Thank you

Delighted to have worked with my GSU HL Faculty

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

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Theme today

Contrast
Brain death = legal death

Variability 1970s

Uniformity

1976

Brain death 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

Right to die jurisprudence shaped by cases of young women

So too brain death debate, most famously

Jahi McMath

2013 - 2016

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”

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
AAN does not measure what the UDDA requires

“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): 213-18

Gestate a fetus
AAN measures only cessation of some functions of part of brain

“must be made in accordance with accepted medical standards”

BUT

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

UDDA requires
Clinicians measure

Attack on Bd broader than we can get into now
Futility

Negative liberty
- to refuse

Positive liberty
- to demand

Appropriate

Inappropriate

Proportionate

Disproportionate

Beneficial

Non-beneficial
1976 - 1991

Clinician: LSMT
Surrogate: CMO

1991 - 2016

Clinician: CMO
Surrogate: 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

### Too fast
- Brain death
- Futility

### Too slow
- UMT
- Unbefriended
- VSED

3 of 5

**UMT**

Doctors Hospital Augusta v. Alicea (Ga. 2016)

Some get UMT because AD or POLST

Ignored
Misplaced
Misread
Most get UMT because
Failed informed consent

Chasm between theory & practice

Only 5 in 100 understand cancer diagnosis

95% fail rate

Patient decision aids

Evidence based educational tools

Accurate Complete Understandable

> 130 RCTs
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)
Unbefriended

3 conditions

Lack capacity

No available, applicable AD or POLST

1

2

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
More elderly live alone outlived, lost touch

Others “have” family members

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

Problem

Nobody to authorize treatment
2 main responses

No treatment

Wait until emergency (implied consent)

Longer period suffering

Increases risks

Under-treatment

2

Over-treatment

Physician acts without consent
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**

**Is VSED assisted suicide?**

**Is VSED abuse or neglect?**
Cinderella picture neglected in academic & policy circles.

Especially important, dementia.

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

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