Brain Death Bioethics
Fundamental Principles & Emerging Issues
Thaddeus Mason Pope, JD, PhD
Eighth Annual Great Lakes Palliative Care Conference
Lake Geneva WI • May 3, 2019

Nothing to disclose

“Restoration of brain circulation and cellular functions hours post-mortem”

Scientists Restore Some Brain Function After Death

Can dead brains come back to life?
Pig brains partially revived hours after death—what it means for people

A dead pig’s brain was brought back to life

Frankenswine: Scientists bring brains of dead pigs ‘back to life’

Brain death = death ?

Case

November 2003
Plan w/d organ-sustaining Tx

Without consent
"tortuous termination of life support"

Alive
Medical futility conflict
Family decision

Dead
Straightforward
Clinician control

"decision-making process is unnecessary when the patient meets . . . brain death" (4.63)
Dead
w/d okay

2006 -
2011

May
2019

What’s
different
today?

Roadmap

4 parts

Part 1
Intro to BD

Part 2
Resistance to BD is growing

Part 3

Consequences of resistance

Part 4

5 legal attacks on BD

1968

LIFE
Picasso

Brill
irreversible cessation of circulatory & respiratory functions

BUT

Only 1 way to determine death

1968
If this position is adopted by the medical community, it can form the basis for change in the current legal concept of death. No statutory change in the law should be necessary, since the law treats this question essentially as one of fact to be determined by physicians.

Risk averse clinicians want certainty & clarity

Legislation Proposed to Recognize Brain Death

LOS ANGELES (AP) - Proposed legislation recognizing so-called brain death will be drafted here, according to Dept. Dist. Atty. John W. Miner.

Such legislation would be the first in the nation recognizing brain death — death when the brain ceases to function, even though the heart and respiration are sustained by artificial means.

Miner said it will define brain death.

The Los Angeles County district attorney’s vital organ transplant committee decided that a clear definition of death is needed now that heart transplants have raised the question as to whether the donor is technically dead or alive at the time his heart is taken.

Variability

Uniformity

1970s
An individual . . . . is dead . . . who has sustained either
(1) irreversible cessation of circulatory and respiratory functions, or
(2) irreversible cessation of all functions of the entire brain

Brain death = Death

Wis. Stat. 146.71
S.B. 327 (1981), Ch. 134

All 56 US jurisdictions
Legally settled since 1980s
Collected 1000 pounds of moon rocks late 1960s.

Growing resistance

More families dispute BD
NEUROLOGY
Aug. 2016

50% report families request organ support after BD

"reject this diagnosis"
"deviate from standard procedures"

Conflict: 10%
56 BD cases 2014-2016

More conflict
Palliative care literature

Many cases to court

2016 - 2018

Why?
1 Diagnostic confusion

“Since there is a heartbeat (and he is warm), he is alive.”

“He’s in a coma.”

“With rehab/time he’ll get better.”

2 Linguistic Confusion

“Brain dead” implies not really dead
“heart dead”

“She is brain dead and being kept alive.”

“Mistrust”

Medical error—the third leading cause of death in the US
<table>
<thead>
<tr>
<th>Disease</th>
<th>Number of Deaths</th>
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<tbody>
<tr>
<td>Heart disease</td>
<td>600,000</td>
</tr>
<tr>
<td>Cancer</td>
<td>600,000</td>
</tr>
<tr>
<td>Medical error</td>
<td>400,000</td>
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<tr>
<td>COPD</td>
<td>140,000</td>
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<tr>
<td>Stroke</td>
<td>130,000</td>
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<tr>
<td>Accidents</td>
<td>120,000</td>
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</tbody>
</table>

John Foster at Fresno Community (April 12, 2007)

“They were declared brain dead. It was written in their charts ... here they are sitting up talking to me.”

Negligent errors

More culpable errors
Mistrust
Confusion
Diagnostic
Linguistic

Taphophobia
Taphophobia
people want to be sure
More vulnerable

More organized opposition

Jahi McMath
Consequences of resistance

$10,000 per day

Find physicians & lawyers

More pro bono

More crowdfund

Dolan Law Firm

FRCP 65
9+ months
$10,000 per day
Harm innocent 3\textsuperscript{rd} parties

Types of dispute

Least

Most serious
Attack
1 of 5

Confusion
Mistrust

Just 1 example

Lisa Avila

“No”
Wrong before
Wrong now

Injunction against removing ventilator

“okay”

Law buys time - to accept or confirm

Other tools

Do not use the term “brain death”
Tawil et al., "Family presence during brain death evaluation in a randomized controlled trial" - Crit Care Med. 2014 Apr;42(4):934-42

That’s 1st attack on BD

Attack 2 of 5

Want religious exemption

“[D]eath . . . shall not be declared . . . neurological criteria . . . violate . . . personal religious beliefs . . .”

