

Practical Problems in the Withdrawal of Nutrition and Hydration From Two Patients in a Persistent Vegetative State

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It is ethically and legally permissible to withdraw and withhold lifesaving medical treatment from patients in a persistent vegetative state (PVS) under certain conditions, but implementing these decisions is still very difficult for physicians and family members.

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We report two cases in which families overcame significant obstacles to fulfill the previously expressed wishes of a family member in a PVS. Tasks physicians should consider in assisting families with these decisions include verifying the diagnosis of PVS, ascertaining advance directives, counseling families and health care providers, consulting with the ethics committee, reviewing legal requirements, arranging for tissue donation if desired, and preparing the family for the patient's death.

Clear communication between families and health care providers regarding the goals of medical interventions for patients in a PVS is essential. The identification of tasks necessary to withdraw life support from patients in a PVS should make this difficult responsibility easier for physicians and families.

Under certain conditions, withdrawal of life-sustaining treatment from patients who no longer have decision-making capacity has become morally and legally acceptable. The decision in *Cruzan v Director, Missouri Department of Health*,¹ affirmed the individual's constitutional right to refuse life-sustaining medical treatment while also affirming the right of each state to set evidentiary standards for such decisions.²⁻⁴ Respect for

the constitutional guarantee of liberty and for patient autonomy are the legal and ethical justifications, respectively, for both withholding and withdrawing life-sustaining treatment.^{5,6} However, while many ethicists appear to have reached a consensus, physicians and families still wrestle with these difficult cases.

The care of these patients is trying for many reasons. Families and physicians may experience guilt or anxiety when deciding to withdraw treatment if, as usually occurs, no written advance directive exists.⁷ Advance directives often are unclear or do not address the patient's circumstances.^{8,9} Families and physicians may also fear opposition from administrators, other health care providers,¹⁰ or outsiders. Physicians may fear making an error in the patient's prognosis, however unlikely,¹¹ or may fear legal liability from withholding or withdrawing life-sustaining treatment.¹² Physicians also may be unaware of the relevant recommendations of professional groups or may not know of their jurisdiction's legal requirements for these decisions.¹³

Once the decision to withhold or withdraw treatment is made, however, families and physicians face other challenges. Physicians and families may be unclear about what constitutes appropriate terminal care.¹⁴ Both providers and family members may not know what to expect when treatment is stopped. Finally, there is little information available regarding the "natural his-

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tory" of patients whose feeding or other treatment has been withdrawn.

These considerations are especially true for patients in a PVS. A PVS is a state of permanent unconsciousness. Although sleep-wake cycles are preserved, no voluntary behavior is observed.^{5,15} To casual observers, however, these patients may appear to be sleeping or, if their eyes are open, observing their surroundings. Families of patients in a PVS often do not understand this condition and frequently believe that relatives in a PVS are aware of their presence or can feel pain.¹⁶ Patients in a PVS may live for years with careful treatment.

THERE IS general agreement that withholding life-sustaining medical treatment, including nutrition, from a patient in a PVS is permissible if the patient indicated beforehand that he or she did not want to be kept alive by such treatment.^{6,17} Despite this theoretical agreement, stopping medical or nursing interventions in patients in a PVS may be difficult for physicians, families, and institutions, as illustrated by the following cases. We suggest steps that physicians can take to reduce the difficulties for health care providers and families. In both cases the families consented to publication of the details of their respective family members' hospitalizations.

REPORT OF CASES

CASE 1

A 28-year-old male carpenter sustained a closed head injury and multiple fractures in a motor vehicle accident that involved a drunk driver. He was stabilized and his fractures were treated at a trauma center, where he was found to be in a deep coma. He was transferred to a rehabilitation facility for coma stimulation.

When the patient had made no improvement 5 months after his injuries occurred, he was transferred to a long-term care facility. After review of the patient's records and a physical examination, his physician made a preliminary diagnosis of PVS.

The patient's mother told his attending physician that her son had stated on several occasions that he would not wish to live in such a condition, and so she wished to have her son's tube feeding stopped. Both the patient's attending physician and the administrator of the hospital supported this decision, but both had concerns that life-sustaining treatment be withdrawn legally. The Attorney General of Maryland issued an opinion in 1988 that decisions to stop nutrition and hydration in patients in a PVS could only be made by a court.¹⁸ The patient's mother was aware of this requirement and petitioned for guardianship and authority to discontinue life-sustaining treatment.

Repeated neurological examinations confirmed the diagnosis of PVS. The patient's eyes were usually open, but he did not track objects. He did not respond to painful or verbal stimuli, including commands. A neurology consultant recommended an electroencephalogram to exclude status epilepticus. The electroencephalogram demonstrated a seizure focus but not status epilepticus; he continued to receive phenytoin oral suspension. A neurosurgeon reviewed a recent computed tomographic scan of the head and excluded a surgically remediable cause for the PVS.

