Medical Futility - Dispute Resolution Options when Parents Demand Potentially Inappropriate Life-Sustaining Treatment

Pediatric Grand Rounds
Cincinnati Children's Hospital
March 21, 2017

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Nothing to disclose

Co-author on policy statement that will discuss

We help the world breathe
PULMONARY • CRITICAL CARE • SLEEP

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

Aggressive viral infection attacked nervous system

Limbs, face paralyzed

On ventilator

No improvement

Irreversible neurological damage

Clinicians & ethics committee: "stop LSMT"

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

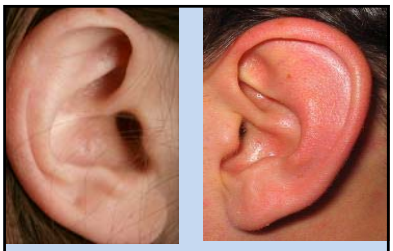
Potentially inappropriate

3 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)

Intubate and vent over objections

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

Clinician	Surrogate
CMO	LSMT

Surrogate will **not** consent to CMO recommendation

Prevalence

"Conflict . . . in ICUs . . . epidemic proportions"

13%

ethics consults

MEMORIAL SLOAN-KETTERING CANCER CENTER

J. Oncology Practice (June 2013)

> 16%

ethics consults

HEC Forum
DOI 10.1007/s10730-015-9293-5

What Ethical Issues Really Arise in Practice at an Academic Medical Center? A Quantitative and Qualitative Analysis of Clinical Ethics Consultations from 2008 to 2013

Katherine Wasson[1,3] · Emily Anderson[1] ·

> 33%

ethics consults

University of Michigan Health System

Physician Executive Journal (37 no. 6)

MGH 1811

2 CPR futility cases per month

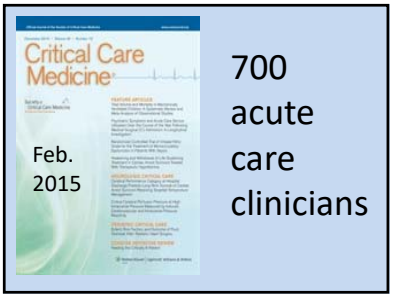
Courtwright, 2015 J Crit Care 30(1):173–77

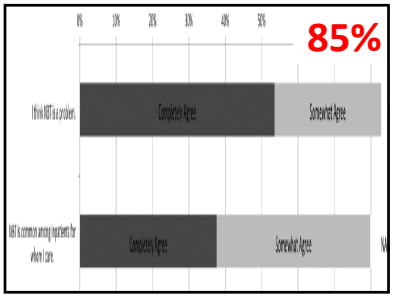
Original Investigation

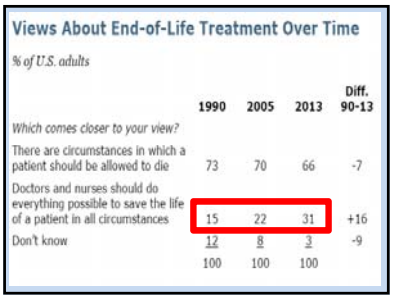
The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care **20%**

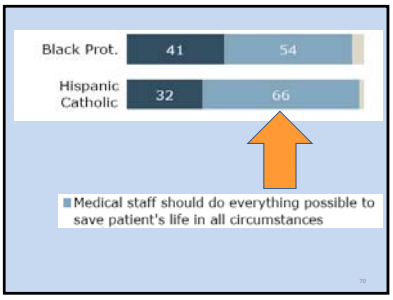
Thanh N. Huynh, MD, MSHS; Eric C. Kleerup, MD; Joshua F. Wiley, MA; Terrance D. Savitsky, MBA, MA, PhD; Diana Guse, MD; Bryan J. Garber, MD; Neil S. Wenger, MD, MPH