Religious objection → No death by BD

Pt may satisfy BD criteria

BUT
May not declare death

Until death by CP criteria

Rejected everywhere outside NJ

Still asked for

CHOP had 2 cases summer 2018

Areen Chakrabarti

Jayden Auyeing

River Styx in Hades, border between underworld and world of the living
AMENDED IN ASSEMBLY APRIL 6, 1987
CALIFORNIA LEGISLATURE—1987 REGULAR SESSION

ASSEMBLY BILL
No. 1390

Introduced by Assembly Member Katz
March 4, 1987

California rejected legislation

Rejected everywhere outside NJ
BUT

New cases

BD guidelines “failed to . . . accommodate . . . religious beliefs, . . . violate . . . constitutional and human rights”
“Plaintiffs are Christians with firm religious beliefs... heart is beating... is alive.”

“removal of CP support... unconstitutional... interferes with... freedom of religion... first amendment”

Oral arg. Jan. 14, 2019
“Hospitals must establish **written procedures** for reasonable accommodation”

Free choice 24 hours

**BUT**

May see more of these cases

That’s 2nd attack on BD

**LIFE LEGAL DEFENSE FOUNDATION**

Attack 3 of 5

Must clinicians obtain consent for BD tests?
Some try to prevent BD diagnosis. Why? This strategy. Clinician duties after BD.

Limited

“After a patient . . . brain dead . . . medical support should be discontinued.”

“all medical interventions should be withdrawn.” Consent not required Dead → Not a patient.
Not a patient → No Tx duty

No post-BD treatment rights

So, Focus on pre-BD rights

Apnea test

Final confirmatory test
BUT

More family refusals

Parental refusals

Almost all pediatric

No apnea test

No BD

No BD

Treatment duties continue until CP

Practically, same as NJ religious exemption
Opt out

BD

No apnea test → ancillary tests

But same consent question

Must clinicians honor the refusal?

Do clinicians need consent for apnea test?

Yes

Allen Callaway

Billings, Montana
6-year-old
"Drowned" July 22, 2016

Mom: "no"

"request . . . permitting . . . testing . . . is denied"

"mother has sole authority to make medical decisions . . . including . . . brain functionality examinations"

Transferred home
Do clinicians need consent for apnea test?

MT said “yes”

KS also said “yes”

Brett Shively
2yo “drown”
Wichita, 2006

Do clinicians need consent for apnea test?

CA also said “yes”
Do clinicians need consent for apnea test?

MT, KS, CA said “yes”
Normally, may not do things to patient without consent

No

Miranda Lawson

Richmond, Virginia

2-year-old Choked popcorn - May 13, 2016
Apnea test

Dad: “no”

Richmond Circuit Court

Hospital “is . . . allowed to administer the apnea test”

Do clinicians need consent for apnea test?

VA said “no”

NV also said “no”

Already amending NUDDA
“determination of the death . . . is a clinical decision that does not require the consent of the person’s . . . representative . . . .”

Do clinicians need consent for apnea test?

“. . . process for determining brain death is underway. Consent need not be obtained . . .”

Conflict continues

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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<td>Montana</td>
<td>Georgia</td>
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<td>New York</td>
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2 more recent cases in McKinley Hawkins

Neurology Aug 2016
87(8) 827-34

That’s 3rd attack on BD

¼ neurologists say need consent

Not only courts

Attack 4 of 5
Dec. 12, 2013
Declared dead

Lost lawsuits against hospital

Transferred to NJ
Sustained organ support 4.5 years!!