The patient had no written advance directives, although members of his family recalled occasions when he stated that if he became so ill that he was confined to bed without any chance of improvement he would not want to live. These statements were precipitated by the deaths of two close relatives who lingered in unresponsive states before dying. The patient's physician had met with all the involved members of his family and found no one who disputed the patient's statements. The family testi-

fied to the patient's statements in a court hearing 5 months after his admission to the long-term care facility. His attending physician testified that the patient was in a PVS and was not expected to regain any function and cited the supportive test and examination results. The judge granted the family's petition, subject to agreement by the long-term care facility's ethics committee. Maryland law requires that all hospitals and nursing homes form such a committee, called a patient care advisory committee.¹⁹

The committee reviewed the patient's prior statements with his family. The committee agreed that it was morally appropriate to stop the tube feeding. After receiving a letter that summarized the committee's decision, the judge ordered that the patient's mother be allowed to decide whether her son would continue to receive artificial nutrition and hydration via his gastrostomy tube.

The patient's mother told his physician to stop his feeding and hydration. She agreed to continue the patient's phenytoin to prevent seizures that might result in the patient's transfer to an emergency department, which had occurred earlier in the patient's stay. Just enough fluid (20 mL three times daily) was given to ensure that the phenytoin would not adhere to his gastrostomy tube.

Prior to the date the patient's nutrition was to be withheld, the unit nurse manager and the attending physician met with the nursing staff to address their concerns. Some staff felt that the patient was responsive and did not agree with the decision to withhold his feeding. These staff chose to work on other units when the patient's tube feeding was stopped, a decision supported by the hospital administration. Despite these efforts, family members reported that some staff approached the family to voice their objections.

The patient's physician met with the patient's family to counsel them regarding the patient's impending death. The patient lived much longer than expected, which the family found

very stressful. Except for an absence of urine output, the patient's condition did not change appreciably for 21 days after feeding was stopped.

The patient died 25 days after his feeding was stopped, surrounded by his family and fiancée. Although his family had made preparations to donate the patient's corneas, skin, and bone for transplantation, the patient's body was requested by the medical examiner's office because his injuries resulted from a drunk driver. Only the corneas were taken for transplantation.

CASE 2

A 24-year-old fitness instructor was injured in a motor vehicle accident involving the vehicle in which he was a passenger. His injuries included a closed head injury that resulted in a deep coma, multiple fractures, a ruptured bladder, and a retroperitoneal hematoma. Several weeks later, the patient began having sleep-wake cycles and he was transferred to a rehabilitation hospital. After 4 months, his parents were told by his physician that the patient was not progressing and was in a vegetative state. Plans were made for his transfer.

The patient's parents met with his proposed attending physician at the long-term care facility prior to the patient's admission and told him of their interest in withdrawing their son's nutrition. As in the case of patient 1, the parents of patient 2 said that their son had stated on many occasions that he would not like to live in such a condition. After the parents learned that neither his attending physician nor the hospital administrator would oppose this decision if a diagnosis of PVS was confirmed, the patient was transferred.

After admission to the long-term care facility, repeated examinations showed that the patient was unresponsive to verbal stimuli. At times he displayed reflex grimacing in response to painful stimuli, but he had no purposeful movements. To confirm the diagnosis of PVS, he was re-

(1) The PVS is a form of permanent unconsciousness with sleep-wake cycles. <ul style="list-style-type: none">(a) No voluntary behavior is present.(b) Diagnosis is by careful, repeated clinical observation supported by laboratory studies (eg, electroencephalography, computed tomography, or magnetic resonance imaging).(c) These patients are not terminally ill, and may survive as long as artificial nutrition and fluids are continued.(d) Patients in a PVS do not have the capacity to experience pain or suffering.
(2) Nutrition and hydration may be discontinued in accordance with principles governing the withdrawal of other treatment. <ul style="list-style-type: none">(a) The decision to withdraw fluids and nutrition should be based on the patient's prognosis, the benefits and burdens of treatment, and the preferences of the patient and family.(b) The provision of nutrition is analogous to other forms of life-sustaining treatment, such as the use of a ventilator.(c) The administration of fluids and nutrition by medical means is a medical, not a nursing, procedure.(d) Physicians must assess the level of medical treatment appropriate to each dying patient. Treatments that provide no benefit to the patient or family may be discontinued.
(3) All further medical therapy may be forgone for patients reliably diagnosed as being in a PVS when it is clear that the patient would not want any further therapy and the family agrees. <ul style="list-style-type: none">(a) This is consistent with the position of the American Medical Association's Council on Ethical and Judicial Affairs and current medical, ethical, and legal principles.(b) This is consistent with the medical community's position that patients in a PVS need not be sustained indefinitely by medical treatment.(c) When the attending physician disagrees with the decision to withhold all medical treatment, the physician should not be forced to act against his or her conscience. In this case the patient may be transferred to another physician or facility where treatment may be discontinued.(d) The Academy encourages health care providers to establish internal consultative procedures, such as ethics committees, to offer guidance in cases of apparent irreconcilable differences.
(4) It is good practice to initiate artificial provision of fluids and nutrition when the patient's prognosis is uncertain. <ul style="list-style-type: none">(a) Complete unconsciousness must last at least 1 to 3 months before the diagnosis of PVS can be made with a high degree of medical certainty. It is appropriate to provide aggressive medical treatment while assessment is taking place.(b) There is no medical, ethical, or legal distinction between withholding and withdrawing medical treatment.(c) Family members must retain the ability to withdraw consent for continued artificial feedings well after initial consent has been obtained.

