

## Session 15. Brain Death, Permanent Vegetative State, and Medical Futility

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### Overview

Technology now allows many patients with severe neurologic disorders who in the past would have died to have their lives prolonged. Some such patients are brain dead, others are in a state of permanent unconsciousness, and still others have severe brain damage but some interaction with their environment. The care of such patients raises controversial questions. Are their lives worth living? At what expense? Should society impose limits on the kind of care that should be offered to patients who have no hope of ever recovering consciousness? When the patients are children, the issues become even more complicated. How much can parents request? Can a physician refuse to provide the treatment if he or she believes the treatment is medically futile? Who determines whether the treatment is futile and by what criteria? Should cost be included when determining whether the treatment is appropriate?

This module will help the participants understand the differences among brain death, coma, permanent vegetative state, and minimally conscious state and help them appreciate how one's determination of futility affects decision making with regard to treatment options.

### Instructor's Guide

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
- Further Reading
- Case Discussion
- Conclusions and Suggestions

### Case Summary

A 4-year-old boy suffered a traumatic brain injury (TBI) in a motor vehicle accident. Now, 6 months after the accident, he has been diagnosed as being in a permanent vegetative state. After multiple episodes of pneumonia, his lung function has deteriorated to the point of requiring long-term mechanical ventilation. His parents provide the ventilation treatment at home, but he is

periodically hospitalized with aspiration pneumonia. The physicians believe that continuing the ventilator is futile.

- Is this treatment futile?
- Who determines whether a treatment is futile?
- Who has the right to decide medical treatment for this child?
- Would these answers be different if the child were brain-dead or in a minimally conscious state?

### **Alternative Cases**

1. A 3-month-old has been declared brain dead. The infant was found apneic and pulseless in his crib and was resuscitated. Since admission to the pediatric intensive care unit, he has not improved. The infant meets all the criteria for the determination of brain death. The parents do not want to withdraw support. Currently, he is receiving intravenous nutrition and hydration and ventilatory support via an endotracheal tube. The parents want a feeding tube placed and a tracheostomy for permanent ventilatory support. The physicians believe this treatment is futile and refuse to provide it.
2. A 6-year-old girl is in a minimally conscious state, living in a chronic care facility as a ward of the state. Her brain injury is a result of nonaccidental trauma as an infant. She has been living in this chronic care facility since initial discharge with no familial involvement. Recently, she has required multiple hospitalizations for pneumonia. Long-term ventilation is recommended. Her caregivers at the facility state that she interacts with her environment at times. She periodically grunts when she is being weighed, withdraws from painful stimuli, and smiles when caregivers sing to her. How does one determine quality of life and, therefore, determine whether long-term ventilatory support would be futile in this case?

### **Learning Objectives**

1. Understand the differences among brain death, coma, permanent vegetative state, and minimally conscious state.
2. Recognize different definitions of futility.
3. Understand parental rights to make medical decisions for children and the potential limitations to these rights.

### **Suggested Reading for Instructor**

American Academy of Pediatrics, Committee on Bioethics. Ethics and the care of critically ill infants and children. *Pediatrics*. 1996;98(1):149–152

## Further Reading

Ashwal S. Pediatric vegetative state: epidemiological and clinical issues. *NeuroRehabilitation*. 2004;19(4):349–360

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The Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state. *N Engl J Med*. 1994;330(22):1499–1508, 1572–1579

Schneiderman LJ. Defining medical futility and improving medical care. *J Bioeth Inq*. 2011;8(2):123-131

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## Case Discussion

***What are the differences between brain death, coma, permanent vegetative state, and minimally conscious state?***

### *Brain Death*

The Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research established guidelines for the diagnosis of brain death in 1981 (Table 1). There are 2 criteria for the determination of death: the irreversible cessation of circulatory and respiratory functions, or the irreversible cessation of all functions of the entire brain, including the brain stem.

