

Brain Death: Do We Know Enough?

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Abstract. Every year, people make decisions based on trust in the certainty of diagnoses of brain death. These decisions range from signing an organ donation card to withdrawing life support from a loved one. Two recent developments have revived concerns about medical standards for determining brain death. One is a recent study on variability in brain death policies in the United States; the other is the filing of a federal lawsuit to rescind the death certificate of Jahi McMath, a teenager who appears to have survived a 2013 declaration of brain death. The author examines these developments and asks whether trust in the certainty of brain-death determinations is currently warranted. *National Catholic Bioethics Quarterly* 16.1 (Spring 2016): 55–59.

Two recent developments on the controversial issue of brain death have revived concerns about the medical standards currently used for determining brain death. One was the publication of a *JAMA Neurology* study of 508 US hospitals, titled “Variability of Brain Death Policies in the United States,” by Dr. David Greer et al., which found major variations in their policies for determining brain death. The study concluded that “hospitals should be encouraged to implement the 2010 AAN [American Academy of Neurology] guidelines to ensure 100% accurate and appropriate determination of brain death.”¹

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1. David M. Greer et al., “Variability of Brain Death Policies in the United States,” *JAMA Neurology* 73.2 (February 1, 2016): 213, doi: 10.1001/jamaneurol.2015.3943.3943. The updated AAN guidelines are presented in Eelco F.M. Wijdicks et al., “Evidence-Based

The other development surrounds a federal lawsuit pushing to rescind the death certificate of Jahi McMath. McMath, a teenager from Oakland, California, was declared brain dead two years ago but is apparently still surviving and may be showing some signs of improvement.²

Every year, people make decisions—to withdraw life support from loved ones or to sign organ donation cards—based on trust in the certainty of a diagnosis of brain death. Is such trust warranted?

A Short History of US Brain-Death Policies

Although the concept of irreversible coma was first introduced in 1959, the current legal and medical concept of brain death gained widespread acceptance after the publication, in 1968, of “A Definition of Irreversible Coma,” the report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death.

The stated purpose of the Harvard report was “to define irreversible coma as a new criterion for death,” because new technology such as ventilators could maintain a patient “whose heart continues to beat but whose brain is irreversibly damaged.” The committee noted that “obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.” The Harvard paper laid out four conditions for a diagnosis of brain death: (1) unresponsivity and unresponsivity, (2) no movement or breathing, (3) no reflexes, and (4) a flat electroencephalogram, providing confirmatory data that should be utilized “when available.”³

Starting in the early 1970s, various state legislatures and courts acted to turn brain death into a legally recognized standard for determining death by loss of all brain function. Patients declared brain dead could then be removed from life support measures, like mechanical ventilation, without legal ramifications or their organs could be harvested while their hearts were still beating and a ventilator kept their lungs functioning.

In 1981, the US Uniform Determination of Death Act formally added “irreversible cessation of all functions of the entire brain, including the brain stem” to the legal definition of death.⁴ However, while the act set the general legal standard for determining brain death, it did not dictate the medical criteria. Many state laws

Guideline Update: Determining Brain Death in Adults—Report of the Quality Standards Subcommittee of the American Academy of Neurology,” *Neurology* 74.23 (June 8, 2010): 1911–1918.

2. *McMath et al. v. State of California et al.*, no. 4:2015cv06042 (N.D. Cal. Dec. 23, 2015); see David DeBolt and Malaika Fraley, “Jahi McMath: Family Sues in Federal Court to Have Brain-Dead Girl Declared Alive,” *Mercury News*, December 24, 2015, <http://www.mercurynews.com/>.

3. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, “A Definition of Irreversible Coma,” *JAMA* 205.6 (August 5, 1968): 337, doi: 10.1001/jama.205.6.337. P. Mollaret and M Goulon identified irreversible coma in their essay “Le Coma Dépassé (memoire preliminaire),” *Revue Neurologique* 101.1 (July 1959): 3–15.

