Resolving Pediatric Medical Futility Conflicts with Efficiency & Fairness

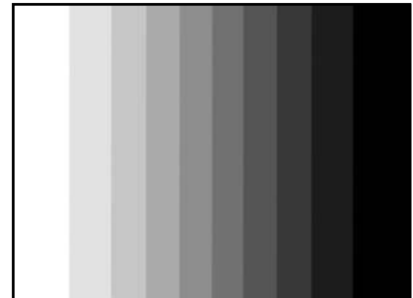
8th Annual Pediatric Bioethics Conference, Wolfson Children's Hospital (November 6, 2015)

Thaddeus Mason Pope, J.D., Ph.D.
Hamline University School of Law

The 8 Absolute Top Cities In the US to Live In

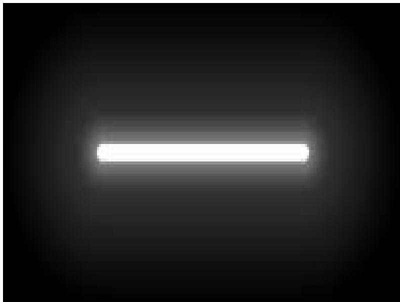
We looked at results from 7 very different, "best of" lists to come up with the 8 top cities in the US for 2015.

By Patch of Earth - October 18, 2015

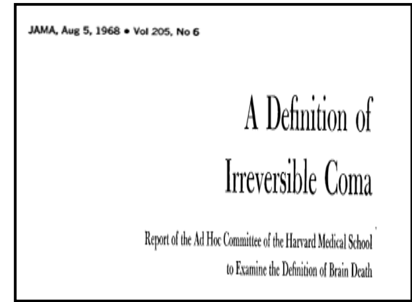


Brain death

After death, **nothing** more for medicine



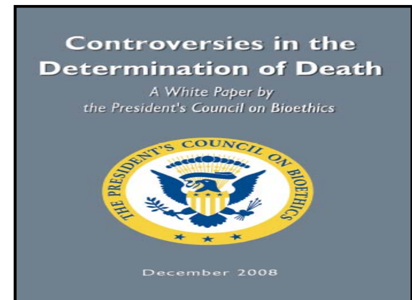
total brain failure = death


JAMA, Aug 5, 1968 • Vol 205, No 6

A Definition of Irreversible Coma

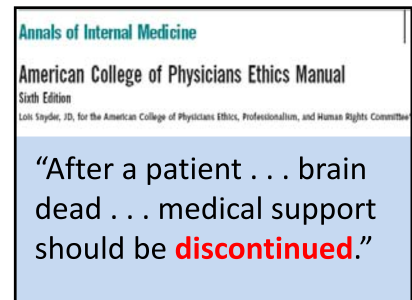
Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death

Legally **settled** since 1980s



total brain failure = death

Dead → **No** duty to treat


Annals of Internal Medicine

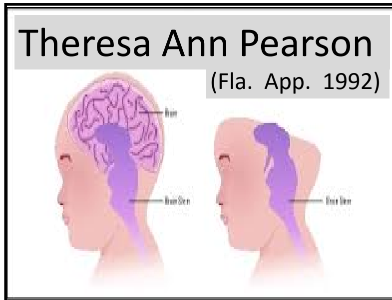
American College of Physicians Ethics Manual

Sixth Edition

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

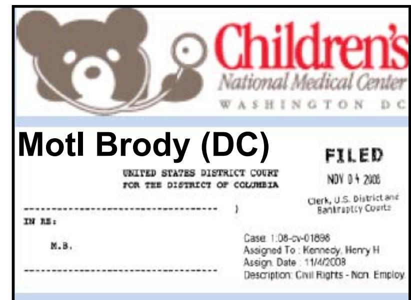
1990s

Poised to **expand**



BUT…

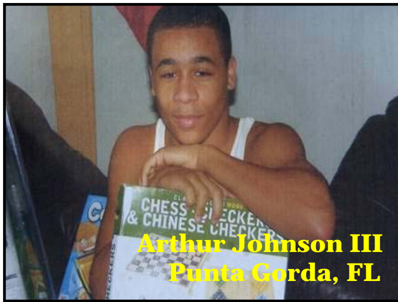
Parental resistance is **growing**



Parents want organ support **despite** death

Misunderstanding

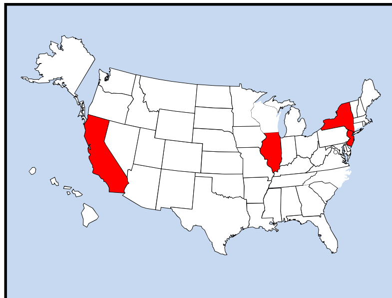
Mistrust



"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

Met AAN criteria for brain death in April 2015

Still on organ support in hospital

That is 7 months !!!!

