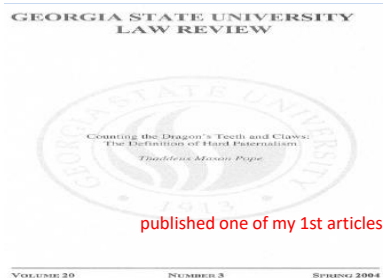


Quinlan at 40: Exploring the Right to Die in U.S. - Remaining Challenges

Georgia State University
November 11, 2016

Thaddeus Mason Pope, JD, PhD
Mitchell Hamline Health Law Institute

Thank you

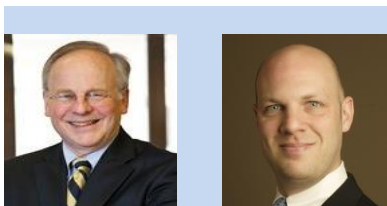


Symposium Explores Baby Doe Rules 25 Years Later



Theme

today



Contrast





Backward
looking

1976 -
2016

milestones



Forward
looking

Still **unsettled**

Newly **unsettled**

Academic
& policy
agenda

2016 -
2026

Selective



Roadmap

5

**Brain
Death**

Futility

UMT

Unbefriended

VSED

1 of 5

Brain Death

Alive | Dead

1976

Kansas' brain death law held up as example for all states

WASHINGTON (AP) — It was Washington's brain death law of 1976, not the Kansas law, that served as the model for other states to pass similar legislation, according to a report by the National Council on Brain Death.

"We just thought we'd do all we could," said Governor Warren E. Hearnes, "when a heart has stopped, that's the most important thing."

But a growing, international body of evidence...

The Kansas law, for instance, states that "a person will be considered dead if he or she has been declared dead by a physician, based on the state's standards of medical practice, based on the absence of spontaneous brain function."

Crutten was a member of the Harvard Medical School committee which in 1968 recommended that states...

Crutten said maintaining brain-dead bodies for months or even years on life-support machines was not feasible.

Crutten said the medical community all over the world very quickly accepted the Harvard committee's recommendations. "The World Medical Association endorsed it in 1968, the American Academy of Neurology in 1970, and the medical societies of the world adopted it."

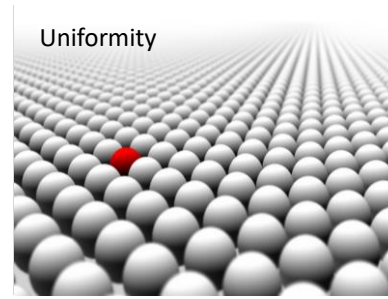
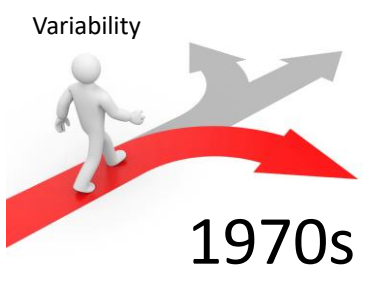
"It makes very good legal sense to adopt the concept of irreversible cessation of all brain functions," said the Harvard report, which became the basis of the Uniform Determination of Death Act.

"It makes very good legal sense to adopt the concept of irreversible cessation of all brain functions," said the Harvard report, which became the basis of the Uniform Determination of Death Act.

Under the strict traditional definition, a person is dead only when the heart has stopped beating. But the Harvard Law Bulletin published by North Carolina University's Institute of Government, "Under the concept of brain death, as permitted by the judge in his jury instructions, they were free of any suspicion."

Brain death = legal death

The Salina Journal (Salina, Kansas) · Sun, Jan 12, 1975 · Page 16



UDDA

Dead . . . sustained *either*

- (1) irreversible cessation of circulatory & respiratory functions, *or*
- (2) irreversible cessation of all functions of the entire brain

All 56 US
jurisdictions
(narrow exception in NJ)

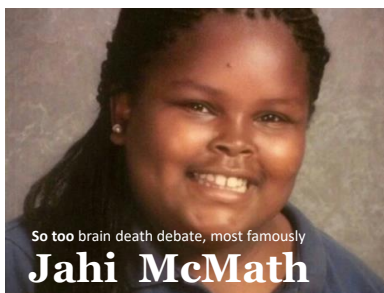
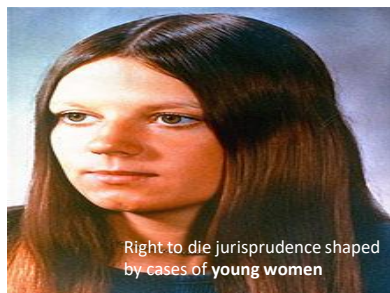
Legally
settled
since 1980s

