Who Are We and What is Our Moral Authority?

- Education
  - College, Medical School, Training
  - Identification of role models for clinical practice and ethics
  - Aristotle's principle: “habit of choosing...”
- Peer Review and Moral Scrutiny
  - Board Certification
  - Character Assessment
  - Reputation
- Continuing Education
  - CME Credits
  - Teaching, Publishing, Lecturing, and more

What Have We Achieved?

- Excellence in Practice and Patient Care
  - Compassion for our patients
  - Long hours of work
  - Stress management
  - Balancing professional life with home life
  - Character Development
    - Temperament; Equanimity; Honesty
  - “Phronesis”; Practical Wisdom
    - Enhanced by a lifetime of learning and reassessment
  - “The unexamined life is not worth living” Plato, The Apology

We Are Therefore Outfitted To Make Clinical (Scientific) as Well as Moral Decisions

- However, Clinical Decisions are not the same as Moral Decisions
- Clinical Decisions are more Scientific, Require More Precision
  - Evidence Based Medicine
  - Clinical Trials
  - Resolution of Clinical Equipoise
- Moral Decisions lack precision; one size doesn’t fit all
  - Politics; Economics; Language; Culture; Religion; Law
  - Complicated by the duality of human behavior
  - Reason vs. Emotion, reason being the slave of emotion*
- * David Hume, Scottish Philosopher

Futility: Approaching a Definition

- Latin (futulis) “leaky”
- Oxford English Dictionary “leaky, hence untrustworthy, vain, failing of the desired end through intrinsic defect”
- Greek Mythology
  - Daughters of Danaus condemned in Hades to draw water in leaky sieves.
  - The Myth of Sisyphus
Hippocratic Teachings and Plato

- Hippocratic writings: three major goals
  - Cure
  - Relief of suffering
  - "Refusal to treat those who are overmastered by their diseases"

- Plato's Republic References
  - Plato objects to a cure consummating in a life that "isn’t worth living"; both qualitative and quantitative aspects relate to a single underlying notion: the result is not commensurate to the effort
  - The effort is, on the part of the agent, a repeated expenditure of energy that is consistently non productive or, if productive, its outcome is far inferior to that intended.

Approaching a Definition: Qualitative and Quantitative

- "A futile action is one that cannot achieve the goals of the action, no matter how often repeated. The likelihood of failure may be predictable because it is inherent in the nature of the action proposed, and it may become immediately obvious or may become apparent only after many failed attempts."
- "We propose that when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile."

Baby Robert

- Robert was a 2 year old who had been born with a large frontal encephalocele
- Robert's parents were young, homeless
- Robert was never responsive and never showed any signs of neurologic development
- He was an inpatient almost continually for two years, with frequent electrolyte abnormalities related to diabetes insipidus

Staff consistently communicated recommendation for comfort care
- Intensive involvement of ethics consultation service and psychosocial support services
- Parents never agreed to any limitations of care
- At two years of age, he was found cyanotic on the ward, and was rushed to the ICU
- The question: should CPR be performed?

What’s underneath the futility debate?

- Power
- Trust
- Money
- Hope
- Integrity

Who gets to say NO?

• The question of the 1970’s & 1980’s:
  – The rights of patients to refuse medical Treatment
    – Ethically and legally resolved, but still a problem in practice
• The question of the 1990’s and 2000’s:
  – The rights of patients to demand medical treatment
    – Ethically, legally, and politically controversial

How should we frame the issues?

• Do patients and families have a right to force doctors to squander scarce time and resources on therapies that have no benefit in order to satisfy their irrational wishes?
• Do doctors have a right to arbitrarily ignore the values and preferences of patients and families, using only their own value systems to make life and death decisions for others?
• In search of the “Golden Mean”


A debate about “Odds and Ends”

• Questions about futility ask:
  – What chance or probability of success is “worth it”? 
  – What quality of outcome is “worth it”?
  – How do we refrain from pursuing long “odds” to achieve bad “ends”?

A debate about “Odds and Ends”

Are these questions within the expertise of the medical profession?

“It is hard not to take sides in such a spirited debate. One lesson quickly learned by anyone who engages in conceptual analysis of a bioethical problem is that a concept should not be expected to bear more weight than it can reasonably sustain.”

