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VERY QUIET PEOPLE:
Ethical, Medical, and Theological Perspectives on Those in “Vegetative” and Other Hypokinetic States

by A. A. Howsepian

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SYNOPSIS

Medical and philosophical fascination with the “vegetative” state long predated the case of Terri Schiavo, a Florida woman who was judged to have been unconscious for 15 years. Nevertheless, the controversy surrounding the removal of her feeding tube focused America’s attention on this most profound condition, its diagnosis, treatment, and prognosis, and the ethical puzzles that it poses. How ought we treat those in “vegetative” and other hypokinetic (i.e., profoundly or totally immobile) states? How do we know whether one in such a state is conscious or not? What ought we do if we are uncertain? Misdiagnosis of persons in such states is relatively common in part because too little is known about which areas of the brain are correlated to consciousness. Some barriers to adequate scientific and clinical clarity concerning the neurobiology of consciousness may, in fact, be insurmountable. Care providers, until recently, often did not appreciate the fact that there is a continuum of consciousness that underlies hypokinetic states: some individuals in these states are robustly conscious, others are wholly unconscious, and others are at some point in between. Further, ethical decisions regarding these individuals are complicated by problems inherent in the construction of advance medical directives and by the sometimes unusual or clearly unethical choices of surrogate decision makers. One ethically impermissible option is to proceed in such a manner, whether actively or passively (e.g., by withholding nutrition, hydration, medications, or medical procedures), that is intended to result in the hypokinetic person’s death. Only by exercising careful clinical judgment, attending to the subtleties of ethical decision making under conditions of uncertainty, and engaging in serious theological reflection, will our exploration of the nature of these most vulnerable of patients and of the ethics of their treatment be most clear.

“Terri, alas, is the unwanted, the inarticulate, the one whose membership card in the human race has been revoked, the lump of flesh, the fetus. The Terri Schiavo case is not a ‘test’ of whether she is a human being ‘in the full sense of the word.’ It is a test of whether we are.” —Julie Loesch Wiley

There are, in several academic quarters, thinkers who wish to abandon more traditional criteria for human death and, instead, to deem “dead” some humans who, although alive in every other respect, have been judged to be permanently unconscious. For example, Terri Schiavo, a Florida woman who existed in a persistent state of apparent unconsciousness (which commenced soon after she suffered a cardiac arrest) for 15 years, was so judged. If these thinkers’ views had been widely adopted, there would have been far less debate concerning whether the withdrawal of care from Terri Schiavo should have been effected sooner during the course of her illness, later, or not at all. Rather, Terri, in virtue of having been judged permanently unconscious, thereby also would have been judged to have been a human corpse all along.
In this article I am not concerned primarily with the fitful controversy concerning the diagnosis of human death. Seeing where pronouncements of human death might lead, however, gives all the greater weight to the ethical questions concerning how we ought to consider and treat the seriously handicapped among us. With this in mind, I am concerned, rather, with carefully exploring conditions of apparent unconsciousness in humans and some of the ethical issues that these conditions raise. Persons who are profoundly disabled, particularly in the way that Terri Schiavo was, present us with several difficult ethical, medical, religious, and, more broadly, philosophical problems that, without the proper guidance, might appear to be insoluble. Fortunately, God’s general revelation (as found through the light of natural reason) and His special revelation (as found in the Bible) concerning how we ought to treat one another are, for all people of good will, available guides in this matter.

