

MINI-REVIEW

Practice Variability in Determination of Death by Neurologic Criteria for Adult Patients

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In 2010, the American Academy of Neurology (AAN[†]) published updated official guidelines for specific practices involved in the determination of death by neurologic criteria for adult patients, otherwise known as brain death. Most states, however, do not have laws mandating the standard adoption of the AAN guidelines. The responsibilities for creating and implementing brain death determination policies thus falls on individual hospitals. As a result, significant variability in practice exists between hospitals and even between providers. This review highlights the ways in which and the extent to which adult brain death determination varies across the US, while also making the case that such persistent levels of heterogeneity call for improvements in standardizing training in brain death determination.

BACKGROUND

Brain death—otherwise known as death by neurologic criteria—is thought of in the US as the “death of the individual due to irreversible loss of function to the entire brain [1].” As a concept, brain death, as distinct from cardiopulmonary death, arose in the past century with the advent of mechanical ventilation and the pressing concern that futile care could be provided to patients with irreversible brain injury, lack of any clinically testable neurologic function, and complete loss of respiratory drive (*i.e.* apnea) [2].

Since the need to have a socially-accepted approach

to these patients was identified, the processes of defining and determining brain death has involved medical, legal, social, and ethical considerations. In 1968, an ad hoc committee at Harvard Medical School published a report proposing formal clinical criteria for defining death by neurologic criteria, including irreversible coma, absence of all brainstem reflexes, and lack of spontaneous respirations [3]. In the US, each state has its own legal definition of death; subsequent to the Harvard report, from 1970 to 1981, 27 states began adopting the concept of brain death as a legal form of death, with considerable variation on the statutes that determined death [4]. As explained in their report entitled “Defining Death,” the

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†Abbreviations: AAN, American Academy of Neurology; UDDA, Uniform Determination of Death Act; NCS, Neurocritical Care Society.

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President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, the Uniform Determination of Death Act (UDDA) came about as a collaboration by the staff of the President's Commission, the National Conference of Commissioners on Uniform State Laws (NCCUSL), the American Medical Association (AMA), and the American Bar Association (ABA) [5]. In addition, the American Academy of Neurology (AAN) also endorsed the UDDA prior to its publication. The purpose of the UDDA, which stated that irreversible cessation of all functions of the entire brain was a state equivalent with death, was to facilitate the adoption of the brain death concept amongst all US states. It has since served as the model for most definitions of death written in state laws across the country. The Medical Consultants report, included in the appendix of "Defining Death," also specified the specific tests physicians should use to determine both brain death and cardiac death [5].

Of note, the language of the UDDA states that brain death simply be determined according to "accepted medical standards" and places the burden of developing the specific testing criteria for death by neurologic criteria on physicians. In 1995, the AAN refined the specific clinical parameters confirming brain death contained in the initial Harvard report, clarifying the need to ensure that a patient's examination is not clouded by medications or metabolic abnormalities and specifying the method for confirming apnea in a more detailed fashion [6]. This guideline was further updated in 2010 and currently remains the most widely-accepted guideline by the medical profession [7].

The practice variability that currently exists across states has direct implications for patient care, as evidenced by recent legal cases stimulated by the ambiguity over brain death determination policies. Most states laws document that brain death be assessed in accordance with "acceptable medical standards." Despite the publication of the AAN professional guidelines, the lack of consistency over what "acceptable medical standards" means creates controversy and inconsistency in clinical practice [8]. Several high-profile court cases in the past decade highlight this lack of clarity [9-11]. One striking example is the case of Aden Hailu, a 20-year-old girl who was declared brain dead by physicians at St. Mary's Regional Medical Center in Nevada whose father, on the other hand, objected to withdrawing organ support. This disagreement resulted in a flurry of legal battles spanning 6 months, during which the county court initially ruling in favor of the hospital, and the Nevada Supreme Court overturning that ruling. In response, the state of Nevada has since amended their state law to specify the AAN guidelines as the method for brain death determination. Ultimately, in the past year, the AAN released a position paper endorsing legislation modeled after the Nevada

statute to be adopted in other states [1].

