Resolving Pediatric Medical Futility Conflicts with Efficiency & Fairness
8th Annual Pediatric Bioethics Conference, Wolfson Children’s Hospital (November 6, 2015)
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Brain death

After death, nothing more for medicine

The 8 Absolute Top Cities In the US to Live In
We looked at results from 7 very different, “best of” lists to come up with the 8 top cities in the US for 2015

Ted Richards

Fulton County, GA DOH
total brain failure = death

Legally settled since 1980s

Dead → No duty to treat

“After a patient . . . brain dead . . . medical support should be discontinued.”
1990s
Poised to expand

Theresa Ann Pearson (Fla. App. 1992)

BUT...

Parental resistance is growing

Motl Brody (DC)

Parents want organ support despite death

Misunderstanding Mistrust
“That's our daughter; that's not a corpse.”
“If you love someone, you don't give up”

Despite death, biological existence has value

Heal wounds
Fight infections
Gestate fetus
Stress response

Are they really dead

Aden Hailu

Met AAN criteria for brain death in April 2015
Still on organ support in hospital
That is 7 months !!!!!

Monday, Nov. 3

AAN criteria not “right” criteria

Dec. 2013
Treatment conflict

Jahi McMath

Mar. 2015
Med Mal lawsuit

Seeking future medical expenses

Transferred to NJ
Sustained on organ support almost 2 years
Re-litigate status as alive

Oct. 2015
May allege facts to establish alive

AAN criteria DDNC
Met in Dec. 2013
Not met now

“as you can see she is still alive and just as beautiful as ever.”

FAC due Nov. 9

Why discuss brain death

Appropriate  Inappropriate
If we cannot draw a line here, can we draw it anywhere?

What is a medical futility dispute

Brain death is one type

Typically patient still alive

Clinician
CMO

Surrogate
LSMT

We call them “futility disputes”

. . . BUT . . .

Disputed treatment might keep patient alive.

Conflicts rarely over whether intervention will “work”
But... is that chance or that outcome worthwhile

“In Ethics... difficulties and disagreements... are mainly due to a very simple cause...”

“the attempt to answer questions, without first discovering precisely what question it is you desire to answer.”

Terms & Concepts
3 categories of treatment

- Futile
- Proscribed
- Potentially inappropriate

Futile

Interventions cannot accomplish physiological goals
May & should refuse

Proscribed

Treatments that may accomplish effect desired by the patient

Laws, applicable judicial precedent, or public policies prohibit or permit limiting use of those treatments

May & should refuse
Potentially Inappropriate

Some chance of accomplishing the effect sought by the patient or surrogate

Not a medical judgment

Value laden

1. A clinician believes ICU admission for a person with end-stage dementia and multiorgan failure is inappropriate.
2. A clinician believes it is inappropriate to initiate dialysis in a patient in a persistent vegetative state.
3. A clinician believes it is inappropriate to continue mechanical ventilation in a patient with widely metastatic cancer.
4. A clinician believes it is inappropriate to place a tracheostomy tube in a child with prolonged respiratory insufficiency and severe irreversible neurological impairment.

E.g. dialysis for permanently unconscious patient

Potentially Inappropriate Treatment

Procedural Resolution Process (Table 4)
“potentially”

Pope’s takeaway

Hubris
Excessive self-confidence

Humility
Not thinking you are better

Standard of Care

Prevalence
“Conflict . . . in ICUs . . . epidemic proportions”

HEC CEC

13% ethics consults

> 16% ethics consults

> 33% ethics consults

> 50% ethics consults

“top healthcare challenge”

11/7/2015
Feb 2015
700 acute care clinicians

Views on End-of-Life Medical Treatments
Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

Dispute Resolution
4 paths
Prevention Consensus Switch parties Intractable
Most patients do **NOT** want futile treatment.
Seek assent
Not consent

Announce plan: “We are going to…”
Silence = assent

Robust evidence shows PtDAs are highly effective

Disputes will arise
Consensus

Negotiation

Mediation

95%

Prendergast (1998)
57% agree immediately
90% agree within 5 days
96% agree after more meetings


Garros et al. (2003)

Hooser (2006)
974
65

5%
Reaching consensus in the 5% Switch parties

New clinician New surrogate Transfer

Rare but possible
Replace Surrogate

Substituted judgment
Best interests

~ 60% accuracy

More aggressive treatment

You’re Fired!

Surrogate Advance directive

Code of Medical Ethics
2.20: “surrogate’s decision . . . almost always be accepted”
LIMITS of surrogate replacement

Providers cannot show deviation
Surrogates get benefit of doubt

Cape Coral Hospital, Lee County
Judge decides not to "pull the plug."

Surrogates loyal & faithful

Truly Intractable

No consensus
No transfer
No surrogate replacement

Consensus
Intractable
Cave-in

“follow the . . . SDMs instead of doing what they feel is appropriate . . .”

“Remove the __, and I will sue you.”

Very few judgments & settlements

Risk > 0

83% physicians practice “defensive” medicine
Physician spending and subsequent risk of malpractice claims: observational study

Anupom B. Jena,1 Lena Schoenmaker,2 Dipa Bhattacharyya,3 Seth A. Sedlery4

“higher resource use by physicians is associated with fewer malpractice claims”

Liability averse

Litigation averse

Even prevailing parties pay transaction costs – time, emotional energy

Patient will die soon
Provider will round off
Nurses bear brunt

Status quo

Bad results
"This is the Massachusetts General Hospital, not Auschwitz."

"not . . . much difference . . . atrocities in Bosnia"

Absenteeism
Retention
Quality

ICU delayed or denied to others who can benefit

Without consent
Covertly or Openly

Without legal support to withhold or withdraw, some do it covertly.


Providers have won almost every single damages case for unilateral w/h, w/d

IIED, NIED

Secretive, Insensitive, Outrageous

Consultation expected, Distress foreseeable
Feb 2015
700 acute care clinicians

Physician may stop LST without consent for any reason, if review committee agrees

48hr notice HEC
Written decision
10 days to transfer
2003  2009
2005  2011
2007  2013

artificially administered nutrition & hydration

What clinicians are getting
Laws, applicable judicial precedent, or public policies **prohibit or permit** limiting use of those treatments.

**Parental demand**

**Appropriate medicine**

**Judicial Guidance**

**Trisomy 18**

22-week gestation

ECMO

Brain death

**Unmasking** what has been presented as objective & scientific truth

1988 - 2015
The next 27 years

Identify permitted limitations

Identify prohibited provision

Develop dispute resolution mechanisms

Focus on triage & distributive justice
Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog is focused on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning medical futility and end-of-life medical treatment conflict. The blog has received over one million direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like Westlaw, Bioethics.net, Wellsphere, and Medpedia.

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