WHAT “VEGETATIVE STATES” ARE NOT

The term persistent vegetative state (PVS) was coined by Bryan Jennett and Fred Plum in 1972 to describe the condition of patients whose initial comatose states had progressed to states of wakefulness but without detectable awareness. Jennett and Plum were careful in their seminal essay to emphasize that, in PVS, awareness, or consciousness, is not detectable, not that it is absent. Later commentators, however, have been less than careful. The consensus statement of the 1994 Multi-Society Task Force (MSTF) on the persistent vegetative state, for example, alleged, “Jennett and Plum thought that patients in a persistent vegetative state could be distinguished clinically from those with other conditions associated with prolonged unconsciousness” (emphasis added). Clearly, being without detectable awareness is compatible with being conscious, while being unconscious (prolonged or otherwise) is not compatible with being conscious. In fact, Jennett and Plum wisely acknowledged “that a continuum [of conscious states] must exist between this vegetative state and some of the others” (to be described below). The MSTF’s insistence that PVS patients are, therefore, uniformly wholly unconscious is inconsistent with the spirit of Jennett and Plum’s insights into this condition.

We would do well, I believe, to return to Jennett and Plum’s conceptualization that highlights the observing person’s inability to detect consciousness in certain seemingly unconscious persons, rather than a conceptualization that highlights the disabled person’s apparent lack of consciousness in all instances. One manner of drawing attention to this issue is by changing our terminology. I suggest, therefore, that we no longer refer to persons who are in states of apparent unconsciousness as vegetative—a term that emphasizes unconsciousness and a term that might be considered pejorative by some severely disabled patients and their caregivers; rather, I suggest we refer to them as hypokinetic—a term that emphasizes a profoundly (or totally) restricted ability to move and is, thereby, neutral with respect to whether or not persons in this state are having (conscious) experiences.

In the peculiar terminology of neurology, wakefulness is compatible with unawareness (and hence, with unconsciousness). What does it mean to say that someone is unconscious, yet awake? It means simply that one in this state is in total phenomenal darkness—not conscious of anything at all—yet continues to exhibit sleep/wake cycles: one “awakens” in the morning by opening one’s eyes, at which times one’s electroencephalogram (EEG) reflects the electrical activity of an awake person’s brain, and one “goes to sleep” at night at which time one closes one’s eyes and one’s EEG reflects this change. These changes in brain electrical activity and spontaneous eye openings/closings are absent in traditional coma where there occurs no wakefulness at all. To be comatose in the traditional sense, therefore, is to be in a state of unconsciousness without wakefulness.

To be in a so-called persistent vegetative state requires wakefulness without detectable awareness that has persisted for at least one month. The causes of this state are, most commonly, head trauma, cardiac arrest, and other conditions that compromise oxygen delivery to the brain, including strokes. According to the MSTF, sometimes persistent vegetative states become permanent vegetative states. One might think that a condition called permanent vegetative state, if accurately diagnosed, would be in fact permanent; but, surprisingly, that is not the case. Being in a permanent vegetative state requires only that one be in a vegetative state for at least 3 months following a nontraumatic brain injury, and for at least 12 months following a traumatic brain injury.
Should one recover after having been in such a vegetative state after, say, multiple years—as has occurred in several cases—as then one would thereby have recovered from a permanent condition. The observation here is not that some patients are misdiagnosed as being in a permanent vegetative state, but that properly diagnosed patients in so-called permanent vegetative states have been known to recover.

ALLIED DIAGNOSES

Some hypokinetic states in which patients are conscious resemble traditional vegetative states to such a degree that there is a real danger that one type of condition might be mistaken for the other. The most unfortunate instances of such errors involve the mistaking of a hypokinetic state, in which the patient is wholly unconscious, for a locked-in state—a condition in which a person appears to be unconscious and is largely or wholly unable to move, but, typically, is as robustly conscious as you and I are. Many persons in locked-in states are able only to move their eyes or to blink, and often can do so in such a manner that limited communication is possible. It is important, therefore, always to presume that an apparently unconscious person is in fact conscious and, subsequently, it is prudent to arrange a system of communication with such a person that would allow one who is in a locked-in (or other less serious hypokinetic) state to convey to caregivers, in a consistent manner, that one is aware (and in the case of purely locked-in patients, fully aware) of what is transpiring in one’s environment. There is, in fact, a technologically sophisticated communication system in the works that, when perfected, promises to allow direct brain communication with such persons—communication that requires no skeletal muscle movement at all, by way of a “thought translation device.”