In addition to legal controversy, the existence of differences in brain death definitions across states and hospitals also has the potential to cause or at least exacerbate public mistrust in the medical profession. The Jahi McMath case [12] that began in Oakland in 2013 illustrated the way that ambiguity over the definition of brain death can foster animosity between patients and physicians. Similar to Hailu, McMath was a 13-year-old girl who was, after a series of unfortunate events, declared brain dead after surgery. When her parents refused to let the hospital withdraw life support, social media erupted with comments supporting the McMath family. One friend wrote on Facebook, "This is a universal chain of DISRESPECT!!! FCK THIS HEALTHCARE SYSTEM!!!" When the case was taken to court, protestors outside the courthouse held signs that read "Justice for Jahi!" and "Doctors Can Be Wrong!" The McMath family ultimately took Jahi to New Jersey, where families with religious or philosophical objections to death by neurologic criteria can rely on cardiac criteria. Though additionally fraught with complicated issues of race, the ambiguity over the precise definition of death acted as a potential space that generated increased distance rather than cooperation between physician and patient. On the other hand, strangers from Change.org petitioned to "stop NJ from paying for a corpse care out of taxpayers money." Ultimately, that someone considered alive in one region of the country could be declared dead in another resulted in controversy with arguments from multiple sides and a state of confusion and mistrust over what was essentially a tragic loss.

While awareness of the need to refine brain death determination laws across the US is rising, adherence of hospital policies for brain death to the AAN guidelines is not guaranteed simply by modification of state laws. In fact, significant between-hospital and between-provider variability currently exists in how physicians declare patients dead by neurologic criteria and presents a significant implementation challenge. Furthermore, the skills and training of individual physicians responsible for declaring patients brain dead also varies tremendously. This mini-review provides an overview as to the extent of variability in (1) state laws and (2) hospital adult brain death determination policies and practices in the US; this article also advocates for the need for standardized training in brain death determination. The practice of properly declaring someone brain dead has direct consequences for questions such as when a hospital can mandate that a patient's body be taken off of organ support and when a patient's body can be considered for organ donation. Ambiguity over the precise definition of brain death and inconsistency in the application of the existing brain death definition has negative consequences for patient care.

VARIABILITY IN BRAIN DEATH PRACTICES

Variability at the State Level

The UDDA codified the expansion of the concept of brain death from observations of extreme medical futility to a legal definition of death. It reads: *An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.*

While all 50 states permit physicians to declare a patient dead who has been shown to have sustained irreversible cessation of all brain functions, they vary in their adoption and incorporation of the UDDA's exact definition into their laws. At the time of this publication, 40 states have adopted the wording of the UDDA into their laws, while nine others additionally specify that brain death can only be applied when artificial organ support is used [13]. North Carolina goes extra lengths to specify that brain death should particularly be applied in the case of artificial organ support and that it should not supersede other medically recognized criteria for determining death [14].

States also vary on who is legally allowed to declare someone brain dead, and include roles for physicians, physician assistants, Advanced Practice Registered Nurses, Registered Nurses, and licensed practical nurses [4]. Only Florida, New Jersey, and Virginia require that someone in a field related to neuroscience or critical care medicine must make the pronouncement of brain death [13].

In terms of objections to brain death determination, only New Jersey explicitly allows for objection to determination of brain death by family members on religious or moral grounds [15]. In fact, New Jersey requires continuation of health insurance coverage when this exemption is invoked [15]. In that same vein, New York and California law allow for "reasonable accommodation" of religious and moral objections to brain death determination, while Illinois indicates that a patient's religious beliefs must be taken into account when documenting time of death [16].

As mentioned earlier, Nevada is the only state which uniformly requires provider adherence to AAN guidelines for death by neurologic criteria; in all other states as of now, the responsibility lies with individual institutions to generate their own protocols [9].

Variability at the Hospital Level

Because most US hospitals are individually responsible for policies for declaring brain death, differences among institutions has presented a significant challenge.

Even prior to the 2010 AAN guidelines update, several studies demonstrated the magnitude of between-hospital variability.