AAN criteria not "right" criteria

Dec. 2013

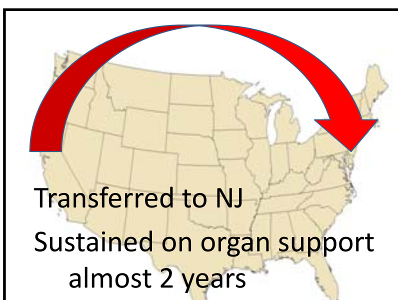
Treatment conflict

CERTIFICATION OF VITAL RECORD

COUNTY OF ALAMEDA

002357979

EXHIBIT



Mar. 2015

Med Mal lawsuit

Seeking **future** medical expenses

Re-litigate status as alive

Collateral estoppel

Oct. 2015

May allege facts to establish alive

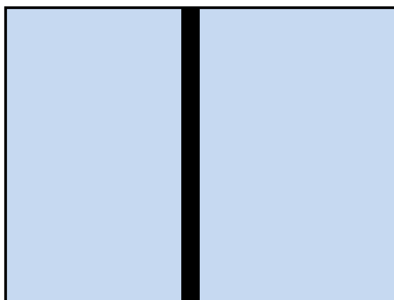
AAN criteria DDNC

Met in Dec. 2013

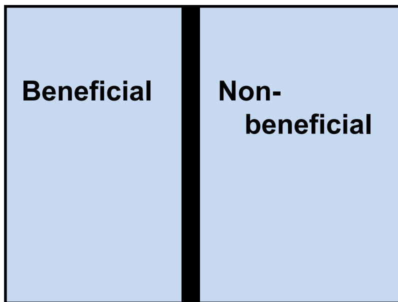
Not met now

FAC due Nov. 9

Why discuss brain death



Appropriate	Inappropriate

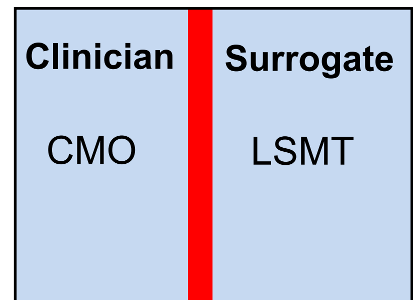


If we cannot draw a line **here**, can we draw it anywhere?

What is a medical futility dispute

Brain death is **one** type

Typically patient still **alive**



We call them "futility disputes"

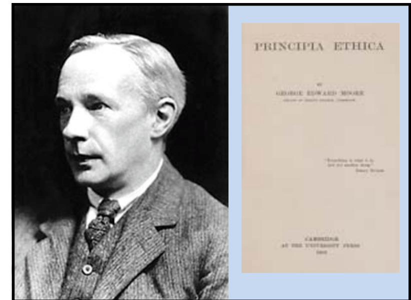
. . . BUT . . .

Disputed treatment **might** keep patient alive.

Conflicts **rarely** over whether intervention will "work"

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

Terms & Concepts



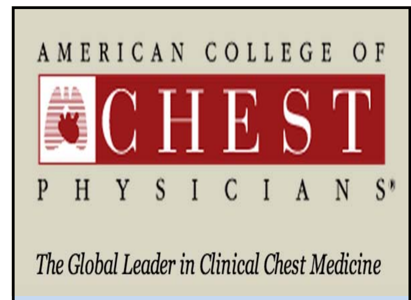
"In Ethics . . . difficulties and disagreements. . . are mainly due to a very simple cause . ."

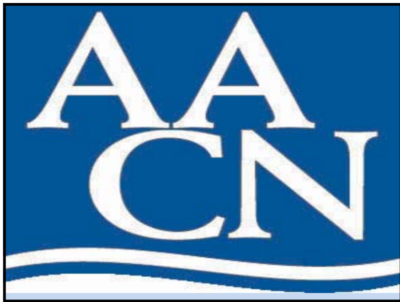
"the attempt to answer questions, without first discovering precisely **what question** it is you desire to answer."

