Laws and policies regarding medical futility

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Children’s Mercy Kansas City
KCMO
Medical futility cases are tough
What do we mean by “futility?”

• Old-fashioned definition: a treatment that simply won’t work.
• Modern definition: an intractable disagreement between doctors and patients (or surrogates) about the appropriateness of providing marginally beneficial treatment.
The (modern) invention of futility: The “Baby Doe” guidelines -1984

• Controversy triggered by a baby with Down Syndrome and esophageal atresia
• Parents did not consent to surgery
• Federal government tried to develop criteria for deciding when parental refusals were permissible.
Treatment may be withheld only if...

• Baby is chronically and irreversibly comatose
• The treatment is medical futile
• The treatment is virtually futile and inhumane
Is CPR sometimes futile?

- Case presentation of a woman with metastatic ovarian cancer for whom no further chemotherapy was available
- Patient wanted “everything done.”
- “Can we just say no?”

- Blackhall LJ. Must we always provide CPR? NEJM, 1987
“CPR is a desperate technique that works relatively infrequently. To solve the ethical dilemmas posed by CPR we must first face that medical fact.”

“The issue of patient autonomy is irrelevant when CPR has no potential benefit. Here, the physician’s duty to provide responsible medical care precludes CPR.”
An avalanche of scholarly writing

- Thousands of articles, dozens of books
- Hospital policies
- Even state laws (well, just Texas)
Real Life Futility Cases
Baby L

• 2 year old
• Pregnancy with fetal hydronephrosis and oligohydramnios.
• L&D: decels, thick mec, Apgars 1, 4, and 5.
• Stabilized in the NICU.
• G-tube at 1 month, trach at 7 months.
• Discharged at 14 months.

Baby L

• Readmissions with pneumonia and sepsis
• Four cardiopulmonary arrests
• Mother “continued to demand that everything possible be done.”
• Doctors thought further treatment futile and told mother: “No more PICU.”

Baby L

• Ethics committee: divided.
• Mother sought court order for treatment.
• Doctors claimed it would violate their conscience to provide treatment.

Baby L

• Court appointed guardian ad litem
• GAL sought a second opinion
• “Patient was severely ill, capable of experiencing pain, it was questionable whether she would survive even with mechanical ventilation.”
• Consultant was willing to do everything possible to accommodate the parental wishes,
• Child was transferred to her care.

• Paris et al NEJM 1989
Baby L

• “Two years later, Baby L remains blind, deaf, and quadriplegic and is fed through the gastrostomy. She averages a seizure a day. Her pulmonary status has improved, but she continues to require intensive home nursing 16 hours a day.”

• Paris et al NEJM 1989
Letters to NEJM about Baby L

• “It should be obvious from the child's continued survival that these expert pediatricians were not basing their decisions on a correct assessment of the futility of treatment. Instead, their moral certainty was based on agreement about the child's poor quality of life.”

• Lantos, NEJM, 1990
Texas law

When an intractable disagreement arises, 7-steps:

• 1. Family must be given written information that an ethics consultation will be called.
• 2. Family must be given 48 hours notice and be invited to participate in the ethics consultation.
• 3. The ethics committee must provide a written report detailing its findings to the family.
Texas futility law

4. If the ethics consultation process fails to resolve the dispute, the hospital, working with the family, must try to arrange transfer to another physician or institution.

