What is a medical futility dispute?

- Patient
- Advance directive
- Proxy
- Agent
- Surrogate
- Conservator

- Health care provider

“Continue to treat”
“Treatment is inappropriate”

Why do surrogates demand non-beneficial treatment?

<table>
<thead>
<tr>
<th>Question and Responses*</th>
<th>Public, %</th>
<th>Professionals, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients have the right to demand care that doctors think will not help?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>72.4</td>
<td>44.8</td>
</tr>
<tr>
<td>No</td>
<td>20.2</td>
<td>44.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option</th>
<th>Public, %</th>
<th>Professionals, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>If doctors believe there is no hope of recovery, which would you prefer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-sustaining treatments should be stopped and should focus on comfort</td>
<td>72.8</td>
<td>92.6</td>
</tr>
<tr>
<td>All efforts should continue indefinitely</td>
<td>20.6</td>
<td>2.5</td>
</tr>
</tbody>
</table>
**Factual Mistakes**

- Absent
- Late
- Wrong
- Bad
- Inconsistent

**Mistrust**

Doubt prognostication

Zier, Critical Care Med. 2008

---

"I'm not going to pull the plug on granny"
Emotional Barriers

Psychological Barriers

Leci n'est pas une pipe.
Externalization

- Costs
- Guilt

Religion

“religious grounds were more likely to request continued life support in the face of a very poor prognosis”

Zier et al., 2009 Chest 136(1):110-117

Why do providers resist surrogate requests?

Table S. Responses Regarding Race, Culture, Ethnicity, and Religion

<table>
<thead>
<tr>
<th>Question and Responses</th>
<th>Public, % (n=1504)</th>
<th>Professionals, % (n=724)</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the doctor treating your family member said death has been reached, would you believe that divine intervention by God could save your family member?</td>
<td>Yes 50.1</td>
<td>19.5</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No 49.9</td>
<td>61.1</td>
<td>&lt;.001</td>
<td></td>
</tr>
</tbody>
</table>

Costs

Guilt

Rom Houben
Avoid patient suffering

“abomination”

“tantamount to torture”

This is the Massachusetts General Hospital.

Moral distress

Integrity of the profession

Stewardship

Distrust surrogate accuracy

66% accurate

50% = pure chance

66%
Moorman & Carr 2010 62%
Barrio-Catelejo et al. 2009 63%
Shalowitz et al. 2006 58%

**Even lower** when most needed: intermediate zones
*e.g.* PVS v. MCS

---

<table>
<thead>
<tr>
<th>Population or percent,</th>
<th>2000</th>
<th>2010</th>
<th>2020</th>
<th>2030</th>
<th>2040</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERCENT OF TOTAL TOTAL</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>54</td>
<td>6.8</td>
<td>6.8</td>
<td>6.6</td>
<td>6.7</td>
<td>6.7</td>
<td>6.7</td>
</tr>
<tr>
<td>5-18</td>
<td>21.1</td>
<td>23.0</td>
<td>19.8</td>
<td>19.8</td>
<td>19.8</td>
<td>19.8</td>
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<tr>
<td>20-44</td>
<td>36.9</td>
<td>33.9</td>
<td>32.3</td>
<td>31.6</td>
<td>31.3</td>
<td>31.2</td>
</tr>
<tr>
<td>45-64</td>
<td>20.2</td>
<td>20.3</td>
<td>24.4</td>
<td>24.6</td>
<td>24.6</td>
<td>24.6</td>
</tr>
<tr>
<td>65+</td>
<td>11.5</td>
<td>11.0</td>
<td>14.1</td>
<td>17.2</td>
<td>19.8</td>
<td>26.0</td>
</tr>
</tbody>
</table>


---

![Providers resist](chart1.png)

**Conflict rate**

![Surrogates demand](chart2.png)

**Increasing surrogate requests**

---

**20%: “More important to prolong life.”**

National Journal (Mar. 2011)
Archives Surgery (Aug. 2008)

---

**Trend: Do everything to save life, or sometimes let patient die?**

- **June 1981:**
  - Do everything to save life: 99%
  - Not possible to save a life: 1%
- **November 2001:**
  - Do everything to save life: 96%
  - Not possible to save a life: 4%

![Attitudes toward EOL Care in California](chart3.png)

Sometimes allow a patient to die: 50%
Doesn’t depend: 16%
Always do everything possible to save a life: 27%
It depends: 70%
THUR: End of Life and Family Views

"most fight with everything they’ve got to hold onto life as long as possible."

