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Brain Death: History, Updates, and Implications for Nurses

A review of what nurses need to know to support families during testing and after declaration.

ABSTRACT: In 1968, the criteria for brain death were established by the Harvard Ad Hoc Committee. Despite what may appear to be unambiguous definitions, clinicians, ethicists, and the public have grappled with the concept of brain death since its inception. In light of recent public discourse on the topic, Harvard Medical School convened a conference to examine research and ethical inquiry conducted over the past 50 years related to death as defined by neurologic criteria. Drawing on the report produced by this conference, this article provides an overview of the development of brain death criteria, describes recent controversies and updates, and discusses implications of these criteria for nurses.

Keywords: bioethics, brain death, critical care, ethics, nursing

In 2018, 50 years after the Harvard Ad Hoc Committee established the criteria for brain death, Harvard Medical School convened a conference to examine the collection of research into death as defined by neurologic criteria that had been conducted over this period. The work of the conference was ultimately published in the form of a special report.[1] Referencing this seminal report and other sources, this article reviews the history of the development of brain death criteria, describes recent controversies and criteria updates, and discusses nursing considerations in the care of patients declared dead by neurologic criteria.

HISTORY OF BRAIN DEATH

The 1968 Harvard conference led by Henry Beecher was the first attempt to define death by neurologic criteria.[2] The committee proposed that death could be defined as when a brain no longer functions and has no possibility of regaining function in a patient who exhibits the following characteristics[3]:

- complete unresponsiveness to stimuli
- inability to move or breathe spontaneously over a period of at least one hour
- absence of elicitable reflexes indicative of loss of brain stem functions

Electroencephalography (EEG) may be used to confirm that the damage is irreversible provided

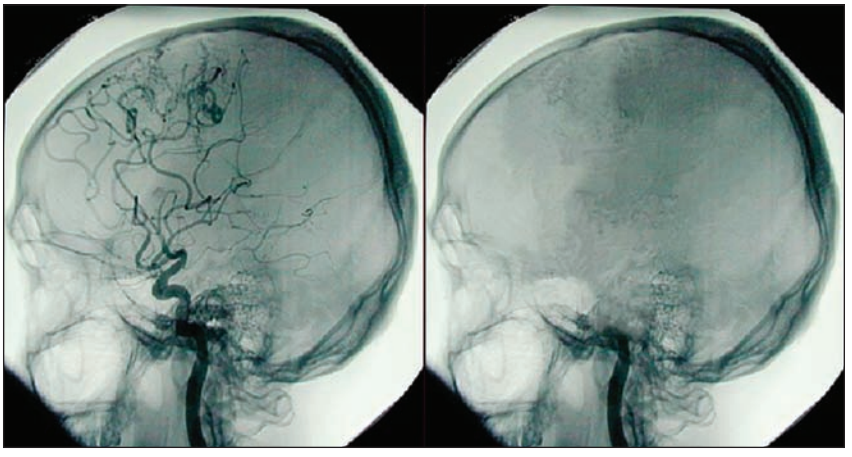
that two conditions have been ruled out: hypothermia and the presence of central nervous system depressants.[3] Defining death by neurologic criteria would allow for patients in this state (previously called "irreversible coma") to be considered candidates for organ transplantation and be withdrawn from ventilatory and cardiac support.

Legal follow-up. In 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research worked with the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws to develop the Uniform Determination of Death Act (UDDA).[4] The UDDA defined death as occurring in the presence of one or both of the following[4]:

- irreversible cessation of circulatory and respiratory functions (cardiopulmonary criteria)
- irreversible cessation of all brain functions, including those of the brain stem (neurologic criteria)

While some neurologic insults may cause temporary cessation of multiple brain functions, resulting in disorders of consciousness, the irreversibility component included in the brain death criteria requires that these functions have ceased permanently, with no hope of resumption through clinical intervention. Numerous medical associations support the UDDA definition of death and have participated in the development of guidelines pertaining to the determination of brain death in both adults and children.[5,6] (See *UDDA Guidelines and Endorsements*.[5,6])

In all but one state, a patient declared dead by neurologic criteria is considered legally dead. The state of New Jersey, however, allows for religious exemptions to the declaration of brain death if family members object. In such cases, death is not declared until the patient has met cardiopulmonary criteria for death.[7]



Angiograms of normal blood flow in an active brain (at left) and lack of blood flow indicating brain death. Photos © Fusionspark Media Inc.