AMERICAN THORACIC SOCIETY DOCUMENTS

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Gabriel T. Bosslet, Thaddeus M. Pope, Gordon D. Rubenfeld, Bernard Lo, Robert D. Truog, Cynda H. Rushton,





3 categories of treatment

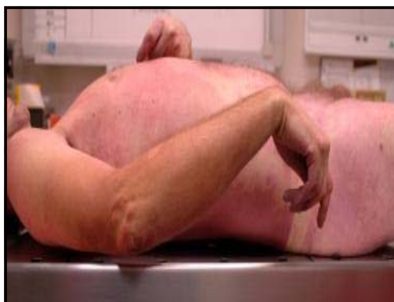
Futile

Proscribed

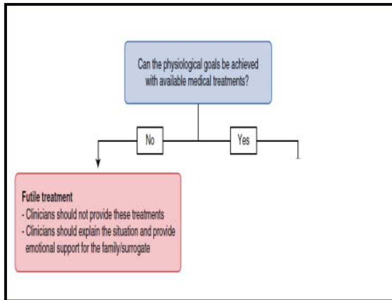
Potentially inappropriate

Futile

Interventions **cannot** accomplish physiological goals



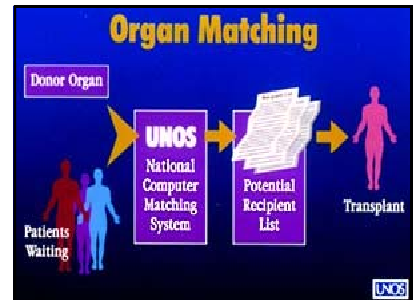
May & should refuse

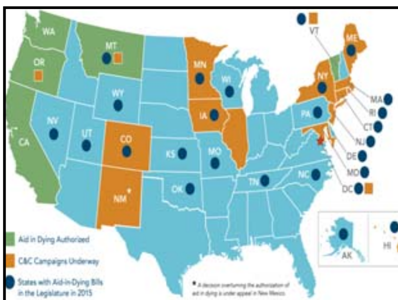


Proscribed

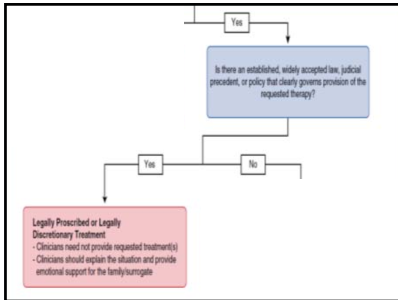
Treatments that **may accomplish** effect desired by the patient

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





May & should refuse



Potentially Inappropriate

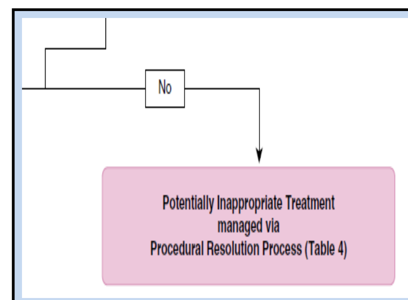
Some chance of accomplishing the effect sought by the patient or surrogate

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

Not a medical judgment

Value laden



“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.

Pope’s takeaway

Peter Paul Rubens

Hubris

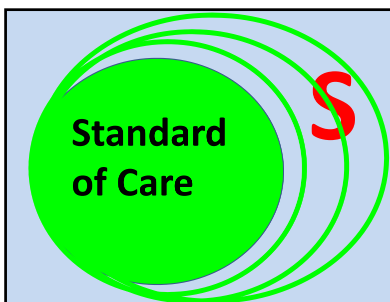
Excessive self-confidence

Humility

Not thinking you are better

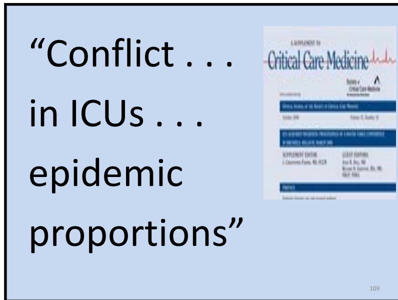
Standard of Care

S



Prevalence

108



HEC

CEC

> 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

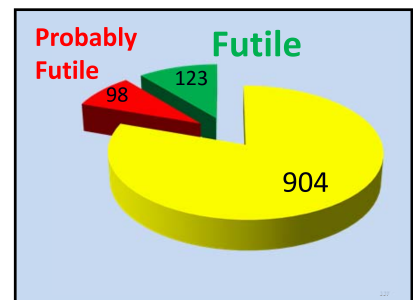
Katherine Wasson[1,3] · Emily Anderson[1] ·