5. If after 10 days (measured from the ethics consultation report) no such provider can be found, the hospital and physician may unilaterally withhold or withdraw “futile” therapy.
Texas futility law

• 6. The patient or surrogate may ask a judge to grant an extension of time before treatment is withdrawn. This extension is to be granted only if the judge sees a reasonable likelihood of finding a willing provider if more time is granted.
Texas futility law

7. If the family does not seek an extension or the judge fails to grant one, futile treatment may be unilaterally withdrawn by the treatment team with immunity from civil and criminal prosecution.
How is it working?
65 hospital-years of data

- 2,922 ethics consults
- 974 were about medical futility
- 65 had 10-day letters issued.
  - 11 patients were transferred within 10 days,
  - 22 patients died during the 10-day period,
  - 27 patients had the disputed treatment withdrawn,
  - 5 patients had treatment extended
    - Fine RL, Chest, 2009 (and Dallas Morning News, 2/15/07)
What could go wrong?
Example: Emilio Gonzalez case

- DOB – 12-3-05,
- G1P0 mother, 35 weeks, 2525g.
- Feeding difficulty and apnea in NICU
- Abnormal head and eye movements →
  - MRI – normal
  - AER – auditory neuropathy
  - EEG – seizures
- DX: Leigh’s disease
Emilio Gonzalez case

- 12/06 (age:1y) – viral illness → PICU → neurologic decompensation
- 2/07 - Semi-comatose, hypotonic, no gag, vent, N-J tube, sub-acute seizure activity, pneumothoraces requiring chest tubes.
- Doctors suggest DNR, withdrawal of life-support.
- Mom refuses.
**Ethics Committee Recommendations**

- Comfort measures only

- Code status should be DNR.

- Spiritual and pastoral care for family.

Ongoing controversy

• Mother did not accept recommendations.
• Doctors sought court order.
• Court ordered withdrawal of vent.
• Mother appealed and went to legislature.
• Treatment continued.

“If they think a mother should give up her son, they're dumb, they're stupid.”
Mom went to the press

Catarina and Emilio Gonzalez, PICU, Brackenridge Hospital. Austin, TX.

Photo from Austin Press Herald
Catarina and Emilio Gonzalez, PICU, Brackenridge Hospital. Austin, TX.
There is something holy about not giving up hope.

It has nothing to do with medical facts or anticipated outcomes.
Why do parents demand futile treatment?

• They may not have been told in terms that they understand. (We are not always as clear as we should be.)

• They may come with ideas shaped by portrayals of medicine on TV.
# Miracles and Misinformation on Television

### Table 3. Survival after CPR in Three Television Series.

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<th>No. of Occurrences of CPR</th>
<th>Short-Term Survival after CPR</th>
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<td>7 (64)</td>
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Diem, Lantos, Tulsky, NEJM 1996
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Resuscitation of E.T.

- Excellent CPR by the LA County trauma team.
- After CPR fails, Elliott's heart-felt love revives his friend.
- E.T.'s red heartlight glows and he miraculously bursts out: "E.T. Phone home."
TV’s take home lesson

• If you truly love someone, you will not give up, even when the doctors have given up.
• Love can succeed where medicine fails.
• There is magic in the world.
• You just gotta believe
## Bioethics take home lesson

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<th>If treatment is:</th>
<th>Parents want</th>
<th>Parents refuse</th>
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<tr>
<td>Clearly beneficial</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Ambiguous</td>
<td>yes</td>
<td>no</td>
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<tr>
<td>Futile</td>
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- President’s Commission 1982 (not much has changed)
Key distinction

Futility controversy

vs.

Intractable disagreement about futility
Futility controversies are common

- One PICU, Boston, 11 months,
  - 55 futility controversies involving 51 patients.
- 21 PICUs in the UK, one day:
  - 111 patients in the PICU
    - “care was felt to be appropriate in 88 (79%)”
    - futile in nine cases (8%)
    - inappropriate in 14 (13%).
- In one children’s hospital in UK, over 6 months, there were 136 episodes of conflict about medical futility.

Intractable disagreements are rare

• Most of the time, doctors and parents come to a mutually acceptable agreement
What is really going on?

• “Parents and healthcare providers may have different values regarding the provision of life-sustaining interventions. However, parents base their decisions on many factors, not just probabilities. The role of emotions, regret, hope, quality of life, resilience, and relationships is rarely discussed. End-of-life discussions with parents should be individualized and personalized.”