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









Getting consent

4 mechanisms

PDA

Negotiation

Mediation

Replace

Surrogate

Transfer

1

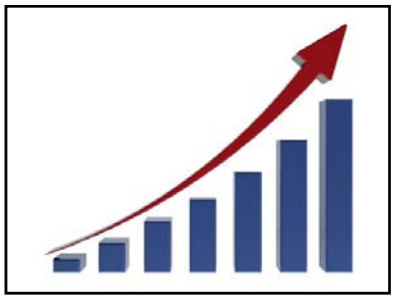
PDA

Robust evidence shows PDAs are highly effective

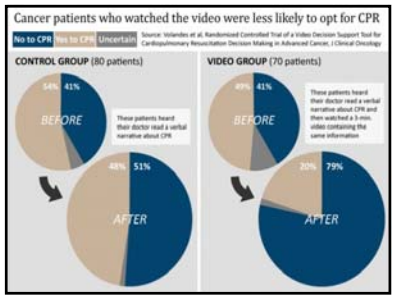
> 130 RCTs

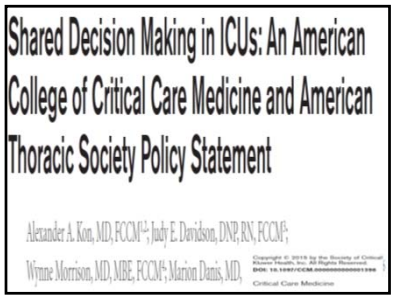
THE COCHRANE COLLABORATION®

Accurate
Complete
Understandable



Informed surrogates request **less** aggressive treatment




Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

Alexander A. Kon, MD, FCCM[1,2]; Judy E. Davidson, DNP, RN, FCCM[3]; Wynne Morrison, MD, MBE, FCCM[4]; Marion Danis, MD,

Critical Care Medicine

"Promise remains elusive"

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

2

PDA → more likely consent

Negotiation

Mediation

95%

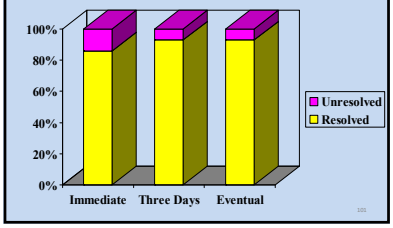
Prendergast (1998)

57% agree immediately

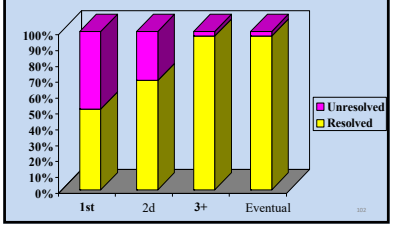
90% agree within 5 days

96% agree after more meetings

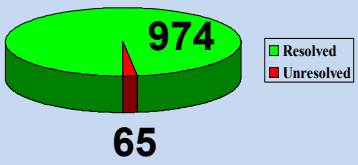
Fine & Mayo (2003)

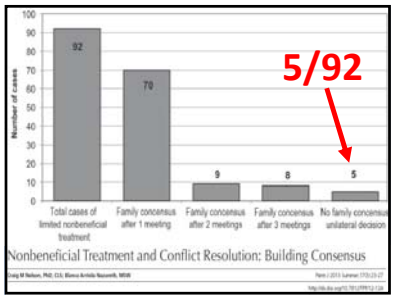


Garros et al. (2003)



Hooser (2006)





5%

3

Tried better communication

- PDA
- Mediation

Still no consent

Replace Surrogate

109

Get consent from **new** surrogate

110

Substituted judgment

Best interests

112

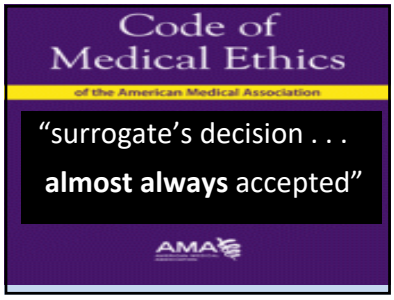
Crum (1991)
(12yo) (viral encephalitis)

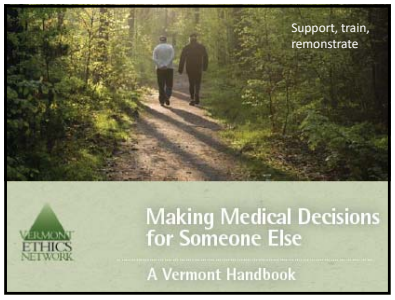
Myers (1993)
(15yo) (MVA)

~ 60% accuracy

More aggressive treatment

115





Akron Children's Hospital

85-90% chance survival

Court forced chemo

Too **little** medicine

Not best interest

Too **much** medicine

Not best interest

BUT

Obstacle 1


Aiden Stein


Justice Evelyn Lundberg Stratton

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

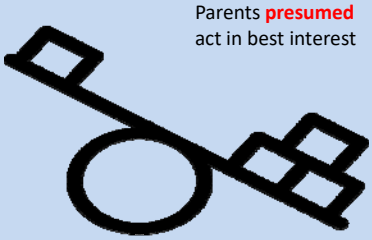
IN THE SUPREME COURT OF THE STATE OF DELAWARE

DAVID HUNT and CAREY LAND,[1]	§	
	§	No. 439/449, 2015
Respondents Below,	§	
Appellants,	§	Court Below–Family Court
	§	of the State of Delaware,
v.	§	in and for Sussex County
	§	
DIVISION OF FAMILY SERVICES	§	File No.: CS15-01879
and OFFICE OF THE CHILD	§	Pet. No.: 15-04833
ADVOCATE,	§	
	§	
Petitioners Below,	§	
Appellees.	§	