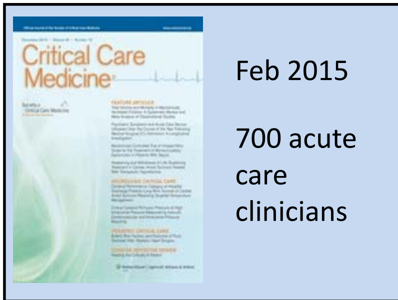
Original Investigation

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

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

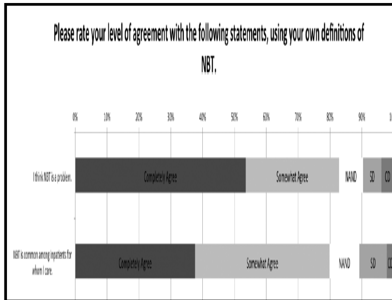
JAMA Intern Med. 2013;173(20):1887-1894. doi:10.1001/jamainternmed.2013.10261
Published online September 9, 2013.





Feb 2015

700 acute care clinicians



PewResearchCenter

NUMBERS, FACTS AND TRENDS SHAPING THE WORLD

NOV 21, 2013

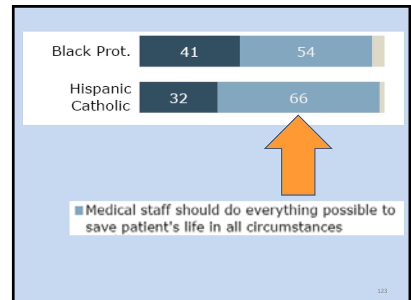
Views on End-of-Life Medical Treatments

Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

Views About End-of-Life Treatment Over Time

% of U.S. adults

	1990	2005	2013	Diff. 90-13
Which comes closer to your view?				
There are circumstances in which a patient should be allowed to die	73	70	66	-7
Doctors and nurses should do everything possible to save the life of a patient in all circumstances	15	22	31	+16
Don't know	12	8	3	-9
	100	100	100	



Dispute Resolution

4 paths

Prevention

Consensus

Switch parties

Intractable

PIT

Prevent Disputes

1

ACP

Better

Earlier

Most patients do NOT want futile treatment

99497

99498

2

Open ended question

More directive

Seek assent

Not consent

136

Announce plan:
“We are going to…”

Silence = assent

137

3

138

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, FCCM[5]; Douglas B. White, MD, MAS[6]

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DOI: 10.1097/CCM.0000000000001396

Critical Care Medicine

Robust evidence shows PtDAs are highly effective

JOURNAL OF PALLIATIVE MEDICINE
Volume 18, Number 11, 2015
DOI: 10.1089/jpm.2015.0048

Caring Decisions:
The Development of a Written Resource for Parents Facing End-of-Life Decisions

Vicki Xafis, BA (Languages, H1 Hons-Linguistics), BSA (DTEFLA), MBioethics, PhD[1,2]

Disputes

will arise

144

Consensus

145

Negotiation

Mediation

146

95%

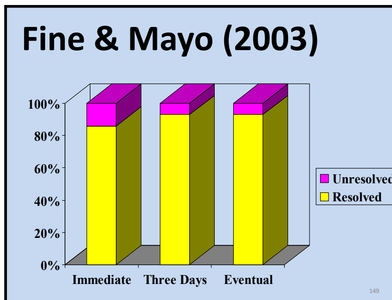
147

Prendergast (1998)

- 57% agree immediately
- 90% agree within 5 days
- 96% agree after more meetings

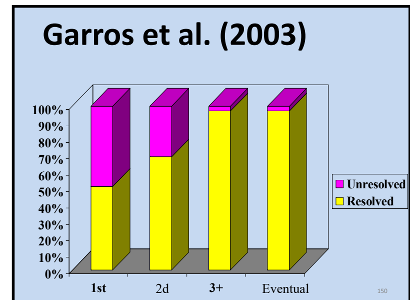
148

Fine & Mayo (2003)



