



Rationales to Revise the UDDA: the Physician's Perspective

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Speaker Disclosures

I am a member of the:

- Steering Committee for the World Brain Death Project
- Determination of Death Act Study Committee
- International Advisor to Canadian Critical Care Society Definition and Determination of Death Committee
- AAN Ethics, Law and Humanities Committee
- AAN Brain Death Work Group
- NCS Ethics Committee

No financial relationships to disclose.

Defining Death

Medical, Legal and
Ethical Issues in the
Determination of Death



President's Commission for the Study of
Ethical Problems in Medicine and
Biomedical and Behavioral Research

Uniform Determination of Death Act

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.

ADEN HAILU, NEVADA, 2015-16

ISRAEL STINSON, CALIFORNIA, 2016

Jahi McMath, California, 2013-18

MIRRANDA GRACE LAWSON, VIRGINIA, 2016

A CHILD, UNITED KINGDOM, 2015

YECHAZKEL NAKAR , NEW YORK, 2017

ALLEN CALLAWAY, MONTANA, 2016

**Objections
to the Use
Of
Neurologic
Criteria to
Declare
Death**

SHALOM OUANOUNOU, ONTARIO, 2017-18

ALEX PIERCE, CALIFORNIA, 2016

**TAQUISHA MCKITTY,
ONTARIO, 2017-18**

JAYDEN AUYEUNG, PENNSYLVANIA, 2018

**AREEN CHAKRABARTI, PENNSYLVANIA,
2018**

DAVID RUIZ, ARIZONA, 2019

Payton Summons, Texas, 2018

IDAN AZRAD, OTTAWA, 2019

BLAIRE BRAVENEC, TEXAS, 2019

BOBBY REYES, MICHIGAN, 2019

TITUS CROMER, MICHIGAN, 2019

RUBEN VATI, ARIZONA, 2019

MIDRAR ALI, UNITED KINGDOM 2019-20

Reasons families object to determination of death by neurologic criteria/discontinuation of organ support

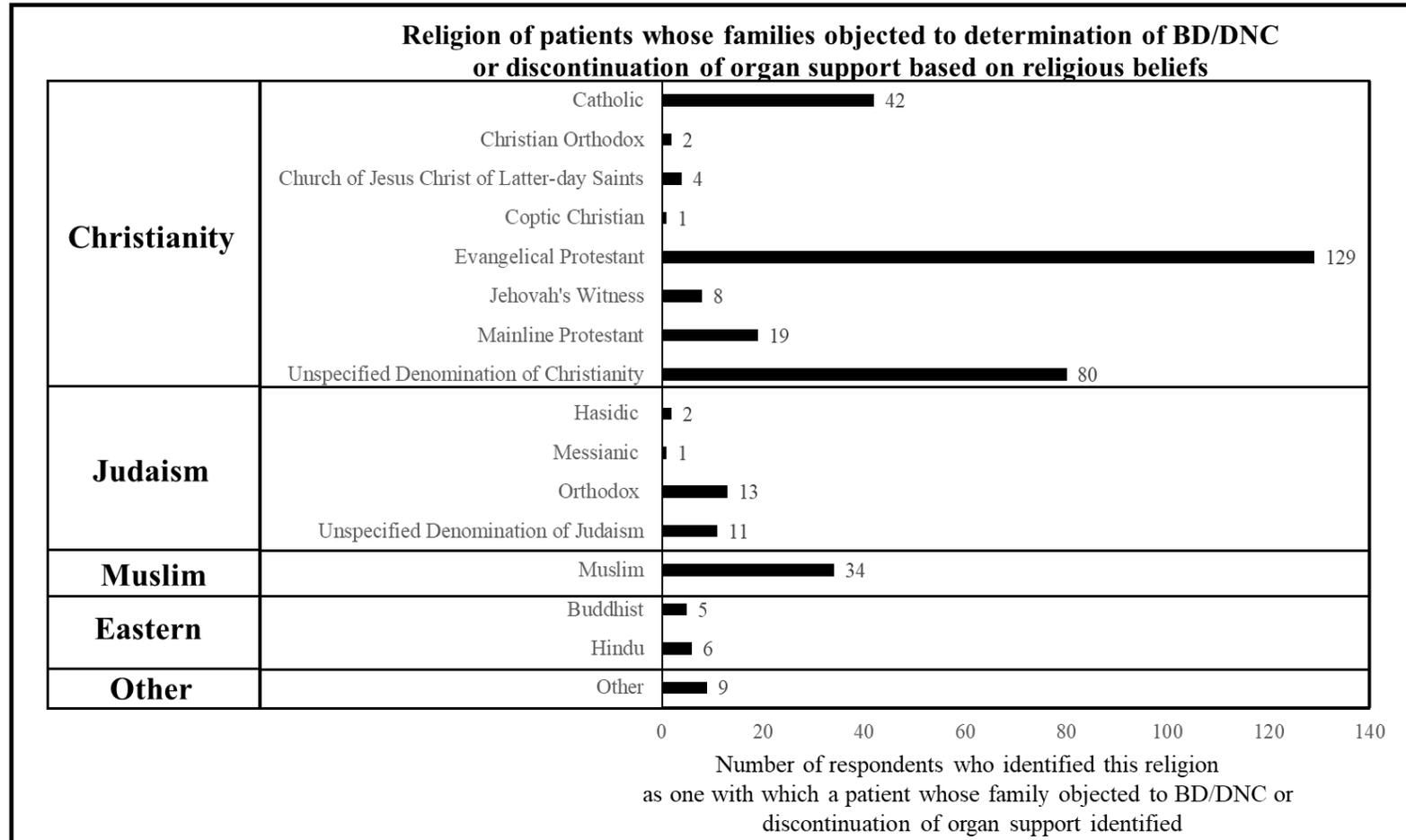
- Religious beliefs
- Belief that recovery of neurologic function is possible
- Lack of acceptance that death can occur when the heart is beating
- Lack of acceptance that spinal reflexes are not purposeful movements