One further segment of the elusive continuum of consciousness about which Jennett and Plum spoke is recognized by the medical community as a minimally conscious state. Persons in a minimally conscious state exhibit unequivocal, but intermittent, and often very difficult to detect, behavioral evidence of being conscious. The minimally conscious state is sometimes conceptualized as a state of limited responsiveness. This is, I suggest, the best way to think about it and in fact suggests a much more illuminating name for the condition—the minimally responsive state (a subtype of hypokinetic state). The idea here is that being minimally responsive is compatible with being as conscious as you and I are when we are awake. One need not be minimally conscious in order to be minimally responsive. In fact, many locked-in state persons are minimally responsive in virtue of their profound motor disability, yet these persons are robustly conscious. There is recent evidence (although with only a very small number of patients) that even those persons who are in a minimally responsive state and who are believed to be minimally conscious exhibit patterns of brain activation (when, e.g., listening to a taped narrative of familiar events recorded by a familiar person) that are similar to normal subjects. There is more surprising evidence that some apparently unresponsive vegetative patients demonstrate normal brain activation to face stimuli presented visually and display what appear to be scattered episodes of clearly purposeful behavior.

DIAGNOSTIC UNCERTAINTY AND THE PROBLEM OF CONSCIOUSNESS

How does one distinguish one hypokinetic state from another? How, for example, does one distinguish a locked-in state from a traditional PVS? Or a PVS from a minimally responsive state? The MSTF in 1994 stated that various neurodiagnostic tests (including EEGs, which are nearly normal in up to 10 percent of alleged PVS cases late in their course, as well as other tests) “do not distinguish reliably between the locked-in and vegetative states.”

In light of the fact that the person in a locked-in state enjoys such a robust level of consciousness, this admission is striking. Only one type of test, cerebral metabolic studies, was picked out by the MSTF as reliably showing higher rates of brain metabolism in locked-in state persons as opposed to those who are in traditional vegetative states. The relevance of this finding is unclear, since even the MSTF admits that
“questions have been raised about the validity of cerebral metabolic studies to determine whether patients in a vegetative state are conscious or can experience pain and suffering. These questions remain unanswered.” According to the MSTF, then, just over 10 years ago, medical science had no reliable way of distinguishing between the states of certain hypokinetic persons who are fully conscious and those who lack consciousness altogether. This situation has not changed. Positron emission tomography (PET) scans have, for example, not yet been sufficiently standardized in this context to be a routinely useful tool for reliably differentiating one hypokinetic state from another; nor have event-related potentials18 (i.e., the brain’s electrical discharges when presented with certain physical stimuli); nor have magnetic resonance or other forms of neuroimaging. Curiously, in the medical literature there are case reports regarding PET scans in which the metabolism of the brain’s gray matter overall does not change from one’s being in a purported vegetative state to having recovered from this condition (although some regional changes in cortical metabolism appear to take place).19 In the event, however, that medical science discovers a fairly reliable test to distinguish those patients that we now call “vegetative” from those that we now call “minimally conscious” or “locked-in,” we would still not be able to state with confidence that all of those that we now call “vegetative” are wholly unconscious, since as Laureys states, “In the absence of a generally accepted neural correlate of human consciousness [i.e., the areas of the brain that are correlated to consciousness], it remains very difficult to interpret functional neuroimaging data [e.g., PET scans] from severely brain-injured patients as a proof or disproof of their ‘unconsciousness.’”20