**Adapted from the American Academy of Neurology.¹⁵*

ferred to the trauma hospital where he was first treated. A computed tomographic scan of the head showed massive infratentorial and supratentorial brain damage. A neurosurgeon reviewed the scan results, examined the patient, and confirmed the diagnosis of PVS.

The attorney for the family of the patient scheduled a court hearing to ask for permission to withdraw the patient's nutrition. In preparation for the court hearing, the patient's attending physician spoke with the family's attorney on multiple occasions, including once at the

patient's bedside, to assure the attorney that the patient was in a vegetative state. The attending physician also provided medical literature about PVS to her. Throughout his final hospitalization, the patient was almost continuously febrile. These fevers were attributed at various times to heterotopic ossification, pneumonia, an infected sacral pressure ulcer, and urinary tract infections. In accordance with his family's wishes, the patient's evaluations were limited to physical examinations and his treatment was limited to comfort measures such as antipyretics and rou-

tine nursing care. He remained on an air-fluidized bed for treatment of a pressure ulcer, but his ulcer worsened.

The patient's family noted that he often appeared to be grimacing in response to pain. Although they were repeatedly assured that the patient did not feel pain, his parents requested that he receive analgesics. Hydromorphone hydrochloride, 1 mg every 4 hours per gastrostomy tube, was given.

A court date was scheduled almost 5 months after the patient's admission to the extended care facility and 14 months after his accident. All family members were in agreement with regard to the patient's previously expressed wishes. Witnesses to the patient's statements were scheduled to come to Maryland from other areas of the country to testify. The patient's condition continued to deteriorate, however, and he died, presumably of overwhelming sepsis, 5 days before the hearing. The family donated the patient's corneas.

COMMENT

ETHICAL AND LEGAL ISSUES

These cases illustrate the difficulties that families face in implementing choices about life-sustaining medical interventions. Families are torn between the desire to prolong life and the indignity and dehumanization of the interventions required to do so. Indeed, it requires "compassion . . . and often . . . courage" to act on behalf of these patients, even when their wishes are known to family members.²⁰ In these two cases, the families acted in accordance with current legal and ethical standards.^{5,15,21-24} As trying as the ethical choices were, however, their greatest difficulties lay in surmounting legal and practical obstacles.

Because no federal or Maryland law clearly defines appropriate decision-making guidelines in these circumstances, the institution's administrators and legal consultants felt strongly that the decision to stop the nutrition and hydration of both pa-

Table 2. Tasks Associated With Withdrawal of Nutrition and Hydration From Patients in a Persistent Vegetative State (PVS)	
Medical	
	Familiarizing self with American Academy of Neurology position statement on the patient in a PVS
	Verifying diagnosis by repeated examinations and by neurologic specialist or specialized studies as necessary
	Obtaining a second medical opinion from a physician not associated with the attending physician is highly advisable
Family	
	Ascertaining written advance directives or prior expressed wishes of patient, if any
	Counseling families about PVS and the stress associated with decisions to withhold treatment
	Arranging for tissue donation if desired
	Preparing the family for death
Hospital administration	
	Presenting before hospital or nursing home ethics committee
	Counseling staff with concerns about patients in a PVS or with ethical concerns about withdrawal of nutrition
Legal	
	Reviewing relevant state law
	Meeting with family's and hospital's attorneys as necessary to clarify legal status and overcome barriers

tients be sanctioned by a judge. This was recommended despite the agreement of the patients' families and physicians, the institution's ethics committee (in the case of patient 1), and the medical community (**Table 1**) that the termination of feeding was ethically permissible in such situations and that this decision should be made by the patients' families and physicians. This meant that additional substantial resources had to be employed by both families. These resources included the following: (1) *Emotional resources*. Going to court greatly prolonged the deaths of these patients and the families' grieving process. (2) *Intellectual resources*. Family members faced complex legal, ethical, and medical issues. (3) *Financial resources*. Both families retained attorneys to marshal the evidence necessary to convince a judge of their arguments.