In 2004, Powner *et al.* compared hospital policies for brain death determination against the AAN guidelines among hospitals selected at random from the American Hospital Association [17]. Significant variability was found among the 106 hospitals in the study group, particularly regarding conditions to be excluded before testing and in specific testing methods used in the physical exam. In terms of exclusion criteria that might preclude brain death testing per the AAN guidelines—such as hypothermia or the presence of certain intoxicating drugs—12 percent of hospitals did not specify any factors at all. In terms of the physical exam, only 13 percent required failure to respond to voice, and only 50 percent required failure to respond to pain. While cranial nerve examination was required in all policies reviewed, instructions outlining the methods for cranial nerve testing was included in only 29 percent of policies. Finally, repeat examination—recommended by, but also deemed as "arbitrary" in, the original 1995 AAN guidelines—[6] was required in 60 percent of hospitals, with variability in terms of the timing of the subsequent exam [17].

In 2008, Greer *et al.* conducted a study comparing guidelines for brain death determination among the top 50 neurology and neurosurgery programs as ranked by the *US News and World Report* against the AAN guidelines [18]. Variability was measured according to five different domains defined by the authors, including: guideline performance, preclinical testing, clinical examination, apnea testing, and ancillary tests. Guideline performance involved questions such as number of examinations required, types of physicians performing the evaluation, and waiting period between repeat exams. In terms of guideline performance, the authors found that multiple examinations were required in 71 percent of guidelines, and distinct physicians were required to conduct repeat testing in 44 percent of guidelines. Eighty-nine percent of policies required patient body temperature to be above a certain temperature, but the minimum temperature varied. For the clinical exam, the poorest compliance with the AAN guidelines existed in testing the absence of pain above the foramen magnum (42 percent), absence of jaw jerk reflex (18 percent), and absence of spontaneous respirations (27 percent). Apnea testing also had relatively poor compliance with official guidelines, with only 66 percent requiring arterial blood gas (ABG) prior to testing, 39 percent requiring normal pCO₂ prior to testing, and 76 percent requiring preoxygenation before disconnection from the ventilator. Finally, guidance regarding specific situations to pursue ancillary testing was included in only 66 percent of guidelines [18].

Multiple studies published more recently have continued to demonstrate persistent variability among centers after the most recent AAN guidelines update. Five years after the 2010 update, the same group that looked at guidelines from the top 50 neurology and neurosurgery programs repeated their 2008 study looking at the same five domains of comparison to determine whether any changes had been made since the update to the guidelines [19]. Of the policies reviewed since the 2008 study, 76 percent had implemented a revised version of their adult brain death testing protocol. Regarding compliance of the 2008 protocols compared to the 2015 protocols with respect to the AAN guidelines, the 2015 hospitals did show some improvement. In 2015, 94 percent of policies required absence of hypothermia (compared to 89 percent previously). Compliance in terms of physical exam (while still low) also improved, with absence of pain above the foramen magnum required in 53 percent from 42 percent, absence of jaw jerk reflex in 24 percent from 18 percent, and absence of spontaneous respirations in 47 percent from 27 percent. The greatest improvement was seen in apnea testing criteria and appropriate use of ancillary testing [19]. Of note, the 2010 AAN updated guidelines are agnostic with regards to the need for repeat examination for brain death declaration, so as long as clinicians believe that enough time has passed to ensure irreversibility of the examination and state law does not explicitly mandate two examinations. Among the 2015 policies examined, 53 percent nevertheless mandated a waiting period between two separately performed brain death examinations.

Greer *et al.* also recently conducted an expanded analysis of hospital brain death testing, analyzing 492 hospital protocols across the US, representing the majority of US hospitals eligible to evaluate brain death [20]. The study, gathering data from 2012 to 2015, once again found significant variability across the five domains in the group's prior papers. The areas of greatest difference from the AAN guidelines were in prerequisites for brain death testing, clinical exam of the lower brainstem, apnea testing, and ancillary testing. Of the hospital protocols included in the study, hypotension and hypothermia were only stipulated as exclusion criteria for the valid pronouncement of brain death in only 56.2 percent and 79.4 percent, respectively. Only 82.9 percent specified that the patient's cause of coma should be established. With respect to the physical exam, only 84.3 percent included the absence of response to deep pain. The aspects of the physical exam included in the least number of policies was the absence of the jaw jerk reflex (22.6 percent) and the absence of spontaneous respirations while continuing to receive mechanical ventilation (62.1 percent).

Regarding apnea testing, only 66.4 percent of policies required an ABG before the exam, and 79.0 percent

provided instructions for preoxygenation. While ancillary testing should only be performed for adult brain death determination when clinical and apnea testing cannot be completed and interpreted successfully, ancillary testing was mandatory in 6.5 percent of policies, and instructions for when ancillary testing should be used was explained in only 64.2 percent of policies [20].