CONTROVERSIES OVER BRAIN DEATH CRITERIA

Despite what may appear to be unambiguous definitions, clinicians, ethicists, and the public have continued to grapple with the concept of brain death. Some are concerned that the concept of brain death doesn't align with "the societal understanding of death."[2] A major point of confusion has arisen from the fact that the physical appearance of a patient who has been declared dead by neurologic clinical criteria may be identical to that of a patient who is comatose or otherwise sedated. In addition, there seems to be some uncertainty among clinicians, including nurses, about what constitutes brain death. For example, a recent study of 721 nursing students from three universities in Spain found that 193 (27%) did not fully understand the concept of brain death and another 20 (3%) believed a person could recover from brain death and lead a normal life.[8]

The philosophical debate surrounding brain death is epitomized in the arguments of such scholars as Bernat[9] and Shewmon.[10] Bernat proposes a conceptual justification for defining brain death as the equivalent of human death, based on the distinction between the "organism as a whole" and its "component parts."[9] He argues that while a number of human tissues and organs may be kept alive outside the body of a deceased person and transplanted to a living person, the survival of these components doesn't alter the fact that the donor "as a whole" is dead. By contrast, because the brain's ability to generate consciousness cannot be technologically simulated, once brain function is irretrievably lost, the "organism as a whole" is dead, even if its component parts can be maintained through technology. Shewmon, on the other hand, rejects this conceptual justification for the definition of brain death because, in rare cases, even when all diagnostic criteria are met, patients have been observed to demonstrate "behavioral evidence" of intermittent responsiveness; the gross structure of the brain may be preserved; and with ongoing physiological support the body may continue such important integrative functions as digestion, immune response, and menstruation.[10] In such cases, he suggests that cerebral blood flow may be reduced to a level that is not detectable, but not completely absent.

The President's Council on Bioethics released a white paper on "Controversies in the Determination of Death" in 2008.[11] While acknowledging that such interventions as mechanical ventilation may preserve certain integrative bodily functions in patients declared dead by neurologic criteria, the white paper argued that such integration isn't sufficient to define these patients as living. Patients who meet the neurologic criteria for brain death can no longer perform the "definitive work" of a living organism, which is to be receptive to and act upon its environment in order to acquire what it needs to preserve itself—for example, by breathing spontaneously, withdrawing from pain, or sleeping and waking. While such behaviors do not signify self-consciousness, they verify that the organism is alive.

LEGAL CHALLENGES AND MEDIA ATTENTION

Although the defining criteria, clinical guidelines, and legal standards developed over the past 50 years provide a solid basis for clinical practice, there has been a recent spike in legal challenges related to brain death, some of which have received significant media attention.[7] Examples include the cases of Marlise Munoz and Robyn Benson, both of whom were pregnant women maintained on organ support for a period of time after being declared brain dead, but under very different circumstances and with different outcomes.[12]

Marlise Munoz was 14 weeks pregnant on November 26, 2013, when a pulmonary embolism left her unresponsive.[12,13] Her husband Erick Munoz, a paramedic, said that his wife, also a paramedic, had made it clear to both him and her parents that she never wanted to be maintained on life support. Nevertheless, Texas state laws concerning terminating the life of a pregnant woman sparked a debate about whether she should be maintained on organ and nutritional support. The following January, the hospital publicly acknowledged that Munoz, then in her 22nd week of pregnancy, had been brain dead since late November and that her fetus was nonviable. At that point, a Texas judge ordered the hospital to remove organ support in accordance with her family's wishes.[13]

Robyn Benson of Vancouver, British Columbia, Canada, was 22 weeks pregnant when declared brain dead following a cerebral hemorrhage on December 28, 2013. Robyn's fetus was healthy and, upon her husband's request, the hospital maintained Robyn's body on organ support in order to keep the fetus alive until he could be delivered safely by cesarean section.[14] The baby was delivered in stable condition six weeks later at 28 weeks' gestation.[14]

