Revise the UDDA to Align the Law with Practice through Neuro-Respiratory Criteria

Author(s):
Adam Omelianchuk, PhD; James Bernat, MD; Art Caplan, PhD; David Greer, MD; Christos Lazaridis, MD; Ariane Lewis, MD; Thaddeus Pope, PhD; Lainie Friedman Ross, PhD; David Magnus, PhD

Corresponding Author:
David Magnus
dmagnus@stanford.edu

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License 4.0 (CC BY-NC-ND), which permits downloading and sharing the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Neurology® Published Ahead of Print articles have been peer reviewed and accepted for publication. This manuscript will be published in its final form after copyediting, page composition, and review of proofs. Errors that could affect the content may be corrected during these processes.
Affiliation Information for All Authors: 1. Stanford Center for Biomedical Ethic; 2. Dartmouth Geisel School of Medicine; 3. NYU Grossman School of Medicine; 4. Boston University School of Medicine; 5. University of Chicago Medical Center; 6. NYU Langone Medical Center; 7. Mitchell Hamline School of Law; 8. Institute for Translational Medicine; 9. University of Chicago; 10. Stanford Center for Biomedical Ethics

Contributions:
Adam Omelianchuk: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
James Bernat: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
Art Caplan: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
David Greer: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
Christos Lazaridis: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
Ariane Lewis: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
Thaddeus Pope: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
Lainie Friedman Ross: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design
David Magnus: Drafting/revision of the manuscript for content, including medical writing for content; Study concept or design

Number of characters in title: 82

Abstract Word count: x

Word count of main text: 3156

References: 36
Figures: 0
Tables: 0
Abstract: Although the Uniform Determination of Death Act (UDDA) has served as a model statute for 40 years, there is a growing recognition that the law must be updated. One issue being considered by the Uniform Law Commission’s Drafting Committee to revise the UDDA is whether the text “all functions of the entire brain, including the brainstem” should be changed. Some argue that the absence of diabetes insipidus indicates that some brain functioning continues in many individuals who otherwise meet the “accepted medical standards” like the American Academy of Neurology’s. The concern is that the legal criteria and the medical standards used to determine death by neurological criteria are not aligned. We argue for the revision of the UDDA to more accurately specify legal criteria which align with the medical standards: brain injury leading to permanent loss of a) the capacity for consciousness, b) the ability to breathe spontaneously, and c) brainstem reflexes. We term these criteria “neuro-respiratory criteria” and show that they are well-supported in the literature for physiological and social reasons justifying their use in the law.
At the end of the 1970s, neurological criteria for death were recognized in roughly half of the United States, resulting in a confusing legal landscape. To achieve uniformity across state lines and alignment of the law with medical practice, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research recommended state legislators adopt The Uniform Determination of Death Act (UDDA):1

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 brainstem, is dead. A determination of death must be made in accordance with accepted medical standards.

Though it has served as a model statute for 40 years, and has been embraced in whole or in part throughout the United States,² there is a growing recognition that the UDDA must be updated.³⁻⁵ The Uniform Law Commission recently approved a Study Committee’s recommendation to form a Drafting Committee that should submit its proposed UDDA revisions by July 2023. Meanwhile, Nevada, Oklahoma, and Texas have already moved to amend their own UDDA statutes (Nev. A.B. 424 [2017], Okla. H.B. 1896 [2021], Tex. H.B. 4329 [2021]). Contentious aspects of the UDDA include interpretation of the phrases “all functions of the entire brain” (vs. some specific set of functions), and “accepted medical standards” (should they be specifically named or not?), and whether accommodations are needed to address religious or principled objections to determining death by neurological criteria (DNC).⁶⁻⁹ Here, we propose a solution to the alleged inconsistency between the meaning of “all functions of the entire brain” and “accepted medical standards” by transitioning from an anatomical approach to DNC to a functional approach, like the approach to death by circulatory criteria. This change will align the law with medical practice, bolster confidence among examiners in
the reliability of the currently accepted medical standards, and transparently communicate to the public what the standards are expected to assess.

The currently accepted medical standards for DNC (published by the American Academy of Neurology in 2010 and the Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology Society in 2011) require documentation of an injury that explains the loss of brain function, the exclusion of confounding conditions, and a clinical examination that demonstrates unarousable unresponsiveness, brainstem areflexia, and apnea. Some argue that the absence of diabetes insipidus in many individuals who meet these standards indicates that some functions of the brain continue after pronouncement of death, namely those in the neurosecretory hypothalamus that regulate salt and water balance. With this in mind, a Nature editorial argued, “The time has come for a serious discussion on redrafting laws that push doctors towards a form of deceit” (p. 570). To align the law with practice, either the “accepted medical standards” must include a more demanding set of tests that exclude neurosecretory functioning or the text requiring cessation of “all functions of the entire brain” must be revised.