One of the most vexing questions in all of neuroscience and in the philosophy of mind concerns the precise manner in which consciousness is related to brain functioning. Even if we were to put aside these questions concerning the metaphysics of consciousness (e.g., whether consciousness is generated by brain function, and if so how it is that brain function could possibly generate the qualitative characteristics of consciousness, such as the taste of an artichoke, the smell of dark chocolate, or the feel of silk), we still are left with questions concerning which brain areas are correlated with consciousness.21 This is, primarily, a question for the neuroscientist or the physician, rather than for the philosopher. One would expect this task to be a relatively simple one, but it is not. In fact, one of what was thought to be the most well-established locations of consciousness—the cerebral cortex itself (i.e., the brain’s grey outside layers)—has recently been shown not to be necessary for consciousness.22 Furthermore, all that we know about the neurobiology of pain perception strongly suggests that one’s being in a vegetative state, as currently understood, is compatible with one’s perceiving pain—including, it would seem, the pain and discomfort that can be associated with starvation and dehydration.23 A central problem with bringing this project to fruition is that the methods that we have for detecting consciousness rely on a conscious subject’s alerting us to the presence of consciousness. There is, therefore, a fundamental conceptual problem in this domain that cannot be ignored: not only are physicians and neuroscientists unsure about which parts of the brain underlie or are correlated with conscious human experience, but it does not even seem possible, even in this era of cyberkinetics, for us to achieve an acceptable degree of clarity on this problem. This is because there does not appear to be a way, perhaps even in principle, for us to discern when consciousness is absent, as opposed to when consciousness is present but not apparent to an outside observer. There is always the real possibility that the conscious person is in such a condition that he is not able to communicate to us his conscious experience.

ETHICAL REFLECTIONS

All living human beings are deserving of respect, love, and care, in virtue of their intrinsic dignity and worth as bearers of God’s holy image. It is always and everywhere, for any reason whatsoever, evil to kill an innocent human being intentionally, on one’s own (private) initiative; to participate in the intentional killing of an innocent fellow human at any stage of development or disability is a grave evil. The circumstances do not matter. The motives do not matter. The consequences do not matter. This is what is meant for an act to be intrinsically evil: the act in itself is evil; nothing outside of the act itself makes the act evil (and, hence, there is no way for an act of this type to be modified so that it is no longer an evil act). In moral theories such as this, including virtue, divine command, natural law, or deontological theories, some acts are judged to be wrong and hence to be avoided no matter what.
On the other hand, in consequentialist moral theories, elements independent of the act itself—specifically, the act’s consequences—solely determine whether an act is right or wrong, good or bad. The result, then, is that any act, no matter how apparently degraded or perverse or heinous, can be morally permissible, or even obligatory, under the “proper circumstances.” The Ten Commandments, however, do not make allowances for bearing false witness or for murder or for coveting under certain circumstances, for example, or even under any circumstances; rather, they admonish us to refrain from such acts under all circumstances. Christians would do well, therefore, to distance themselves from consequentialist moral theories.

Much of what is written these days concerning what is often called “end-of-life care” is couched in consequentialist terminology. What is important, it is claimed, is that a patient’s care is dictated by the relative values of the overall outcome of that care alone. If caring for someone in a hypokinetic state resulted, in the long run and in general, in less overall happiness for humanity (as those who are consequentialists of the utilitarian persuasion would have it), then it would be either permitted or obligatory to end that person’s life, perhaps as quickly, directly, and intentionally as possible.

**NUTRITION, HYDRATION, AND FUTILITY**

Is it ever morally permissible to withdraw food and fluids, elements that sustain human life? Let’s explore this possibility using the case of Terri Schiavo. Her condition required tube feeding to maintain her survival. In the end, her feeding tube was withdrawn by court order against the wishes of her parents and in accord with the wishes of her husband, Michael Schiavo, who argued that he had knowledge of Terri’s not wanting to be kept alive in a PVS by artificial means. Her parents’ legal appeals to have the feeding tube reinstated failed. The end result of this series of events was Terri Schiavo’s death on March 31, 2005, at the age of 41.

Was it ethically permissible to remove Terri’s feeding tube in accord with the demands of her husband? There are several reasons to doubt the moral propriety of this removal. First, she might not in fact have been in a PVS, but in another hypokinetic state—one in which consciousness is present (there was, in fact, provocative evidence for this conjecture in Terri’s case). Second, perhaps Michael intended his wife’s death in virtue of this directive. Although it is legal for the time being in the United States for those with homicidal intentions to order or perform the removal of one’s feeding tube resulting in one’s death, such acts would not, simply in virtue of their legality, thereby be ethically permissible.