4. National Conference of Commissioners on Uniform State Laws, *Uniform Determination of Death Act*, approved 1980/1981, <http://www.uniformlaws.org/>.

just cite “accepted medical standards” for determining brain death. Over the years, efforts were made to standardize these medical criteria, most recently by the AAN guidelines established in 2010.⁵

Not All Hospitals Comply with the Guidelines

In an interview with *Medscape*, David Greer, the lead author of the study in *JAMA Neurology*, expresses concern that not all of the 508 US hospitals surveyed were “100% compliant” with the 2010 guidelines by the American Academy of Neurology. Of the hospitals surveyed, the *Medscape* article notes that only “about a third of policies (33.1%) required specialist expertise in neurology or neurosurgery, but 150 policies had no mention of who could perform the determination.”⁶ The article also notes that not all hospital policies require testing of lower brainstem function to establish the loss of all brain function, and not all comply with other AAN recommendations such as establishing the cause of the brain dysfunction, the absence of effects of specific medications like sedatives, and crucial aspects of the apnea test.

One of the potentially disastrous consequences of these inconsistencies in hospital testing policies is that a person can be treated as a living patient at one hospital but declared brain dead at another.

Would full compliance with the 2010 guidelines “ensure 100% accurate and appropriate determination of brain death”? Probably not, given the findings of the 2010 report updating the AAN guidelines.⁷ Eelco Wijdicks et al. observe that “many of the details of the clinical neurologic examination to determine brain death *cannot be established by evidence-based methods*. The detailed brain-death evaluation protocol that follows is intended as a useful tool for clinicians. It must be emphasized that this guidance is opinion-based. Alternative protocols may be equally informative.” They also note that there is “insufficient evidence” to determine such crucial standards as “the minimally acceptable observation period to ensure that neurologic functions have ceased irreversibly,” “the comparative safety of techniques used for apnea testing,” and the accuracy of “newer ancillary tests [in confirming] the cessation of function of the entire brain.”⁸

The significance of these criteria is highlighted in a 2012 article, “A Survey of American Neurologists about Brain Death: Understanding the Conceptual Basis and Diagnostic Tests for Brain Death,” by Ari Joffe et al.⁹ The authors note, “It has been shown that some brain functions continue after accurately clinically diagnosed BD (brain death), including EEG activity in 20%, evoked potential activity in 5%, and

5. Allison Gandey, “New Brain Death Guidelines Issued,” *Medscape.com*, June 10, 2010, <http://www.medscape.com/>.

6. Pauline Anderson, “Not All Hospital Brain Death Policies Comply with Guidelines,” *Medscape.com*, December 30, 2015, <http://www.medscape.com/>, emphasis added.

7. Wijdicks et al., “Evidence-Based Guideline Update.”

8. *Ibid.*, 1911, 1914, emphasis added.

9. Ari Joffe et al., “A Survey of American Neurologists about Brain Death: Understanding the Conceptual Basis and Diagnostic Tests for Brain Death,” *Annals of Intensive Care* 2.1 (February 17, 2012): 1–8, doi: 10.1186/2110-5820-2-4.

hypothalamic neuroendocrine function in > 50%. These activities may be explained by the finding that continued brain blood flow occurs in 5–40% of BD patients, and pathologic destruction of brain does not occur in more than 40% of BD patients (even after over 24–48 hr of maintained circulation).”¹⁰ Thus there seems to be reasonable cause for concern whether even 100 percent compliance with AAN guidelines would completely ensure the accuracy of a diagnosis of brain death or the validity of some critical brain-death tests.

Jahi McMath

In December 2013, thirteen-year-old Jahi McMath suffered cardiac arrest after undergoing surgery for sleep apnea at Children’s Hospital Oakland, in California. Although doctors managed to resuscitate her, they declared McMath brain dead and prepared to remove the ventilator. Hoping she might recover, however, the family insisted that it remain in place.

After several court battles, a judge permitted McMath’s family to transfer her to a facility in New Jersey that allowed the continued use of the ventilator. Two years later, McMath’s family is still fighting, suing in federal court have her death certificate rescinded.¹¹ According to the family’s attorneys, “Jahi does not fulfill California’s statutory definition of death, which requires the irreversible absence of *all brain function*, because she exhibits hypothalamic function and intermittent responsiveness to verbal commands.”¹²

A ruling to rescind McMath’s death certificate would have profound implications for the medical and legal determination of brain death, especially since her initial diagnosis was confirmed by multiple doctors in a well-respected hospital.