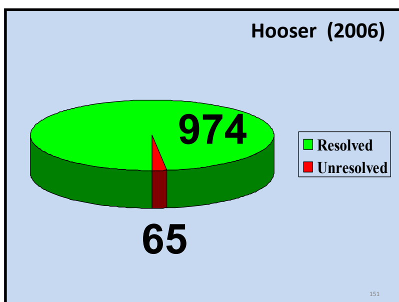
149

Garros et al. (2003)

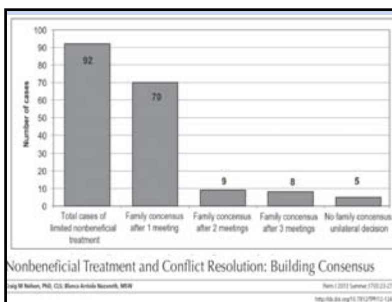


150

Hooser (2006)



151



5%

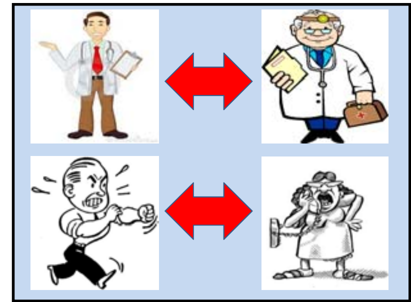
153

Reaching consensus in the 5%

154

Switch parties

155



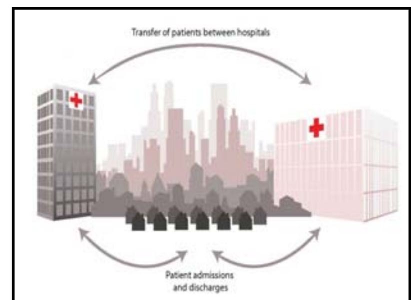
New clinician

New surrogate

157

Transfer

158



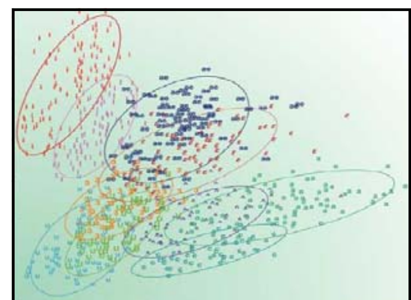
Rare

160

but

possible

161



Replace

Surrogate

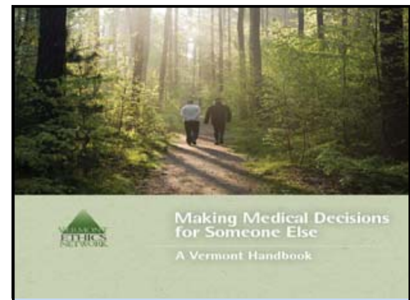
Substituted judgment

Best interests

~ 60%

accuracy

More aggressive treatment



Code of Medical Ethics

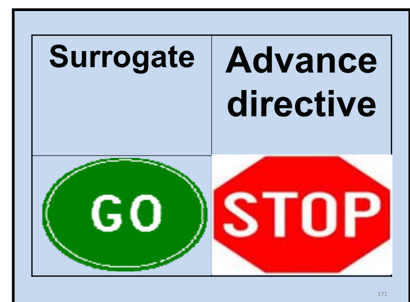
of the American Medical Association

Council on Ethical and Judicial Affairs

2.20: "surrogate's decision . . . **almost always** be accepted"

