REQUESTS FOR POTENTIALLY NON-BENEFICIAL TREATMENT

Disclosure of ABIM Service: Robert Macauley, MD

- I am a current member of the Test-Writing Committee on Hospice and Palliative Medicine.
- To protect the integrity of certification, ABIM enforces strict confidentiality and ownership of exam content.
- As a current member of the Test-Writing Committee on Hospice and Palliative Medicine, I agree to keep exam information confidential.
- No exam questions will be disclosed in my presentation.
Hippocrates on the Goals of Medicine

Doing away with the suffering of the sick, lessening the violence of their diseases, and refusing to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless.

History of Futility

- Pre-mid-20th century
  - Physicians simply wouldn’t mention/off offer things they didn’t think would help
- Mid-20th century: Shift toward patient autonomy
  - Recognition of importance of informed consent
    - First in battery law, then in negligence law
    - Coincided with other “rights” movements
- Right to refuse treatment
  - American Hospital Association Patient Bill of Rights (1973)
  - California Natural Death Act (1976)
  - In re: Karen Ann Quinlan (New Jersey Supreme Court, 1976
    - Competent patients have the right to reject medical treatment
Positive and negative rights

- Negative rights are those of non-interference
- Positive rights are *entitlement* rights
  - Which incur the obligation for someone else to assist in acquiring what someone has a “right” to

Extending rights

- The “right to die” was originally a negative right, and some have attempted to expand that to a positive right (i.e., “medical aid in dying”)
  - Which we’ll cover in the other session
- But here we’re talking about extending the negative right to physicians
  - The “right to die” movement was about patients having the right to say no. Do physicians have the same right?
The Futility Movement

• Literature
  – 1987: First reference to “futility”
• Position statements
  – 1987: Hastings Center
  – 1990: Society of Critical Care Medicine
  – 1991: American Medical Association
• Legislation
  – 1999: Texas Advance Directive Act

Texas Advance Directives Act (1999)

• Hospital ethics committees authorized to function as courts in reviewing requests for “futile treatment”
• Process
  – “Futile” request for treatment is reviewed by hospital ethics committee
  – Family given 48 hour notice to participate in the committee consultation
  – If ethics committee concurs with physician, family has 10 days to identify a facility willing to accept transfer
  – If no transfer after 10 days and no court order for extension, then a unilateral decision to withdraw treatment
No Ethical Obligation to Provide “Futile” Interventions

Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them.

American Medical Association Code of Medical Ethics (1994)

Medline References to “Futility”
Problems

• Definitions
• Reasoning backward
• Implementation
Medical futility’s many definitions

Futility has a “variety of meanings ... including the narrow sense -- physiologic inefficacy and inability to postpone death -- and a broad sense -- inability to prolong life for a time, inability to maintain an acceptable quality of life, very low probability of achieving any one of the foregoing.”

Youngner, "Who Defines Futility?"  
*JAMA* 1988
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Physiologic
Qualitative (normative)


Probabilistic
Futility’s Many Definitions

- **Physiologic futility**
  - The procedure **definitely** won’t achieve its goals
  - E.g., IV medications in an asystolic patient who has refused chest compressions

- **Probabilistic futility**
  - The procedure is very **unlikely** to achieve its goals
  - E.g., out-of-hospital CPR

- **Qualitative futility**
  - Even if the goal is achieved, it may not be worth it
  - E.g., artificial nutrition in a PVS patient

Futility is Defined by the Patient’s Goals

- Something is **futile** if it won’t achieve its goal
  - A certain procedure may be “futile” for one patient and not for another
  - E.g., endotracheal intubation may be useful in a patient who wants to survive at all costs, but futile in a patient whose goal is comfort care

- **Futility is inherently a value-laden term.**
  - It’s not a question of physiological effect, but rather **benefit**
  - “Benefit” as defined by the patient
Problems

- Definitions
- Reasoning backward
- Implementation

Reasoning backward

- If an intervention has a 1:1,000 chance of saving a patient’s life
  - Physicians likely would not want to provide it
  - But if it’s the patient’s *only* chance at survival, the patient/family might well request it
- There are only three reasons not to provide a potentially beneficial treatment
  - Patient/surrogate refusal
  - Rationing
    - Otherwise known as “the R-word” in the United States
  - “Futility”
Elegant Logic

a. Physicians aren’t obligated to provide “futile” treatment.
b. Treatment ___ is “futile”.
c. I am not obligated to provide ____.