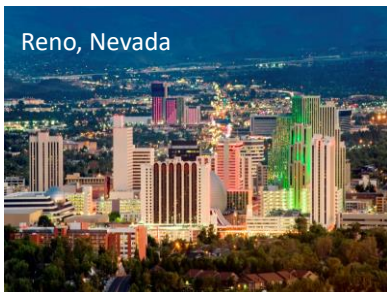


BUT



2013 -
2016





April 1, 2015

Catastrophic anoxic brain injury during exploratory laparotomy

May 28, 2015

Met AAN criteria for brain death



Trial court

AAN criteria met
Aden **is** dead

Aden's father

Appeals to Nevada Supreme Court



Irrelevant if Aden meets AAN criteria

They are **not** the "right" criteria

2 reasons

1

AAN does **not**
measure what
the **UDDA**
requires

UDDA

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

BUT

Brain dead
people
do stuff

Heal wounds
Fight infections
Stress response



Sexually responsive
UMN, *J Neurosurgery* 35(2): 211-18



Gestate
a fetus

AAN measures only cessation **some** functions of **part** of brain

2

UDDA

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

BUT

Research

Original Investigation

Variability of Brain Death Policies in the United States

David M. Greer, MD, MA; Hilary H. Wang, BA; Jennifer D. Robinson, APRN; Panayiotis N. Varelas, MD, PhD; Galen V. Henderson, MD; Eelco F. M. Wijdicks, MD, PhD

Supplemental content at jamaneurology.com

IMPORTANCE Brain death is the irreversible cessation of function of the entire brain, and it is a medically and legally accepted mechanism of death in the United States and worldwide.

Variability of brain death determination guidelines in leading US neurologic institutions

David M. Greer, MD, MA; Panayiotis N. Varelas, MD, PhD

ABSTRACT

Background: In accordance with the Uniform Determination of Death Act, guidelines for brain death determination are developed at an institutional level, potentially leading to variability of practices. We evaluated the differences in brain death guidelines in major US hospitals with a

Number of physicians
Qualifications
How tests administered

Hailu = AAN
AAN ≠ UDDA

Upshot

Legal standard
may demand
more than
medical criteria

UDDA

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



May need to **amend**
Legal criteria
Medical criteria
Both



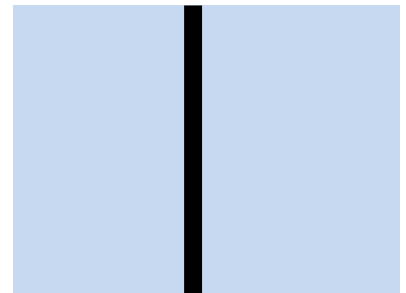
2 of 5

Futility



Negative liberty ✓
to refuse

Positive liberty ?
to demand



Appropriate | **Inappropriate**

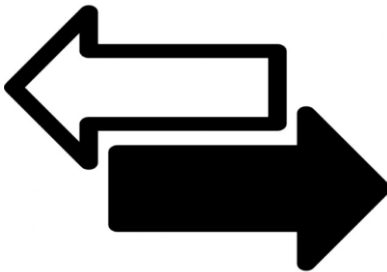
Proportionate | **Disproportionate**

Beneficial | **Non-beneficial**

1976 -
1991
RTD

Clinician	Surrogate
LSMT	CMO

1991 -
2016
RTL

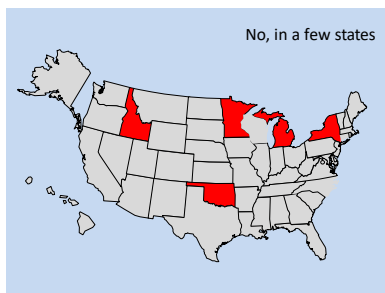


Clinician	Surrogate
CMO	LSMT

Clinicians want to know:
May we stop
LSMT **without**
consent?



Yes, in TX



No, in a few states



Everywhere else
not sure



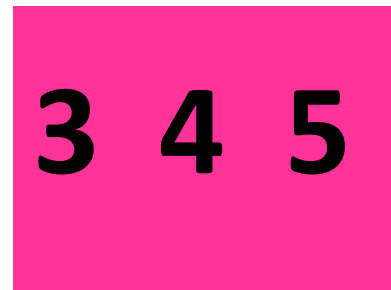
Very little judicial, legislative, or regulatory guidance

Original Investigation

The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care **20%**

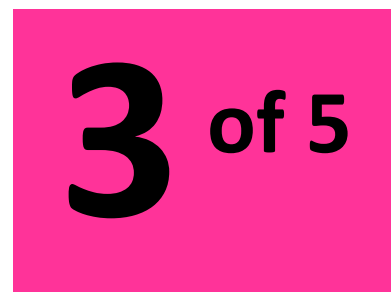

Thanh N. Huynh, MD, MSHS; Eric C. Kleerup, MD; Joshua F. Willey, MA; Terrance D. Savitsky, MBA, MA, PhD; Diana Guse, MD; Bryan J. Garber, MD; Neil S. Wenger, MD, MPH

JAMA Intern Med. 2013;173(20):1887-1894. doi:10.1001/jamainternmed.2013.10261
Published online September 9, 2013.