Mar. 2015
Med Mal lawsuit

Future medical expenses

Dead people do not have medical expenses
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<tbody>
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<td></td>
<td>Argument over <strong>facts</strong>, not law</td>
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<table>
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<th>364</th>
<th>Does not attack medical criteria <strong>themselves</strong></th>
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<tbody>
<tr>
<td>365</td>
<td>No longer meets criteria</td>
</tr>
<tr>
<td>366</td>
<td>Dead at T1, Not dead at T2</td>
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<thead>
<tr>
<th>367</th>
<th><strong>Problem</strong></th>
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<tr>
<td>368</td>
<td><strong>stay dead</strong></td>
</tr>
<tr>
<td>369</td>
<td><strong>Death should be irreversible</strong></td>
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Collateral estoppel

**Chance to prove**

“Triable issue . . . whether changed circumstances”

**BUT**

June 2018

Certificate of Death

**That’s 4th challenge**

**Attack 5 of 5**
Most serious attack

Are medical criteria for BD legally sufficient?

Reno, Nevada

Aden Hailu

April 1, 2015
Catastrophic anoxic brain injury during exploratory laparotomy

May 28, 2015
Met AAN criteria for brain death

Dad: “she is not dead”

Dad loses
Trial court
AAN criteria met
Aden is dead

Dad appeals
Nevada Supreme Court

Dad wins

Irrelevant if Aden meets AAN criteria
NOT the "right" criteria

2 reasons

1

UDDA

“must be made in accordance with accepted medical standards”
BUT

Trial court did not consider whether AAN are "accepted medical standards".

Hospital policies

Clinicians

Number of physicians

Qualifications

How tests administered

Hailu = AAN

AAN ≠ UDDA

Court throws BD into doubt
uncertainty

Nevada legislature steps in

“AAN / AAP authoritative criteria”

“AAN does not measure what the UDDA requires”

Wis. Stat. 146.71

S.B. 327 (1981), Ch. 134

Supreme Court of Nevada
November 2015
“irreversible cessation . . . all functions of . . . entire brain”

BUT

Brain dead people do stuff

Controversies in the Determination of Death
A White Paper by the President’s Council on Bioethics

Acknowledge conceptual problems

Gestate a fetus

Acknowledge conceptual problems

AAN measures only cessation some functions of part of brain

Supposed to measure: “all functions” “entire brain”
UDDA requires Clinicians measure

Predictable

“silent on . . . diagnostic tests . . . procedures”

“medical profession remains free to formulate acceptable . . . practices”

Defers to medical profession

BUT

Discretion not unfettered
Medical criteria must measure legal standards

“irreversible cessation . . . all functions of . . . entire brain”

Medical criteria drifted too far from statute

Legal standard may demand more than medical criteria

January 2019

Brain death, the determination of brain death, and member guidance for brain death accommodation requests

AAN position statement

Correspondence
James E. Raccatt, DSC, E. John Steinberg, MD, Donald S. S. Blume, MD, Matthew Kocher, MD, PhD, Michael H. Aminoff, MD, and Bruce I. Gross, MD, on behalf of the Brain Death Working Group

https://doi.org/10.1212/WNL.0000000000006874
“neuroendocrine function may be present”

“not inconsistent with the whole brain standard of death.”

Supposed to measure:
“all functions”
“entire brain”

Medically dead ≠ Legally dead

Conclusion

Debate has been academic
“critics and skeptics have not gained much traction with lawmakers”

Not true anymore

Courts and legislatures are tackling this

Not just academic debate

Now it is a public policy question

U.S. hospitals will see more cases
“Determining whether a patient is alive or dead is the most fundamental aspect of providing medical care.”
But we’ve got to verify it legally, to see if she is morally, ethically spiritually, physically positively, absolutely undeniably and reliably Dead.

She’s not only merely dead, She’s really most sincerely dead.

References
Materials from the cases discussed in this presentation are available at http://thaddeuspope.com/braindeath

Medical Futility Blog
Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning medical futility and end-of-life medical treatment conflicts. The blog has received nearly 4 million direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like WestlawNext and Bioethics.net.

Brain Death and the Law, World Brain Death Project (in progress).


Brain Death: Legal Duties to Accommodate Religious Objections 147 CHEST e69 (2015).


Pregnant and Dead in Texas: A Bad Law, Badly Interpreted, LOS ANGELES TIMES (Jan. 16, 2014) (with Art Caplan).


Thaddeus Mason Pope, JD, PhD
Director, Health Law Institute
Mitchell Hamline School of Law
875 Summit Avenue
Saint Paul, Minnesota 55105
T 651-695-7661
C 310-270-3618
E Thaddeus.Pope@mitchellhamline.edu
W www.thaddeuspope.com
B medicalfutility.blogspot.com