AMA

Surrogate	Advance directive
GO	STOP



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

LIMITS of surrogate replacement

179

1

Providers cannot show deviation

2

Surrogates get benefit of doubt

3

Surrogates

loyal & faithful

Truly Intractable

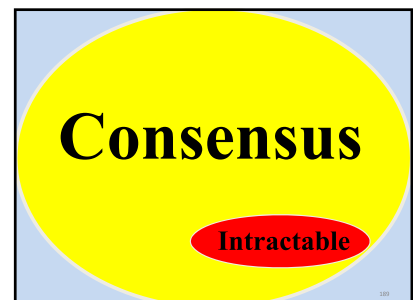
187

No consensus

No transfer

No surrogate replacement

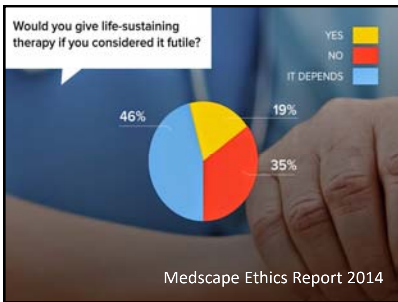
188



Cave-in

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

CMAJ 2007;177(10):1201-8

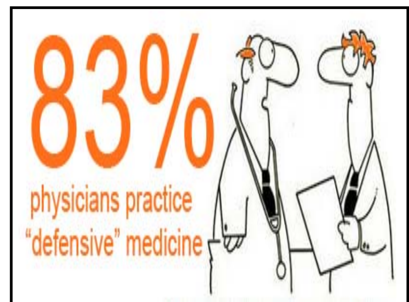


Medscape Ethics Report 2014

"Remove the __, and I will **sue you**."

Very few judgments & settlements

Risk > 0



Physician spending and subsequent risk of malpractice claims: observational study

Anupam B Jena,[1,2] Lena Schoemaker,[3] Jay Bhattacharya,[2,3] Seth A Seabury[2,4]

Cite this as: *BMJ* 2015;351:h5516
doi: 10.1136/bmj.h5516

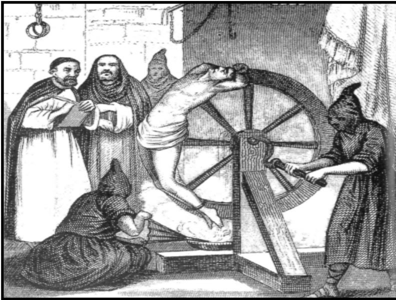
"higher resource use by physicians is associated with **fewer** malpractice claims"

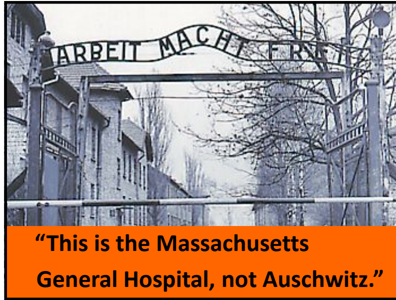
Liability averse

Litigation averse

Status quo

Bad results





Absenteeism

Retention

Quality

Moral Distress Amongst American Physician Trainees Regarding Futile Treatments at the End of Life: A Qualitative Study

Elizabeth Dzeng, MD, MPH, MPhil, MS[1,2,3,4], Alessandra Colaianni, M.D., M.Phil.[1], Martin Roland, B.M., B.Ch., D.M.[3], David Levine, M.D., M.H.S., Sc.D.[1], Michael P. Kelly, Ph.D.[3], Stephen Barclay, B.M., B.Ch., M.D.[3], and Thomas J. Smith, M.D.[2,5]

J Gen Intern Med
DOI: 10.1007/s11606-015-3505-1
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ICU **delayed or denied** to others who can benefit

Without consent

Covertly

or

Openly

217

Covertly

218

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)

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

222

IIED

NIED

223

Secretive

Insensitive

Outrageous

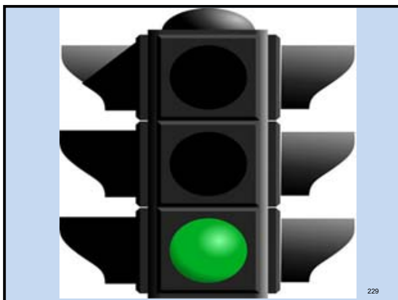
224

Consultation expected

Distress foreseeable

225

What clinicians want



Critical Care Medicine

Feb 2015

700 acute care clinicians

TABLE 3. Support for Proposed Solutions to Nonbeneficial Treatment

Proposed Solution	Effective (% "Somewhat" or "Completely" Agree)	Morally Acceptable (% "Somewhat" or "Completely" Agree)
Creating and implementing committees (with medical and nonmedical representatives) who could be consulted to resolve cases that are felt to be NBT. These committees would issue binding decisions about the care to be provided	61	60