Precision vs. ambiguities inherent in any case “hos epi to polu”**

“The greater the trust between physician and patient in the United States, the more willing patients will be to refrain from pursuing long odds to achieve bad ends.”*

• *Caplan; **Aristotle

What’s underneath the futility debate?

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Trust and the Futility Debate

• To the extent that patients trust doctors and agree about values, the “futility debate” disappears
• Doctors will tell patients that they believe further treatments futile, patients will believe their doctors, and together they will decide to forego treatment.
• Futility debate begins when this process breaks down

Trust and the Futility Debate

Why would patients want a treatment that is futile?
- They don’t believe that it is futile
- Misunderstanding of the conditions, clinical endpoints, and chances of complication free survival
- Informed consent is not clear
- Patients don’t believe their doctors; distrust
- Patients exhibit pure denial


Trust and the Futility Debate

- If patients don’t trust doctors to begin with, then doctors’ claims to a unilateral right to make decisions to withhold life-sustaining treatment will only exacerbate an already tense and hostile situation.
- Patients who believe that there is hope, and look to their doctor to affirm that belief, will not only reject a futility assessment but will likely reject the doctor that is making the assessment as well.


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Is it all just a question of money?

- Futility debates rarely arise around therapies that are cheap and easy to provide
- Arguments about futile therapy take on significance only when millions are at stake
- “Given limited resources it is ethically justifiable to limit access to treatments that are expensive and offer minimal benefit”
- Doctors will be subjected to financial conflicts of interest between their loyalty to their patients, their loyalty to their organizations, and their social responsibilities. At risk is whether or not our patients continue to trust us

Would futility guidelines save money?

“The low frequency of futile in an adult intensive care unit setting.”

“The frequency of futile interventions appears to be low unless one is willing to accept a definition that includes patients who could survive for many months... This suggests that concepts of futility will not play a major role in cost containment.”

“What about the chronic vegetative state?”

Would futility guidelines save money?

“Resource consumption and the extent of futile care among patients in a pediatric intensive care unit setting.”

“Despite our use of broad definitions of medical futility, relatively small amounts of resources were used in futile PICU care... attempts to reduce resource consumption in the PICU by focusing on medical futility are unlikely to be successful.”
Patients Demands for Futile Treatments

• Reimbursement incentives have changed
  – Offering futile treatments lose money for caregivers and institutions.
  – Shifted responsibility to limit excessive treatment given limited resources
  – Some believe that “decisions by doctors to curtail use of those treatments are socially responsible”
  – “In such a world, the need to separate our obligations and to be honest with ourselves about which master we are serving, will become more and more important. It will determine whether or not our patients can continue to trust us.”

What’s underneath the futility debate?

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Hope

• The issue of “miracles”
  – David Hume: “A miracle is a suspension of a law of nature”

• Is hope just a denial of the facts?

“Hope is a state of mind independent of the state of the world. If your heart is full of hope, you can be persistent when you can’t be optimistic. You can keep the faith, despite the evidence, knowing that only in so doing does the evidence have any chance of changing. So, while I’m not optimistic, I’m always very hopeful.”

Reverend William Sloane Coffin, as interviewed on NPR radio in 1994

Hope has nothing to do with probabilities

Eric Cassell, MD
The author of The Healer’s Art, The Place of the Humanities in Medicine, Changing Values in Medicine, two volumes on doctor patient communication entitled Talking with Patients, Doctoring: The Nature of Primary Care Medicine, and The Nature of Suffering, now in its second edition. The Nature of Healing is in the works.

“The Anatomy of Hope”
What’s underneath the futility debate?

- Power
- Trust
- Money
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Integrity

- In some cases, clinicians experience moral distress from the belief that their efforts to keep patients alive are profoundly wrong.
- “Moral distress is psychological disequilibrium that occurs when the ethically right course of action is known but cannot be acted on.”

Integrity – “I often equate my job with ‘keeping dead people alive.’ On these days, I dread coming to work.”
- “I’m scared that I’m causing undue pain and suffering, and this causes me great distress.”
- “Some days I feel (physically) sick.”


Resolution?