Increasing provider resistance

<table>
<thead>
<tr>
<th>Question and Response</th>
<th>Public, % (n=1006)</th>
<th>Professionals, % (n=774)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients have the right to demand care that doctors think will not help?</td>
<td>Yes 72.4</td>
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</tr>
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<td>No 20.2</td>
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EPEC® Education in Palliative and End-of-life Care

Typical dispute resolution pathway

Prendergast (1998)

57% surrogates immediately agree
90% agree within 5 days
4% continue to insist on LSMT
Earliest attempts . . . deliberate over and negotiate prior understandings . . .

Joint decision-making should occur . . . maximum extent possible.

Attempts . . . negotiate . . . reach resolution . . ., with the assistance of consultants as appropriate.

Involvement of . . . ethics committee . . . . if . . . . irresolvable.

5. . . .

6. If the process supports the physician’s position and the patient/proxy remains un-persuaded, transfer . . .

7. If transfer is not possible, the intervention need not be offered.

Consensus & hospitals handle intractable disputes
Surrogate selection

Act in accord
directive, decisions
preferences, wishes
best interests

Wis. Stat. 155.20(5)
[A]gent shall act in good faith consistently with the desires of the principal . . . with any valid declaration . . . in the best interests of the principal

Wis. Stat. 155.60(4)
The court may . . . “direct the . . . agent to act in accordance . . . [or] rescind all powers”

Famous failure
Helga Wanglie (Minn. 1991)

Increasingly proven

85-year-old
End-stage kidney failure
Chronic respiratory failure
Dementia

SDM Lana Barnes
“Continue”

“This is not right for Albert”
Not just an **option** but sometimes a **duty**

<table>
<thead>
<tr>
<th>Surrogate</th>
<th>Advance directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>B</td>
</tr>
</tbody>
</table>

Court: “Your own personal issues are “impacting your decisions”
“Refocus your assessment”

Material COI

Pascentia McDonald, 74yo

Advance directive:
1. Bobby Miles - agent
2. Cynthia Cardoza - alternate
3. “Do No prolong life if incurable condition”
Aug. 14
PM: surgery thoracoabdominal aneurysm
PM: post-op infections

Aug. 30
PM: sepsis, non-cognitive

Aug. - Sept.
BM: continued LSMT
BM: 3 more surgeries
CC: Disagrees w/ brother
Sept. 17
CC: threatens to sue
USC stops
PM dies

California Court of Appeals:
“Operation of the immunity here is not so certain.”
“Compliance with an agent’s decision that is at odds with the patient’s own expressed decision, in her AHCD, would probably not qualify as in good faith.”

CC still sues (for damages)
USC & providers argue:
Probate Code 4740 immunizes providers who “in good faith comply with a health care decision made by one whom they believe authorized.”

The agent was not authorized to depart from the patient’s AD.
USC should have known that.

Train surrogates

UPOAA Statement to Agent
Agent’s Duties
When you accept the authority granted under this power of attorney, a special legal relationship is created between you and the Principal. This relationship imposes upon you legal duties that continue until you resign or the power of attorney is terminated or revoked. You must:

Agent’s Certification
I, ... have read the attached durable power of attorney and the foregoing statement, and I am the person identified as the Agent for the Principal. To the best of my knowledge, this power has not been revoked. I hereby

Agent’s Signature
Date
Limits of surrogate replacement

Providers cannot show deviation

But absence of evidence means objective best interest standard

Healthcare providers get more deference

In the case of Cardoza v. Smith, the court stated that healthcare providers cannot show deviation from the standard of care by merely proving that their actions were not in the patient's best interest. Instead, providers must demonstrate that they followed the objective standard of care. This is because the absence of evidence does not necessarily mean that the provider acted contrary to the patient's best interest.