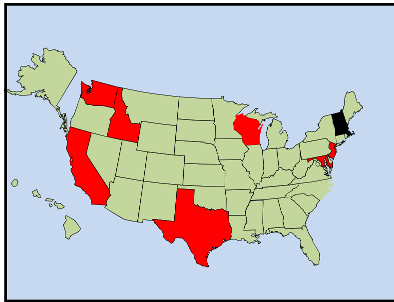
DOI: 10.1097/CCM.0000000000000704

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

48hr notice HEC

Written decision

10 days to transfer

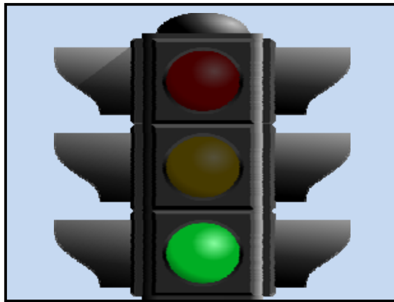


2003 2009
2005 2011
2007 2013

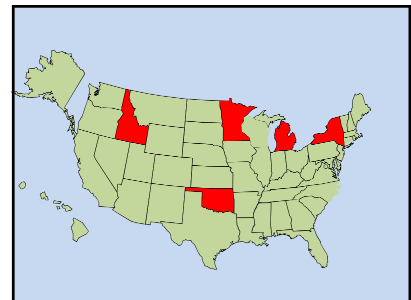
H.B.
3074

artificially administered nutrition & hydration

What clinicians are getting



Consent **always**



Moving forward

AMERICAN THORACIC SOCIETY DOCUMENTS

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

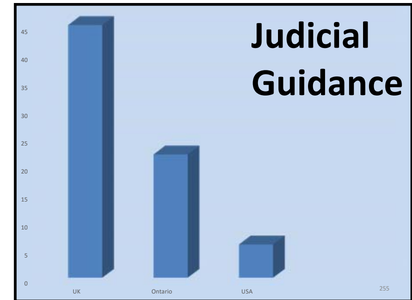
Gabriel T. Bosslet, Thaddeus M. Pope, Gordon D. Rubenfeld, Bernard Lo, Robert D. Truog, Cynda H. Rushton,

Proscribed

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

Parental demand

Appropriate medicine



Trisomy 18

22-week gestation

ECMO

Brain death

Unmasking what has been presented as objective & scientific truth

1988 - 2015

HIPAA PERMITS DISCLOSURE OF COLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

DNR/COLST
CLINICIAN ORDERS
for DNR/CPR and OTHER LIFE SUSTAINING TREATMENT

Patient Last Name
Patient First Middle Initial
Date of Birth

FIRST follow these orders, **THEN** contact **Clinician**.

(If patient/resident has no pulse and/or no respirations)

A

DO NOT RESUSCITATE (DNR)
☐ **DNR/Do Not Attempt Resuscitation (Allow Natural Death)**

CARDIOPULMONARY RESUSCITATION (CPR)
☐ **CPR/Attempt Resuscitation**

For patient who is breathing and/or has a pulse, GO TO SECTION B – G, PAGE 2 FOR OTHER INSTRUCTIONS. CLINICIANS MUST COMPLETE SECTIONS A-1 THROUGH A-5

A-1 Basis for DNR Order
Informed Consent - Complete Section A-2
Futility - Complete Section A-3

A-2 Informed Consent
Informed Consent for this DO NOT RESUSCITATE (DNR) Order has been obtained from:

Name of Person Giving Informed Consent (Can be Patient) | Relationship to Patient (Write "self" if Patient)

A-3 Futility (required if no consent)

☐ ... patient should the patient experience cardiopulmonary arrest. Another clinician has also so determined.

Maryland Medical Orders for Life-Sustaining Treatment (MOLST)

Page 1 of 2

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 Health 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.

The **next** 27 years

1

Identify **permitted** limitations

2

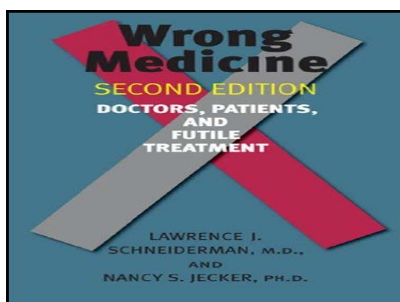
Identify **prohibited** provision

3

Develop dispute resolution mechanisms

4

Focus on triage & distributive justice



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References

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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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