Brain Death and Religion

Religion	Perspective on BD/DNC
Buddhism	BD/DNC is accepted as death by some scholars, but this position is not universally held
Christianity	<ul style="list-style-type: none"> American Baptists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death Anglicanism: BD/DNC is accepted as death Eastern Orthodoxy: BD/DNC is neither accepted nor rejected Evangelicalism: it is accepted that no medical treatment can reverse BD/DNC and noted that “life support” should be removed in the case of BD/DNC to “facilitate the process of dying” Jehovah’s Witnesses: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death Lutheranism: there are mixed opinions on use of neurologic criteria to determine death Presbyterianism: BD/DNC is acknowledged to be widely accepted as death Roman Catholicism: BD/DNC is generally accepted as death Seventh Day Adventists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death Southern Baptists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death United Methodists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death Unitarian Universalists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death
Hinduism	BD/DNC is accepted as death by some authorities, but this position is not universally held
Islam	<ul style="list-style-type: none"> Shiism: BD/DNC is generally accepted as death Sunnism: mixed opinions on BD/DNC
Judaism	<ul style="list-style-type: none"> Conservative Judaism: BD/DNC is accepted as death Orthodox Judaism: mixed opinions on BD/DNC Reform Judaism: BD/DNC is accepted as death

Brain Death and Religion



Jewish and Muslim Views on Brain Death

View of Jewish Rabbis

- 78% believed brain death is death
- There is a significant relationship between denomination and
 - Belief a person who is brain dead can recover
 - Belief a person who is brain dead is dead
 - Belief mechanical ventilation should be continued after brain death

Views of Allied Muslim Healthcare Professionals

- 84% believed brain death is death
- Half of respondents believed
 - Families should be able to choose whether an evaluation for brain death is performed
 - Families should be able to choose whether organ support is discontinued after brain death

Is consent needed prior to determination of brain death?



How should physicians handle objections to determination of brain death or discontinuation of organ support after declaration of brain death?