#### ***Table 1. Guidelines for the Diagnosis of Brain Death<sup>a</sup>***

1. An individual with irreversible cessation of all functions of the entire brain, including the brainstem, is dead.
2. Cessation is recognized when evaluation discloses findings of (a) AND (b)

- a. Cerebral functions are absent
- b. Brainstem functions are absent
3. Irreversibility is recognized when evaluation discloses findings of (a) AND (b) AND (c)
  - a. The cause of coma is established and is sufficient to account for the loss of brain functions
  - b. The possibility of recovery of any brain functions is excluded
  - c. The cessation of all brain functions persists for an appropriate period of observations and/or trial of therapy
4. Complicating conditions confounding the diagnosis of brain death
  - a. Drug and metabolic intoxication
  - b. Hypothermia
  - c. Children (particular caution in applying neurological criteria to determine death in children <5 years old)

<sup>a</sup>Banasiak KJ, Lister G. Brain death in children. *Curr Opin Pediatr.* 2003;15(3):288-293

In 1987, the American Academy of Pediatrics Task Force for the Determination of Brain Death in Children developed the guidelines for the determination of brain death in children, and these were later revised and updated in 2011. Table 2 shows the Guidelines for Determination of Brain Death in Children.

**Table 2. Guidelines for the Determination of Brain Death in Children<sup>b</sup>**

Reversible conditions or conditions that can interfere with the neurologic examination must be excluded prior to brain death testing.

1. Coma: Patient must exhibit complete loss of consciousness, vocalization, and volitional activity.
2. Loss of all brain stem reflexes, including:
  - a. Midposition or fully dilated pupils that do not respond to light.
  - b. Absence of movement of bulbar musculature including facial and oropharyngeal muscles.
  - c. Absent gag, cough, sucking, and rooting reflex.
  - d. Absent corneal reflexes.
  - e. Absent oculovestibular reflexes.
3. Apnea: The patient must have complete absence of documented respiratory effort (if feasible) by formal apnea testing demonstrating a PaCO<sub>2</sub> ≥60 mm Hg and ≥20 mm Hg increase above baseline.
4. Flaccid tone and absence of spontaneous or induced movements, excluding spinal cord events such as reflex withdrawal or spinal myoclonus.

<sup>b</sup>Adapted from Nakagawa TA, et al. Clinical report – guidelines for the determination of brain death in infants and children: an update of the 1987 task force recommendations. *Pediatrics.* 2011;128(3):e720-e738

The initial examination should occur at least 24 hours after the brain injury was sustained or cardiopulmonary resuscitation took place. Two clinical examinations must be performed by 2 different physicians, and both tests should include the apnea testing. An ancillary test (ie, electroencephalogram or cerebral blood flow study) is not necessary unless the apnea test cannot safely be performed on the initial test. An observation period of 24 hours for term newborn infants (37 weeks' gestation to 30 days) or 12 hours for older infants and children (31 days to 18 years) should be present between examinations, however, this can be shortened in both age groups if ancillary testing confirms initial examination (Nakagawa).

### Coma

Coma is a "state of deep, unarousable, sustained pathologic unconsciousness with the eyes closed which results from dysfunction of the ascending reticular activating system either in the brain stem or both cerebral hemispheres."<sup>1</sup> This state must persist for greater than 1 hour. Patients are unconscious because they lack both wakefulness and awareness.<sup>3</sup>

### Vegetative State

A patient that is in a vegetative state can exhibit wakefulness but is unaware of herself or her environment.<sup>2</sup> This condition is further divided into persistent vegetative state if the condition lasts for more than 1 month or as permanent vegetative state if it lasts more than 3 months after a nontraumatic brain injury or 12 months after a traumatic brain injury. Permanent vegetative state is described as state of "complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain stem autonomic functions."<sup>3</sup> Patients show all the following characteristics, as developed by the Multi-Society Task Force on PVS:

