A. Patient Versus Physician

The futility debate is sometimes characterized as simply a decision about whether the doctor’s or the patient’s values will triumph.225 Such a characterization is misleading in a number of respects. It is at best unhelpful to suggest that the debate over futility is a dispute between the doctor and her patient, because it may in fact be others who are setting the criteria for futility—medical boards, Congress, an administrative agency, the American Medical Association, or society at large.226
“Why futility policies are not the answer”
- Discusses BANEC guidelines and concerned that it keeps the existing imbalance of power between physicians and patients.

“Respect for patients should dominate health care decisions”
- Supports BANEC guidelines “as an important addition to the growing number of community policies”
Are Futility Policies Good for Patients?

General Reference (not clearly pro or con)

Paul Heff, MD, Director of Fairbanks Center for Medical Ethics. Mark Siegel, MD, Professor at the University of Chicago and John Lantos, MD, Professor at the University of Chicago, wrote in their July 27, 2000 article, "The Rise and Fall of the Futility Movement," that appeared in the New England Journal of Medicine:

"The movement to establish a policy on futile treatment was an attempt to convince society that physicians could use their clinical judgment or epidemiologic skills to determine whether a particular treatment 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."

July 27, 2000 - Mark Siegel, MD ★★★
John D. Lantos, MD ★★★
Paul Heff, MD ★★★

Grace Huffman, MD, Associate Medical Director at Brooke Grove Retirement Village, wrote in her Oct. 1, 1999 article, "Considering Futility of Care: Report of a Fair Process," that appeared in the American Family Physician:

"Defining when medical care is considered ‘futile’ for critically ill patients continues to be a challenging and controversial dilemma for physicians. The Council on Ethical and Judicial Affairs of the American Medical Association recently recommended a process by which determinations about futility may be made for patients with life-threatening illnesses. However, the Council was careful to avoid specifying what does and does not constitute futile medical care.

Claims of futility often increase when the patient, the physician and family members disagree on the goals of treatment... The law does not appear to favor either side consistently. In some cases, the court has sided with the patient’s (or proxy’s) right to choose care that has not been recommended by the physician. In other cases, the court has agreed that physicians do not have to provide care that is considered medically futile."

Oct. 1, 1999 - Grace Huffman, MD ★★★

Are Futility Policies Good for Patients?

<table>
<thead>
<tr>
<th>PRO (yes)</th>
<th>CON (no)</th>
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<tbody>
<tr>
<td>Tom Tomlinson, PhD, Director of the Center for Ethics and Humanities in the Life Sciences at Michigan State University, and Diane Czolajka, Staff member of the Michigan State</td>
<td>Wesley Smith, JD, Consultant to the International Anti-Euthanasia Task Force, wrote in his 1998 article &quot;Futile Care Theory and Medical Fascism: The Duty to Die,&quot; that</td>
</tr>
</tbody>
</table>
Sec. 166.046. PROCEDURE IF NOT EFFECTUATING A DIRECTIVE OR TREATMENT DECISION. (a) If an attending physician refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient, the physician's refusal shall be reviewed by an ethics or medical committee. The attending physician may not be a member of that committee. The patient shall be given life-sustaining treatment during the review.

Texas lawmakers have grappled year after year over whether families or medical professionals should decide when to end a terminally ill patient's life-sustaining care. This year, they seem closer to a compromise.
Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes About Medical Futility

Robert L. Fine

_Chest_ 2009;136;963-967
DOI 10.1378/chest.09-1267

The online version of this article, along with updated information and services can be found online on the World Wide Web at: http://chestjournal.chestpubs.org/content/136/4/963.2.full.html

Counterpoint: The Texas Advance Directives Act Is Ethically Flawed

Medial Futility Disputes Must be Resolved by a Fair Process

Mr. J.’s case and cases like it are among the most frustrating problems experienced by clinicians.

