Controversy in the Determination of Death: Cultural Perspectives

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J Pediatr Intensive Care 2017;6:245–247.

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Abstract

The definitions of death have changed throughout recorded history to include not just cardiac death but death by neurological criteria as well. Given the many cultures present in the world, it comes as no surprise that declaring death takes many forms. In the Western world, brain death has gained common acceptance (though not universal), while other cultures and religions have struggled with this issue, especially as it surrounds the controversy of donated organs. There is legal precedent to support death by neurological criteria, as well as support for hospital systems and physicians to terminate somatic support of the brain-dead patient; however, these laws differ greatly from country to country. When dealing with a controversial topic, differing laws, and grief-laden families, it becomes especially crucial that health care staffs are educated regarding varying cultural beliefs surrounding death. In the majority of cases, with kindness and compassion, common ground between science and social perspectives can be found, leading to resolution of care for this group of patients.

Keywords

- brain death
- Japan
- somatic support
- culture

Historical Perspective

Since the time of Plato, Pliny, and Socrates, man has struggled to define death. Although certain criteria could be met to make certain diagnosis of death, physicians and laypersons have longed to delineate the moment at which death occurred for scientific, public health and safety, and spiritual reasons. Historically, rigor mortis, putrefaction, the nonresponse of the body to pain from incision, electricity, or other methods, and the lack of respiration, heartbeat, and wound healing all were sufficient to demonstrate irrecoverability of personhood and life. The necessity of a timely declaration of death was made most urgent when prolonged observation of the body for recovery of life was no longer feasible, that is to say, with the crisis of the black plague in 14th century Europe.¹ The urgency of burial to limit further contagion precipitated near panic in the public forum at the thought of premature interment. In the intervening centuries, medical care has made such progress that the definitions of death

have, again, become unclear. It is now possible to sustain the biological functions of the body in the absence of neurologic input, leading to significant debate in the medical, legal, ethical, and public settings about defining death by neurologic criteria, not just cardiorespiratory factors.

Legal Concepts

In 1968, the ad hoc committee of the Harvard Medical School to examine the definition of brain death convened.² This committee had two aims: to lessen the burden on patients, families, hospitals, and society of individuals who were neurologically devastated and to minimize controversy surrounding organ donation. This landmark article sought to achieve those aims by expanding the definition of death to include a neurologic one. However, while they defined death by neurologic criteria, brain death is a concept that is oftentimes difficult for medical personnel to comprehend, much less laypersons. In fact, if one turns to the internet for a

received
May 2, 2017
accepted after revision
May 28, 2017
published online
June 27, 2017

Issue Theme Pediatric Brain Death;
Guest Editors: Mark J. McDonald, MD,
FAAP, and Melissa B. Porter, MD

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DOI <https://doi.org/10.1055/s-0037-1604014>.
ISSN 2146-4618.

definition of death (www.rightdiagnosis.com), the symptoms listed are “stop of breathing” and “stop of heart rate.” Types of death listed on the same Web site are sudden death, maternal death, fetal death, infant death, sudden infant death syndrome, premature death, accidental death, suicide, and early death; brain death remains unlisted. To better define death, the Uniform Determination of Death Act (UDDA) was enacted in the United States in 1981 and expanded the definition of death to include the neurologic state as well as the cardiac condition of the patient. It was then publicly supported by the 1981 U.S. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the American Medical Association, and the American Bar Association.³ The UDDA allows that when neurologic function ceases, then so does life. It does not provide medical procedures for the declaration of brain death, but instead allows for medical judgment to be applied.⁴ Thus, there is no uniformly accepted procedure to declare neurological death and many hospitals, states, and countries have varying guidelines regarding this diagnosis of death.⁵ The UDDA does allow for discontinuation of life support modalities and procurement of organs or tissues for donation without legal consequences to the medical team after death has been declared.

Though there are variances from state to state and institution to institution, traditionally, whole brain death is diagnosed based on history, physical exam, and depending on circumstances, confirmatory testing. The clinical exam consistent with brain death includes deep coma with a known cause, absence of brain stem reflexes, lack of spontaneous movement, lack of response to pain, and no spontaneous breathing. The patient must not be hypothermic or under the influence of sedative or paralytic agents. Other confirmatory tests that are sometimes used include the radionuclide brain flow study, electroencephalograph, cerebral angiography, brain stem auditory evoked response, and computed tomography/magnetic resonance imaging. Further discussions regarding the procedure for declaring neurologic death are outside the scope of practice of this article.

In 2011, Burkle et al reviewed pertinent legal cases related to brain death which highlight the importance of a timely declaration of death as well as supporting the medical practitioners when there is disagreement between the family wishes and the physician recommendations at the time of death.⁴ In 398 cases, the courts upheld the diagnosis of death based on neurologic criteria. Delays in the diagnosis of brain death and charges of pain and suffering were commonly at the center of disputes, as well as the diagnosis itself. Within the United States, New York and New Jersey have legislation (“conscience clauses”) which requires physicians to honor religious objections by families and maintain somatic support of the brain-dead patient.⁴ Otherwise, the UDDA has been supported legislatively in all 50 states and the District of Columbia.

Cultural and Religious Perspectives

The diagnosis of brain death can be especially difficult when dealing with cultures unfamiliar to the medical treatment

team. In Western philosophy, the mind and body are perceived as separate with personal identity residing in the brain. In Eastern cultures, the mind and body are much more unified, and the perspective of death encompasses the entire body, not just the heart or brain. The Japanese perspective places as much or more importance on the heart; therefore, the diagnosis of death in a warm, heart-beating person is problematic.⁶ The concepts of life and death are centered around the family, not just one person. In effect, the death of a patient is more of a social construct rather than a purely medical event.