PRACTICAL ISSUES

As more families of patients in a PVS become aware that life-sustaining

medical treatment for their family members need not continue indefinitely, more physicians will be approached to stop this treatment. Physicians wishing to aid families in similar circumstances need compassion, tenacity, and patience.

Many tasks must be accomplished to prepare for withdrawal of nutrition and hydration from patients in a PVS (**Table 2**). These tasks encompass medical, family, hospi-

Families are torn between the desire to prolong life and . . . dehumanization of . . . interventions

tal, and legal issues. Recognition of these tasks will help the physician and family implement decisions to withdraw feeding and hydration from patients in a PVS.

The diagnosis of PVS should be verified through repeated examinations and, if necessary, consultation with a neurologic specialist familiar with the American Academy of Neurology criteria for PVS (Table 1). Ad-

ditional testing or neurosurgical evaluation may be necessary to exclude a surgically remediable problem such as hydrocephalus or subdural hematoma. It is important to remember, however, that PVS is a clinical diagnosis made primarily by repeated physical examinations, not by laboratory studies. Tests of struc-

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ture (eg, computed tomographic scans or magnetic resonance imaging) usually add little prognostic information but may reassure families that a reversible condition is not present. In any event, a second opinion by another physician is strongly recommended to reassure family, care providers, and the patient's physician and may be required in some states (eg, Illinois).⁷

Physicians also need to determine whether the patient has any written or verbal advance directives. If the patient's advance directives consist only of verbal statements to family members or friends, the physician should make a reasonable effort to ascertain that there is no disagreement about these statements. If disagreement exists, then legal consultation is recommended. In most contested cases, a court hearing will be necessary to decide who will speak for the patient and which advance directive will be followed.²³

Families often question the diagnosis of PVS and may require reassurance regarding withdrawal of treatment. Physicians and other health care providers can help prepare families for the patient's death by providing guidance as to the time the patient may die, thus allowing for as many friends and family members as possible to be present.

Where available, ethics com-

mittees can give families, administrators, physicians, and other health care providers advice from professionals such as clergy and attorneys not directly involved in the actual case.^{25,26} Staff who have moral difficulties with the decision may also use the committee to answer questions and to discuss their opinions.

Communication with all health care providers is essential.²⁷ Once the family and physician are in agreement that withdrawal of nutrition and hydration is acceptable, it is important for physicians to counsel all staff who work with the patient and family. Other members of the health care team may not be aware of the definition of PVS or the ethical issues regarding these patients. Administrators also may need to speak with staff. Flexibility in staff scheduling, as illustrated in the first case, may reduce the stress for both the family and the health care providers. Education and support of all who provide health care for the patient can help to ensure that all who meet the patient's family are sensitive to their stress.

Last, physicians may experience considerable anguish and soul-searching when they participate in actions that allow a patient's life to end.¹¹ These feelings are only enhanced when death does not come quickly. The desire to cure these patients must be rechanneled into comforting the family and staff.²⁷

Patient proxies and physicians are best advised to communicate clearly the intended purpose of any medical interventions on behalf of the patient.^{27,28} For patients in a PVS, the decision to maintain organic life aggressively or to limit care to comfort measures is a value judgment. It is not clearly settled that one decision is always better than another, but that one decision is better for a particular patient.

The legal issues and standards

in these cases, while complex, are becoming clearer, as other courts interpret the *Cruzan* ruling.^{23,29} However, the standards that each state applies and the process to be followed are still to be determined in many jurisdictions. Thus, physicians need to familiarize themselves with the relevant law in their own states. In support of the emerging legal consensus,²³ we believe that courts have no role in decisions to withdraw feeding from patients in a PVS when surrogates and physicians are in agreement or the patient has a written advance directive that clearly states his or her decision regarding life-sustaining medical treatment. Adoption of statutes similar to Illinois' Health Care Surrogate Act (Ill Pub Act 87-749) should obviate legal obstacles in many cases.⁷

These cases of withdrawal of life-sustaining treatment did not address the costs of care, the clarity of the evidence pertaining to the patient's prior expressed values, or the implications of moral change in our society. These issues must also be addressed if our society is to reach a consensus on the treatment of these and other patients who cannot decide their own care.

Clear procedures that go beyond current legal and ethical guidelines are needed for such tragic cases. Physicians, proxies, caregivers, and society would all benefit from such directions.

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