persistent vegetative state this idea is important for subsequent care.

If the vegetative state persists, or more particularly if it is permanent, then that patient is not capable of the experience of being a person and will not recover that capacity. It may then be possible to withdraw artificial life-sustaining measures, without harming the person (because the person is in some sense, already gone.) This is reflected in practice and in the things that families say about their loved ones and care teams say about their patients. If the person is no longer capable of experience and is no longer aware of him or herself as a person then he or she is already “gone” and all we are doing is caring for that person’s body.

I should point out that this is a judgment from the outside and is importantly different from saying that the person concerned would not wish to live this way. Generally (although the law varies from jurisdiction to jurisdiction) the task of a substitute decision-maker is to make the decisions that he or she was instructed to make by the patient when that patient was capable of making decisions, or if there are no such instructions, the decisions the person concerned would have made had he or she been able to do so (that is, decisions in accordance with that person’s values). This is where statements like “She would not wish to live this way...” or “He was always really active and in control, he would hate to be like this.” become important.

It is also worth noting that the exact state of the person’s consciousness or awareness under these conditions may not be a determining issue. A person could say: “The worst thing I could imagine would be to be aware and trapped inside my own body unable to do anything or communicate, I would hate to live that way.” Or, he or she could say: “If I was unaware and unconscious with no real prospect of a recovery I would hate to have my body kept alive like that...” But, of course, people also say and believe things that lead in the opposite direction. Some people, particularly those with certain religiously grounded views (or in some cases as a result of personal choice), believe that the essential part of a person is that person’s “soul,” which is present in that person’s body until the time of death (or sometimes shortly thereafter.) From this perspective it might be appropriate to argue that, regardless of consciousness or awareness, the person’s body should be kept alive as long as possible.

What we should do in cases like these, who has the power and authority to make what decisions, what we, as a community, owe to persons in these states are all contested territory. Clearly, patients and their substitute decision-makers, as described above, are entitled to decline further care. But can physicians or health care teams decline to provide continued care, if in their professional medical opinions, such care would be “futile or inappropriate?”

Finally, what must we, as a community fund? Are we obliged to pay for care for a person’s body beyond the time when there is any reasonable prospect of a meaningful recovery? It is hoped that in Canada some direction on these issues will be provided by the Supreme Court when they hear the Rasouli case in December 2012.

So now to the potentially game-changing new evidence: recent media reports have highlighted the work of Dr. Adrian Owen in London, Ontario. Basically, his technique involves scanning the brains of patients in a fMRI. The patient is instructed to imagine performing a vigorous activity, such as playing tennis. If the patient is capable of understanding and responding to such a command his brain will show characteristic patterns of activity which start and stop in accordance with the command. By contrast the patient may be asked to imagine performing a more sedate activity such as moving from one room to another in his house. This too results in a characteristic pattern of activity. Those two activities can now be linked to yes and no, and act as the answers to yes/no questions.

Dr. Owen's research over the last few years has shown that about twenty per cent of the patients he has seen who have been diagnosed as being in a persistent vegetative state are able to answer yes/no questions of this type appropriately. The breakthrough reported recently involves a local patient who was able to respond to the question: "are you in pain?" (He indicated that he was not.) The "game-changing" nature of this research is that it shows that some patients who were clinically determined to be in a persistent vegetative state, are, in fact, not in such a state at all, but rather are aware and "conscious."

The key components of the definition of a "vegetative state" were that there was no evidence of "awareness of self or environment." Until now, "evidence" was taken to mean clinical evidence. Dr. Owen's technique introduces a new way of providing evidence of awareness of self and environment. So what are the ethical implications?

First, there will be increased demand for the type of testing that Dr. Owen has employed. In media interviews Dr. Owen has stressed the highly complex and involved nature of his procedures and the very specific conditions that need to be met in order for the testing to be undertaken – including the medical stability of the patient and the possibility that the patient can travel to the fMRI. It is not clear how medical practitioners, and their funding agencies, will respond to increased demand for this procedure.

Second, if it can be shown that patients who were thought to be unaware and therefore incapable of making decisions about their own medical care are in fact shown to be aware, then maybe they can be shown to be capable of making decisions about their care. In which case, if this technology became more readily available it could be a tool to empower patients to make their own decisions about care.

Third, there is an important human dimension to all of these discussions. Families often say that they see signs of awareness in their loved ones that are not picked up by the medical professionals. Families often say that they believe their loved one is "still there" somehow trapped inside, despite medical evidence and belief to the contrary. Dr. Owen's work shows that some of those families are right.

And finally, what are the impacts on other areas of care? If there is increased demand for these procedures and increased demand for prolonged medical treatment what impact does that have on other areas of care – does the pot get bigger or do we simply redistribute what is already in the pot. Lots of questions... What do you think?

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