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Legal Guidance Re: Consent Prior to Brain Death Evaluation

- **Montana:** judicial precedent requiring consent
- **Nevada:** “Determination of death...is a clinical decision that does not require the consent of a person’s authorized representative or the family member with the authority to consent or withhold consent.”
- **New York:** “Consent need not be obtained”
- **Virginia:** judicial precedent that consent is not required

Management of Religious Objections to Brain Death

Jurisdiction	Law/Legal Guideline
California	"If [there are] any special religious or cultural practices...the hospital shall make reasonable efforts to accommodate those religious and cultural practices and concerns."
Illinois	"Every hospital must adopt policies and procedures...to take into account the patient's religious beliefs concerning the patient's time of death."
New Jersey	"Hospitals should establish written procedures for the acknowledgement of the patient's religious beliefs, if...such a declaration of death by neurological criteria would violate the personal religious beliefs of the patient. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria."
New York	"Hospitals must establish written procedures for the reasonable accommodation of the individual's religious or moral objections to use of the brain death standard...policies may include specific accommodations, such as the continuation of artificial respiration under certain circumstances, as well as guidance on limits to the duration of accommodation"

Frequency of Objections

- 61% of surveyed pediatric neurologists and intensivists have encountered a situation in which a family objected to determination of brain death or discontinuation of organ support after brain death
- 47% of surveyed adult neurologists have encountered a situation in which a family objected to determination of brain death or discontinuation of organ support after brain death

Should consent be required to perform a brain death evaluation?

- 72% of surveyed pediatric neurologists and intensivists say NO
 - 78% of surveyed adult neurologists say NO

Should accommodation to religious objections to use of neurologic criteria to declare death be incorporated into the legal definition of death everywhere?

- 16% of surveyed adult neurologists in the USA believe that every state should allow for religious or moral objection to death by neurologic criteria
- 13% of surveyed pediatric neurologists/intensivists in the USA believe that every state should allow for religious or moral objection to death by neurologic criteria



Consent Should Not Be Required to Perform a Brain Death Evaluation

- **All forms of death should be treated the same:**
 - Informed consent is not required for determination of death by cardiopulmonary criteria, so it would be unethical to require it for determination of death by neurologic criteria.
- **A determination of death should not represent a choice:**
 - Families should not be allowed to decide whether or not an assessment for determination of death can be performed.
- **It is not standard practice to obtain consent before a brain death evaluation:**
 - A survey of neurologists found that 78% of respondents strongly or somewhat disagreed that physicians should obtain consent from a patient's family before performing a brain death evaluation.

Consent Should Be Required to Perform a Brain Death Evaluation

- **Consent should be obtained for all procedures:**
 - Patients/proxies provide consent for all tests and procedures.
- **A person does not benefit from being declared brain dead:**
 - Consent should be obtained if it cannot reasonably be assumed a person would want a procedure.
- **There are risks associated with apnea testing:**
 - Hemodynamic instability, tension pneumothorax, pneumomediastinum, cardiac arrhythmias, and cardiac arrest.
 - Raising PaCO₂ could raise ICP and cause brain damage.
- **Persons of all religions and cultures should be treated with respect:**
 - If a person does not believe brain death is death, their beliefs should not be ignored.

Arguments in Favor of Continuing Organ Support in Complicated Brain Death Cases

- **Desire to avoid conflict**
- American values:
 - Autonomy
 - Individualism
 - Privacy
 - Religious freedom
- A family should be seen as an extension of a patient
- Ethics and compassion dictate respect for families
- Delay in discontinuation of organ support can allow a family to come to terms with a patient's death
 - **Hope that the family will ultimately change their mind**
- Cardiopulmonary arrest may be imminent

Arguments Against Continuing Organ Support in Complicated Brain Death Cases

- Hospitals are facilities for the living to receive necessary medical care, not for the dead to be maintained
- Ongoing treatment after death can be seen as a violation of bodily integrity and abuse of a corpse
- There is an ethical hazard associated with allowing a negotiated standard for determining death
 - patients who are dead by cardiopulmonary criteria should be treated the same as those who are brain dead

How did neurologists respond to their most recent request to continue organ support after declaration of brain death*?

