
19. Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support

Introduction

Recent public debates and judicial decisions have highlighted the issue of when it is justifiable to end life support for persons with loss of higher brain functions. In cases involving persons classified as permanently unconscious, several courts have authorized caretakers to withdraw or withhold treatments that served only to sustain vegetative functions and offered no prospect of restoring cognition or sapience.¹⁻¹¹ Judges have articulated various rationales, but common themes are that patients have a legally enforceable right to decline life-prolonging treatments and that their caretakers have no legal duty to prolong life when treatment will not restore consciousness or produce other medically definable benefits. The suggestion that ending treatment in this circumstance is a form of criminal homicide has been firmly rejected.^{1,4,8,9} Dissenting judges and some commentators, however, have raised questions about the correctness of particular decisions, have challenged the logic of denying a causal relationship between ending treatment and inducing death, and have expressed concern that the category of persons whose deaths may be hastened will be expanded beyond morally tolerable limits once society begins to allow permanently unconscious persons to die.^{2,9 12-16}

This review addresses concerns regarding the reliability of determinations of permanent unconsciousness, indicates criteria that permit a reasonably certain diagnosis of permanent unconsciousness, and considers the matter of distinguishing between severely impaired persons who will not improve from those who may. The Councils will not offer an ethical or social policy analysis because an abundant literature already exists in this area, but will try to identify significant legal decisions and trends relating to the role of physicians in deliberations about whether to refrain from providing life support.

Diagnosis of Permanent Unconsciousness

Definition. Consciousness has two dimensions: arousal and the cognitive content of the aroused state. Arousal is a function maintained by deep brainstem-medial diencephalic structures in the brain in contrast to learning, memory, self-awareness, and adaptive behavior, all of which depend upon the functional integrity of the cerebral cortical mantle and its associated subcortical nuclei.

Pathologic loss of consciousness may follow a variety of insults to the brain including, among others, nutritional insufficiency, poisoning, stroke, infections, direct physical injury, or degenerative disease. Complete loss of consciousness may develop abruptly or slowly. Abrupt loss of consciousness usually consists of an acute sleep-like state of unarousability called *coma* that may be followed either by varying degrees of recovery or severe, chronic neurologic impairment. The stage of coma itself, however, is invariably temporary and in progressive disease is often absent altogether. In either event, persons with overwhelming damage to the cerebral hemispheres commonly pass into a chronic state of unconsciousness called the *vegetative state* in which the body cyclically awakens and sleeps but expresses no behavioral or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events or stimuli. This condition of total cognitive loss can follow acute injuries causing coma or can develop more slowly as an end result of progressive structural disorders, such as Alzheimer's disease, that in their end stages also can destroy the psychological functions of the cerebrum. When such cognitive loss lasts for more than a few weeks, the condition has been termed a *persistent vegetative state* (PVS) because the body retains the functions necessary to sustain vegetative survival.^{17,18} Some have applied the term "cognitive death" as a synonym for the state.

Recovery from the vegetative state is possible, especially during the first few days or weeks after onset, but the tragedy is that many persons in PVS live for many months or years if provided with nutritional and other supportive measures.¹⁹ Present requirements of health reporting fail to provide an accurate estimate of the incidence and prevalence of PVS in the United States. Ten years ago, a prevalence of 2 to 3 per 100,000 was estimated for Japan.²⁰ It seems likely that the absolute number of such cases has risen appreciably as a consequence of current practices in critical medicine, cardiorespiratory support, parenteral feeding, and control of infections in severely brain damaged patients. How to deal with this emotionally painful, financially costly, and generally unwanted outcome of modern medical treatment is an increasing problem.