The court also noted that healthcare providers in the state of California are entitled to a presumption of good faith and reasonable care, which is known as the objective standard of care. This presumption is intended to protect healthcare providers from unjustified lawsuits and to encourage them to perform their duties without fear of liability.
Surrogates often faithful

If cannot replace surrogate, then provide the treatment

Dispute resolution mechanisms for intractable cases in which surrogates are “irreplaceable”

Consent and Capacity Board

“Remove the __, and I will sue you.”
“Why they follow the instructions of SDMs instead of doing what they feel is appropriate, almost all cited a lack of legal support.”

**Criminal liability**
- e.g. homicide

**Licensure** discipline

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

**Providers typically lose**
- only claims for IIED
- Secretive
- Insensitive
- Outrageous

**Risk > 0**

**Exposure to civil liability**
- State HCDA
- Battery
- Medical malpractice
- Informed consent
- EMTALA

**Legal Support for Nontherapeutic Treatment Decisions**

Barber (Cal. 1983)
- Manning (Idaho 1992)
- Rideout (Pa. 1995)
- Bland (Tex. 1995)
- Wendland (Iowa 1998)
- Causey (La. 1998)

**State HCDA**

**Legal Support for Nontherapeutic Treatment Decisions**

Barber (Cal. 1983)
- Manning (Idaho 1992)
- Rideout (Pa. 1995)
- Bland (Tex. 1995)
- Wendland (Iowa 1998)
- Causey (La. 1998)
"It is not settled law that, in the event of disagreement... the physician has the final say."


"The only fear a doctor need have in denying heroic measures to a patient is the fear of liability for negligence"


Process itself can be punishment
Even prevailing parties pay transaction costs
  Time
  Emotional energy

Liability averse
Litigation averse too


<table>
<thead>
<tr>
<th>Action</th>
<th>% ordered for defensive reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital admissions</td>
<td>13.0%</td>
</tr>
<tr>
<td>Labs</td>
<td>17.9%</td>
</tr>
<tr>
<td>X-rays</td>
<td>21.0%</td>
</tr>
<tr>
<td>Ultrasound studies</td>
<td>24.0%</td>
</tr>
<tr>
<td>MRI studies</td>
<td>27.4%</td>
</tr>
<tr>
<td>CT scan</td>
<td>27.6%</td>
</tr>
<tr>
<td>Specialty referrals</td>
<td>28.4%</td>
</tr>
</tbody>
</table>

Bad law

Override
Accede to surrogate

Typical response to “bad law” claims

Safe harbor immunity

UHCDA model

New Mexico (1995)
Maine (1995)
Delaware (1996)
Alabama (1997)
Mississippi (1998)
California (1999)
Hawaii (1999)
Tennessee (2004)
Wyoming (2005)

16 Del. Code 2508(f)
Provider may decline to comply
“medically ineffective treatment”
“contrary to generally accepted health-care standards”

16 Del. Code 2510(a)(5)
A provider... in good faith
and in accordance with
generally accepted health-care standards... is not subject
to civil or criminal liability
or to discipline for
unprofessional conduct for...
declining to comply...

Safe harbor attributes
Clear
Precise
Concrete
Certain

“generally accepted health care standards”
No quantitative measures

Wide variation on threshold
Some: 0%
Some: 1%
Others: 13%

Lantos, Am. J. Med. 1989
Uncertainty in extrapolating from populations to individuals

No qualitative measures

Goals of Medicine
- Cure disease
- Alleviate pain & suffering
- Restore function
- Prevent disease
- Prolong corporeal existence

Result of Ambiguity
- Few futility policies
- Rare “full” implementation

Easier to ask for forgiveness, than to ask for permission

Get an injunction

Courts almost always grant temporary injunctions

Know it when I see it
Likelihood of success on the merits

Substantial threat of irreparable damage or injury

Patients often **die** before adjudication of merits

*De jure* loss

*De facto* win

---

**Betancourt v. Trinitas Hospital**

- 73yo male
- PVS
- COPD
- End-stage renal disease
- Hypertensive cardiovascular disease
- Stage 4 decubitus ulcers
- Osteomyelitis
- Diabetes
- Parchment-like skin

"The only organ that's functioning really is his heart."

"It all seems to be ineffective. It's not getting us anywhere."

"We're allowing the man to lay in bed and really deteriorate."

