Exploring Futility and Non-beneficial Treatment

Disclosure Statement
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Objectives
- The Intractability of Futility and Non-benefit:
- Quantitative (thin) & qualitative (thick) futility
- The nature of Benefit
- Helga Wanglie – 30 years later
- Possible solutions to difficult clinical cases

The Classic Case of Helga Wanglie
- Helga Wanglie was an active, well educated woman of 85 when in Dec. 1989 she tripped over a rug & broke her hip.
- The hip fracture was successfully treated initially and Mrs W. was transferred to a NH.
- Alas, she was readmitted to HCMC in Jan 1990 when she developed respiratory failure and was placed on a ventilator. Mrs. W was unable to be weaned form the vent and was transferred to a facility that specialized in caring for respirator-dependent patients.
- While at the facility Mrs. Wanglie survived cardiopulmonary arrest.

Helga Wanglie (part 2)
- The family requested that Mrs. W be returned to HCMC where she was diagnosed to be in a persistent vegetative state. 20 to severe hypoxic-ischemic encephalopathy.
- The medical team viewed Mrs. Wanglie’s prognosis as “extremely poor.”
- Physicians approached family re: the withdrawal of her ventilator.
- Family requested, indeed insisted upon, continued “aggressive” care and
- An Ethics consultation was requested

Helga Wanglie/HCMC (part 3)
- The hospital maintains that the family cannot demand that physicians continue to provide treatment that they believe is not in the best personal or medical interests of the patient.
- Helga’s family understood that she was unaware of their visits, unaware of her surroundings and that she would never be free of her ventilator or tube feedings. Oliver Wanglie (quoted as saying
- “Only God can take life and doctors should not play God.”
- The hospital requested the court to appoint a conservator on behalf of the patient to consider non-treatment.
True or False?
- Treatments that offer no benefit and serve to prolong the dying process should not be offered nor continued.
  - What if there is disagreement about what constitutes a benefit?

Futility defined...
- The quality of not leading to a desired result.
- A technical judgment that a particular intervention will not produce the intended result.
- Those procedures that lack the ability to improve the prognosis for recovery (Barber v Superior Court)

The Conceptual Issue ...
- Medical futility the judged futility of medical care.
  - Four reasons for making this judgment are:
    - (1) to prevent patient suffering,
    - (2) to avoid a protracted death,
    - (3) to protect clinician integrity and
    - (4) to be good stewards of scarce resources

Futility continued ...
- Normative futility a judgment of medical futility made for a treatment that is seen to have a physiologic effect but is believed to have no benefit. (AKA qualitative)
- Physiologic futility a judgment of medical futility based on the observation of no physiologic effect of the treatment. (AKA quantitative)

Autonomy
- Respect for Autonomy - Respect (Honor) an individual’s right to self-governance
  - Positive Rights - the holder is entitled to some provision or special consideration.
  - Negative Rights - the holder is entitled to non-interference

John Stuart Mill, On Liberty (1859)
“That the only purpose for which power can be rightfully exercised over any member of the civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do for forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise or even right.”
Approaches to Resolving “Futility” Conflict:

- Replacing the Surrogate
- Goals of Medicine
- Transfer Care of Pt.
- Policy
- Standard of Care
- Justice & Fairness

Keeping Focus on Beneficial Treatment: Why is it so hard?

Exploring Futility and Non-beneficial Treatment

Purpose

- Discuss our “North Star”
  - Beneficial Treatment
  - Nonbeneficial Treatment (going South)
- Wandering
  - Professional Responsibility
  - Shared Decision Making
- What makes the Navigation difficult?

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Case

- October 27
- 77 yo w/f with a history of right occipital glioblastoma multiforme last year in May, resected partially in June and losing healthcare decision making capacity at that time.
- Radiation therapy and chemotherapy
- Tracheostomy performed about August this year to prevent aspiration
- Markedly diminished cognitive function
- Admitted to outside hospital after Cardiopulmonary arrest revived by paramedics.
Case
- Inferior myocardial infarction with depressed cardiac function, sacral decubitus, and UTI
- Examination clinically consistent with death by neurologic criteria
- EEG nonconfirmatory due to technical limitations
- Transferred 10/23
- On 10/24 pronounced dead.

Case
- The son represents:
  - Holocaust survivor
  - Member of a Chabad orthodox synagogue
  - Believes the patient would not have accepted a diagnosis of death on the basis of neurologic criteria.
  - Continue cardiopulmonary support until the heart stops or "a miracle" happens.
- The ICU physician: discontinue all medical interventions.
- Son and ICU physician independently request ethics review.