Variability at the Level of Individual Physicians

Beyond variability in hospital protocols, differences in knowledge of guidelines and institutional protocols, as well as variable level of training and competence, contribute to notable between-provider differences in the practice of brain death determination.

Shappell *et al.* conducted a retrospective chart review of adult brain death organ donors in 2011 [21]. Comparing 226 brain death determinations over 68 hospitals, Shappell *et al.* found that only 44.7 percent of cases strictly adhered to AAN guidelines. Of note, 15.5 percent of subjects had a documented core body temperature below 36.0°C, and brainstem reflexes were variably documented, with cough (68.6 percent), oculovestibular (65.9 percent), and oculocephalic (79.6 percent) reflexes being the least documented. Apnea testing was not attempted in 20.8 percent of cases, and of those without a complete apnea test (a situation that does warrant ancillary testing), only 93.3 percent had ancillary testing [21].

Most recently, Braksick *et al.* attempted to quantify the degree of training and practice performance of brain death determination by individual physicians by surveying physicians at three separate academic medical centers [22]. Of the 68 respondents, 23.9 percent reported that they had received no training on how to perform a brain death examination, and only 25 percent reported performing an examination consistent with AAN guidelines. On the other hand, 85.3 percent reported self-competence in completing a brain death examination. Twenty-three percent of the respondents reported completing a full brain death examination including apnea testing and excluding unnecessary exam components. Of note, apnea testing once again emerged as an area of potential confusion: 10.4 percent of physicians reported that they do not perform apnea testing as part of the brain death exam at all, and 30.3 percent routinely order ancillary testing as part of their standard practice [22].

CONCLUSION

The improvement in adherence of US hospital policies to the AAN guidelines between 2006 and 2015 is promising in that it shows a capacity for change towards a consistent practice. The adoption of the AAN guidelines in Nevada state law is also a step in the right direction. As considerable variability in implementation remains,

however, additional efforts beyond updating professional society guidelines must be made to increase congruency. At the same time that institutional efforts are made to establish more consistent national standards, individual physicians must also be given the tools and training to properly execute the changes reflected in the guidelines. The 2016 study by Greer *et al.* found that only 33.1 percent of the hospital policies examined required that the examiner have expertise in neurology or neurosurgery, and only 43.1 percent required that an attending make the determination [20]. While having a neurologic specialist on hand for all brain death determinations is not feasible at all hospitals, improving training programs for all clinicians responsible for brain death determination is an important step in the right direction.

One model of what formal brain death training might look like has recently been described at Yale School of Medicine. MacDougall *et al.* created a two-part training course that involved a didactic session and hands-on simulation session and tested whether participation in such a course could increase physician knowledge and competence in clinical brain death determination [23]. Knowledge was assessed before and after the training amongst the 90 participants of the course, and a significant improvement in mean score of the 20-question knowledge assessment was observed from a mean pre-test score of 45.5 percent to 73.3 percent ($p < 0.001$).

While no central program currently exists for certification of physician competence in the brain death exam, the Neurocritical Care Society (NCS) has developed an online Brain Death Toolkit (<https://www.pathlms.com/ncs-ondemand/courses/1223>), which offers web-based resources for developing hospital protocols that mirror the AAN guidelines and instructional videos demonstrating critical exam techniques [24]. Creating hospital-mandated brain death checklists can help promote compliance with AAN guidelines by requiring physicians determining brain death to perform each test and verify completion of the finding at each stage of determination. Standardized training for individual physicians responsible for brain death determination is a high priority of the AAN and the NCS moving forward to help move towards more uniformity in determining life or death among adults in the US.