Clinical Criteria of PVS. The distinguishing feature of PVS is chronic wakefulness without awareness. Such unconscious wakefulness can be accompanied by spontaneous eye opening, the utterance of unintelligible, instinctive sounds such as grunts or screams or even brief smiles, as well as sporadic movements of facial muscles and non-paralyzed limbs. Despite an "alert demeanor", observation and examination repeatedly fail to demonstrate coherent speech, comprehension of the words of examiners or attendants, or any capacity to initiate or make consistently purposeful movements. Movements are largely confined to reflex withdrawals or posturing in response to noxious or other external stimuli. Since neither visual nor auditory signals require cortical integrity to stimulate brief orienting reflexes²¹, some vegetative patients may turn the head or dart the eyes toward a noise or moving objects. However, PVS patients neither fixate upon nor consistently follow moving objects with the eyes, nor do they show other than startle responses to loud stimuli. They blink when air movements stimulate the cornea but not in the presence of visual threats per se.

By themselves, no confirmatory tests provide an accurate diagnosis or prognosis, but positron emission tomography in PVS patients has shown severely depressed energy metabolism uniformly distributed throughout the cortical and immediate subcortical areas of the cerebral hemispheres; this is equivalent to what is found during deep general anesthesia in normal persons¹⁸.

Brain imaging studies may or may not reveal multifocal or diffuse lesions and cortical atrophy, depending on the duration of the condition. Most persons in PVS show tonic reflex oculovestibular movements freed of normal cortical restraint. As noted, some will meaninglessly smile, many chronically chew or clamp the teeth, and most have impaired motor functions with varying degrees of weakness, spasticity, posturings, and contractures of the limbs. If provided with supporting nursing care in the chronic state, nearly all maintain near normal body temperatures. All are incontinent of urine and stool. Cardiorespiratory activity, swallowing, and digestive and other non-neurologic vital functions are usually preserved to the extent that standard nutritional and supportive measures will sustain life indefinitely. Persons in PVS ordinarily require neither long-term respiratory support nor circulatory assistance.

Once qualified clinicians have determined that a person is awake but unaware, the permanence of the vegetative state depends on the nature of the brain injury, the duration of the period of unawareness, and the estimated prognosis. Some persons less than 35 years old with coma after head trauma, as well as an occasional patient with coma after intracranial hemorrhage, may recover very slowly; thus, what appears to be a PVS at one to three months after an event causing coma may rarely evolve into a lesser degree of impairment by six months.^{22,23} On the other hand, the chances of regaining independence after being vegetative for three months are vanishingly small. Rare exceptions are claimed,^{24,25} but some of these may have represented patients who entered an unrecognized locked-in state shortly after reawakening from a coma-causing injury.²⁶ Ultimately, all have been severely disabled.

These rare examples notwithstanding, the data indicate that awareness for six months predicts non recovery or over whelming disability with a high degree of certainty regardless of the nature of the insult

to the brain^{27,28}. Therefore, a conservative criterion for the diagnosis of PVS would be observed unawareness for at least 12 months although cognitive recovery after six months is exceedingly rare in patients over 50. Based upon an extrapolation of epidemiological data from foreign studies,^{19,24} it can be estimated that there are approximately 5,000 cases of PVS in this country. The number may actually be higher given the extent to which critical care is employed in all initial cases of head trauma. If the handful of reported occurrences of cognitive recovery in patients with PVS²⁵ are divided by the total estimated number of PVS cases, the odds of recovery are less than 1 in 1,000. Therefore, the risk of prognostic error from widespread use of the above criterion is so small that a decision that incorporates it as a prognostic conclusion seems fully justifiable.

