

Disputes & Debates: Editors' Choice

Steven Galetta, MD, FAAN, Section Editor

Editors' note: An interdisciplinary response to contemporary concerns about brain death determination

"An interdisciplinary response to contemporary concerns about brain death determination" generated several readers' responses. Commenting on the paper, Verheijde et al. argue that cardiopulmonary death is not the equivalent to brain death and add that public trust in brain death requires that there be zero false-positive determinations of death. Dr. Sethi suggests that lawsuits related to brain death may be linked more to breakdowns in communication between the medical teams and patient families rather than validity of determination of death by neurologic criteria. Machado et al. suggest that ancillary tests should have a decisive role in helping to delineate the brain death concept since clinical evaluation might have pitfalls. Finally, Dr. Shabtai feels that it is an error to frame the debate as one of religious or moral beliefs vs science, and suggests continued discussion, including broad public debate. Authors Lewis et al. defend their article citing several prominent American medical societies who support that brain death is equivalent to cardiopulmonary death. They add that when the American Academy of Neurology guidelines are appropriately applied, there are zero false-positive determinations of death. They suggest including a social worker, psychologist, palliative care specialist, chaplain, and religious figure in conversations about brain death. They explain that ancillary testing is recommended to assess for lack of intracranial blood flow or cerebral activity if a clinical evaluation cannot be completed, but the gold standard for determination of brain death is a full clinical evaluation. Further, they add that ancillary testing is imperfect and there are risks when performing testing and interpreting the results. Finally, they remind the reader that the 1981 President's Commission determined that death should be defined based on complete loss of function of the brain or the heart and lungs, but deferred to the medical community to establish the specific criteria for determination of death. They stress that it is the medical community's responsibility to ensure that it is clear what constitutes "accepted medical standards" for determination of death and that these criteria are adhered to consistently and accurately.

Chafic Karam, MD, and Steven Galetta, MD
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Reader response: An interdisciplinary response to contemporary concerns about brain death determination

Joseph L. Verheijde (Scottsdale), Mohamed Y. Rady (Phoenix), and Michael Potts (Fayetteville)
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We disagree with redefining death "based on loss of clinical function of the heart and lungs or the brain,"¹ because it deviates from the legal definition of irreversible cessation of cardiorespiratory function or of all functions of the brain, including the brainstem. The latter was intended to protect the general public from injury and harm due to incorrect death declaration. The contemporary clinical criteria have been challenged on scientific, philosophical, legal, and religious grounds.²⁻⁴ Lewis et al. reduce this opposition to "moral or religious beliefs, hope that a patient will recover, or a lack of acceptance that a determination of brain death is the legal equivalent of

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a determination of cardiopulmonary death.”¹ Religious objection stems from incongruence with the hylomorphic Thomistic concept of death (body-soul connection) underlying Abrahamic faith traditions. The “lack of acceptance” originates from low-level supporting scientific evidence and absence of a coherent philosophical rationale.⁴ Furthermore, American Academy of Neurology practice guidelines are more consistent with the brainstem rather than the whole-brain death definition.

Public trust depends on determining death using a criterion with zero false-positives. Although some have advocated silencing opposing views and ending dissension on brain death,⁵ we welcome a broad public debate on the basis of contemporary (neuro)science advances, philosophical reasoning, and anthropologic and theologic considerations.

1. Lewis A, Bernat JL, Blosser S, et al. An interdisciplinary response to contemporary concerns about brain death determination. *Neurology* 2018;90:423–426.
2. Joffe AR. Brain death is not death: a critique of the concept, criterion, and tests of brain death. *Rev Neurosci* 2009;20:187–198.
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Reader response: An interdisciplinary response to contemporary concerns about brain death determination

Nitin K. Sethi (New York)

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I read with interest the response of the interdisciplinary committee to contemporary concerns about brain death determination.¹ A deeper analysis of the lawsuits related to brain death determination reveals that, in a significant number, the issue was not the validity of determination of death by neurologic criteria or the inconsistency with the 2010 American Academy of Neurology practice guideline prevalent among different institutions in the United States and abroad; rather, the crux of the problem lies in the manner death by neurologic criteria was conveyed to the family by the physician.

While patients who meet either cardiopulmonary or brain death criteria are in both cases legally dead, it is far easier and final for the grieving family to accept that their loved one is dead when the heart has stopped beating than to be told that the brain has been irreversibly damaged and that the “death of the brain” is equivalent to the “death of the person as a whole.”

“They say you die twice. One time when you stop breathing and a second time, a bit later on, when somebody says your name for the last time” is a quote attributed to Banksy. A large segment of the public still feels that one dies twice. Once when the heart stops and once when the brain stops. The first step to dispelling this myth is to stop using terms such as “brain death” or “death by neurologic criteria” when talking to a patient’s family. “Death is death no matter whether the heart dies or the brain dies” is the message we need to get out.