At some level, the criteria used to determine death must be a matter of convention and consensus. The relevant question is not whether any brain functions remain, but, rather, whether those functions contradict a determination of death. Unlike consciousness, responsiveness, or spontaneous respiratory effort, outside of a discussion about the phrase “all functions of the entire brain,” the presence of neurosecretory functioning is not recognized as a contradiction to determination of death. While we welcome further debate on its significance, we see no reason to reject the
recommendations of consensus statements like that of the World Brain Death Project’s\textsuperscript{26} that the persistence of neurosecretory function is consistent with DNC.

Therefore, we support revision of the UDDA to more accurately specify legal criteria which align with the medical standards: brain injury leading to permanent loss of a) the capacity for consciousness, b) the ability to breathe spontaneously, and c) brainstem reflexes.\textsuperscript{3-4} We term these amended criteria “neuro-respiratory criteria.” We recognize that there may be different and competing reasons to believe \textit{why} neuro-respiratory criteria are appropriate, as there is even disagreement about this amongst us, but we all agree that the law would be more clearly aligned with practice if the phrase “all functions of the entire brain” were replaced with language clearly specifying neuro-respiratory criteria. The use of neuro-respiratory criteria is well-supported in the literature for physiological and social reasons justifying its use in the law.

\textbf{Worldwide Support for Neuro-Respiratory Criteria}

The motivation to declare DNC arose in the context of the critical care setting in which some ventilator-dependent patients were found to be comatose, lacked the capacity to initiate breathing, and no longer had reflexes that mediate pupillary reaction to bright light, spontaneous eye-tracking of objects when the head is abruptly turned, and cough or gag responses.\textsuperscript{27} According to the 1981 President’s Commission’s report,\textsuperscript{1} which articulated justifications for the UDDA, neurological criteria for death, like circulatory criteria, provide sufficient evidence for the death of the patient and are to be used if there is reason to believe circulatory functioning does not reliably indicate the presence of life.

Many of the arguments made by the President’s Commission in \textit{Defining Death} are consistent with the neuro-respiratory criterion. The “whole-brain” formulation
never meant that every neuron had to fail; rather, it was meant to contrast with the so-called “higher brain” formulation, according to which the permanent loss of consciousness alone is decisive for determining death. “What is missing in the dead,” the drafters argued, “is a cluster of attributes, all of which form part of an organism’s responsiveness to its internal and external environment” (p. 36). The relevant “cluster of attributes” becomes clearer in their explanation of the language of “all functions of the entire brain, including the brain stem:”

This may be thought doubly redundant, but at least it should make plain the intent to exclude any patient who has lost only “higher” brain functions or, conversely, who maintains those functions but has suffered solely a direct injury to the brain stem which interferes with the vegetative functions of the body (p. 75, emphasis original).

Thus, if one is conscious or spontaneously breathes, one is not dead. While not explicitly stated, the implication is that if the cause of brain injury is known and confounding factors like hypothermia or drug intoxication are excluded, then permanent loss of the capacities for consciousness and the drive to breathe clinically indicate the permanent loss of the relevant “cluster of attributes” necessary for an organism to live (p. 36).

These attributes are clearly affirmed in the U.K. by the Academy of Royal Medical Colleges’ Code of Practice for Diagnosing and Confirming Death. It states, “when the brain-stem has been damaged in such a way, and to such a degree, that its integrative functions (which include the neural control of cardiac and pulmonary function and consciousness) are irreversibly destroyed, death of the individual has occurred” (p. 13).

As to the definition of death, the Royal Colleges assert that:

Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe (p. 11).
The relationship between the destruction of the brainstem’s “integrative functions” and the irreversible loss of the capacities for consciousness and the drive to breathe could not be clearer. Supporters of the brainstem formulation of DNC in the U.K. have maintained for decades that neuro-respiratory criteria are philosophically and culturally accepted, not only because of their critical importance for continued life, but also because they represent at the neurophysiological level the departure of the “conscious soul” and the “breath of life.”

The President’s Council on Bioethics’ 2008 white paper *Controversies in the Determination of Death* is another landmark document that supports neuro-respiratory criteria. After reviewing the criticisms of the 1981 President’s Commission’s report, the majority view of the President’s Council (“Position Two”) was that DNC should be accepted as a way to determine the loss of the organism’s capacity to perform its “vital work” (p. 60). The authors noted that the loss of the organism’s capacity to engage in need-driven interaction with its environment, sensing what it needs (oxygen) and acting to meet those needs (striving to take in air), is what marks the end of the organism. This vital activity was explicitly operationalized in terms of neuro-respiratory criteria:

“If there are no signs of consciousness and if spontaneous breathing is absent and if the best clinical judgment is that these neurophysiological facts cannot be reversed, Position Two would lead us to conclude that a once-living patient has now died” (p. 64, emphasis original). Like the U.K. model, Position Two further says, “From a philosophical-biological perspective, it becomes clear that a human being with a destroyed brainstem has lost the functional capacities that define organismic life” (p. 66). Although they did not recommend changing the law to a “brainstem-only” formulation, they did clearly
recommend using neuro-respiratory criteria to determine what they call “total brain failure” (or DNC) (p. 12).³³

