

VIEWPOINT

Understanding Brain Death

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The concept of brain death, or the determination of death by neurological criteria, was first proposed by a Harvard committee in the United States in 1968,¹ and then adopted into the Uniform Determination of Death Act (UDDA) in 1981.² Although the UDDA was widely accepted and endorsed by medical professional organizations, in recent years the concept has come under greater scrutiny and is increasingly the focus of legal challenges. Most urgent is that the current diagnostic standards do not satisfy the wording of the law. The UDDA defines brain death as the "irreversible cessation of all functions of the entire brain." Yet, it is now widely acknowledged that some patients who meet the current diagnostic standards may retain brain functions that are not included in the required tests, including hypothalamic functioning.³ Until the UDDA is revised to be more specific about which functions must be lost to satisfy the definition (such as, for example, consciousness and the capacity to breathe), current medical practice will not be in alignment with the legal standard.

Fixing this problem will require resolution of a long-standing debate about what brain death actually means. Beecher,⁴ the chair of the 1968 Harvard committee, clearly thought that brain death was a new and distinct definition of death, different from biological death. He wrote that "when consciousness is permanently lost... this is the 'moment' of death."⁴ But in 1981, the authors of the UDDA completely rejected this view in proposing both a cardiorespiratory and a neurological standard for determining death, insisting that "the use of two standards in a statute should not be permitted to obscure the fact that death is a unitary phenomenon."^{2(p7)} To support this position, the UDDA authors pointed to evidence that the brain is the master integrator of the body's functions, such that once the brain is severely damaged, bodily functions deteriorate, with cardiac arrest and biological death invariably following the injury within several days. This unified view has continued to be the position of most experts, with one asserting that "Globally, [physicians] now invariably equate brain death with death and do not distinguish it biologically from cardiac arrest."⁵

In recent years, this view has been challenged by multiple reports of cases of prolonged biological survival in patients who meet criteria for brain death. One well-known case is that of Jahi McMath, a teen-aged girl who survived biologically for almost 5 years after being diagnosed as brain dead following surgery at age 13 years. During most of this time, she was cared for at home, continuing to grow and develop, along with the onset of menarche. In another case, a boy diagnosed as brain dead from meningitis at age 4 years survived biologically for more than 20 years. At autopsy, his brain was completely calcified, with no identifiable neural tissue, either grossly or microscopi-

cally. Recently, a woman was found to be 9 weeks pregnant when she was diagnosed as brain dead at age 28 years; she was maintained for several months until she delivered a healthy baby followed by donation of multiple organs.

The relative rarity of these cases is because brain death is typically a self-fulfilling prophecy; biological death usually quickly follows the diagnosis, either from organ donation or ventilator withdrawal. But in cases for which organ support is continued, as when a brain-dead woman is pregnant or when a court order requires physicians to continue treatment, prolonged biological survival may occur. As counterintuitive as it may seem, when functions such as breathing and nutrition are medically supported, the brain is not essential for maintaining biological integration and functioning.

If brain death is neither the absence of all brain function nor the biological death of the person, then what is it? Current tests for determining brain death focus on establishing 3 criteria: unconsciousness, apnea, and irreversibility of these 2 states. First, unconsciousness is diagnosed by demonstration of the absence of response to painful stimuli and absence of brainstem reflexes. While individual brainstem reflexes are irrelevant to whether the patient is alive or dead (for example, people can live normal lives with nonresponsive pupils), demonstrating that the brainstem is nonfunctional is an indirect way of inferring that the reticular activating system is nonfunctional. This neural network in the brainstem is essential for maintaining wakefulness, and thereby is a necessary substrate for consciousness. Second, apnea is diagnosed by removing patients from the ventilator for several minutes and demonstrating that they make no effort to breathe despite a high level of carbon dioxide in the blood. Third, irreversibility is assumed if the cause of the injury is known, no reversible causes can be identified, and the patient's condition does not change over several hours. Collectively, the testing for brain death is designed to show that the patient is in a state of "irreversible apneic unconsciousness."

Irreversible apneic unconsciousness is not the same as biological death. But should patients in this condition be considered to be legally dead? This is a complex question that hinges on metaphysical and moral views about the necessary and sufficient characteristics of a living person. The British position on this point is interesting and relevant. While the United Kingdom does not have a law on brain death, the Code of Practice of the Academy of Royal Medical Colleges explicitly endorses the view that irreversible apneic unconsciousness should be recognized as death.⁶ The Code states, "Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person

and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe.”⁶ Contrary to the US position, the Code does not insist that brain death is the same as biological death. It states that while “the body may continue to show signs of biological activity ... these have no moral relevance to the declaration of death.”⁶ Following Beecher,⁴ the British consider brain death to be a moral determination that is distinct from biological death, based on a particular view about what constitutes the essential characteristics of a human person.

One option for reconciling the discrepancy between the UDDA and the current diagnostic standards for brain death in the United States would be to revise the UDDA along the lines of the British model. This would align the legal definition of death with current diagnostic standards. It would, however, also raise questions about how to respond to individuals who reject the concept of brain death. Even though there is nothing irrational or unreasonable about preferring a biological definition of death over other moral, religious, or metaphysical alternatives, there are concerns about the potential effects of allowing citizens to opt out of being declared brain dead. The experience in New Jersey may be relevant to this question because for more than 25 years that state has had a law permitting citizens to opt out of the determination of death by neurological criteria, and this law has not had any documented influence on either organ donation or intensive care unit utilization.⁷

Another potential benefit of adopting the British approach would be to facilitate improvement and refinements in the tests that are used. It is remarkable that the core tests in use today to diagnose brain death are virtually the same as those first proposed in 1968, and the authors of guidelines have commented on the “severe limitations in the current evidence base” for the determination of brain death.⁸ In particular, concerns have been raised about the irreversibility of the diagnosis and the certainty of the determination of unconsciousness. The latter is particularly important because studies have suggested that the behavioral bedside tests used to diagnose unconsciousness in the vegetative state may be wrong as much as 40% of the time.⁹ In addition, the safety of the apnea test has been questioned,¹⁰ and alternatives that do not require acutely raising the level of carbon dioxide in the patient’s blood to potentially dangerous levels could be advantageous. Incorporating modern imaging techniques and new diagnostic technologies into the routine testing for brain death could give more confidence to the claim that the patient is unconscious, provide stronger evidence of irreversibility, and reduce concerns about the safety of the tests.

Until the UDDA or individual state laws are revised, lawsuits are likely to continue because current tests do not fulfill the language of the law. This challenge provides an opportunity to clarify the meaning of brain death, better educate the public about the diagnosis, and improve the tests to make them as safe and reliable as possible.

ARTICLE INFORMATION

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