1. Lewis A, Bernat JL, Blosser S, et al. An interdisciplinary response to contemporary concerns about brain death determination. *Neurology* 2018;90:423–426.

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Reader response: An interdisciplinary response to contemporary concerns about brain death determination

Calixto Machado, Mario Estevez (Havana), Phillip A. DeFina (Flanders), and Gerry Leisman (Haifa)
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We read with interest the Contemporary Issues by Lewis et al.¹ Previously, Dr. Bernat defended the whole-brain concept of brain death (BD),² and the US President's Commission recommended its adoption by all US states.³ In 2015, Wijdicks stated, "the irreversible absence of functions of the brainstem is the necessary and sufficient component of brain death."⁴ This view fully pertains to brainstem death, and not to the whole-brain criterion.⁵ The American Academy of Neurology summit concluded that "BD is defined by irreversible loss of consciousness and brainstem function," according to the whole-brain criterion.¹

Well-designed surveys have shown discrepancies with the American Academy of Neurology guidelines on the use of ancillary tests.^{1,5} ECG monitoring is routinely used by physicians to diagnose a cardiac arrest. Patients' relatives more easily accept death when an ECG isoelectric line is observed in bedside monitors. There is no perfect confirmatory test, as clinical evaluation might have pitfalls. Ancillary tests should have a decisive role in helping to delineate the BD concept, as they have for outlining the cardiorespiratory view of death.

Is there a diagnosis of any disease in which a confirmatory test is not used? BD determination is the most challenging diagnosis. This might significantly reduce institutional protocol divergences in BD diagnosis.⁵

1. Lewis A, Bernat JL, Blosser S, et al. An interdisciplinary response to contemporary concerns about brain death determination. *Neurology* 2018;90:423–426.
2. Bernat JL. A defense of the whole-brain concept of death. *Hastings Cent Rep* 1998;28:14–23.
3. DigitalGeorgetown. Defining death: medical, legal and ethical issues in the determination of death [online]. Available at: hdl.handle.net/10822/559345. Accessed February 10, 2018.
4. Wijdicks EFC. The clinical determination of brain death: rational and reliable. *Semin Neurol* 2015;35:103–104.
5. Machado C, Estevez M, DeFina PA, et al. A reason for care in the clinical evaluation of function on the spectrum of consciousness. *Funct Neurol Rehab Ergon* (in press 2017).

Reader response: An interdisciplinary response to contemporary concerns about brain death determination

David Y. Shabtai (Boca Raton)
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It is reassuring that questions surrounding the proper diagnosis of brain death are continuously being debated.¹ However, while Lewis et al. acknowledge the existence of dissent regarding accepting brain death as the death of the individual, they frame the debate as one of beliefs vs science. This is an error.

The question of defining death is not one that lends itself to assertions by medical associations or physicians. Science and medicine are disciplines of facts and numbers, answering questions that ask what or how, but not questions of why. Indeed, assessing whether the criteria for death have been met requires precise medical determination. It necessitates expertise and precision, evaluating advancing technologies, and diagnostic acumen to evaluate specific physiologic parameters.

However, establishing those very criteria are questions of values and ethics. Selecting particular physiologic parameters for death requires assessing the values, ethics, and morals behind these

decisions.² These are not questions of science, but rather of philosophy and ethics. These are not questions to which additional scientific data are relevant, but must reflect the values and ethics of society.

Continued discussion—including broad public debate—should not only be welcome, but is necessary. Steering this discourse toward medical associations assumes that they accurately and effectively represent the values of society—an assertion that many would not quickly accept.

1. Lewis A, Bernat JL, Blosser S, et al. An interdisciplinary response to contemporary concerns about brain death determination. *Neurology* 2018;90:423–426.
2. Veatch RM. *Transplantation Ethics*. Washington: Georgetown University Press; 2000.

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Author response: An interdisciplinary response to contemporary concerns about brain death determination

Ariane Lewis (New York), James L. Bernat (Lebanon), Sandralee Blosser (Pittsburgh), Richard J. Bonnie (Charlottesville), Leon G. Epstein (Chicago), John Hutchins (Minneapolis), Matthew P. Kirschen (Philadelphia), Michael Rubin (Dallas), James A. Russell (Burlington), Justin A. Sattin (Madison), Eelco F.M. Wijdicks (Rochester), and David M. Greer (Boston)
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We appreciate the interest and comments of Verheijde et al., Dr. Sethi, Machado et al., and Dr. Shabtai.

We acknowledge that, as evidenced by the comment of Verheijde et al., some people, including physicians, do not believe that brain death is equivalent to cardiopulmonary death. Nonetheless, our multidisciplinary statement equating the two is supported by prominent American medical societies including the American Academy of Neurology, American Academy of Pediatrics, American College of Chest Physicians, American College of Radiology, American Neurological Association, American Society of Neuroradiology, Child Neurology Society, and Neurocritical Care Society.¹ Of course, we welcome continued discussion on this topic, particularly if relevant scientific data emerge.