Differential Diagnosis. Inherent in the process of diagnosing PVS is to distinguish it from other severe neurologic impairments that may produce less cognitive impairment or have a different prognosis. The greatest difficulty lies in deciding if the various sounds and movements occasionally encountered in a totally demented, speechless person reflect cognitive responses to internal or external stimuli or, rather, merely have a reflex or instinctive origin emanating from deep undamaged cortical structures. A less difficult problem, but one that has arisen in some legal disputes over decisions to remove life support,^{2,7} consists of distinguishing PVS from the "locked-in" syndrome or de-efferented state. The locked-in state can result from interruption of descending motor pathways any place along their course from the ventral pons to the peripheral nerves.²⁹⁻³¹ In this condition, paralysis, not cognitive failure, leads to a lack of ability to communicate. Both vocal control and all appropriate bodily responses to stimuli can be lost. Nevertheless, awareness may be partially or fully preserved; in those with ventral pontine or bulbar intramedullary lesions, communication often can be established using an eyeblink or other signaling strategy.²⁹ Positron Emission Tomography studies in such patients indicate that cerebral energy metabolism is only moderately reduced below normal in contrast to the profound disturbances observed in PVS.¹⁸ EEGs do not distinguish between vegetative and locked-in patients, since vegetative persons can have near normal EEGs, and abnormal EEG-blocking responses have been found in persons awake and self-aware but totally paralyzed from peripheral neuropathy (Plum-Personal Communication). In these circumstances, serial examinations by neurologically trained physicians usually will resolve any residual confusion. If uncertainty remains after careful clinical appraisal, however, PET studies may be helpful if available. In any event, if characteristic signs and symptoms of PVS are lacking and any doubt exists, the diagnosis should be avoided or deferred because of its connotations for decisions about levels of future care.

Pain and PVS. One aspect of the debate about stopping treatment in PVS focuses on a concern that the afflicted person will suffer after treatment is stopped (e.g., will experience dyspnea after removal of a respirator or face discomfort associated with starvation and dehydration after removal of a feeding tube). The most obvious contradiction to this projection is that, by definition, in PVS both the person's capacity to perceive a wide range of stimuli and the neocortical or higher brain functions that are needed to generate a self-perceived affective response to any such stimuli are destroyed. It follows that any detectable sentient response to noxious or other stimuli or any consistent affective response to a non-noxious stimulus, if confirmed, indicates that the diagnosis of PVS has been wrongly made. While certain neurologic circumstances refute the assertion that a person who appears unaware cannot possibly suffer, it contradicts physiology to suggest that suffering can remain when other unequivocal neurologic signs and tests indicate a profound loss of cerebral cortical activity.

Ethical and Legal Implications or Decisions to Withhold or Withdraw Life-Prolonging Medical Treatment

Background. A physician's determination that a person is unlikely to regain consciousness is the usual prelude to deliberations about withdrawing or withholding life support. Although the family may be the

first to raise the issue, until a physician has ventured an opinion about prognosis, the matter of withholding treatment is not generally considered. Once the question of withholding or withdrawing life support has been raised, its legal and ethical dimensions must be considered.

Over the past decade, there has been a broad societal consideration of the ethics of withdrawing or withholding life support from patients who are permanently unconscious. After careful study, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,³¹ the Council on Ethical and Judicial Affairs of the American Medical Association,³² and the Hastings Center,³³ have reached similar conclusions:

Physicians should honor the patient's previously expressed desires regarding the use of life support. Thus, if the patient has chosen to forego life-sustaining measures, they should be withheld or withdrawn. However, in many cases, the patient will not have indicated his or her desires before becoming permanently unconscious. In such cases, the decision whether to use life support should be based on the patient's perceived preferences and values, and the decision should be made by the family or legal representative. If the patient's preferences or values are not ascertainable, the family or legal representative should decide on the basis of the patient's best interests.

The legal aspects of decisions to forego life-sustaining medical treatment are more complicated. Courts in several states have addressed a variety of cases in which caretakers sought authority to withhold or withdraw ventilators or nutritional support from patients who are permanently unconscious. While most of these rulings have approved requests to end life support, there have been notable exceptions.

