Objectives

- Summarize strengths and weaknesses of 3 main legal regimes governing unilaterally withholding or withdrawing life-sustaining treatment
- Apply the official ATS/ACCN/ACCEP/ESICM/SCCM policy regarding requests for potentially inappropriate treatment in their own practices

Case Study:

Marwa Bouchenafa 1y

Aggressive viral infection attacked nervous system

Limbs, face paralyzed

On ventilator

No improvement

Irreversible neurological damage

Clinicians & ethics committee: “stop LSMT”
Parents do not consent

4 options

1. Cave-in to parents
2. Act w/o consent
3. Get new SDM & get their consent
4. Get court permission

Dispute resolution pathways

Asked local court in Marseilles
Denied

Roadmap

2 parts

Part 1
Background
Consent & right to die
What is a medical futility dispute

Prevalence of futility conflicts
Ways to get consent
Part 2

When you cannot get consent
Stopping LSMT without consent
4 types of LSMT
Futile
Proscribed
Discretionary
Potentially inappropriate

Main legal approaches

Right to Die

Clinicians need consent

Treat w/o consent is battery

Mohr v. Williams (Minn. 1905)

Leach v. Shapiro (Ohio App 1984)

Corollary of right to consent

Right to refuse
Even LSMT
Even minors
Even Ohio

In re Crum
(Ohio Prob. 1991)

Negative liberty

BUT

Positive liberty?

Right to demand?

Our question

What is a medical futility dispute

Surrogate will not consent when you think they should
Futility is about line drawing

Appropriate  Inappropriate
Advisable  Inadvisable

Proportionate  Disproportionate
Beneficial  Non-beneficial
Inside the standard of care  Outside the standard of care

Therapeutic obstinacy

Surrogate driven overtreatment
Surrogate will **not** consent to CMO recommendation

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

13% ethics consults

> 16% ethics consults

> 33% ethics consults

2 CPR futility cases per month

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

Prevalence
700 acute care clinicians

"top healthcare challenge"

Big problem – moral distress, etc

Getting consent
Consensus within reach

4 mechanisms

PDA

Negotiation
Mediation

Replace
Surrogate

Transfer

1
PDA
Robust evidence shows PDAs are highly effective

> 130 RCTs

Accurate
Complete
Understandable

Informed surrogates request less aggressive treatment

"Promise remains elusive"
Agency in charge is CMS

PDA → more likely consent

Negotiation Mediation

95%
Prendergast (1998)
57% agree immediately
90% agree within 5 days
96% agree after more meetings


Garros et al. (2003)

Hooser (2006)

Tried better communication
PDA
Mediation

Still no consent
Replace Surrogate

Get consent from new surrogate

Substituted judgment

Best interests

Crum (1991)
(12yo) (viral encephalitis)

Myers (1993)
(15yo) (MVA)

~ 60% accuracy

More aggressive treatment

"surrogate’s decision . . . almost always accepted"
Sarah Hershberger – lymphoblastic lymphoma

85-90% chance survival
Court forced chemo

Too little medicine
Not best interest

Too much medicine
Not best interest

BUT
Obstacle 1

Aiden Stein

Obstacle 2

Guardian cannot w/h w/d until parental rights terminated

Obstacle 3
Surrogates 
loyal & faithful

Parents consistent with child wishes

Crum (1991) 
(12yo) (viral encephalitis)

Myers (1993) 
(15yo) (MVA)

Transfer

New provider
Rare but possible

The luck of the draw: physician-related variability in end-of-life decision-making in intensive care


Fail

No consent
No new SDM
No transfer

When may / should / must a clinician stop LSMT without consent?

It depends
4 types of LSMT

<table>
<thead>
<tr>
<th>Futile</th>
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<tbody>
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<td>Legally Proscribed</td>
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<tr>
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<tr>
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Why start with vocabulary?
“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.”

Conceptual clarity

Ethical clarity

Futile

Legally Proscribed

Legally Discretionary

Potentially inappropriate

Interventions cannot accomplish physiological goals

Scientific impossibility

Futile
Example 1

Example 2

Example 3

Example 4

“Futile”
Value free objective

- BUT

May the clinician stop LSMT?

“Futile”

May & should refuse

Futile
- Legally Proscribed
- Legally Discretionary
- Potentially inappropriate
Legally Proscribed

Treatments that may accomplish effect desired by the patient

>0%

Not “futile”

Prohibited by applicable laws, judicial precedent, or widely accepted public policies

Example 1

Might “work”

But illegal

Example 2
Example 3

If treatment request is legally proscribed → May & should refuse

Legally Proscribed
Legally Discretionary
Potentially inappropriate

Legally Discretionary
Permitted limiting laws, judicial precedent, or policies that give physicians permission to refuse to administer them.