We heartily agree with Verheijde et al. that public trust in brain death requires that there be zero false-positive determinations of death. Review of the literature from 1996 to 2009 demonstrated that when the American Academy of Neurology guidelines were appropriately applied, there were zero false-positive determinations of death.² However, inconsistent adherence to the guidelines can lead to false-positive determinations. We are working to avoid this by (1) promoting educational initiatives and brain death credentialing programs to ensure physicians performing evaluations for brain death determination are knowledgeable about the guidelines and comply with them, and (2) advocating for regulatory oversight to ensure determinations are performed according to the guidelines. Any alleged false-positive determination requires careful study.

To respond to Dr. Sethi's thoughtful comments: we believe that the triggers for the recent lawsuits related to brain death are multifactorial, but we agree that it is possible that breakdowns in communication between the medical teams and patient families had a role. Educating families about brain death can be challenging. It is important for physicians to bear in mind that religious formulations of death vary and that the public's perception of brain death is often based on misinformation published in the media and misrepresentations depicted in television and film.^{3–5} It is imperative that physicians who are involved in brain death determination be

adept at patiently explaining the concept of brain death and its implications while demonstrating cultural competence, compassion, and empathy for families. Discussions about brain death may precipitate a deluge of emotions including anger, fear, depression, distrust, and even guilt. As a result, consideration should be given to including a social worker, psychologist, palliative care specialist, chaplain, and/or religious figure in conversations about brain death. Recommendations by Lewis et al.⁶ for pediatric intensivists on communicating with families about brain death are universally applicable and should be included in brain death determination training sessions.

In regard to the concern by Machado et al. of protocol divergence, the legal and medical standards for determination of death by neurologic criteria in patients of all ages in the United States require irreversible cessation of all functions of the whole brain, including the brainstem.^{2,7,8} The guidelines for determination of brain death in both pediatric and adult patients define death based on clinical criteria. Ancillary testing is recommended to assess for lack of intracranial blood flow or cerebral activity if a clinical evaluation cannot be completed, but the gold standard for determination of brain death is a full clinical evaluation.^{2,8} However, we agree with Machado et al. that the clinical evaluation can have pitfalls. The solution to this is not mandating ancillary testing, though. Ancillary testing is imperfect and there are risks both when performing testing and interpreting the results.⁹ Despite this, some institutions require ancillary testing.¹⁰ To address these issues and ensure brain death determinations are consistent and accurate, we aim to (1) advocate for uniform institutional policies throughout the United States by implementing regulatory oversight, and (2) develop educational initiatives and credentialing programs.

We agree with Dr. Shabtai that the task of defining death requires input from specialists in a diverse range of fields. Accordingly, in 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research addressed this topic with emphasis on the question of whether brain death should be incorporated into the societal definition of death.¹¹ This committee was composed of experts in bioethics, epidemiology, health economics, law, medicine, nursing, philosophy, public health, research science, and sociology and sought counsel from the American Bar Association, the American Medical Association, the National Conference of Commissioners on Uniform State Laws, and religious officials.¹¹ The President's Commission determined that death should be defined based on complete loss of function of the brain (including the brainstem) or the heart and lungs, but deferred to the medical community to establish the specific criteria for determination of death. All 50 states adopted the definition of death the President's Commission created, or a variation thereof.¹² As a result, it is the medical community's responsibility to ensure that it is clear what constitutes "accepted medical standards" for determination of death and that these criteria are adhered to consistently and accurately. In addition, we would argue Dr. Shabtai's implication that medical societies are epistemologically confined to the scientific method given that physicians, such as Aristotle and Maimonides, have always been key contributors to the philosophical discourse of medical ethics.

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Author disclosures are available upon request (journal@neurology.org).

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CORRECTION

Subcutaneous ofatumumab in patients with relapsing-remitting multiple sclerosis

The MIRROR study

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In the article “Subcutaneous ofatumumab in patients with relapsing-remitting multiple sclerosis: The MIRROR study” by A. Bar-Or et al.,¹ there is an error in the Disclosure section. The original disclosure statement erroneously indicated Dr. Bar-Or was an employee and stockholder in GlaxoSmithKline. However, it should have read “A. Bar-Or has received consulting fees from GlaxoSmithKline.” All other disclosures are correct as originally published. The authors regret the error.

Reference

1. Bar-Or A, Grove RA, Austin DJ, et al. Subcutaneous ofatumumab in patients with relapsing-remitting multiple sclerosis: the MIRROR study. *Neurology* 2018;90:e1805–e1814.

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Subcutaneous ofatumumab in patients with relapsing-remitting multiple sclerosis: The MIRROR study

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