Of the contemporary brain death cases, however, perhaps the most noteworthy is the tragic case of Jahi McMath, a 13-year-old girl who underwent pharyngeal surgery for obstructive sleep apnea in December 2013 in California.[15] After a postoperative hemorrhage and subsequent cardiac arrest, she was declared brain dead. Her family objected to this diagnosis on religious grounds and a complex legal battle ensued, which ended in an agreement between the family and the hospital that Jahi could be released to her mother with continued ventilatory support and IV fluids. She was eventually transferred to a hospital in New Jersey, where state law prohibits the determination of death by neurologic criteria if the declaration violates the patient's or family's religious beliefs.[15] With ongoing ventilatory and nutritional support, Jahi's heart continued to beat, she grew, entered puberty, and reportedly had three menstrual periods in the years that followed.[10,15] In June 2018, following liver failure and exploratory surgery for unexplained bleeding, Jahi was declared dead in the state of New Jersey on the basis of cardiopulmonary criteria.[15]

UDDA Guidelines and Endorsements

The Uniform Determination of Death Act (UDDA) definition of death is supported by the American Academy of Neurology, which published the 2010 "Evidence-Based Guideline Update: Determining Brain Death in Adults,"[5] and by a multidisciplinary committee representing medical and surgical subspecialists from the pediatric section of the Society of Critical Care Medicine, the section on critical care of the American Academy of Pediatrics, and the Child Neurology Society under the auspices of the American College of Critical Care Medicine, which published the 2012 "Guidelines for the Determination of Brain Death in Infants and Children: An Update of the 1987 Task Force Recommendations—Executive Summary."[6] In addition to the associations that participated in the authorship of these documents, the 2010 guideline pertaining to adults was endorsed by the Neurocritical Care Society, Child Neurology Society, Radiological Society of North America, and American College of Radiology[5]; the 2012 guideline pertaining to children was endorsed by the American Association of Critical-Care Nurses, Child Neurology Society, National Association of Pediatric Nurse Practitioners, Society for Pediatric Anesthesia, American Society of Pediatric Neuroradiology, and World Federation of Pediatric Intensive and Critical Care Societies.[6] Both documents provide guidance on diagnosing brain death and conducting a clinical examination that can establish functional loss of the entire brain, including the brain stem.

The prolonged biological survival of Jahi McMath reignited questions in the public, clinical, and philosophical spheres related to the diagnosis of brain death. Some authors have argued that this case provides evidence that clinical testing procedures for diagnosing brain death need to be reexamined.[9] In any case, legal battles related to brain death cases are likely to continue, fueled by advocacy groups that reject the concept, patients' families with religious objections, and the "renewed emphasis on conscience-based objection in health care" both in state legislatures and federal courts.[7]

THE AMERICAN ACADEMY OF NEUROLOGY'S 2019 POSITION STATEMENT

Following the McMath and other high-profile brain-death cases, the American Academy of Neurology (AAN) released a 2019 position statement reaffirming its earlier support of the UDDA definition of death by neurologic criteria and endorsing legislation that encourages ongoing research, enhanced professional and public education on brain death, and the development of institutional policies across U.S. medical facilities that reflect uniformity in the following areas[16]:

- procedures for determining brain death that comply with medical standards
- training and credentialing for all physicians involved in brain death declarations

The AAN's rationale in calling for uniformity stems from the inconsistency among both institutional and state policies and protocols related to the diagnosis of brain death. A 2016 data analysis of policies pertaining to brain death determination in use at the majority of U.S. hospitals between June 26, 2012, and July 1, 2015, found significant variability among the policies in all five categories studied, which were as follows[17]:

- type of health care professional who would make the determination
- prerequisites for clinical testing
- clinical examination requirements
- apnea testing requirements
- ancillary testing

As legal and philosophical debates surrounding neurologic criteria for death determination continue, nurses need to be prepared to answer patient and family questions on the subject.

IMPLICATIONS FOR NURSES

Although brain death is relatively rare, representing only 15,000 to 20,000 deaths per year in the United States,[18] and most such cases proceed without major conflict, nurses in the critical care setting may encounter brain death cases that become ethically complex. They must be prepared to care for patients undergoing brain death testing, as well as patients who have been declared brain dead, and to answer questions from family members, particularly if disagreement arises over the testing or diagnosis.