REFERENCES

1. Russell JA, Epstein LG, Greer DM, Kirschen M, Rubin MA, Lewis A. Brain death, the determination of brain death, and member guidance for brain death accommodation requests: AAN position statement. *Neurology*. 2019; Epub 2019 Jan 04. <https://doi.org/10.1212/wnl.00000000000006750>.
2. Wijdicks EF. Deliberating Death in the Summer of 1968. *N Engl J Med*. 2018;379(5):412–5. Epub 2018 Aug 02.
3. A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. *JAMA*. 1968;205(6):337–40. Epub 1968 Aug 05.
4. Lewis A, Cahn-Fuller K, Caplan A. Shouldn't Dead Be Dead?: The Search for a Uniform Definition of Death. *J Law Med Ethics*. 2017;45(1):112–28. Epub 2017 Jul 01.
5. Defining Death: Medical, Ethical, and Legal Issues in the Determination of Death. Washington, DC: U.S. Government Printing Office, 1981.
6. Practice parameters for determining brain death in adults (summary statement). The Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 1995;45(5):1012–4. Epub 1995 May 01.
7. Wijdicks EF, Varelas PN, Gronseth GS, Greer DM. Evidence-based guideline update: determining brain death in adults: report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2010;74(23):1911–8. Epub 2010 Jun 10.
8. Lewis A, Bernat JL, Blosser S, Bonnie RJ, Epstein LG, Hutchins J, et al. An interdisciplinary response to contemporary concerns about brain death determination. *Neurology*. 2018;90(9):423–6. Epub 2018 Feb 02.
9. Lewis A. Contemporary Legal Updates to the Definition of Brain Death in Nevada. *JAMA Neurol*. 2017;74(9):1031–2. Epub 2017 Aug 02.
10. Lewis A, Varelas P, Greer D. Controversies After Brain Death: When Families Ask for More. *Chest*. 2016;149(2):607–8. Epub 2016 Feb 13.
11. Robbins NM, Bernat JL. Practice Current: When do you order ancillary tests to determine brain death?. *Neurol Clin Pract*. 2018;8(3):266–274. doi:10.1212/CPJ.0000000000000473.
12. Aviv R. What Does It Mean To Die? The New Yorker. January 29, 2018 February 5, 2018;Sect. *Annals of Medicine*.
13. Nikas NT, Bordlee DC, Moreira M. Determination of Death and the Dead Donor Rule: A Survey of the Current Law on Brain Death. *J Med Philos*. 2016;41(3):237–256. doi:10.1093/jmp/jhw002.
14. Death; determination by physician (1979).
15. Son RG, Setta SM. Frequency of use of the religious exemption in New Jersey cases of determination of brain death. *BMC Med Ethics*. 2018;19(1):76. Published 2018 Aug 14. doi:10.1186/s12910-018-0315-0.
16. Lewis A, Varelas P, Greer D. Prolonging Support After Brain Death: When Families Ask for More. *Neurocrit Care*. 2016;24(3):481–7. Epub 2015 Oct 23.
17. Powner DJ, Hernandez M, Rives TE. Variability among hospital policies for determining brain death in adults. *Crit Care Med*. 2004;32(6):1284–8. Epub 2004 Jun 10.
18. Greer DM, Varelas PN, Haque S, Wijdicks EF. Variability of brain death determination guidelines in leading US neurologic institutions. *Neurology*. 2008;70(4):284–9. Epub 2007 Dec 14.
19. Wang HH, Varelas PN, Henderson GV, Wijdicks EF, Greer DM. Improving uniformity in brain death determination policies over time. *Neurology*. 2017;88(6):562–568. doi:10.1212/WNL.0000000000003597.
20. Greer DM, Wang HH, Robinson JD, Varelas PN, Henderson GV, Wijdicks EF. Variability of Brain Death Policies in the United States. *JAMA Neurol*. 2016;73(2):213–8. Epub 2016 Jan 01.

21. Shappell CN, Frank JI, Husari K, Sanchez M, Goldenberg F, Ardelt A. Practice variability in brain death determination: a call to action. *Neurology*. 2013;81(23):2009–2014. doi:10.1212/01.wnl.0000436938.70528.4a.
22. Braksick SA, Robinson CP, Gronseth GS, Hocker S, Wijdicks EF, Rabinstein AA. Variability in reported physician practices for brain death determination. *Neurology*. 2019;92(9):e888–94. Epub 2019 Feb 26.
23. MacDougall BJ, Robinson JD, Kappus L, Sudikoff SN, Greer DM. Simulation-based training in brain death determination. *Neurocrit Care*. 2014;21(3):383–91. Epub 2014 Apr 03.
24. Brain Death Toolkit. Neurocritical Care Society; 2017. Available from: <https://www.pathlms.com/ncs-ondemand/courses/1223>.