Rebuttal From Dr. Fine

I thank the editors and Dr. Truog for the opportunity to participate in this debate and hope our readers find it enlightening. The major argument leveled against the TADA is that it “excludes the involvement of the courts” and may be unconstitutional. The law does not exclude the courts, but directs the court to review matters it is most qualified to judge: compliance with procedure, not medical decision making. The most recent court arguments against TADA occurred in the Gonzales case that Dr. Truog previously criticized. Plaintiff’s attorney alleged TADA violated both

Rebuttal From Dr. Truog

Robert D. Truog

_Chest_ 2009;136:972-973
DOI 10.1378/chest.09-1270
Not dead yet? 2013

Show
What does NDY say about ...
Show

posted on AUGUST 1, 2013 by STEPHEN DRAKE

Diane Coleman P
Futility at July 25
A growing resistance? April 2014

Dialogue Begins About Feeding Tubes and Breathing Devices With Respecting Choices Program

Last December, a significant number of national and local disability rights organizations as well as individuals with disabilities and supporters signed onto a letter addressed to the Respecting Choices advance care planning program at Gunderson Health Systems in LaCrosse, Wisconsin. The letter criticized two documents for inaccuracy and bias in their discussions of feeding tubes, bipaps and ventilators. The documents were first discovered by Second Thoughts Connecticut activist Stephen Mendelsohn.
WITHDRAWING OR WITHHOLDING MEDICALLY INAPPROPRIATE LIFE SUSTAINING TREATMENT

Defined

- UCLA Healthcare also supports the principle that health care providers are not required to offer or continue to provide any medical treatment that is medically ineffective or contrary to generally accepted health care standards referred to in this Policy as “medically inappropriate treatment”) as described in California law.

Examples provided: The following are examples of medically inappropriate treatment: a). Medical treatment that serves only to maintain survival in an intensive care unit without the reasonable possibility of prolonging life in a non-comatose state; or b). Medical treatment without the reasonable possibility of clinical improvement to live outside of an intensive care unit. Inappropriate medical treatment may cause undue suffering, loss of dignity, or unnecessary pain for the patient. This means that some patients will not be offered treatment that they might want, even if previously specified.

- Clear responsibilities for physician, nurse, and social worker or chaplain
- Clearly defines unique criteria for infants (<1 year old)
- “Reasonable” efforts for transfer and reasonable time for court
Medically Ineffective (Futile) Treatment

- Defined?

Medically Ineffective Treatment
“Medically ineffective” refers to treatment which would not offer the patient any significant benefit. If an attending physician believes treatment is not medically ineffective and assumes care of the patient, treatment is not considered medically ineffective.

- Requires ethics consult
- Requires attending physician documenting clinical rationale
- Reasonable time-limited opportunity
- Physician and/or hospital to assist in the transfer
  - Unless patient/surrogate refuses assistance
KP Socal Experience

Background: In 2007 adapted parts of the VA integrated ethics model

- Started process for hiring medical bioethics directors at each SoCal KP Facility
- Quickly there was a request to consider developing our own nonbeneficial treatment policy.
  - In general physician members desired to wait on developing a policy
    - Concerned about appearance of conflict of interest
    - Importance of having a wider community standard was emphasized
    - Recommended to wait until a CMA statewide model policy was completed.
- In general bioethics directors desired to develop a policy
  - To ensure a standardized process would be available to patients and staff regardless of which KP facility a member might be admitted.
  - Reasonable to wait until the CMA completed a model policy
Approved a local nonbeneficial treatment policy in 2009 based on a ‘fair and explicit’ process.

Goal was to “create ‘moral space’ for patients, families, and the treatment team by nurturing shared decision making…”

- Pol'y re'd on quality conversations

Qualitative retrospective evaluation of consults from November 2009 to August 2012

- 146 cases had treatment level conflict, in 92 of the cases the process outlined in the policy was invoked.
- At 1st meeting 70 cases had resolution (22 left) – second opinion then obtained
- At 2nd meeting 9 cases had resolution (13 left) – formal ethics consultation then obtained
- At 3rd meeting 8 cases had resolution (5 left) – Unilateral decision then made
KP SoCal Development Process

- Subcommittee on Policy Suggestion (SOPS) convened after CMA published their model policy. SOPS then developed and finalized a draft policy modeled after the CMA policy.
  - Discussed and reviewed for many months
- Forwarded to entire regional bioethics committee
  - Discussed for another year (or two).
- Forwarded final version to multiple KP stakeholder groups for review
- Adopted late 2013 as a regional policy.
- Sent to local hospitals for individual facility adoption
  - In process…
KP SoCal Policy Overview