Brain death testing. When brain death is suspected, a clinical assessment is performed, which typically involves testing to establish the following[5,6]:

- irreversible loss of consciousness and its proximate cause
- apnea as demonstrated by a carbon dioxide challenge in the absence of such reversible conditions as hypothermia, hypotension, medication effects, and metabolic disturbances
- the absence of brain stem reflexes

When such testing does not definitively confirm brain death, ancillary testing may include EEG, cerebral angiography, nuclear scan, transcranial doppler, computed tomography scan with contrast, magnetic resonance imaging, or magnetic resonance angiography.

Brain death causes changes in the cardiovascular, respiratory, endocrine, and metabolic systems, often contributing to significant hemodynamic instability that must be managed in the midst of brain death testing procedures.[19] Nursing care, therefore, can be quite demanding.

Some nurses may struggle with how to treat brain-dead patients, wondering whether their nursing care should differ from the care they provide to 'living' patients.

Supporting families. The brain death testing process is very challenging for families as they grapple with the possibility that their loved one has died. In certain cases, inviting the family to be present at the patient's bedside during brain death testing can promote acceptance by helping them better understand the concept of brain death. One randomized controlled trial included 58 immediate family members of 17 patients undergoing brain death evaluation; the family members were randomly assigned to be either present or absent during evaluation.[20] Family members randomly assigned to observe the brain death evaluation had significantly higher postevaluation scores on scales measuring the understanding of brain death than family members randomly assigned to be absent. Importantly, the intervention included a specialist from donor services who worked with the

physician performing the brain death evaluation to "explain each step of the examination and the significance of the findings."[20] If family members choose to observe brain death testing, it's important for nurses to arrange for such an expert to be present to reduce the possibility of confusion and distress.

During brain death testing and for a certain period following a brain death declaration, the brain-dead patient continues to receive intensive nursing and medical care, similar to the care provided prior to the brain death declaration. The brain-dead patient's body is thus warm to the touch, the chest moves with ventilatory support, vital signs are present, and in some cases the extremities move reflexively. Nurses and other clinicians should be prepared to manage family grief reactions, including the rejection of the diagnosis. Families who have heard of cases in which patients are misdiagnosed as brain dead, such as the cases of Trenton McKinley[21] and Anahita Meshkin,[22] may be particularly prone to mistrust and confusion about the diagnosis.

The Role of Clinical Ethicists

In cases where there is family disagreement about the legitimacy of the brain death diagnosis, a clinical ethicist (typically, a health care provider from the hospital who has additional training in ethics) can help clarify the values underlying the objection in order to determine whether it's based on a misunderstanding or a religious or moral position. The ethicist can help the family, nurse, and interdisciplinary team arrive at a plan that respects the family's perspective and addresses the clinical reality of the patient's situation. (Another type of professional often brought into such cases is a chaplain, particularly if the family is religious.)

Clinical ethicists can also be useful when there are staff concerns about brain death. In the same way that families may have religious or moral objections to the declaration of death by neurologic criteria or to caring for such patients, so too may some nurses or other clinicians. Ethicists can help clinicians reflect on and sort through their feelings and values in order to develop an increased awareness of how these affect the provision of care. In particular, ethicists can help clinicians discover whether conscientious objection in the case of legitimate moral or religious objection is appropriate, and how to balance conscientious objection with the obligation to provide care. The American Academy of Neurology supports the provider's ability to object conscientiously to the provision of ongoing organ support in the brain-dead patient, but in such cases, care of the patient should be transferred to a clinician who is willing to provide care.[27]

ACCOMMODATIONS FOR MORAL OR RELIGIOUS OBJECTIONS

Families may also object on moral or religious grounds to the diagnosis of death by neurologic criteria. Some religious traditions, including Orthodox Judaism, Buddhism, some Christian sects, and some Native American traditions, accept cardiopulmonary death, but do not accept death by neurologic criteria.[23,24] These beliefs can lead to ethically complicated situations in which questions arise about how and when to discontinue organ support.