---

**Intramural process**

- No consensus

**Unilateral withdrawal**

- DNR order written
- Dialysis port removed

---

**January 2009**

- Jacqueline files
- Court issues TRO

---

**February 2009**

- Evidentiary hearings
- Medical experts
- Family members
March 2009
Permanent injunction

April 2010
NJHA
MSNJ
NJP
GNYHA
CHPNJ
Disability coalition
Jewish coalition
Pope

August 2010
Appeal dismissed
No guidance
No clarity

You may stop LSMT for any reason - if your hospital ethics committee agrees

Texas H&S Code 166.046
[N]ot civilly or criminally liable or subject to review or disciplinary action . . . complied with . . . procedures

1. 48hr notice
2. HEC meeting
3. Written decision
4. 10 days to transfer
5. Unilateral WH/WD

---

**Step 1: Notice HEC meeting**

**Step 2: HEC Meeting**

**Step 3: HEC written decision**

The Ethics Committee further recommends that
- The treatment plan for the patient be modified to allow only necessary measures such as hypothermia, pain control and other interventions designed to decrease the patient's suffering.
- No complications that develop should not be treated, except with additional palliative measures, if appropriate.
- The patient's outcome may be changed to a DNR.
- Appropriate spiritual and pastoral care resources should be provided to the patient's medical and family members.

In summary, the consulted members of the Ethics Committee concern with the recommendations by the Attending Physician and patient care team to withdraw aggressive care measures, including use of the ventilator, and to offer palliative care only. The Attending Physician, with the help of the Children's Hospital of Austin, will continue to care for the patient's family in trying to ease the physician and facility suffering to provide the requested treatment. The family may wish to consult providers of their choice to get help in arranging a transfer.

---

**Step 4: Attempt transfer**

**Step 5: Unilateral withdrawal**

- No transfer
- Withdraw 11th day

There is no step 6

There is no judicial review

The HEC is the forum of last resort
If process is all you have, it must have integrity and fairness.

Dues Process
- Notice
  - Opportunity to present
  - Opportunity to confront
  - Assistance of counsel
  - Independent, neutral decision-maker
  - Statement of decision
  - Judicial review

Survived a “storm” of bills
- 2007
- 2009
- 2011

TX safe harbor
- Measurable procedures
- Safe harbor protection certain

DE safe harbor
- Vague substantive standards
- Safe harbor protection uncertain

Texas seen as model
No substantive criteria
Pure procedural justice
Conscientious Objection

Make sure dealt fairly
- Attend HEC
- Get second opinion
- Help find transfer

No treatment relationship
- May refuse to treat for any reason

Existing treatment relationship
- Must continue to treat

Termination: normally
- Sufficient notice to find alternative
- Medical Board may require ~30 days

Life-and-death situation
- "free to refuse . . . upon providing reasonable assurances that basic treatment and care will continue"
  [Couch (N.J.A.D. 2000)]

Del. Code 2508(e)
- "... provider may decline to comply . . . for reasons of conscience."

Del. Code 2510(a)(5)
- "... provider . . . not subject to civil or criminal liability or to discipline . . . for . . . [d]eciding to comply . . . because . . . conscience"
Del. Code 2508(g)

[If] decline to comply . . .

(2) Provide continuing care, including continuing life sustaining care, . . . until a transfer can be effected.

Want to refuse → Try transfer

No transfer → Must comply

Not always

Cal. Probate Code 4736

(c) Provide continuing care . . . until a transfer can be accomplished OR until it appears that a transfer cannot be accomplished.

Comprehensive Conscience Clauses

Idaho Code 18-611

No health care professional . . . shall be civilly, criminally or administratively liable for . . . declining to provide health care services that violate his or her conscience.

. . . in a life-threatening situation . . . professional shall provide treatment and care until an alternate health care professional capable of treating the emergency is found.

Not always

Miss. Code 41-107-5

A health care provider has the right not to participate, . . . violates his or her conscience. . . .

No emergency exception

No duty to refer
Offensive medicine is the far bigger threat


Pope, Legal Briefing: Medical Futility and Assisted Suicide, 20(3) J. CLINICAL ETHICS 274-86 (2009)
‡ Pope, The Case of Samuel Golubchuk: The Dangers of Judicial Deference and Medical Self-Regulation, 10(3) AM. J. BIOETHICS 59-61 (Mar. 2010).