Example 1
Example 2

Total brain failure = death

Dead No duty to treat

Surrogate
Appropriate medicine
Anencephaly
“After a patient . . . brain dead . . . medical support should be discontinued.”

Example 3

- Aden Hailu
- Jahi McMath

UDDA requires Clinicians measure
Trisomy 18 / 23
22-week gestation
ECMO

Example 4

Example 5

Vermont
Montpelier
Green Mountain State

Maryland

[Image of map of Vermont and Maryland]
Not ATS “futility”

Might restore CP function

“imminent death”

3 days

Permitted limiting

http://healthvermont.gov/regs/ad/dnr_colst_instructions.pdf

“medically ineffective”

“[not] prevent the impending death”

imminent = impending

May the clinician stop LSMT?
Legally discretionary

May & should refuse

Tiny category – not much explicitly prohibited or permitted

No reasonable expectation patient will improve sufficiently to survive outside the acute care setting

No reasonable expectation patient’s neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment

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

Not “futile” because might “work”

E.g. dialysis for permanently unconscious patient

E.g. vent for patient w/ widely metastatic cancer

We call them “futility disputes” . . . BUT . . .

Disputed treatment might keep patient alive.

But . . . is that chance or that outcome worthwhile

Not a medical judgment

Value judgment
**PIT**

Futility conflicts

**Legal focus**

- Potentially inappropriate

**Clinician family conflict**

- Not futile
- Not proscribed
- Not discretionary

**Table 4.** Recommended Steps for Resolution of Conflict Regarding Potentially Inappropriate Treatments

1. Unless otherwise requested, the patient’s usual provider should be informed of the patient’s request. The treating clinician should note the patient’s request in the patient’s medical record and should provide high-quality patient care.

2. If the patient refuses to consent to treatment, the health care provider should consider alternative treatment options. The treating clinician should discuss the patient’s treatment options with the patient and the patient’s family. The treating clinician should provide high-quality patient care.

3. If the patient refuses to consent to treatment, the health care provider should consider alternative treatment options. The treating clinician should discuss the patient’s treatment options with the patient and the patient’s family. The treating clinician should provide high-quality patient care.

4. If the patient refuses to consent to treatment, the health care provider should consider alternative treatment options. The treating clinician should discuss the patient’s treatment options with the patient and the patient’s family. The treating clinician should provide high-quality patient care.

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10. If the patient refuses to consent to treatment, the health care provider should consider alternative treatment options. The treating clinician should discuss the patient’s treatment options with the patient and the patient’s family. The treating clinician should provide high-quality patient care. 
No surrogate consent
No “new” surrogate
No transfer

May you stop LSMT?

Traffic Lights

Many clinicians need a green light.

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

Give the surrogate
48hr notice RC  
Written decision RC  
10 days to transfer

Stop LSMT without consent

BUT

H.B. 3074 (2015)
artificially administered nutrition & hydration

Consent always

Nondiscrimination in Treatment Act November 2013
“health care provider shall not deny . . . life-preserving health care . . . directed by the patient or [surrogate]”

Medical Treatment Laws Information Act
November 2014

If surrogate directs [LST] . . . provider that does not wish to provide . . . shall nonetheless comply . . . .”

Discrimination in Denial of Life Preserving Treatment Act
“Health care . . . may not be . . . denied if . . . directed by . . . surrogate”

Simon’s Law

Trisomy 18
“incompatible with life”
“uniformly lethal”

DNR without parents’ consent or knowledge

Trisomy 18
13% - live 10 years

“No healthcare . . . staff shall withhold, withdraw or place any restrictions on life-sustaining measures for any . . . under 18 years of age without the written permission . . . .”
Recap

No explicit permission
No explicit prohibition

Very little judicial, legislative, or regulatory guidance

Typical response

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

Would you give life-sustaining therapy if you considered it futile?
Patient will die soon
Provider will round off
Nurses bear brunt
How to proceed

1

Follow ATS or AMA process

2

Overt & Open

Unilateral DNR
Slow code
Show code

Consultation expected
Distress foreseeable

Janet Tracey

Joy Wawrzyniak

Summa Health™

3

Transparent enough
Seek assent

Not consent

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

Open ended question
More directive

References

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Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com.

This blog reports and discusses legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received over two million direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like Westlaw, Bioethics.net, Woltersk, and Medpedia.

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<td>Institutional and Legislative Approaches to Medical Futility Disputes in the United States</td>
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