Case
- Patient's specific beliefs on this issue are unknown.
- But: "every member of this particular sect including my mother would agree to the decision from the Rabbi."
- Son declines to accept current medical and legal understanding.

Case
- Son says that his Rabbi has advised him not to accept a definition of death based on neurologic function.
In addition, the son advises that he has:
  - Retained an attorney
  - Community Support
  - Will take case public

Why hard?
Technical Aspects
- Physicians and Bad News: Fear of Failure
- Forms of Failure:
  - Loss of life
  - Disclosure of sensitive events
  - Finding the proper, empathic words

Why so hard?
Mythology of Death
- To come to accept ideas most difficult to understand:
  - The inevitability of individual death
  - Conscious awareness that all for whom we care will die
  - Combine with the idea of the enduring quality of the social order
- Versus: the individual cannot die or should not be allowed to die naturally
Why hard?
Unfamiliar Territory
- Goals of Medicine and of the profession are not generally taught
- Religious/Cultural expertise
- Moral distress when religion/beliefs conflict with ends of medicine: Ethical Concerns
- Legal Concerns
- Media Interaction

Futility
- Nonbeneficial
- Medically ineffective
- Medically inappropriate
- Inability to achieve a stated purpose
- A proposed medical intervention that can no longer serve the good of the patient

Hippocratic Corpus
“First I will define what I conceive medicine to be. In general terms, it is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless.”


The Good of the Patient
Medicine must be concerned with the “good” of the patient. As David Thomasma and I have emphasized elsewhere, the patient’s good is a compound notion. It is not synonymous with the patient’s medical good. Healing means “to make whole again.” Therefore, ascertaining and enhancing all four realms of the patient’s good are involved in healing—the patient’s biomedical good, his own conception of the good for him as an individual, his good as a member of the human species (i.e., the good for humans), and his good as a spiritual being (i.e., the good for the soul). The concept of wholeness, together with its asymptotic attainment through relationships between, and among, persons is the specific end of medicine. It is not an end proper to any of the sciences basic to medicine. But without a concept of healing, medicine as such does not exist.

—Edmund Pellegrino, MD (1920-2013)

Focus on Offering Beneficial Treatment
Promotes the good of the patient 4 perspectives:
- biomedical
- patient
- humanistic/societal
- spiritual

Healthcare as a Moral Enterprise
- The notion of doing “good” has a moral valence
- “Goals” or “Ends” of Medicine
- Define benefits that medicine ought to offer patients
- Delineate limitations
- Focus on healing the patient
Professional Responsibility
Those who practice medicine have an obligation to the profession to commit themselves to these goals. Those who do not, damage the profession.

Nonbeneficial (Futile) Actions
Actions which do not pursue the goals of medicine are not healing acts even when informed by medical knowledge and performed with medical skill.

Exercising Moral Agency
Patient permission does not make a morally wrong act right.
Patient insistence does not negate the right and responsibility of medical professionals to refuse to do that which is wrong.

Ethics Consultation
“Whether it is ethical to honor the request for a religious exception to the laws in California and our medical policies and procedures with regard to the diagnosis of death”

Ethics Review
- Rabbi unavailable to multiple calls
- Son declines to accept advice from another Rabbinical consultant
- Son begins to order nurses to change medications and provide treatments based on his understanding of physiology

Patient Autonomy has Limits
- Patients do not have an exclusive right to determine what counts as a benefit because such a right would eliminate the moral agency of the physician to determine which therapeutics should be offered (or not) to promote the good of the patient and consistent with the ends of medicine.
Professional Autonomy
- Arguments that insist that patients alone can define therapeutic goals and benefits ignore or deny core realities in the patient/medical professional relationship
- The moral agency of healthcare professionals
- The moral nature of medicine
- The responsibility of physicians to the goals of the profession

Shared Decision Making
Moral Agency
- Healthcare decisions: made by patients.
  - Accept or decline offered medical treatments or to change providers/delivery systems
- Medical decisions: made by physicians.
  - Which treatments should be offered/not offered.

So What Happened?
- Given specific time for planned extubation
- Dopamine was discontinued.
- A restraining order was sought by the son
- Discussion among the attorneys.
- Cardiac cessation

Focus
Treatment
Beneficial for the Patient