Too fast
Brain death
Futility

Too slow
UMT
Unbefriended
VSED

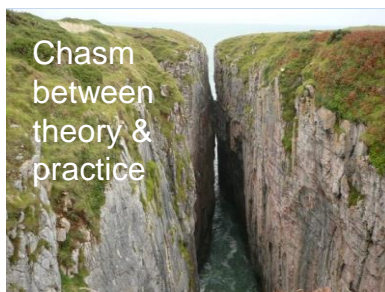
Doctors Hospital Augusta v. Alicea (Ga. 2016)

Some get UMT because AD or POLST

Ignored
Misplaced
Misread

Most get UMT because

Failed informed consent



Only **5 in 100** understand cancer diagnosis

95% **fail** rate

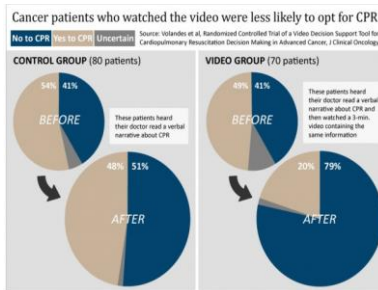


Evidence based educational tools



Accurate
Complete
Understandable

> 130
RCTs



BUT

Very little clinical usage

“Promise remains elusive”

Move PDAs from lab to clinic

No PDA

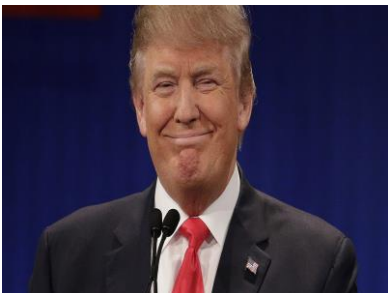
Assure PDA **quality**

Certification



Labor & Delivery (2016)

Next priority area:
End of life care (2018)



NATIONAL QUALITY FORUM

National Standards for the Certification of Patient Decision Aids

DRAFT REPORT FOR COMMENT

September 21, 2016



4 of 5

Unbefriended



3 conditions

1

Lack
capacity

2

No available,
applicable
AD or POLST

3

No reasonably available authorized surrogate

Nobody to consent to treatment

Big problem

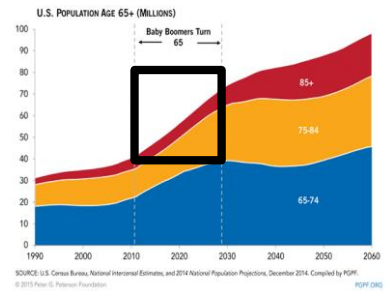
5% ICU deaths

3 - 4%
U.S. nursing home population

~80,000

Growing problem

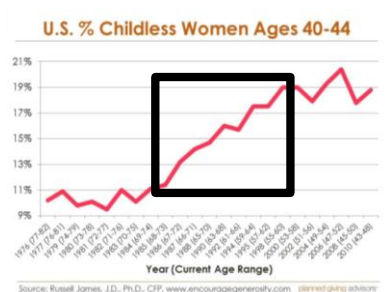
1



2



3



4

Others
“have”
family
members

No contact (e.g. LGBT,
homeless, criminal)
Also lack capacity
Unwilling

Problem

Nobody to
authorize
treatment

2 main responses

1

No treatment

Wait until emergency (implied consent)

Longer period suffering
Increases risks

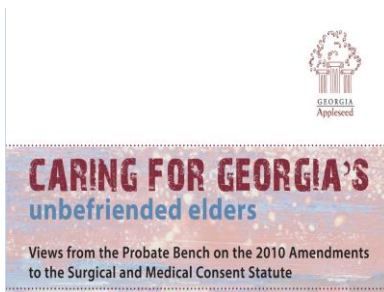
Under-treatment

2

Over-treatment

Physician acts **without** consent

Bias
COI
Careless



5 of 5

VSED

Voluntarily
stop eating
& drinking



3

Physiologically
able to take food
& fluid by mouth

Voluntary,
deliberate
decision to stop

Intent: death
from dehydration

Peaceful
Comfortable

Why?

Physical or
existential
suffering

Nothing to
“turn off”
Not eligible
for MAID



Vent
Dialysis
CPR
Antibiotics
Feed tube

VSED

Is VSED
assisted
suicide?

Is VSED
abuse or
neglect?



Advance directive
now for VSED later,
when reach point
you define as
intolerable

2023



Georgia State University | COLLEGE OF LAW

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

194