The Futility of Futility: How to Address Goals of Treatment

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Conflicts of Interest

- No monetary conflicts of interest

Disclosure

This lecture will not:

- Provide any easy answers to difficult cases
- Does not contain the magic bullet

This lecture will:

- Provide some direction on how to approach these cases

Case 1

- A is a 4 year old boy who was involved in a motor vehicle accident
  - Severe traumatic brain injury and high cervical spine injury
- Prognosis
  - Very unlikely to have meaningful neurologic recovery
  - Quadriplegic / ventilator dependent
- Parents would like to pursue aggressive treatment
  - Tracheostomy and ventilator dependence
  - Facility placement
- Is this treatment futile?

Case 2

- B is a 43 year old female with metastatic pancreatic cancer and chronic blood loss from tumors in her bowels.
  - No longer receiving chemotherapy or any other treatment for her cancer
  - Requiring 1 unit of packed red blood cells every 2-4 days depending on the rate of bleeding
  - Hospitalized for pain control and ongoing anemia
- B would like to continue receiving intermittent blood transfusions
- Is this treatment futile?

Case 3

- C is a 64 year old male with advanced liver failure, which has progressed to multisystem organ failure
  - Intubated, altered, on dialysis, requires frequent blood products
  - Not a candidate for liver transplant
- His wife is his DPOA-H and requests aggressive treatment
- Patient and wife were Christian missionaries for many years – she believes that God would not want her to limit treatment
- Is this treatment futile?

Medical Futility

Interventions that are unlikely to bring about benefit to the patient

- Physiologic futility
  - Antibiotic to treat viral infection

Medical Futility

Interventions that are **unlikely** to bring about benefit to the patient

- Quantitative futility
  - Likelihood that the intervention will succeed is very low

Medical Futility

Interventions that are unlikely to bring about **benefit** to the patient

- Quantitative futility
  - Likelihood that the intervention will succeed is very low
- Qualitative futility
  - Quality of the benefit to the patient is very poor

Medical Futility

Interventions that are unlikely to bring about benefit to the patient

- Quantitative futility
  - “I don’t think the intervention will work”
- Qualitative futility
  - “Even if the intervention works I don’t think it will help you”

Medical Futility

Interventions that are unlikely to bring about benefit to the patient

- Quantitative futility
  - “I don’t think the intervention will work”
  - Physicians are quite poor at prognostication
- Qualitative futility
  - “Even if the intervention works I don’t think it will help you”
  - Physicians and patients have different perceptions of quality of life

Medical Futility

- Easy to define, difficult to apply
- Easier for those in power (i.e. clinicians) to carry out life-altering decisions based on:
  - Subjective perception of futility
  - Commonly accepted values
- How to protect the vulnerable?
- Are there justifiable but competing values to argue for treatment?
- Who ultimately decides?
  - What if clinician disagree?

Medical Futility

- Can be used inappropriately as a bludgeon
- Discourages communication
  - Adversarial instead of collaborative
- Could promote inappropriate use of courts
- Removes the focus from the patient

Medical Futility

- Futility cases isn't really about "futility" but a fundamental disagreement about values
- Futility is goal dependent
  - If it achieves the goal, it is not futile
  - Goal may be ill-advised
- Don't use the word "futility"
  - Potentially inappropriate treatment (PIT)

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Gabriel T. Bosslet, Thaddeus M. Pope, Gordon D. Rubenfeld, Bernard Lo, Robert D. Truog, Cynda H. Rushton, J. Randall Curtis, Dee W. Ford, Molly Osborne, Cheryl Misak, David H. Au, Elie Azoulay, Baruch Brody, Brenda G. Fahy, Jesse B. Hall, Jozef Kesecioglu, Alexander A. Kon, Kathleen O. Lindell, and Douglas B. White; on behalf of The American Thoracic Society *ad hoc* Committee on Futile and Potentially Inappropriate Care