- Covers both nonbeneficial treatment or contrary to generally accepted medical standards.
- Designed to encourage communication
- 5 definitions for non-beneficial treatment
  - Ineffective for producing the physiological effect desired
  - Cannot be experienced by the patient as furthering their expressed and medically obtainable goals.
  - Harm > Benefit
  - No realistic chance of returning the patient to a level of health that permits survival outside of a general acute care hospital.
  - Permanently unconscious unless there is evidence that the patient would value remaining alive in that state.
Step 1 – Identify non-beneficial treatment (any medical team member can feel it is in their professional judgment).
- Consider ethics consultation early in the process
- Notify attending physician that makes the determination and should facilitate consensus and understanding among the team members (implies care conference among the medical team 1st)
- Family mtg #1 is held and documented. Any non life-sustaining interventions can be stopped or not offered at this point while awaiting further steps.

Step 2 – Offer 2nd opinion from another KFH physician with needed expertise. Should be documented.
- Found to be ‘not non-beneficial’ this physician should be willing to assume care or should be transferred to another physician or facility
- Else Family mtg #2 is held with attending.
Step 3 – Ethics consultation for formal Ethics Review

- At least 3 members, at least one physician and one non-physician
- Documentation in the medical record with recommendation based on the ethical values and moral factors directly related to the non-beneficial treatment being discussed.
- If supporting the previously identified non-beneficial treatment then the ethics review should identify the medical team that is willing to provide the treatment within a reasonable time period.
- If does not support continued non-beneficial treatment (i.e. agrees with the initial physicians determinations) then patient/surrogate informed and if desired transfer attempts should be made.
  - Attending physician to use clinical judgment whether to continue non-beneficial treatments already initiated.
  - If not transferable or not desired appropriate time provided to allow family to gather at the bedside.
KP SoCal Policy
Draft Flowchart

Responding to Requests for Non-Beneficial Treatment (NBT)

The complete policy can be found on Docshare and should be reviewed at onset.

* Indicates an ideal time for an ethics consultation

However, Ethics may be consulted at anytime

Ethics Review assesses, provides a recommendation, & Documents

Transfer Patient with Hospital Assist

Ethics Review will work Medical Team willing to continue Tx

Patient/LH/CM selects facility that will accept

Discontinue NBT, giving reasonable time for family to gather at bedside

2nd Opinion (Reviewing Physician) reviews to consider NBT
Documents Review

* Offer 2nd Opinion: Document 1st meeting outcome

Consensus?

Consensus?

* Care Conference with Patient/LH/CM and Attending + Reviewing Physicians

Green = Decision Maker
Yellow = Involve Ethics

Red = Normal Process

 Agree NBT?

No

Yes

No

Yes

Blue = End Step

Continue to Offer Tx

No

Bezoans initiate Ethics Review

Decision Possible?

Yes

Ethics Review explains Tx (not medically appropriate) will not be offered

Care Conference with Patient/LH/CM

Document that you consider Tx to be NBT in medical record

Care Team with Patient/LH/CM

Determine Tx to be NBT

Consider Ethics Consultation

Criteria

“Non-Beneficial Treatment” (NBT) is any treatment that a physician determines, in the exercise of his or her professional judgment:

1. Will be ineffective for producing the physiological effect that the Patient/LH/CM desires or expects of the medical treatment; or
2. Will produce no effects that can reasonably be expected to be experienced by the Patient as furthering the Patient’s expressed and medically obtainable goals; or
3. Will cause harm to the Patient, significantly disproportionate to the benefit; or
4. Has no realistic chance of returning the Patient to a level of health that permits survival outside of a general acute care hospital as defined in Health and Safety Code section 1259(a); or
5. Would serve only to maintain the Patient’s life in a permanently unconscious state, unless there is evidence that the patient would value remaining alive in that state.