Despite the different legal rulings in the various states that have decided whether treatment can be withheld or withdrawn, some general principles emerge. First, mentally competent patients have a general right to refuse medical treatment, even at the risk of death.³⁴ In addition, if a person has indicated whether life-sustaining treatment should be administered or withheld in the event of permanent unconsciousness, the courts will respect the person's previously expressed desires.³⁵ This is known as the "subjective test." In order to ensure that the patient truly would have wanted life-sustaining treatment to be withheld or withdrawn, many states require a showing that the patient's desires were "clearly and convincingly" expressed.³⁶ In one case, for example, where the patient had participated in formal discussions about the Karen Quinlan case at a Catholic high school and stated that he would not want to be maintained on a ventilator in a persistent vegetative state, the court sanctioned removal of the ventilator.³⁷

In practice, the subjective test has limitations. This is because courts often discount a person's prior statements when they were made in general terms, in casual circumstances, as a spontaneous reaction to another person's medical treatment or while the person was young and in excellent health.³⁸ Hence, in the absence of formal documentation or of repeated expressions in the setting of formal discussions, courts may find that the patient's wishes were not clearly expressed. The court's finding will sometimes turn on the nature of the life-sustaining measure. For example, some courts are more likely to permit withdrawal of a ventilator than withdrawal of artificial feeding.³⁹ This difference primarily reflects the fact that ventilators are more readily viewed as "heroic" or "extraordinary" than are artificial feedings. However, most courts and ethicists reject this distinction and treat artificial feedings in the same way as ventilators.⁴⁰

Some state legislatures have recently created devices (e.g., living wills or designation of an agent to make health care decisions in the event of mental incompetence) which facilitate the documentation of an individual's future desires in the event of permanent unconsciousness.⁴¹

If patients have not expressed their wishes clearly and convincingly, it is important to determine what standards of decision making apply. In general, family members or other guardians are permitted to make treatment decisions on behalf of the patient on the basis of what they believe the patient would have chosen if competent to decide. This is known as "substituted judgment."⁴² A few recent developments, however, raise questions about how broadly this general rule applies. In Missouri, the state supreme court has refused to honor the request of the parents to discontinue gastrostomy feedings for their daughter, who was in a persistent vegetative state as the result of an automobile accident.⁴³ Moreover, the court left open the question whether artificial feedings can ever be discontinued. Oklahoma passed a statute which prohibits the withdrawal of food and water in the absence of very specific directions by the patient that withdrawal would be the desired course.⁴⁴ And, in a case involving nasogastric tube feedings and a patient who was not permanently unconscious but was severely demented, New York's highest court suggested that artificial life support can never be withdrawn in the absence of clear expressions by the patient.⁴⁵

As this discussion indicates, surrogate decision making by family members or other representatives is more likely to be disregarded when they seek the withdrawal of food and water rather than ventilators, or when the patient has severe impairments but is not permanently unconscious. In any event, it is unlikely that a court would overrule a decision to withdraw a ventilator from a permanently unconscious patient.

When a situation arises in which it is permissible to withdraw treatment, the medical profession has a very specific, technical role. The attending physician must make the diagnosis of permanent unconsciousness, and, in some states, at least two other physicians with no interest in the case must confirm the diagnosis. These other physicians have been characterized as the "prognosis board."⁴⁶ Whether or not required by law, consultation with other physicians in determining prognosis is both desirable and appropriate.

Once a diagnosis of permanent unconsciousness has been made, decisions to withhold or withdraw life-prolonging medical treatment ordinarily can be implemented without resorting to the courts. Although judicial intervention has been sought for a variety of reasons by a variety of parties, it is appropriate only when there is a dispute among family members or other guardians about the patient's wishes or among physicians regarding the diagnosis.⁴⁷ Consultations with ethics committees can play an important role in helping the family come to a decision.

Situations may arise in which a request is made to discontinue treatment, but the attending physician is personally opposed to participating in the withdrawal. In those cases, the physician should transfer the patient to a physician who is willing to carry out the decision.⁴⁸ There is a New Jersey Supreme Court case, however, that suggests that the treatment must be withdrawn over the objection of the physician if the transfer cannot be carried out without inordinate delay so as not to frustrate the patient's right to refuse treatment.⁴⁹

As indicated, the law in this area turns very heavily on court cases and legislation in the different states. As the federal courts issue more decisions in this area, the law should become more uniform across the country, particularly if the U.S. Supreme Court decides the questions involved.