Suppose, however, that we knew all along that Terri was in a PVS (and hence wholly unconscious); is not the treatment of such an individual futile? Not necessarily; for a treatment to be futile for some particular individual, it must be the case that the “treatment” not benefit that particular individual overall. Clearly many available treatments for persons in hypokinetic states—including the administration of nutrition and hydration—benefit them greatly, namely, by saving their lives. Granted we are often uncertain whether people in such states consciously appreciate these benefits, although clearly some of those who deeply care about them do. Still, they benefit nonetheless. If they did not, that is, if our “treatment” were killing them or otherwise causing them to decompensate medically, or if their death were imminent in spite of the “treatment,” then it would be morally permissible to discontinue such procedures, even if they involved the administration of food and fluids.

**RUSHING IN THE WRONG DIRECTION?**

In light of Terri Schiavo’s case, there have been cries from many quarters that the best solution regarding ethical treatment in all conditions of medical extremity is to adopt an advance directive strategy. An advance directive is a document, prepared while one is competent to make sound medical decisions, that is intended to make clear one’s treatment wishes should one ever fall into a state of incompetence with respect to medical decision making. It appears that at least with an advance directive, one might avoid the problem, made so clear in the Schiavo case, of a surrogate decision maker (or “durable power of attorney”) making decisions on one’s behalf that are counter to one’s best interests, perhaps for motives that are less than pure. An advance directive would codify one’s wishes in the event of a medical catastrophe, preventing one’s being treated in ways that are contrary to one’s expressed wishes.
Advance directives themselves, however, are for a number of reasons also potentially problematic. First, advance directives are static documents, whereas human minds are dynamic faculties that often change, and the documents are not quickly amended to reflect these changes. Second, it is sometimes unclear what the directives specified in advance directives mean. Third, often there are significant omissions in advance directives simply in virtue of the enormous scope of possible treatment decisions one might encounter in the context of medical disability. For example, if you were filling out your own advance directive, it may be clear that you would want to be taken off a ventilator under certain medical conditions. It may be, however, that you would not want to be taken off of a ventilator if you knew that this would cause profound emotional disturbance in certain family members of yours, but this particular reason for staying on a ventilator may not cross your mind while filling out your advance directive on your own. There are likely to be numerous such issues that arise in the context of grave medical disability—issues that one would never have thought about unless one is specifically asked. Fourth, advance directives can be lost or destroyed. Fifth, it is very hard to say ahead of time how it is that one really would want to be treated medically, even in broad outline, if one becomes severely disabled at some future time. For all of these reasons and more, some, including myself, have argued that perhaps the best end-of-life strategy is primarily to designate a surrogate decision maker, one who you are confident would do nothing intentionally to harm (much less kill) you (whether “actively” or “passively”) and who is virtuous—one who displays temperance, fortitude, justice, wisdom, faith, hope, and charity in various other aspects of his or her life. This is not to say that an advance directive that is very precise and very narrow in scope in addition to a surrogate decision maker might not be optimal.

CLOSING REFLECTIONS: ON BEING HUMAN

It is difficult, on an emotional level, for many people to care for those who, whether at the very beginning of life, toward the very end of life, or suspended somewhere in the middle, do not appear to respond to the care given to them in a way that is reenforcing for their caregivers. All of these disabled persons are, nevertheless, our neighbors in the biblical sense. Sometimes these neighbors of ours surprise us by acting in ways that we would not have expected—including their waking up and talking to us after years of being “vegetative.” Much more often, nothing this dramatic occurs; rather, we see subtle signs that are often maddeningly ambiguous, of what might be awareness or purposeful activity or intentional response. Commonly, we do not even enjoy that degree of hopefulness, but must endure and suffer with these very quiet people in the midst of their silence and our uncertainty. Still, these are our neighbors, and more so. They depend on us for their survival; they are as vulnerable, or more vulnerable, than newborns; and not only do they bear God’s image—not only are they mirrors of God—they are also, as Julie Loesch Wiley implies, mirrors of our humanity. To abandon them or to mistreat them is to neglect and to deform what is most human about us—our capacity to love and care for the most helpless among us and our corresponding capacity to reflect the glory of Christ.