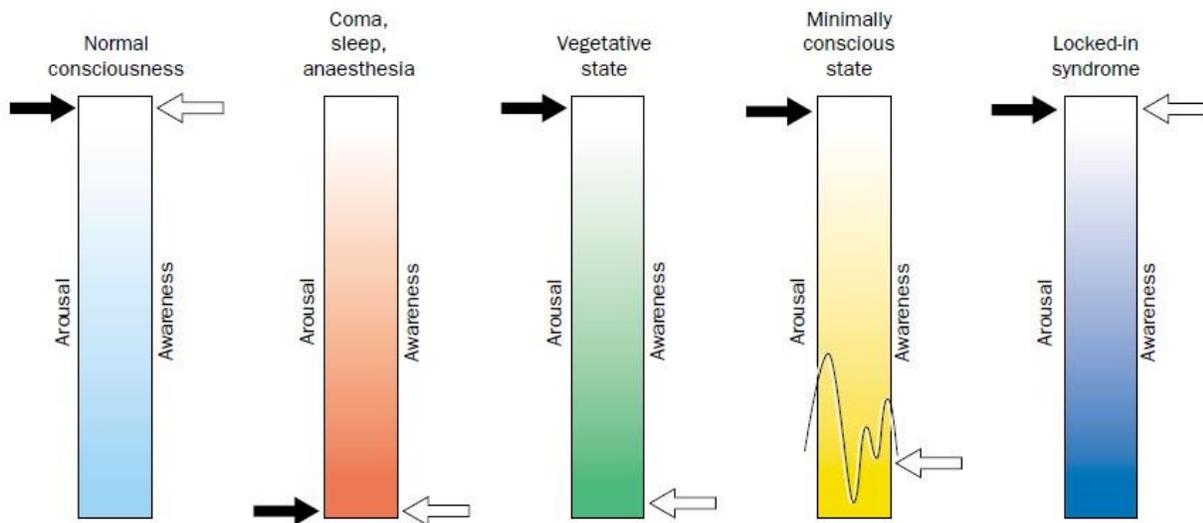
- No evidence of awareness of themselves or their environment; they are incapable of interacting with others.
- No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli.
- No evidence of language comprehension or expression.
- Intermittent wakefulness manifested by presence of sleep-wake cycles.
- Sufficiently preserved hypothalamic and brain stem autonomic functions to survive if given medical and nursing care.
- Bowel and bladder incontinence.
- Variably preserved cranial nerve (papillary, oculocephalic, corneal, vestibule-ocular, gag) and spinal reflexes.

### Minimally Conscious State

Minimally conscious state is a condition of "severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated."<sup>1</sup> Diagnostic criteria from the Aspen Neurobehavioral Work Group<sup>4</sup> are as follows:

1. Simple command following.
2. Gestural or verbal “yes/no” responses (regardless of accuracy).
3. Intelligible verbalization.
4. Purposeful behavior including movements or affective behaviors that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity. Some behaviors include the following:
  - a) Appropriate smiling or crying in response to the linguistic or visual content of emotional but not to neutral topics or stimuli.
  - b) Vocalization or gestures that occur in direct response to the linguistic content of questions.
  - c) Reaching for objects in a way that demonstrates a clear relationship between object location and direction of reach.
  - d) Touching or holding objects in a manner that accommodates the size and shape of the object.
  - e) Pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli.

**Figure 1. Differentiation Among Brain Death, Coma, Permanent Vegetative State, and Minimally Conscious State<sup>c</sup>**



<sup>c</sup> Figure adapted from: Laureys S, Owen AM, Schiff ND. Brain function in coma, vegetative state, and related disorders. *Lancet Neurol.* 2004;3(9):537-546

The patient with brain death will show evidence meeting the diagnostic criteria listed previously demonstrating completely destroyed brain stem. Normal consciousness has maximal arousal and awareness while minimal arousal and awareness are seen with coma, sleep, and anesthesia.

Patients in a vegetative state will have complete or partial preservation of brain stem and hypothalamic function but will have no awareness of self or the environment with periods of wakefulness. The minimally conscious state is used to categorize those patients who are not in a vegetative state and have behaviors associated with conscious awareness but are unable to communicate consistently because of fluctuating awareness. The term “locked-in syndrome” was introduced by Plum and Posner to describe the quadriplegia and anarthria resulting from the disruption of corticospinal and corticobulbar pathways, respectively. In this state, the patient is unable to move or talk but has intact arousal and awareness.<sup>2</sup>

***Do these categories make up the whole spectrum of severe brain damage?***

No. These categories reflect individuals with severe neurologic damage. There are many patients who have more awareness and behaviors than individuals in minimally conscious state.