**Futility**: the “F-word” in medical ethics.

Physicians’ Assessment of Futility

McCary et al., *J Clin Ethics* 5 (1994):100-4
Physicians’ Assessment of Futility

Percentage of physicians selecting cutoff point

McCrary et al., J Clin Ethics 5 (1994):100-4

Problems

• Definitions
• Reasoning backward
• Implementation
“So how’s TADA working out?”

— Question I posed over lunch to Director of Ethics at large Texas hospital

“Well, if you don’t count having to move your family to a secure location under cover of darkness, I’d say pretty well.”

BETWEEN 1987, WHEN THE CONCEPT OF “MEDICAL FUTILITY” was debated in the medical community with a seriousness that few philosophical concepts elicited, and 1999, when 124 articles on the topic were published, and has subsequently vanished, a Medline search of the key word “futility” for the year 1999 yielded only 21 articles. The movement to establish a policy on futile treat-
ment was an attempt to convince society that physi-
cians could use their clinical judgment or epidemi-
ologic skills to determine whether a particular treat-
ment would be futile in a particular clinical situation. The idea was that once such a determination had been made, the physician should be allowed to withhold or withdraw the treatment, even over the objections of a competent patient.

In this article, we analyze the rise and fall of the “futility movement.” Broadly speaking, discussions of futility can be grouped into four categories: attempts to define medical futility, attempts to resolve the debate with the use of empirical data, discussions on the limits of the autonomy of patients and the autonomy of physicians, and attempts to develop a process for resolving disputes over futility.

Pain care in hospitals is still very much an issue, yet doctors today are no more empowered to de-
terminate a treatment futile unilaterally than they were 15 years ago.

ATTEMPTS TO DEFINE FUTILITY

ed a patient’s total dependence on intensive medi-
cal care.2,8

Using these definitions, Schneiderman et al. ar-
gued that once a treatment has been deemed futile, medical professionals have no ethical obligation to provide it. Their underlying assumption was that just as a physician can choose not to treat a patient who does not necessarily benefit the patient, this discretion between an option and a benefit becomes an in-
thetical question. With and without an ex-
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terminate a treatment futile unilaterally than they were 15 years ago.
So What Happened?

- We couldn’t agree on the definition
- Even if we had agreed on the definition, we couldn’t agree on who should apply the definition
- Even if we had agreed on the definition and who should have applied it, we couldn’t agree on what to do when people disagreed on the final decision
- So we gave up, and fell back on narrowly defined procedural policies that are rarely used
  - Except in Texas
- Ultimately, our discussion of futility was futile (depending on your definition and who applies it)
Medical Futility in End-of-Life Care (AMA, 2005)

When further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure. However, there are necessary value judgments involved in coming to the assessment of futility. These judgments must give consideration to patient or proxy assessments of worthwhile outcomes.

But then people started talking about it again
Why are we interested in futility again?

Medline References to "Futility"

Why are we interested in futility again?

Health Care Spending as a Percentage of GDP, 1980–2013

* 2013.

Notes: GDP refers to gross domestic product. Data and Swiss data are for current spending only, and exclude spending on capital formation of health care providers.