Summary

The poignant situation of human beings who are alive but unaware has evoked wide-ranging debate, major court decisions, and new legislation. Even as intimate participants in decisions about how vigorously to treat comatose or vegetative patients who are unlikely to improve, physicians may question their appropriate role. On the one hand, they recognize that their capacity to achieve a diagnosis and

highly probable prognosis represents the indispensable basis for any decision. In this respect, clear clinical criteria have been enunciated and are strongly supported by scientific data, with prognostic probabilities available from several sources.¹⁸ But they also are at risk of having their personal attitudes enmeshed in the ethical and legal ramifications of decisions about levels of care and of becoming advocates of a particular choice based on their own principles and interpretations of the facts. If this occurs, it is well to recognize that a central legal concern is to try to discern what the patient would have chosen, not what physicians or other caretakers believe is desirable. In this respect, decisions necessarily will be influenced by the laws of the particular jurisdiction. To date, the states have not enacted uniform laws or judgments. Nevertheless, the record to date indicates that when physicians and families agree on a particular course, the prospect of adverse legal consequences is greatly diminished.

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References

1. *Barber v Superior Court*, 147 Cal. App. 3d 1006, 195 Cal Rptr. 484 (1983).
2. *Brophy v New England Sinai Hospital*, 398 Mass. 417, 497 N.E.2d 626 (1986).
3. *Corbett v D'Alessandro*, 487 So. 2d 368 (Fla. Dist. Ct. App. 1986).
4. *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).
5. *In re Gardner*, 534 A.2d 947 (Me. 1987).
6. *In re Guardianship of Grant*, 109 Wash. 2d 545, 747 P.2d 445 (1987).
7. *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).
8. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied, sub nom Garger v New Jersey*, 429 U.S. 922 (1976).
9. *In re Storar*, 52 N.Y.2d 363, 420 N.E.3d 64, *cert. denied*, 454 U.S. 858 (1981).
10. *Rasmussen v Fleming*, 741 P.2d 683 (Ariz. 1986).
11. *In re Torres*, 357 N.W.2d 332 (Minn. 1984).
12. Beresford HR. The Brophy case: Whose life is it? *Neurology* 1987;37:1357-1358.
13. Brennan T. Silent Decisions: Limits of consent and the terminally ill patient. *Law, Medicine and Health Care* 1988; 16:204-209.
14. Schauer F. Slippery slopes. *Harvard Law Rev* 1985; 99:361-383.
15. Schiedermayer DL, LaPuma J. Do positron emission tomographic scans measure quality of life? *Ann Neurol* 1988; 24:288.
16. Smith DR. Legal recognition of neocortical death. *Comell Law Rev* 1987; 71:850- 888.
17. Jennett B, Plum F. The persistent vegetative state: A syndrome in search of a name. *Lancet* 1972; 1:734-737.
18. Levy DE, Sidtis 11, Rottenberg DA, et al Differences in cerebral blood flow and glucose utilization in vegetative versus locked-in patients. *Ann Neurol* 1987; 22:673-682.
19. Higashi K, Sakata K, Hatano M, et al Epidemiological studies on patients with a persistent vegetative state. *J Neurol Neurosurg Psychiat* 1977; 40:876-885.
20. Sato S, Ueki K, Arai H, et al Epidemiological survey of vegetative state patients in Tohoku District in Japan. *NeurologMed-Chir* 1978; 18:141-145.
21. Plum F, Posner JB. *The Diagnosis of Stupor and Coma* 1982; FA Davis Cb., Philadelphia, 3d ed, pp 330-348.
22. Jacobson SA. Protracted unconsciousness due to closed head injury. *Neurology* 1956; 6:281-287.
23. Berrol S, Evolution of the vegetative state. *J Head Trauma Rehabilitation* 1986; 1:7- 16

