

Witness:

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Testimony

Executive Summary

Human consciousness has two clinical dimensions: wakefulness, served by the brain stem ascending reticular activating system (ARAS) and its connections; and awareness of self and environment, served by the thalamus, the cerebral cortex, and their connections.

Coma is an eyes-closed state of pathological unconsciousness from which subjects cannot be aroused to wakefulness, caused by a disorder of the brainstem ARAS. The vegetative state is a disorder featuring the ironic combination of wakefulness but absent awareness, caused by damage to the thalamus, the cerebral cortex, and their connections. Vegetative state patients have sleep-wake cycles. Their eyes are open when awake and closed when asleep. They breathe, blink, move their eyes, may make noises (though no words), and show reflex responses. But to the fullest extent testable, they have no awareness of themselves or their environment. When the vegetative state has been present for at least a month it is called the persistent vegetative state (PVS). The minimally conscious state (MCS) is a disorder of limited responsiveness in which patients retain awareness but their responses are so deficient that the evidence of their awareness may be difficult to detect. The most common causes of PVS and MCS are head trauma, brain damage from lack of oxygen during cardiac arrest, and stroke.

The vegetative state usually is classified as a state of unconsciousness, but the terminology is ambiguous because, although PVS patients are unaware, they are awake. Because awareness is the most relevant component of consciousness, the loss of awareness counts as unconsciousness despite their open eyes.

There is a biological limitation to our ability to know the awareness of another person. We cannot get inside their minds and experience what they experience. Therefore, we can know their awareness only by inference: we interact and stimulate them and study their responses. We infer whether they are aware by analyzing the quality of their responses and judge if a response is such that could be made only by an aware person. Responses produced by reflexes or so-called stereotyped responses do not count because they are integrated at a purely subcortical level.

Physicians diagnosing PVS have the duty to show the complete absence of any evidence of awareness. Testing should include observing the patient, interacting with the patient during a neurological examination, talking to nursing caregivers and family members, and examining laboratory tests such as EEGs and CT scans or MRIs. The examination should be directed toward eliciting any sign of awareness. We talk to patients to see if they respond appropriately to commands, make clear eye contact, follow a moving object with their eyes consistently and intently, react to emotional stimuli such as seeing a photograph of a loved one or talking about a loved one. The examination is long, tedious, repetitive, and thorough. Because a random response might be interpreted as showing awareness, we test to see if it is reproducible. We interview nursing staff and family

members to ask if they have observed any responses that they believe prove the patient is aware. If so, we ask them to demonstrate it to us. Only in the utter absence of evidence of awareness should we issue the diagnosis of PVS. EEGs commonly show diffuse, profound abnormalities and neuroimaging studies show brain atrophy if the injury or illness was many months or years earlier. Newer technologies such as brain PET scanning and functional MRI have an important role in research – to help us learn about the brain centers necessary for awareness – but are not currently used in clinical diagnosis.

The prognosis for recovery of awareness in PVS has been quantified. In general, the prognosis depends on the cause and duration of PVS. It is worse after cardiac arrest and after a long duration of PVS. Patients remaining in PVS for greater than 3 months after cardiac arrest have only a slight chance of recovery of awareness. Recovery of awareness is unprecedented after 2 years. With head injury causing PVS, the times necessary to show these levels of prognostic certainty are 1 year and 5 years respectively.

The level of treatment we give patients is based on their prior stated wishes in light of their prognosis. We aggressively support and treat patients who would have wanted that level of treatment and cease treatment when patients have indicated that they would not want to be maintained on life-sustaining treatment in their current condition. If the patient has left no clear directives, we seek advice from their family and primary care physician about their understanding of the patient's preferences for treatment in light of their diagnosis and prognosis. It is the responsibility of the medical team and the family to fulfill the patient's wishes for treatment. We do everything possible to achieve this goal.

Oral Testimony of James L. Bernat, M.D.

Good morning ladies and gentlemen. Thank you, Senator Gregg, for the kind introduction. I thank Senators Enzi and Kennedy for inviting me on behalf of the American Academy of Neurology to testify about the medical, scientific, and ethical issues involved in the diagnosis, treatment, and decision making for patients with disorders of consciousness resulting from severe brain damage.

The American Academy of Neurology is the principal scientific, clinical, educational, and policy organization for North American neurology, representing over 18,000 neurologists and related clinicians and scientists. The Academy has a long and distinguished concern for optimizing the care of patients with disorders of consciousness.

Although my comments today will be scientific and conceptual, I want to emphasize that I am mindful of the profound human tragedy of the patients I describe. The objectivity of my comments should not be construed as implying any lack of compassion for their tragic plight or for the unspeakable suffering endured by their families.

In my limited time, I wish to briefly clarify the medical syndromes causing disorders of consciousness. In my written testimony I have provided further detailed information regarding diagnosis, treatment, and the elements of clinical decision-making on these unfortunate patients. I have also included practice guidelines from the American

Academy of Neurology.

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During the question and answer time I hope we can further discuss the difficult issues of medical treatment, the complex ethical issues in medical decision making on these tragic patients, the importance of clear and compassionate communication with families, and some of the innovative scientific investigations that are being performed to better understand their illnesses. Thank you very much.