Submitted: September 15, 2015
Decided: September 16, 2015

Obstacle 2

Parents **presumed** act in best interest



Obstacle 3

Surrogates

loyal & faithful

State of Minnesota
District Court—Probate Court Division
County of Hennepin
Fourth Judicial District

In Re: The Conservatorship of Helga M. Wanglie

File No. PX-91-283

Findings of Fact:
Conclusions of Law And Order

Parents **consistent** with child wishes

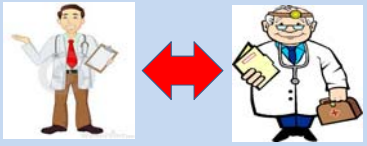
Crum (1991)
(12yo) (viral encephalitis)

Myers (1993)
(15yo) (MVA)

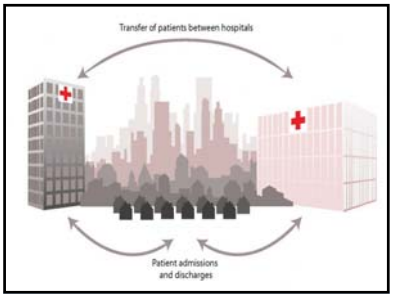
4

Transfer

141



New provider

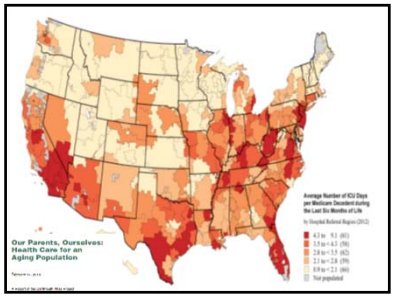


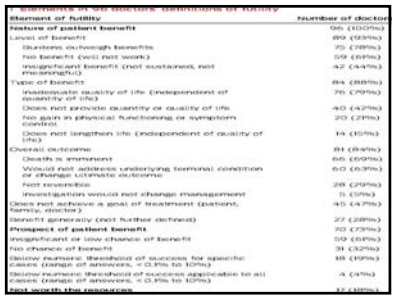
Rare

145

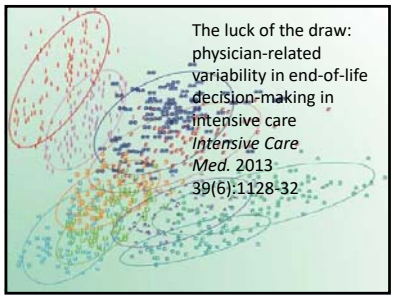
but possible

146





Element of futility	Number of doctors
Nature of patient benefit	95 (100%)
Level of benefit	89 (93%)
Burdens outweigh benefits	75 (78%)
No benefit (will not work)	59 (61%)
Insignificant benefit (not sustained, not meaningful)	42 (44%)
Type of benefit	84 (88%)
Inadequate quality of life (independent of quantity of life)	76 (79%)
Does not provide quantity or quality of life	40 (42%)
No gain in physical functioning or symptom control	20 (21%)
Does not lengthen life (independent of quality of life)	14 (15%)
Overall outcome	81 (84%)
Death is imminent	66 (69%)
Would not address underlying terminal condition or change ultimate outcome	62 (63%)
Not reversible	28 (29%)
Investigation would not change management	5 (5%)
Does not achieve a goal of treatment (patient, family, doctor)	45 (47%)
Benefit generally (not further defined)	27 (28%)
Prospect of patient benefit	70 (73%)
Insignificant or low chance of benefit	59 (61%)
No chance of benefit	31 (32%)
Below numeric threshold of success for specific cases (range of answers, < 0.1% to 10%)	18 (19%)
Below numeric threshold of success applicable to all cases (range of answers, < 0.1% to 10%)	4 (4%)
Not worth the resources	17 (18%)



The luck of the draw: physician-related variability in end-of-life decision-making in intensive care *Intensive Care Med.* 2013 39(6):1128-32

Fail

No consent

No new SDM

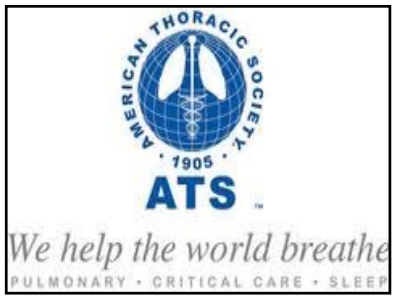
No transfer

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

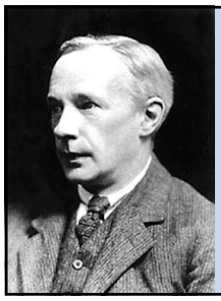
It depends

4 types of LSMT

- Futile
- Legally Proscribed
- Legally Discretionary
- Potentially inappropriate