Is there a way to identify reasonable limits to what patients and families can demand, while adequately respecting different values and perspectives?

Attempts to define “Futility”

- Bedfast metastatic cancer
- Child’s class C cirrhosis
- HIV infection with > 2 episodes PCP pneumonia
- Dementia, requiring long term care
- Coma lasting > 48 hours
- Multiple organ failure with no improvement for > 3 days
- Unsuccessful out-of-hospital CPR


Attempts to define “Futility”

- When physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of published empirical data) that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile.
- If a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile.

The Failure to Define Futility

- This insight lies behind the movement to develop procedural rather than definitional approaches to determining futility.
- Judgments of futility cannot be made by reference to rules or definitions, but must be determined on a case by case basis.

Futility Policy: Children’s Hospital Boston

- Requires ethics committee consultation
- Requires attempts to transfer patient
- Requires that family be informed of legal options
- Offers to pay for legal representation if the family cannot afford the cost
- Permits unilateral decision-making

Beyond Hospital Policy…

- Some states are now adopting futility legislation
- These laws follow the procedural approach that has been developing in hospitals
- Most of the experience so far has been in Texas

Texas Advance Directives Act

- The physician’s refusal to treat must be reviewed by a hospital ethics committee.
- The family must be given 48 hours’ notice and be invited to participate in the process.
- The hospital must make reasonable efforts to transfer the patient’s care to others.

Advantages of the Texas Law

- Even families who vigorously argue for maintenance of life-sustaining treatments, sometimes seem relieved by the process:
  - "If you are asking us to agree with the recommendation to remove life support from our loved one, we cannot. However, we do not wish to fight the recommendation in court, and if the law says it is OK to stop life support, then that is what should happen."
Baby Robert: coda

- Full resuscitation attempted
  - Ventilated through trach, CPR performed
  - Multiple failed attempts at PIVs, CVLs, Ios
- Code called after ~15 min
- Family notified
- Dr. Truog met with the family

A cost / benefit approach

- Benefit
  
  “Even though we understand that you think it would be totally useless, all we are asking is for you and your team to spend 20 minutes doing CPR. This will be of enormous help to our family in coping with our loved-one’s death and in feeling reassured that “everything” was done.”

A cost / benefit approach

- Costs to Society:
  - Money & resources
- Costs to Patient and Family:
  - Patient suffering
  - Patient dignity
- Costs to Caregivers:
  - Moral distress for caregivers
  - Caregiver burnout

Conclusions

- Clinicians have no obligation to offer treatments that do not offer a benefit
- Futility policies are ethically defensible
  - Legislation is probably necessary to make them effective
  - But the laws need to protect against the “tyranny of the majority”
- Clinicians have no obligation to offer futile CPR, but sometimes the cost / benefit ratio may make it permissible to do so
If the talk ended here…

- Since futility judgments –
  - Are often a power-play by clinicians to enforce their values on power-less patients and families
  - Are used as a trump card when trust has broken down in the patient-physician relationship
  - Can squash whatever therapeutic value there may be in hope, however irrational it may seem
  - Will save very little money under even the most optimistic of circumstances…

Futility judgments should have no role in limiting treatments for patients and families who want them

Problems with the Texas law

- Hospital ethics committees have sole authority to decide whether treatment is futile
  - Most members are physicians, nurses, etc.
  - Even “community members” are not impartial
- Families have no legal recourse
  - Judges can extend date to find alternative providers, but cannot change judgment
  - Denies “due process” protections to those who hold unpopular values

Where should we go from here?

- Most important: any unilateral decisions represent a failure of shared-decision making
- Although the actual legal risk is low, few physicians will act unilaterally without civil & criminal immunity
- Legislation is needed

The Texas law can be “fixed”

- Extra-judicial committees and procedures can be both fair and effective, but…
  - They must be fully independent of the clinicians and the hospital
  - They must permit limited access to court appeal (eg, for issues of process, not substance)
Is It Always Wrong to Perform Futility CPR?

Robert H. Young, M.D.

Although there is currently much debate about the types of cases in which patients are enrolled, one thing on which everyone can agree is that non-therapeutic care would be ethically correct although unethical if the patient were a child.