No health care professional has an ethical obligation to provide or participate in the provision of a Non-Beneficial Treatment.
Patients who make wrong choices

Robert Macauley, MD

- There are goals beyond that of respect for autonomy, goals that may appear at first glance to be universally held and thus uncontentious. For example, “The goal of palliative care is to prevent and relieve suffering.”
- In reality there are situations where patients or families opt for treatment plans whose burdens outweigh the benefits. Somewhere between choices that are understandable though not recommended, and those that are clearly futile, lie informed decisions that are overwhelmingly inadvisable.
- Such a patient presents the clinician with an impossible choice: either respect the patient’s wishes, or minimize suffering. This dilemma brings to mind the opening stanza of Dylan Thomas’s famous poem: ‘Do not go gentle into that good night, Old age should burn and rage at close of day; Rage, rage against the dying of the light.’ Which, in turn, prompts the question: Were more antipalliative care words ever written?”
- Rather than working with patient and family to achieve consensus may resolve this dilemma. Nevertheless, it is critical to note that implicit within this approach is the assumption that if such patients really understood what they were requesting, they wouldn’t request it.” … “Often, however, the basis of the patient’s choice is more emotional than cognitive.”
- Three care biases? “four areas where we have reached firm, yet ultimately questionable, conclusions:
  1. Patients should be comfortable with (or at least conversant in) death, just as we are.
  2. We pride ourselves on being persuasive communicators.
  3. We recognize the impact of suffering, and know what to do about it.
  4. We like to believe that our assumptions are universally held, and thus don’t constitute biases.”
- “often, we can do is share with the patient that it is difficult for us, too. Done in a sensitive fashion, this will ensure they know how much we care for them, even if they did not find our recommendations compelling. They’ll also know we’re ready to help them, if they decide to let us. In the end, we will have given the patient permission to be true to themselves (and their very un-palliative philosophy of life).”
Discussing Treatment Preferences With Patients Who Want “Everything”
Timothy E. Quill, MD; Robert Arnold, MD; and Anthony L. Back, MD

Step 1 – Understand what “doing everything” means to the patient

- Everything to prolong life even if only a small chance regardless of suffering?
- Everything has a reasonable chance of prolonging life even if it increases suffering
- Everything has a reasonable chance of prolonging life, but not if it would increase suffering
- Everything might provide maximum relief of suffering, even if it might unintentionally shorten life

Underlying meanings?

- Don’t give up on me. I’m scared of dying. I don’t want to leave my family.
- Do everything you think is worthwhile doctor. Don’t leave any stone unturned.
- I value every moment of life regardless of suffering (Does your faith provide any guidance in these matters?).
- I will leave my fate in God’s hands / I’m hoping for a miracle (How might we know when God thinks it is your time?)
Discussing Treatment Preferences With Patients Who Want “Everything”
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Step 2 and 3 – Propose a philosophy of treatment and then recommend a clear plan
- After meaning of “everything” has been explored, then propose a treatment plan consistent with the patient’s values and physician’s assessment of condition/prognosis.
- Given what we know about (both patient and illness), it sounds like…, I recommend… Does that make sense to you?
- Plans could include time limited trials, signs if treatments working or not, and options for various scenarios

Step 4 – Support emotional responses and reiterate commitment to continue care no matter what the future holds.
- These are difficult discussions
- Tell me what is the hardest part for you
- I can imagine that the future looks much less certain now that we had this discussion.
Discussing Treatment Preferences With Patients Who Want “Everything”
Timothy E. Quill, MD; Robert Arnold, MD; and Anthony L. Back, MD

➤ Step 5 – Negotiate disagreements
- Reevaluate understanding of patient’s values and philosophy to ensure a common understanding of his/her values.
- Reiterate assessment of condition and prognosis
- Look for common ground and try to invent new solutions that might accommodate all perspectives

➤ Step 6 – Use a harm-reduction strategy for continued requests for burdensome treatments that are very unlikely to work
- Some patients and families may value life extension much more highly than avoiding preventable suffering, other may have high distrust of the medical system, or other reasons. If this is clear continued attempts to negotiate limit setting is unlikely to be productive and may feel abusive.
- Propose honoring patient’s philosophy and request for CPR by providing it and stopping after 1 full cycle.
Concluding Thoughts

- Nonbeneficial treatment policies are best seen as tools to improve and standardize a process of communication (and not just to provide patients and physicians a fair process for conflict resolution).

- Controversy regarding policies or unilateral decision making will not likely go away despite a growing community standard.
  - This is seen with brain death definitions where there has been a national community standard (allowing for some tiny differences in a handful of states) but not yet a globally agreeable standard despite decades of experience.