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

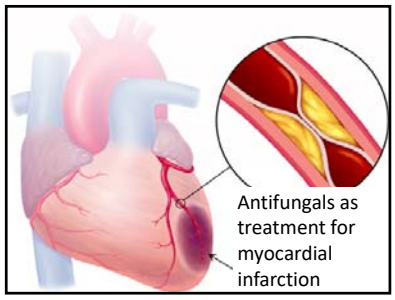
Futile

Interventions **cannot** accomplish physiological goals

Scientific impossibility

Example 1

Example 2

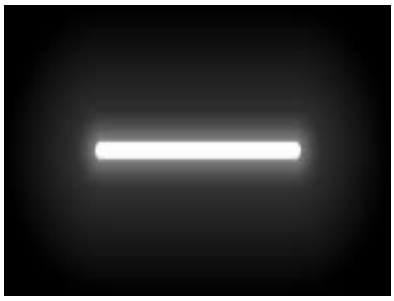


Example 3

Example 4

"Futile"

Value free objective



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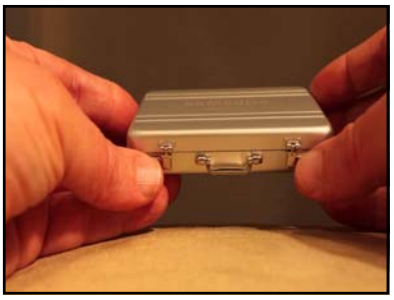
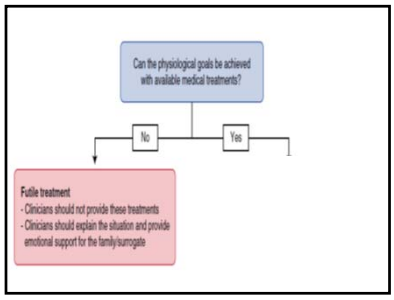


May the clinician stop LSMT?

“Futile”

May & should refuse



~~Futile~~

Legally Proscribed

Legally Discretionary

Potentially inappropriate

Legally Proscribed

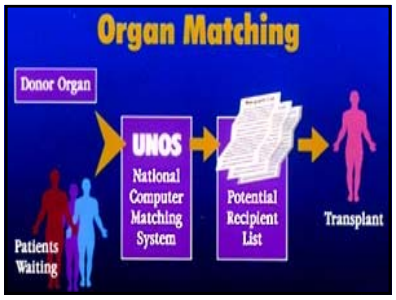
Treatments that **may accomplish** effect desired by the patient

>0%

Not "futile"

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

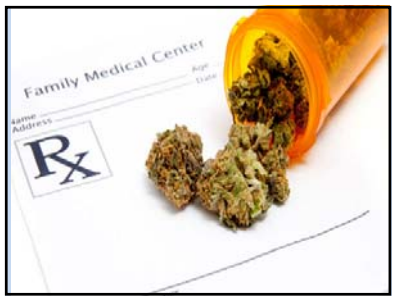
Example 1



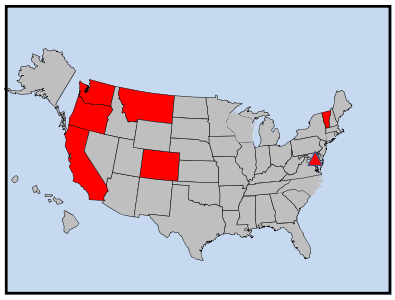
Might "work"

But illegal

Example 2

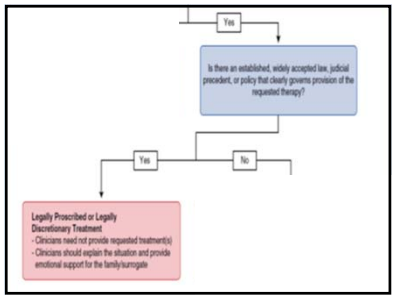


Example 3



If treatment request is legally proscribed →

May & should refuse



~~Futile~~

~~Legally Proscribed~~

Legally Discretionary

Potentially inappropriate

Legally Discretionary

Permitted limiting

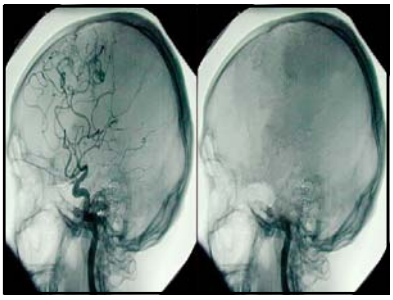
Laws, judicial precedent, or policies that give physicians **permission** to refuse to administer them.