***Is life-sustaining treatment futile for infants or children in any of these categories? What is the definition of futility?***

A strict definition of futility would be the complete absence of any efficacy in reaching any physiologic goal. In clinical medicine, the term is usually used to mean that a treatment or therapy will not improve or benefit the patient in any way. Schneiderman et al defined futile as

“any effort to achieve a result that is possible but that reasoning or experience suggest is highly improbable and that cannot be systematically produced.”

***Is there a difference between physiologic futility and qualitative futility?***

Futility has been expanded to mean many different things to many different people. Diekema states there are 2 different types of futility: strict physiologic futility and qualitative futility. Strict physiologic futility means that an “intervention would not achieve its intended immediate physiologic effect.” The treatment simply would not work. Examples of strict physiologic futility include the use of antibiotics to cure a viral illness or cardiopulmonary resuscitation for a patient who has been pulseless for longer than 1 hour. Qualitative futility “weighs the potential benefit of an intervention with the quality of its effects.” Qualitative futility is controversial because it requires a value judgment about the quality of the effects of treatment. Such a value judgment could be made by physicians, patients, or surrogates for the patient. If these parties agree (as is often the case), they can act on the futility determination. If they do not, one must prevail.

***Is cost-effectiveness relevant to determinations of futility?***

One should not confuse cost-effectiveness with medical futility. Just because a treatment is not cost-effective, such as long-term ventilation in a patient with neuromuscular disorder, does not mean that it is futile. When physicians use cost-effectiveness as a determinant of the appropriate level of care for patients with serious neurologic impairment, they are incorporating a value judgment to the decision making, a judgment about quality of life that is usually left to the patient and family.

## *Are there limits to parents' rights to make treatment decisions for their children?*

### *In Brain-Dead Children*

Laws in every state allow the physician to forgo life-sustaining medical treatment in individuals who are determined brain dead, regardless of age. There have been cases in which parents have protested the removal of life support on the basis of brain death criteria and prevailed. These are rare. In most cases of disagreement, the child's respiratory and circulatory systems fail before the court decision is made.

### *In Permanent Vegetative State or Minimally Conscious State*

A child who is in permanent vegetative state or minimally conscious state is not dead. Therefore, parents have the right to make health care decisions for this child. A few states allow physicians to override patients or surrogates if the physician determines that further treatment is futile.

### *How do these concepts apply to the cases?*

In this case, the child is not brain dead. Mechanical ventilation for a patient in persistent vegetative state is not physiologically futile. The ventilator will achieve its intended effect; it will support his respiratory status, decreasing his risk for pneumonia. With regard to qualitative futility, the physicians may believe that this child's quality of life is poor based on their own values. The parents, on the other hand, may feel that their child's quality of life is acceptable. When determining futility based on quality of life, one must recognize that their values play a role in this determination. Therefore, if the parents believe the child has an acceptable quality of life, a decision to provide mechanical ventilation for their child, even if it is not the medical recommendation, must be respected.

In alternative case #1, the child meets the criteria for brain death. In that case, they could legally withdraw the ventilator without the parents' permission. In some such cases, parents have sought legal protection, through restraining orders or other legal means, and courts have allowed their wishes to continue mechanical ventilation to prevail. Those cases are rare.

The patient in alternative case #2 is awake, alert, and has some interaction with her environment. She does not appear to be in pain. Although many people would consider her quality of life miserable and would withhold or withdraw life-sustaining treatment, others would opt to continue treatment. In such a case in which a patient is neither permanently unconscious nor in intractable pain, either option is permissible.

## **Conclusions and Suggestions**

Caring for individuals with severe neurologic disorders can be very difficult, especially when the question of medical futility arises. It is important to remember the difference between physiologic futility and qualitative futility, with determination of qualitative futility being based on one's personal values. At this point in our society, when we do not deem something to be medically futile based on financial implications, we need to respect the parents' determination of what is best for their severely neurologically devastated child.

## References

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*This instructor's guide is part of a collection edited by Douglas S. Diekema, MD, MPH, FAAP; Steven R. Leuthner, MD, MA FAAP; Felipe E. Vizcarrondo, MD, MA, FAAP on behalf of the American Academy of Pediatrics Committee on Bioethics and Section on Bioethics.*

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