24. Higashiki D, Hatano M, Abiko S, et al. Five-year follow up of patients with persistent vegetative state. *J Neurol Neurosurg Psychiat* 1981; 44:552-554.
25. Arts WFM, Van Dongen HR, Hof-Van Duin, Lammens E. Unexpected improvement after prolonged posttraumatic vegetative state. *J Neurol Neurosurg Psychiat* 1985; 48:1300-03.
26. Snyder BD, Cranford RE, Rubens AB, et al. Delayed recovery from post anoxic persistent vegetative state. *Ann Neurol* 1983; 14:152.
27. Levy DE, Caronna1J, Singer BH, et al. Predicting outcome from hypoxic-ischemic coma. *JAMA* 1985; 253:1420-1426.
28. Sazbon L. Prolonged coma. *Prog Clin Neurosci* 1985; 2:65-81. +
29. Plum F., Posner J.B. *The Diagnosis of Stupor and Coma*. First edition FA Davis co., Philadelphia 1966; pp 92-93.
30. Kotsoria H., Schleifer L., MenkenM., Plum F. Total locked-in state resembling brain death in polyneuropathy. *Ann Neurol* 1984; 16, 150.31. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 189-96 (1983)
31. *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association-1986*, § 2.18
32. The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* 26-29 (1987)
33. *Bouvia v. Superior Court*, 225 Cal.Rptr. 297, 300 (1986); *In re Conroy*, 98 NJ. 321, 486 A.2d 1209, 1222 (1985); *John F. Kennedy Memorial Hospital. Inc. v. Bludworth*, 452 So.2d 921, 923-24 (Fla. 1984).
34. *Conroy*, supra note 34, 486 A.2d at 1229; *In re O'Connor*, 72 N.Y.2d 517, 531 N.E.2d 607, 613 (1988).
35. *O'Connor*, supra note 35, 531 N.E.2d at 613.
36. *In re Eichner*, 423 N.Y.S.2d 580 (1979), *aff'd sub nom. In re Storar*, 52 N.Y.2d 363, 420 N.E.3d 64, *cert. denied*, 454 U.S. 858 (1981).
37. *In re Jobes*, supra note 7, 529 A.2d at 443; *In re Colyer*, supra note 4, 660 P.2d at 748.
38. Compare *In re L.H.R.*, 321 S.E.2d 716, 723 (Ga. 1984) with *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc).
39. *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association-1986*, § 2.18; *Conroy*, supra note 4, 486 A.2d at 1236; *Brophy v. New England Sinai Hosp.. Inc.*, supra note 2, 497 N.E.2d at 637.
40. Areen J. The legal status of consent obtained from families of adult patients to withhold or withdraw treatment. *JAMA* 1987; 258:229-235.
41. *Bludworth*, supra note 34, 452 So.2d at 926; *Jobes*, supra note 7, 529 A.2d at 444-47; *In re L.H.R.*, supra note 39, 321 S.E.2d at 723.
42. *Cruzan v. Harmon*, 760 S. W.2d 408 (Mo. 1988) (en banc).
43. 3Okla. Stat. Ann. tit. 63, §§ 3080.1-3080.5.

45. *O'Connor*, supra note 35, 531 N.E.2d at 617 (Hancock, J. concurring)
46. *L.H.R.*, supra note 39, 321 S.E.2d at 722-23; *Colyer*, supra note 5, 660 P.2d at 749-50; *Bludworth*, supra note 34, 452 So.2d at 926; *lobes*, supra note 7, 529 A.2d at 447-48.
47. *Jobes*, supra note 7, at 529 A.2d at 449; *Colyer*, supra note 4, 660 P.2d at 750; *Bludworth*, supra note 34, 452 So.2d at 926-27.
48. *Brophy*, supra note 2, 497 N.E.2d at 639
49. *Jobes*, supra note 7, 529 A.2d at 450.