Surrogate

Appropriate medicine

Example 1

Example 2



total brain failure = death

Dead → **No** duty to treat

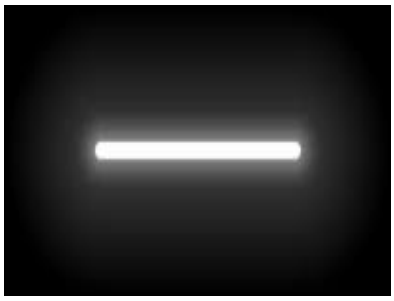
Annals of Internal Medicine

American College of Physicians Ethics Manual

Sixth Edition

Lois Snyder, JD, for the American College of Physicians Ethics, Professionalism, and Human Rights Committee*

"After a patient . . . brain dead . . . medical support should be **discontinued**."



BUT

Example 3

Trisomy 18 / 23

22-week gestation

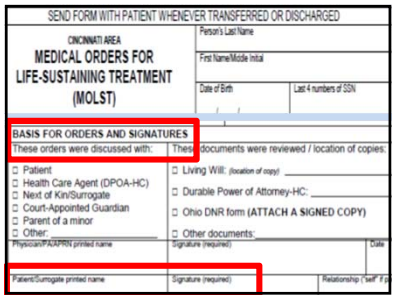
ECMO

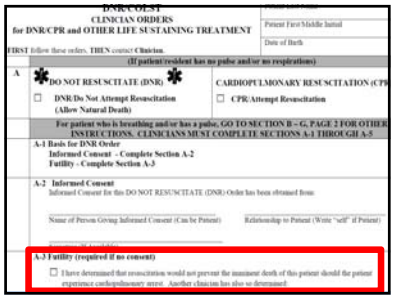
Example 4

Also disaster plans

Oregon HEALTH PLAN

Example 5





Not ATS "futility"

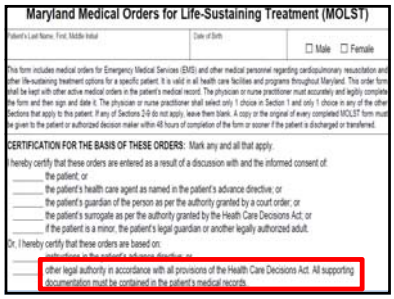
Might restore CP function

"imminent death"

3 days

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

Permitted limiting



Maryland Medical Orders for Life-Sustaining Treatment (MOLST)

Patient's Last Name, First, Middle Initial | Date of Birth | ☐ Male ☐ Female

This form includes medical orders for Emergency Medical Services (EMS) and other medical personnel regarding cardiopulmonary resuscitation and other life-sustaining treatment options for a specific patient. It is valid in all health care facilities and programs throughout Maryland. This order form shall be kept with other active medical orders in the patient's medical record. The physician or nurse practitioner must accurately and legibly complete the form and then sign and date it. The physician or nurse practitioner shall select only 1 choice in Section 1 and only 1 choice in any of the other Sections that apply to this patient. If any of Sections 2-9 do not apply, leave them blank. A copy or the original of every completed MOLST form must be given to the patient or authorized decision maker within 48 hours of completion of the form or sooner if the patient is discharged or transferred.

CERTIFICATION FOR THE BASIS OF THESE ORDERS: Mark any and all that apply.

I hereby certify that these orders are entered as a result of a discussion with and the informed consent of:

_____ the patient; or
_____ the patient's health care agent as named in the patient's advance directive; or
_____ the patient's guardian of the person as per the authority granted by a court order; or
_____ the patient's surrogate as per the authority granted by the Heath Care Decisions Act; or
_____ if the patient is a minor, the patient's legal guardian or another legally authorized adult.

Or, I hereby certify that these orders are based on:

_____ other legal authority in accordance with all provisions of the Health Care Decisions Act. All supporting documentation must be contained in the patient's medical records.

"medically ineffective"

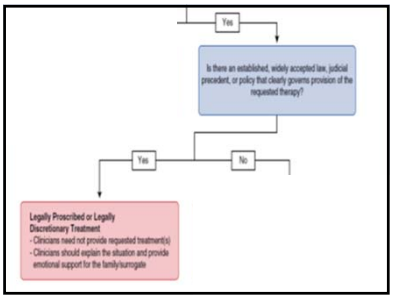
"[not] prevent the **impending death**"

imminent **=** impending

May the clinician stop LSMT?