NOTES

5. Multi-Society Task Force on PVS, 1499.
6. Jennett and Plum, 737.
7. Hypokinetic states include (among multiple other states) coma, akinetic mutism, and catatonic stupor in addition to what is currently termed persistent vegetative state and permanent vegetative state. The late Pope John Paul II, in the context of his March 20, 2004, address to the International Conference, “Life Sustaining Treatments and Vegetative State: Scientific Advances
and Ethical Dilemmas,” also protested that the term vegetative state was demeaning, that it failed to evince proper respect for the dignity of one who is in such a state.


15. These include computerized tomography (CAT) scans or magnetic resonance imaging (MRI) scans of the head; evoked responses, during which a person is presented with a stimulus (e.g., a sound or a light) and changes in that person’s brain waves are measured; and single photon emission computed tomatogram (SPECT) scans. It is well known, for example, that some persons diagnosed to be in vegetative states have normal evoked responses to physical stimuli. See Eric Brunko and Diederik Zegers de Beyl, “Prognostic Value of Early Cortical Somatosensory Evoked Potentials After Resuscitation from Cardiac Arrest,” Electroencephalography and Clinical Neurophysiology 15 (1987): 15–24.

16. This is not to say that we will always be in this predicament. Cyberkinetics labs may well be on their way to improving brain/computer interface technologies that will aid in reliably distinguishing between the two states.

17. Multi-Society Task Force on PVS, 1506.


19. See Steven Laureys et al., “Brain Function in Vegetative State,” in Machado and Shewmon (2004): 229–38. Note that although there is an overall decrease in cerebral metabolism in the vegetative state, overall brain metabolism in normal human slow-wave sleep is also known to decrease up to 60 percent.


21. One frequently cited model for how consciousness is supposed to be related to brain function likens the ascending reticular activating system (located in the brainstem) and its connections to a generator, and the cerebral cortex and the thalamus and their connections as light bulbs. In this simplistic model, shutting down the cerebral cortex (the light bulbs) or the brainstem (the generator) will lead to the loss of consciousness. There are multiple clinical counterexamples to this model. For a discussion of the metaphysics of human mind and consciousness embedded in a general theory of persons, see A. A. Howse, “Toward a General Theory of Persons,” Christian Bioethics 6, 1 (2000): 15–35.


24. That is not to say that it is always clear or easy to discern when an act is in fact an instance of lying or murder or coveting, only that such acts on one’s private initiative ought never be performed under any circumstances.

25. It is quite misleading to say of all people who are in hypokinetic states that they are at the “end” of their lives. If they were to be neither fed nor given fluids, then, of course, their lives would end; but on that score, newborns would be at the end of their lives as well; and, of course, so we all would be.

26. Primarily, it was not at all clear that this removal was in accord with her wishes. In addition, her husband had, for several years, been involved in a sexual relationship with another woman with whom he fathered two children, raising the possibility that there were ulterior motives involved in his sanctioning an action that would end his wife’s life. Yet, even if it could be known that Terri clearly and convincingly conveyed to her husband or someone else her wish not to be kept alive by artificial means if she were ever found to be in a PVS, and even if her husband had remained faithful to her throughout the course of her illness (and if there were no reason to be suspicious of any other ulterior motives on his part), it might still be morally impermissible to remove her feeding tube for at least the two reasons noted in the text.


29. For a more detailed discussion of, especially, the logical problems with the advance directive strategy, see A. A. Howse, “Are Advance Directives an Advance?” Ethics and Medicine 14, 2 (1998): 34–41.