This Official Policy Statement of the American Thoracic Society (ATS) was approved by the ATS, January 2015, the American Association for Critical Care Nurses (AACN), December 2014, the American College of Chest Physicians (ACCP), October 2014, the European Society for Intensive Care Medicine (ESICM), September 2014, and the Society of Critical Care Medicine (SCCM), December 2014

Bosslet, *AJRCCM*, 2015

Potentially Inappropriate Treatment

- Do not provide physiologically inappropriate treatment
- Focuses on the patient (or family) and the patient's (or family's) goals
- Does not shut off communication
  - Potentially inappropriate
  - Encourages further inquiry
  - Acknowledges other valid viewpoints
- Goal is to have a deliberative, multidisciplinary, and transparent process to attend to these questions
- Communication is what is heard, not said

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Case 1

- A’s parents are hoping for any neurologic recovery
  - They are ok with sustaining A’s life with technology to give him a chance to recover
- Doctors are “too negative”
  - A will prove the doctors wrong
- “I want to feel like I’ve given A every single chance”

Case 2

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Case 2

- B has three young children and would like to spend as much time as possible with her family before she dies
  - Understands the blood transfusion will not cure her cancer
  - Wants blood as long as her pain control can provide her with enough lucidity to interact with her family

Potentially Inappropriate Treatment

- Why it may feel unsatisfactory to clinicians
  - Clinician fatigue
    - Loss of control
  - Justice / fairness
    - Limited resource
    - Family / patient are not “contributing” enough to justify cost
  - Existential angst
    - Burden / benefit
  - Slow trajectory of improvement
- When there are competing values – who decides?

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Potentially Inappropriate Treatment

- Do not provide physiologically futile treatment
- Practice good medicine
- Focus on the goal(s) of treatment
  - Time limited trial for reassessment
- Focus on whether the treatment goals are consistent with the patient's lived and stated values
- Communication is what is heard, not said
- Support the clinicians
  - Talk about potential biases

Case 4

- 11 month old male with spinal muscular atrophy type I
  - Parents do not want tracheostomy / ventilator dependence
  - Admitted with respiratory infection and respiratory insufficiency
- Parents requesting CPR with no intubation, at least 5 minutes of chest compressions, further intervention to be decided after 5 minutes
- First physician agreed, second physician refused, nursing staff stated they thought this was futile treatment

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Really Hard Case – Charlie Gard

- http://blog.practicalethics.ox.ac.uk/
- Born full term, healthy child
- Progressive muscle weakness starting at a few weeks of life
- Admitted to the hospital at 2 months and diagnosed with infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS)
- Paralyzed, required ventilator support, congenital deafness, other organs affected (heart, kidney, lung)

Really Hard Case – Charlie Gard

- Experimental treatment, never tried on humans and never tried on Charlie's particular variant of disease, could theoretically reduce the severity of disease
- Charlie developed seizures and the severity of his overall condition led his physicians to decide that he was not a candidate for this therapy
- Treating physicians recommended withdrawal of life sustaining treatment
- Parents disagreed, found a US physician willing to provide the treatment, and raised the necessary funds for travel

Really Hard Case – Charlie Gard

- Physicians asked the court for permission for withdrawal of treatment
- Ruling for withdrawal upheld to the highest levels → exhausted legal avenues of appeal
- Because of intense interest the court that issued the initial ruling agreed to look at the evidence / case again
- US physician examined Charlie and concluded it was too late for treatment to have worked
- Treatment was withdrawn and Charlie died

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Really Hard Case- Charlie Gard

- Who should determine burden / benefit for a child?
  - More beneficial to try than not to try at all?
  - More burdensome to try than not try at all?
- How does financial burden affect the final decision / outcome?
- Is the suffering physical or existential?
- How long does one wait for improvement?

Really Really Hard Case – Jahi McMath

- 13 year old female with obstructive sleep apnea
- Underwent tonsillectomy
- Post-operative bleeding → cardiac arrest
- Diagnosed with brain death → issued death certificate → protracted legal battle → moved to New Jersey
- Still on organ support 4 years later
- Family is suing to reverse death certificate