Legally discretionary

May & should refuse



Sept. 2016

Society of Critical Care Medicine

The Intensive Care Professionals

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**

~~Futile~~

~~Legally Proscribed~~

~~Legally Discretionary~~

Potentially inappropriate

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"

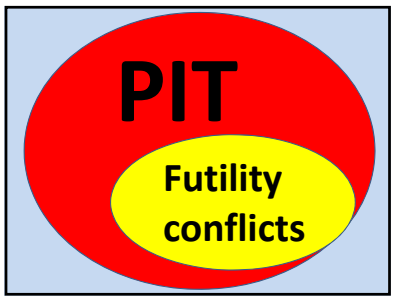
. . . BUT . . .

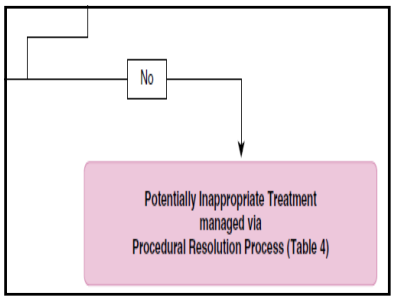
Disputed treatment **might** keep patient alive.

But . . . is that chance or that outcome **worthwhile**

Not a medical judgment

Value judgment





"potentially"

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

1. Before initiation of and throughout the formal conflict-resolution procedure, clinicians should enlist expert consultation to aid in achieving a negotiated agreement.
2. Surrogate(s) should be given clear notification in writing regarding the initiation of the formal conflict-resolution procedure and the steps and timeline to be expected in this process.
3. Clinicians should obtain a second medical opinion to verify the prognosis and the judgment that the requested treatment is inappropriate.
4. There should be case review by an interdisciplinary institutional committee.
5. If the committee agrees with the clinicians, then clinicians should offer the option to seek a willing provider at another institution and should facilitate this process.
6. If the committee agrees with the clinicians and no willing provider can be found, surrogate(s) should be informed of their right to seek case review by an independent appeals body.

7a. If the committee or appellate body agrees with the patient or surrogate's request for life-prolonging treatment, clinicians should provide these treatments or transfer the patient to a willing provider.

7b. If the committee agrees with the clinicians' judgment, no willing provider can be found, and the surrogate does not seek independent appeal or the appeal affirms the clinicians' position, clinicians may withhold or withdraw the contested treatments and should provide high-quality palliative care.

Turn to

Legal focus

Clinician family conflict

268

Not futile

Not proscribed

Not discretionary

269

Potentially inappropriate

270

No surrogate consent

No "new" surrogate

No transfer

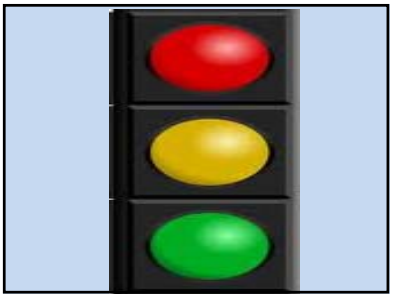
271

May you stop LSMT?

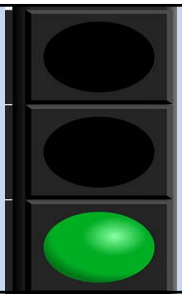
272

Traffic Lights

273



Many clinicians want a green light



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

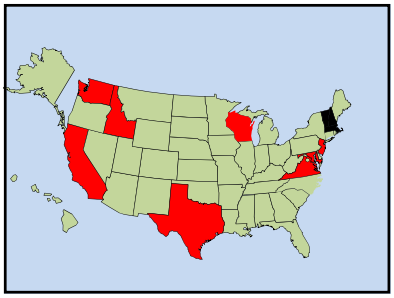
Give the surrogate

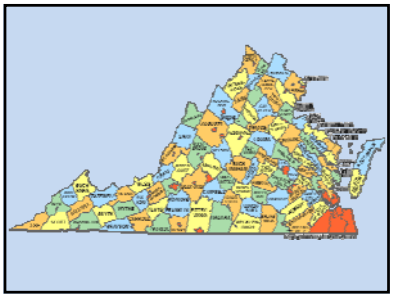
48hr notice RC

Written decision RC

10 days to transfer

Stop LSMT without consent

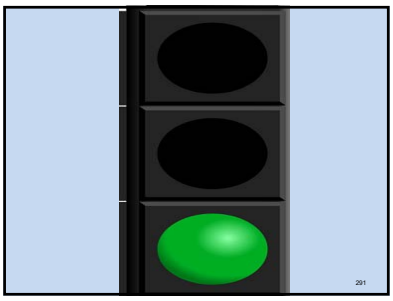


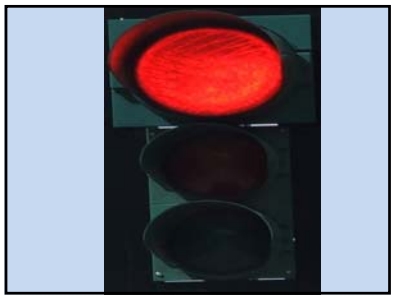


BUT

H.B. 3074 (2015)