“Pediatric intensivists prefer a collaborative approach with families, one that avoids staking out adversarial positions in cases where there is disagreement about the best course of action in a child’s care.

Approaching such disagreements with a desire to understand and acknowledge a family’s position and offering support to the family before, during, and after a death is far preferable to attempting to push them to change their minds more rapidly than they are prepared to do.”

Different Approaches
Simon Crosier

• Born 9/7/10
• Died 12/3/10
• Parents told T18 was incompatible with life
Parents became advocates
Bills in KS and MO legislature

- 2015: KS H.B. 113
- 2016 KS H.B. 1915 and MO S.B. 437
- 2017 KS S.B. 85: Two parts:
    - “Upon the request . . . shall disclose in writing any policies . . . involving resuscitation or life-sustaining measures, including any policies related to treatments deemed non-beneficial, ineffective, futile or inappropriate”
S.B. 85
• 2017 KS S.B. 85: Two parts:
  – 2. Specifically for minors:
    • No DNR unless at least one parent has first been informed.
    • A reasonable attempt to find the other parent.
    • Info about DNR provided to both verbally and in writing
    • Either parent may refuse DNR, either orally or in writing
Signed 4/7
Kansas is not alone
Simon’s Law spreading
“If surrogate directs [LST] . . . provider . . . 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”
Nondiscrimination in Treatment Act

Nov. 2013
“shall not deny . . . life-preserving health care . . . directed by . . . [surrogate]”
Medical Treatment
Laws Information Act
Nov. 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:
• If patient/surrogate directs life-preserving treatment, you may not deny it:
  – On the basis of a view that treats extending the life of an elderly, disabled or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled or not terminally ill; or
  – On the basis of disagreement with how the patient/surrogate values the trade-off between extending the length of the patient’s life and the risk of disability.
But then there’s this...

- “You are not required to begin or continue CPR when, in reasonable medical judgment, it would not prevent the imminent death of the patient.”
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
There is a need for Simon's Law nationwide. In many hospitals across America it is legal for a child to be denied life-sustaining care and for a 'do not resuscitate' order (DNR) to be placed on a child's medical chart without parental knowledge or

http://www.ipetitions.com/petition/simons-law
Conclusions
Conclusions

• There are “true” futility cases
• They are rare
• They are troublesome
• Most cases that cause moral distress are not truly about “futility.”
Two central distinctions

• Quality of life determinations
  – In PVS, mechanical ventilation “works”
  – The problem is that it is not futile!

• Resource allocation decisions
  – If they treatment truly will not work, then the downside is the cost...and if the treatments really don’t work, the cost is minimal.
The central paradox of futility

• Futile treatments are only deeply problematic when they work.
• Futile treatments that truly don’t work are not particularly troubling.
Key distinctions

• Futility as a concept to help communication and shared decision making

vs.

• Futility as a way to avoid communication and shared decision making
Unilateral futility decisions

• When policies allow unilateral decisions...
  – Undermines trust
  – Exacerbates, rather than solves the problem
  – Is a short-term, short-sighted solution to a long-term, fundamental moral problem
Remember

• Parents have to make a decision that will profoundly change their lives forever.
• You just have to help them.
• Seems unlikely that laws are going to solve these problems.
• But they set the parameters within which we work.
• Trend: toward full disclosure and patient empowerment.
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.
Welcome to the Children’s Mercy Hospitals and Clinics Bioethics Center Website

We have developed some tools for clinicians and teachers to help analyze ethical issues that arise in pediatrics.

For each of the topic areas on the right, we offer a brief introduction to the ethical issues, a power point presentation to use in your teaching, interviews with leading figures in the field about those issues, and an annotated list of references.

We will be adding topics all the time. If you have an issue that you'd like us to address, or feedback on the materials we've developed, please contact us. All of the original materials can be used without permission. Please give us credit, though, and send colleagues our way.

We give links to full-text reference material that is in the public domain. For other reference material, we give links to abstracts.

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