Several states, including New York, Illinois, and California, have established "reasonable accommodations" in the law for families with moral or religious objections to death by neurologic criteria.[24,25] For example, in California such accommodations include providing cardiopulmonary support, but not artificial nutrition, hydration, or other medical care, for "a reasonably brief period" in order to allow family members to gather at the patient's bedside. In New York, accommodations are also offered for "a short, specified period," though during this period support may include nutrition, hydration, and other medical care, as well as ventilation. Illinois law requires hospitals to adopt policies and procedures that "allow health care professionals, in documenting a patient's time of death at the hospital, to take into account the patient's religious beliefs."[24,26]

In rare cases in which a family objects to their loved one's declaration of death by neurologic criteria and efforts by the health care team to provide reasonable accommodation are not successful, institutions may transfer the patient to another facility or discontinue organ support without family consent, since the patient is legally dead.[25] Ideally, such conflicts can be avoided through early conversations between the family and health care team facilitated by clinical ethicists. (See *The Role of Clinical Ethicists*.[27]) Nurses are well positioned to identify conflict in its early stages and to recommend such intervention.

UNIQUE CONSIDERATIONS FOR PEDIATRIC CASES

While brain death testing of children is similar to that of adults, nurses working in pediatric settings, particularly pediatric ICUs, where most children undergoing brain death evaluation are accommodated, should be aware of the variations. One major distinction in the 2012 pediatric guidelines, the "Guidelines for the Determination of Brain Death in

Infants and Children: An Update of the 1987 Task Force Recommendations—Executive Summary," is that children require two neurologic examinations conducted by two different physicians and two apnea tests, both of which may be conducted by the physician managing ventilator care.[6] Examinations should follow an observation period of 24 hours for neonates less than 30 days old and 12 hours for older infants and children up to age 18.[6] Adults usually require only one neurologic and apnea evaluation, though some states require two, and there is no mandatory period of observation.[5] It's important to note, however, that there may be institutional differences in the way these criteria are interpreted, and pediatricians may adjust their brain death testing methods to take into account the age-related anatomical and physiological differences between neonates, infants, and children.

Parents and other family members of children undergoing brain death testing may require close attention and additional support.

ORGAN DONATION

Depending on the clinical circumstances, some patients who have been declared brain dead are eligible for organ donation. If a patient declared brain dead has viable organs or tissue, trained personnel from an organ procurement organization, rather than the health care team, should initiate organ donation conversations.[25] In some cases family members may object to the idea of organ donation. Since refusals to donate organs may arise out of misinformation or misunderstanding, it's important for all health care providers to be respectful of the family's feelings as they explore the rationale for their objection.

Brain-dead patients are maintained in the ICU on organ-supporting technology in order to maintain hemodynamic stability while the viability of transplantable organs is assessed. The process of assessing a patient for organ donation is complex, often involving multiple invasive procedures. It is, however, possible that one organ donor can provide as many as 50 different organs or tissues to compatible recipients.[28] This intensive period of nursing care thus has tremendous potential benefit.

In addition to maintaining perfusion to potentially transplantable organs, nurses must also manage the limbo that families find themselves in during the period after brain death has been declared but before organs can be procured.

ETHICAL CHALLENGES

Nurses may face additional ethical challenges when caring for patients declared brain dead. In the same way that philosophers, scholars, and the public have wrestled with questions about brain death, nurses may experience distress in caring for a brain-dead patient, especially if they do not personally believe in the validity of death by neurologic criteria. Such distress may become heightened when questions of organ donation arise. Even some neurologists disagree on the rationale for accepting brain death as death. Of 218 board-certified neurologists responding to a survey about the conceptual basis and appropriate diagnostic tests for brain death, more than half indicated they did not consider brain death to be equivalent to circulatory death.[29]

Some nurses may also struggle with how to treat brain-dead patients, wondering whether they should talk to them, or how their nursing care should differ from the care they provide to "living" patients. Nurses may not know how to communicate such nuances in care to family members. As society continues to navigate the complex conversation surrounding death by neurologic criteria, nurses and other clinicians will be increasingly required to examine their own assumptions and perspectives on the issue. ▼

Important Milestones in the History of Defining Brain Death

1968
Harvard Ad Hoc Committee
First attempt to define death by neurologic criteria

1981
Uniform Determination of Death Act
Established physiological standards defining death as irreversible cessation of circulatory and respiratory functions (cardiopulmonary criteria) AND/OR irreversible cessation of all functions of the brain, including the brain stem (neurologic criteria)

2008
President's Council on Bioethics
Affirmed the concept of brain death

2019
American Academy of Neurology Position Statement
Called for uniformity of brain death determination criteria, citing variation in law and policy regarding testing procedures

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