McMath is not the first person to survive for a prolonged time after a brain-death diagnosis. Alan Shewmon, MD, studied approximately 175 cases of long-term survival after a declaration of brain death, for periods ranging from one week to more than fourteen years.¹³ In other cases, pregnant women declared brain dead have been able to gestate unborn babies for weeks or months until a healthy delivery.¹⁴

Most concerning of all are cases like that of Zach Dunlap, a young man from Oklahoma who was declared brain dead after an all-terrain vehicle accident in 2008. Testing showed no blood flow to his brain, and Dunlap was being considered for organ donation when a relative discovered a physical response from Zach. Four months later and already making plans to return to work, Dunlap appeared on NBC’s *Today*

10. *Ibid.*, 4.

11. DeBolt and Fraley, “Jahi McMath.”

12. *Winkfield v. Children’s Hospital Oakland*, no. RG-15760730, first amended complaint (CA, Super. Ct. Alameda County, Nov. 4, 2015), para. 36, original emphasis.

13. D. Alan Shewmon, “Chronic ‘Brain Death’: Meta-Analysis and Conceptual Consequences,” *Neurology* 51.6 (December 1998): 1538–1545.

14. Majid Esmaeilzadeh et al., “One Life Ends, Another Begins: Management of a Brain-Dead Pregnant Mother—A Systematic Review,” *BMC Medicine* 8.74 (November 18, 2010): doi: 10.1186/1741-7015-8-74.

show, where he told hosts that he heard a doctor say he was dead, and it “just made me mad inside.”¹⁵

Alarming, there have been other reported “near misses” like Dunlap’s that also did not lead to rigorous medical investigations to determine what went wrong with the initial brain-death determinations. Yet experts continue to maintain that there is “no documented report of patients regaining brain function after being declared brain dead,” although some allow that “maybe mistakes happened and they weren’t reported.”¹⁶

Persistent Controversies

Controversy about brain death has simmered for years in bioethical and medical circles. Influential experts such as Robert Truog and Franklin Miller argue that doctors should drop the rule requiring that people be declared dead before vital organs are taken, and instead merely obtain “valid informed consent for organ donation from patients or surrogates before the withdrawal of life-sustaining treatment in situations of devastating and irreversible neurologic injury.”¹⁷

The Catholic Church has been involved in the controversy over brain death since the Harvard report cited Pope Pius XII’s 1957 address “The Prolongation of Life” to support its recommendations.¹⁸ Since then, there have been several papal statements and conferences on the determination of brain death. Collectively, these are widely seen to indicate a cautious acceptance of the concept of brain death that is based on the assurance of medical certainty to provide moral certainty.

When the issue is death, medical ethics must be backed up by accurate medical facts. In the case of the legal and medical definition of brain death as “irreversible cessation of all functions of the entire brain, including the brain stem,”¹⁹ medical science, not philosophical speculation, must provide the proof beyond a reasonable doubt.

When cases like those of McMath and Dunlap are routinely dismissed instead of rigorously investigated to establish the facts, medical certainty is not achieved and medical integrity is undermined. In addition, when hospitals set their own standards and policies for determining brain death without external accountability, lives—as well as the essential and necessary trust in the health care system—can and possibly will be lost.

15. Natalie Morales, “‘Dead’ Man Recovering after ATV Accident,” *NBC News*, March 24, 2008, www.nbcnews.com/.

16. Pauline Anderson, “Not All Hospital Policies Comply.”

17. Robert D. Truog and Franklin G. Miller, “The Dead Donor Rule and Organ Transplantation,” *New England Journal of Medicine* 359.7 (August 14, 2008): 675, doi: 10.1056/NEJMp0804474.

18. Ad Hoc Committee of Harvard Medical School, “Definition of Irreversible Coma,” 88 note 1, citing Pius XII, “The Prolongation of Life,” Address to an International Congress of Anesthesiologists (November 24, 1957), *The Pope Speaks* 4 (Spring 1958): 393–398.

19. Commissioners on Uniform State Laws, “Uniform Determination of Death Act,” sec. 1.