artificially administered nutrition & hydration





Consent always

295

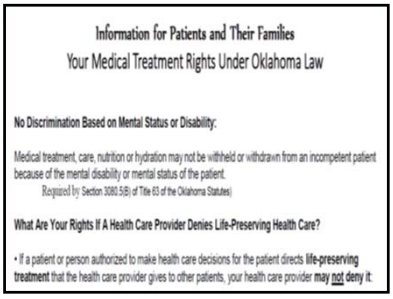
Nondiscrimination in Treatment Act

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



Information for Patients and Their Families

Your Medical Treatment Rights Under Oklahoma Law

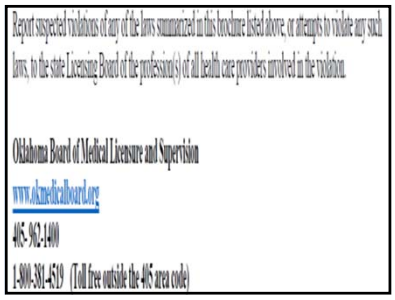
No Discrimination Based on Mental Status or Disability:

Medical treatment, care, nutrition or hydration may not be withheld or withdrawn from an incompetent patient because of the mental disability or mental status of the patient.

Required by Section 3080.5(B) of Title 63 of the Oklahoma Statutes)

What Are Your Rights If A Health Care Provider Denies Life-Preserving Health Care?

• If a patient or person authorized to make health care decisions for the patient directs **life-preserving treatment** that the health care provider gives to other patients, your health care provider **may not deny** it.



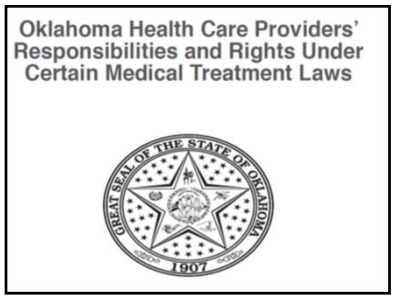
Report suspected violations of any of the laws summarized in this brochure listed above, or attempts to violate any such laws, to the state Licensing Board of the profession(s) of all health care providers involved in the violation.

Oklahoma Board of Medical Licensure and Supervision

www.okmedicalboard.org

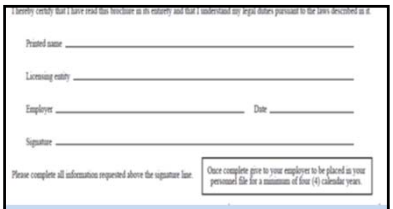
405-962-1400

1-800-381-4519 (Toll free outside the 405 area code)



Oklahoma Health Care Providers' Responsibilities and Rights Under Certain Medical Treatment Laws

GREAT SEAL OF THE STATE OF OKLAHOMA 1907



I hereby certify that I have read this brochure in its entirety and that I understand my legal duties pursuant to the laws described in it.

Printed name _____

Licensing entity _____

Employer _____ Date _____

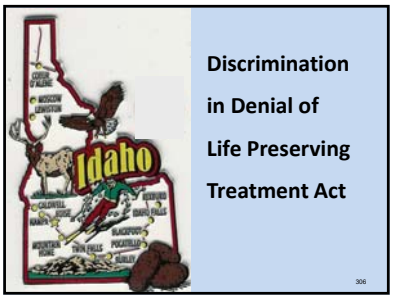
Signature _____

Please complete all information requested above the signature line. Once complete give to your employer to be placed in your personnel file for a minimum of four (4) calendar years.

Review & sign once per year

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

305



Discrimination in Denial of Life Preserving Treatment Act

306

"Health care . . . **may not be . . . denied** if . . . directed by . . . surrogate"

307

Simon's Law

308

Trisomy 18

"incompatible with life"

"uniformly lethal"