Source: OECD Health Data 2015.
Consensus recommendation #2

• Use “potentially inappropriate,” rather than “futile”
• Advocate for an appropriate treatment plan
• Continued requests should be managed by a fair process
  1. Enlist expert consultation to continue negotiation during the dispute resolution process
  2. Give notice of the process to surrogates
  3. Obtain a second medical opinion
  4. Obtain review by an interdisciplinary hospital committee
  5. Offer surrogates the opportunity to transfer the patient to an alternate institution
  6. Inform surrogates of the opportunity to pursue extramural appeal
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Consensus recommendation #3

Clinicians should not provide “futile” interventions (i.e., those that won’t achieve the physiologic goal).

Clinicians should not provide “legally proscribed” or “legally discretionary” non-beneficial treatments.
Consensus recommendation #4

The medical profession should lead public engagement efforts and advocate for policies and legislation about when life-prolonging technologies should not be used.

Consensus recommendation #1

Institutions should implement strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of expert consultation.
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Consensus recommendation #1

Institutions should implement strategies to **prevent** intractable treatment conflicts, including **proactive** communication and **early** involvement of expert consultation.

Steps to prevent “futility” conflicts
Steps to prevent “futility conflicts”

**DO**
1. Address legal concerns
2. Clarify patient goals
3. Offer recommendations with those goals in mind
4. Take into account burdens as well as benefits
5. Utilize informed assent

**DON’T**
1. Dwell on treatments which do “not have a reasonable chance of benefiting the patient”
2. Use the F-word

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**DO address legal concerns**

- In the U.S., if a family sues to keep treatment in place, they’ll usually win
  - But they usually don’t sue
- If a family subsequently sues because treatment was withdrawn and patient died, they generally won’t win
  - Unless the physicians were really callous

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DO clarify patient goals

- Recognizes that benefit is defined by the patient’s goals
- Time-intensive (in the beginning)
  - Time-, effort-, and pain-saving in the end
  - Ideally involves Interdisciplinary Team
- Verify that goals are
  - Real: a specific treatment is rarely a goal in itself
  - Realistic (i.e., achievable)
DO offer recommendations based on those goals

- Recommend treatments that are consonant with the patient’s goals
  - Apply expert knowledge and perspective
- Seek confirmation, engage in dialogue
- Not paternalistic
  - Recognizes physician’s fiduciary responsibility

DO take into account burdens as well as benefits

- Most potentially non-beneficial treatment also incurs suffering or loss of meaning
DO utilize informed assent

- Provide full information about risks and benefits
- Convey specific recommendations about medically proposed course
  - Inform patient/family that they are entitled to accept medical team’s recommendations
  - Clearly indicated that patient and family are entitled to disagree


DON’T dwell on non-beneficial treatments

- We don’t need to focus on things we’re not going to be doing for the patient
  - Instead focus on what we will be doing, to help achieve the patient’s goals
- How did CPR become a universal human right?
- Cautions
  - Focus on individual patient (not rationing, one patient at a time)
  - Requires significant self-reflection to determine bias (a.k.a. “qualitative futility”)
Categories of disclosure

1. Withholding treatments that patients/families are not likely to expect for the patient’s specific condition
   - Ex lap for dying patient is MSOF
2. Withholding treatments that are clearly not indicated but that most patients/families have come to expect
   - CPR
3. Withdrawing a therapy no longer indicated


DON’T use the F-word

• We might think we know what we mean by it
  - Although we probably don’t
• But to patients and families, it sounds like we’re saying, “It isn’t worth our effort to try to save this patient.”
Case

• A 78-year-old patient with oxygen-dependent chronic obstructive pulmonary disease presents to the Emergency Department in acute respiratory distress. He has no advance directive and no family is present. He is intubated and admitted to the ICU.

• When his family arrives, they state that he is a “fighter” and has pulled through defied gloomy expectations in the past.

• They identify his primary goals as living at home and not being dependent on other people.

• They demand maximal treatment.
Case

1. What questions should you ask?

2. What treatments should be offered?

3. What treatments should not be offered?

4. What do you do if the family does not concur with your recommendations?