	Accommodation state respondents (n=39)	Non-accommodation state respondents (n=42)
Discontinuation of organ support without family consent (%)	0%	0%
Discontinuation of organ support with family consent (%)	44%	33%
Continuation of organ support for a set amount of time (%)	31%	45%
Continuation of organ support indefinitely (%)	10%	2%
Other (%)	15%	19%

*outside of organ donation
Lewis A et al. Neurology. 2016; 87 (8): 827-34.

Effects of Complicated Brain Death Cases

- On the family:
 - Increased risk of complicated grief
 - Confusion about the patient's status
- On healthcare professionals:
 - Moral distress
 - Weakened therapeutic alliance with staff and family
- On society:
 - Resource allocation
 - Time and energy of healthcare professionals
 - Medical equipment/bed
 - Medications

Physician Feedback

- Legal guidance is needed for both physicians and the public
 - Management of objections prior to a brain death evaluation/discontinuation of organ support
 - The specific scenarios in which physicians should/can continue organ support
 - The timeframe for continuation of organ support



**Advocate for a
consistent legal
approach to
brain death
determination in every
state in the US**

CONTEMPORARY ISSUES

An interdisciplinary response to contemporary concerns about brain death determination

Ariane Lewis, MD, James L. Bernat, MD, Sandralee Blosser, MD, Richard J. Bonnie, LLB, Leon G. Epstein, MD, John Hutchins, JD, Matthew P. Kirschen, MD, PhD, Michael Rubin, MD, MA, James A. Russell, DO, Justin A. Sattin, MD, Eelco F.M. Wijdicks, MD, PhD, and David M. Greer, MD, MA

Neurology® 2018;90:423-426. doi:10.1212/WNL.0000000000005033

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Abstract

In response to a number of recent lawsuits related to brain death determination, the American Academy of Neurology Ethics, Law, and Humanities Committee convened a multisociety quality improvement summit in October 2016 to address, and potentially correct, aspects of brain death determination within the purview of medical practice that may have contributed to these lawsuits. This article, which has been endorsed by multiple societies that are stakeholders in brain death determination, summarizes the discussion at this summit, wherein we (1) reaffirmed the validity of determination of death by neurologic criteria and the use of the American Academy of Neurology practice guideline to determine brain death in adults; (2) discussed the development of systems to ensure that brain death determination is consistent and accurate; (3) reviewed strategies to respond to objections to determination of death by neurologic criteria; and (4) outlined goals to improve public trust in brain death determination.

MORE ONLINE

Podcast

Dr. Andy Schomer
interviews Dr. Ariane Lewis
about her paper on brain
death.

[NPub.org/6wum9n](https://www.npub.org/6wum9n)

It's Time to Revise the Uniform Determination of Death Act

Ariane Lewis, MD; Richard J. Bonnie, LLB; and Thaddeus Pope, JD, PhD

- Should consent be required to perform an evaluation for brain death?
- How should religious objections to the use of neurologic criteria to declare death be handled?
- What is meant by “all functions of the entire brain”?
- What are the “accepted medical standards”?

Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Determination of Death Act

Ariane Lewis, Richard J. Bonnie, Thaddeus Pope, Leon G. Epstein, David M. Greer, Matthew P. Kirschen, Michael Rubin, and James A. Russell



Uniform Law Commission

Better Laws. Stronger States.

Determination of Death Act Committee

This study committee will study the need for and feasibility of updating the Uniform Determination of Death Act (1980), which has been enacted in 44 states. Issues to be considered include lack of uniformity in the medical standards used to determine death by neurologic criteria, the relevance of hormonal functions, and whether notice should be provided before a determination of death.

The Scope and Program Committee recommended, and the Executive Committee approved, the creation of a Drafting Committee to Update the Uniform Determination of Death Act. As stated in the Minutes from the Executive Committee meeting:

“Scope [and Program] approved the following resolution for consideration, recommending that a drafting committee to Revise the Uniform Determination of Death Act be formed.

RESOLVED, that the Committee on Scope and Program recommends to the Executive Committee that a Drafting Committee to Revise the Uniform Determination of Death Act be formed.

The Executive Committee approved this resolution by a unanimous vote, 11 – 0.”

THANKS!

¡Gracias!
Gràcies!
Thank you!
DANKE!
Merci!
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