Further support for neuro-respiratory criteria can be adduced from two other representative professional societies. First, the Canadian Medical Association’s 2006 report on the neurological determination of death³⁴ recommends that the “concept and definition of neurological death” be defined “as the irreversible loss of the capacity for consciousness combined with the irreversible loss of all brain stem functions [named elsewhere in the document], including the capacity to breathe” (p. S3). Second, the World Health Organization’s 2012 statement on death criteria says, “Death occurs when there is permanent loss of capacity for consciousness and loss of all brainstem functions” (p. 31).³⁵ Although the capacity to breathe is not explicitly mentioned, its loss is implied since they recognize that “respiratory arrest” is “secondary to the loss of brainstem function” (p. 13).

The most recent highly influential publication to acknowledge neuro-respiratory criteria is the World Brain Death Project (2020), an international consensus statement endorsed by 5 world federations and numerous medical societies. They recommended that neurological criteria for death be defined as “the complete and permanent loss of brain function as defined by an unresponsive coma with loss of capacity for consciousness, brainstem reflexes, and the ability to breathe independently” (p. 1081).²⁶

One final note: the President’s Commission, the Royal Medical Colleges, the President’s Council, the Canadian Medical Association, the World Health Organization, and the World Brain Death Project all highlighted the importance of brainstem functioning for the capacities of consciousness and spontaneous breathing. The overlap of functions attributable to the brainstem nuclei — emotion, wakefulness and sleep,
basic attention, and of course consciousness itself—are essential for the homeostatic balance of a living organism. The principal nuclei involved in modulating cortical activation lie in the upper pons and midbrain, however lower brainstem structures have been also implicated. Detailed examination of the functions of all clinically accessible brainstem nuclei increases certainty that the functions of consciousness and spontaneous breathing have been permanently lost.

**Advantages of Neuro-Respiratory Criteria**

We recognize that there can be varying philosophical, religious, cultural, metaphysical, or biological views on when death occurs, but it is necessary for the law to clearly stipulate legal criteria for determining death and for these criteria to align with medical standards. As we have demonstrated, neuro-respiratory criteria, which have the advantage of basing the determination of death on the loss of key vital functioning rather than anatomical mortality (e.g. “whole-brain death,” “brainstem death,” “cardiac death”) or the presence of cellular electrical activity, are widely accepted and should be incorporated into the UDDA.

When the neuro-respiratory criteria are satisfied, they afford just as bright a line between life and death as the accepted medical standards for circulatory criteria. Though this “bright line” is constructed for social purposes, it is rooted in observable facts, enabling confidence in the determination and the ability to make the distinction between life and death in a timely and efficient manner. These purposes included determining when the grieving process begins, when a marriage ends, when life-insurance pays out, when constitutional rights no longer apply, when multiple vital organs can be procured, when requests for autopsy are initiated, and when plans for burial begin.
Conclusion

Although additional revisions to the UDDA are necessary to address other concerns, such as whether the law should specify the medical standards themselves rather than loosely referring to “accepted medical standards,” or whether accommodations are needed to address religious or principled objections to DNC, we recommend that the first sentence of the UDDA be revised to reference cessation of neuro-respiratory functions to bring the law in alignment with practice. Rather than require “irreversible cessation of all functions of the entire brain, including the brainstem,” the UDDA should instead require “brain injury leading to permanent loss of a) the capacity for consciousness, b) the ability to breathe spontaneously, and c) brainstem reflexes.”
References


Revise the UDDA to Align the Law with Practice through Neuro-Respiratory Criteria
Adam Omelianchuk, James Bernat, Art Caplan, et al.
Neurology  published online January 25, 2022
DOI 10.1212/WNL.0000000000200024

This information is current as of January 25, 2022

Updated Information & Services
including high resolution figures, can be found at:
http://n.neurology.org/content/early/2022/01/25/WNL.0000000000200024.full

Subspecialty Collections
This article, along with others on similar topics, appears in the following collection(s):
All Ethics in Neurology/Legal issues
http://n.neurology.org/cgi/collection/all_ethics_in_neurology_legal_issues
Brain death
http://n.neurology.org/cgi/collection/brain_death

Permissions & Licensing
Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
http://www.neurology.org/about/about_the_journal#permissions

Reprints
Information about ordering reprints can be found online:
http://n.neurology.org/subscribers/advertise

Neurology® is the official journal of the American Academy of Neurology. Published continuously since 1951, it is now a weekly with 48 issues per year. Copyright © 2022 The Author(s). Published by Wolters Kluwer Health, Inc. on behalf of the American Academy of Neurology. All rights reserved. Print ISSN: 0028-3878. Online ISSN: 1526-632X.