310

DNR without parents' consent **or** knowledge

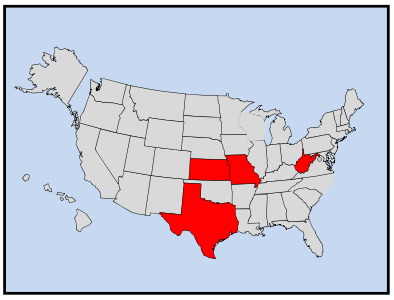
311

Trisomy 18

13% - live 10 years

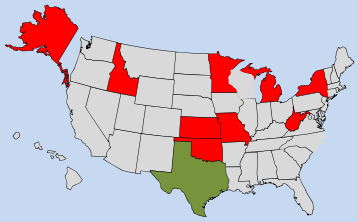
312

"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

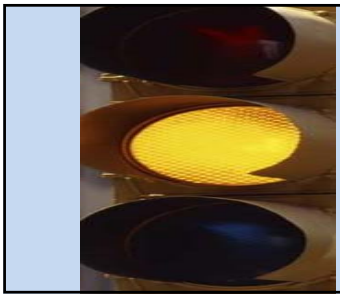
316



No explicit permission

No explicit prohibition

Very little judicial, legislative, or regulatory guidance

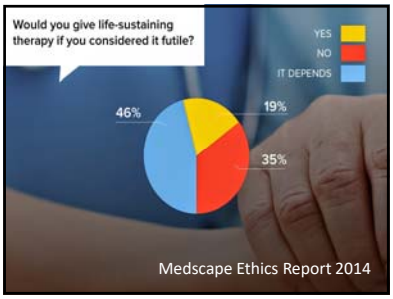


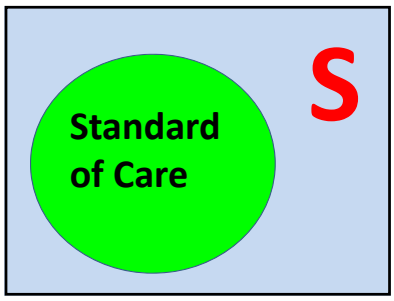
Typical response

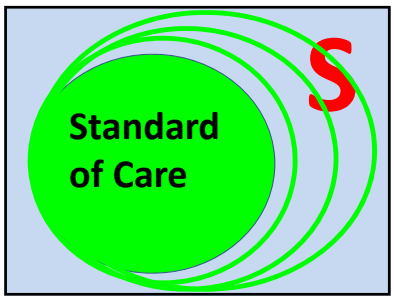
322

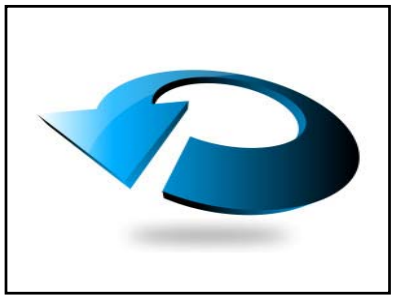
"follow the . . . SDMs **instead** of doing what they feel is appropriate . . ."

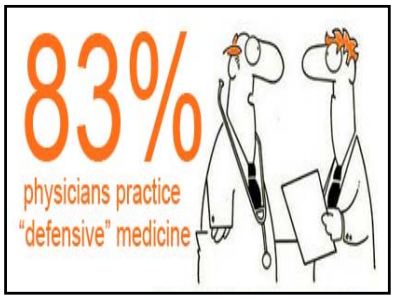
CMAJ 2007;177(10):1201-8











Patient will die soon

Provider will round off

Nurses bear brunt

How to proceed

335

1

336

Follow ATS or AMA process

337

2

338

Overt & Open

339

PROPORTION OF PHYSICIANS (n = 726) WHO WITHHELD LIFE-SUSTAINING TREATMENT ON THE BASIS OF MEDICAL FUTILITY

Consent Status	n (%)
Without the written or oral consent of the patient or family	219 (25%)
Without the knowledge of the patient or family	120 (14%)
Despite the objections of the patient or family	28 (3%)

D. Asch, ***Am. J. Resp. Crit. Care Med.*** (1995)

Unilateral DNR

Slow code

Show code

342

IIED

NIED

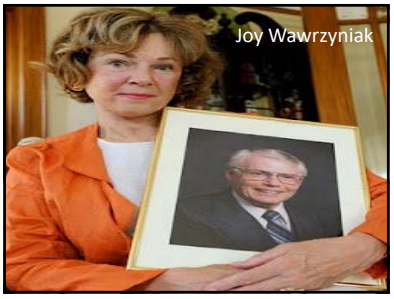
Secretive

Insensitive

Outrageous

Consultation expected

Distress foreseeable



Summa Health

3

Transparent enough

Seek assent

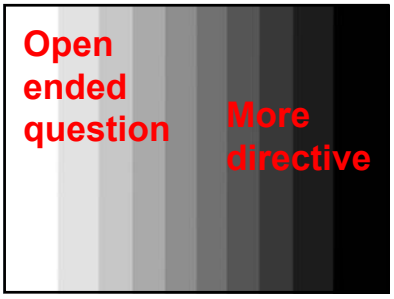
Not consent

352

Announce plan:
"We are going to…"

Silence = assent

353



Thank you

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Medical Futility Blog

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, Wellsphere, and Medpedia.

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