The discussion of brain death is intimately connected to that of organ donation, cultural differences, and faith perspectives. Japan has a rocky history regarding the concept of brain death: in 1968, the second heart transplant in the world was performed there. Subsequently, the physician was arrested for murder, accused of illegal human experimentation, and poor decision making in defining death. Although he was acquitted after 6 years of litigation, heart transplantation was prohibited in Japan for the next decade and a half, and organ transplantation was surrounded by distrust.⁶ Even now, the majority of transplanted organs in Japan are from living donors and frequently, patients in need of transplanted organs will seek medical care outside the country due to limited organ availability. In 1983, a Ministry of Health & Family Welfare committee was convened in Japan to separate medical criteria for death from the “concept of human death” as defined by the public. There was no uniform definition of death proscribed: the default description is traditional death. However, for the first time, this committee did not preclude the possibility of organ donation. Documentation of a desire to donate and the consent to a possible diagnosis of brain death must be in writing on a donor card, and family consent is required—death is still considered a social construct, not necessarily a medical one. There is still such disagreement with the concept of organ donation that some religious groups distribute antidonor cards.

The law was revised in 2009 to allow organ donation in the circumstance that the patient wishes were unknown but the family desired donation. However, if the patient has a documented desire for the diagnosis of brain death and organ donation and the family does not, the patient wishes may be overridden.⁷ Despite significant public discourse and changes in law, the concept of brain death is surrounded by social controversy, and in excess of 100 books have been written on the topic in Japan. The primary objection seems to surround testing for brain death: the bedside examination for the absence of functional aspects of the brain, it does not evaluate for death at the cellular level, and critics maintain that without this evidence of demise, one cannot diagnose death.⁷

In addition to the cultural differences facing physicians in the diagnosis of neurologic death, faith-based objections are commonly seen, particularly when the diagnosis leads to a discussion of organ donation. Frequently, these religious objections to organ donation are at the heart of family controversy at the diagnosis of brain death. It is unclear whether family members who cite a religious base for declining organ donation after brain death are educated regarding the scriptural basis of this belief or if their decision is based on personal interpretation

of scripture, both of which are certainly valid.⁸ While the decision remains with the family, this highlights the importance of clergy involvement and education in the public discourse surrounding organ donation. Sensitivity to issues of the soul and whether it immediately departs the body on death can be important to the discussion of brain death with most religions. Again, these beliefs may be individually held and not based in doctrine necessitating sincerity and sensitivity in discussions with families. Faiths that hold dear the cycle of reincarnation, such as Hinduism, can provoke discussion about treatment of the body after demise and whether this treatment begins at the time of neurologic death or circulatory standstill. Practitioners of the Jewish and Muslim faith typically inter the body within 24 hours of death; Hindus and Sikhs cremate soon after death. Ensuring that these faith traditions are met within the context of care at the end of life is important in maintaining a working relationship with family members, acceptance of the diagnosis of brain death, and assuring the discussion surrounding the potential for organ donation remains open.⁸

Somatic Support of the Brain-Dead Patient

Making the acceptance that death has occurred in the patient diagnosed with brain death even more difficult for laypersons is the ability of medical science to provide somatic support which can sustain the appearance of life for an unknown period of time. It has been long-held generally accepted medical dogma that cardiac death will occur within hours to a short number of days after the diagnosis of brain death; however, there are increasing reports of more prolonged somatic survival. In 1982, Parisi et al described support of a 49-year-old man for 74 days after the generally accepted criteria for brain death were met.⁹ Other reports of prolonged somatic survival include a 43-year-old woman who was maintained for 165 days after the clinical diagnosis of brain death.¹⁰ Perhaps, the most compelling evidence that somatic support can be provided for a prolonged period of time are the case reports of pregnant women who have been supported pending viability of the fetus. Reports of somatic support of the brain-dead mother for up to 107 days have been made with delivery of viable and neurologically normal infants.¹¹ At this point, legislature has not taken a stand on the rights of the fetus, next of kin, or patient. These unique situations call upon grieving families, physicians, and nursing staff, stressed hospital systems, and bioethicists to work collaboratively in decision making regarding the best interest of both patients at risk.

Somatic support of the brain-dead patient frequently requires hormonal replacement with corticosteroids, thyroid hormone, and vasopressin for pituitary failure, as well as the expected thermal and ventilator support. After an initial period of hemodynamic compromise, most reports describe patients who are remarkably stable despite the long-held beliefs about the compromise of the body after neurologic demise. Importantly, younger patients have the greatest ability for prolonged somatic survival, up to years in some instances.¹² Shewmon highlights the difficulty in predicting somatic survival as typically the diagnosis of brain death and

the ultimate cessation of cardiorespiratory functions is a self-fulfilling prophecy as the vast majority of patients diagnosed brain dead will be disconnected from life-sustaining therapies, or proceed to organ donation.¹²

Conclusion

Before the advent of modern critical care, the notion of a neurological definition of death was unnecessary as cardiac death would quickly follow the loss of brain function; however, the ability to provide somatic support to the irreversibly comatose patient as well as the advent of organ donation continues to necessitate a more formal process for the declaration of neurological death.¹³ The cultural, religious, and ultimately very personal views of patients, families, and medical staff must all interact in an empathetic manner to provide the best of care at times of great stress.

Conflict of Interest

None.

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