Managing Conflicts Around Medical Futility

Robert M. Taylor, MD
Medical Director, OSUMC Center for Palliative Care
Associate Professor of Neurology
The Ohio State University – James Cancer Hospital

Medical Futility - Definitions

- **QUANTITATIVE FUTILITY**
  - Treatment will not achieve desired physiological effect
- **QUALITATIVE FUTILITY**
  - Treatment may have desired physiological effect, but will not benefit the patient
    - Merely preserves permanent unconsciousness
    - Fails to end patient's total dependence on intensive medical care

Objectives

- Understand why medical futility is such challenging and distressing problem
- Develop approaches to managing conflicts around medical futility
- Learn ways to prevent intractable conflicts from developing
- Provide better care for seriously ill and dying patients and their families

Medical Futility: an Enduring Problem

- Improvements in medical technology
- Increased emphasis on respect for patient autonomy and surrogate decision-making
- Differences of opinion about benefits & burdens
- Lack of trust of physicians and hospitals
- Concerns about bias and discrimination
- Economic constraints
- Poor communication

Patient/Surrogate Refusals vs. Requests

- Patients and surrogates have a clear right to refuse medical treatments in most situations
  - Negative right - right to be left alone
  - "Every human being of adult years and sound mind has a right to determine what shall be done with his own body" - Benjamin Cardoza, 1914
- Right to demand treatment is less clear
  - Positive right - places demands on others
    - Our society does not acknowledge this distinction

Primary Sources of Conflict

- Dissociation of Benefits and Burdens
- Differing opinions about the value of Life-itself vs. Quality-of-Life (QOL)
- Differing stages of Grief
- Distrust

Common Features of Cases

- Patients with multiple co-morbidities
- Communication issues – limited information, language barrier, mixed messages, denial, etc.
- Family stressors
- Family dynamics – guilt, distrust, secondary gain, belief in miracles, various biases
- Value of life – quantity vs quality
- Conflicting perspective on goals

Benefit-Burden Analysis - 1

- What constitutes a benefit?
  - Survival, recovery, pain relief, etc.
  - Life itself?
- What constitutes a burden?
  - Pain and suffering, disability, physical distress etc.
  - Emotional and spiritual distress, moral distress
  - Financial cost, unproductive effort, etc.

Benefit-Burden Analysis - 1

- Who experiences the benefits and burdens?
  - Traditionally, related to patient's experience and perception
  - However, also affect family, HCPs, hospital, society
  - "Futility" often reflects a dissociation of benefits and burdens

Values: Life-itself vs QOL

- Those who value quality-of-life over life-itself tend to want to stop aggressive treatment sooner - or even "right now"
- Those who value life-itself, or view life as God's gift, tend to want to stop aggressive treatment later, or never

Benefit-Burden Analysis - 2

- The "benefits" accrue to the patient and family while the "burdens" are experienced by the medical staff caring for the patient
  - The patient and family may perceive a benefit but may not experience, or may discount, any burdens
  - The HCPs may perceive no (or minimal) benefit but may experience oppressive burdens and great moral distress in providing medical care to the patient

Differing Stages of Grief

- Stages of Grief
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

Differing Stages of Grief

- All who care about the patient experience these stages
- Conflicts arise when invested parties, at different stages of acceptance, seek control
  - Families may get "stuck" in the Denial or Anger stage
  - Fostering unrealistic hope may interfere with normal grieving
  - Futility conflicts allow families to put off the difficult work of grief

Managing Conflicts

Distrust

- Some sources of Distrust
  - Providing incomplete information
  - Minor (or major) medical errors
  - Socio-economic, racial, or ethnic factors
    - Feeling devalued
  - Failure to listen to, and respond to, concerns
    - Aggravated by avoiding meetings and discussion
  - Feeling pressured or rushed to make difficult decisions

Building Trust

- Mistrust often underlies conflicts over futility
- Focus on strengthening the physician-family relationship
- Avoid trying to persuade (e.g. no arm-twisting)
- Keep Coming Back
- Tincture of Time, Repeated Brief Conversations
- Don't Talk: Listen - Understand the family's views
- Look for areas of agreement, a place to begin

Be Aware of Emotions

- Ask about emotions
  - "This is such a hard time. How you are doing?"
- "NURSE" the Emotions – gently and carefully
  - Name: "It seems like you are angry, frustrated, etc."
  - Understand: "I can hardly imagine how difficult this must be for you."
  - Respect: "I am really impressed by your caring and effort."
  - Support: "We'll do everything we can to help you get through this."
  - Explore: "Tell me more."

Therapeutic Trials

- May be able to PREVENT some problems by emphasizing Therapeutic Trials
- Often there are no definitive diagnoses and no definitive treatments
- We often make provisional diagnoses and institute Therapeutic Trials – but we are not always explicit about it
- We assess the clinical outcomes of a Therapeutic Trial, and change treatments accordingly

Allow Time for Processing

- Understand that coming to terms with the reality that a family member is dying is always a SLOW process
- Reassure patient / family of non-abandonment
- Permit the processing to begin early, in small doses, by GENTLY introducing the possibility that the treatments may not succeed
  - Provide support for family and patient
  - Readdress situation frequently but gently
  - Redefine "hope" as achieving realistic goals

Therapeutic Trials

- Must distinguish between Short-Term (ST) and Long-Term (LT) goals
  - LT goal depends on achieving a series of ST goals
- Sometimes fail to make this distinction ourselves
- We often fail to make this distinction explicit to patients and families

Therapeutic Trials

- We don't WITHDRAW treatment (or "CARE")
- We determine whether the treatment has achieved hoped for outcomes in the designated time
  - If not, a New Course of Treatment is instituted
  - Sometimes we transition to comfort care because it is the BEST and MOST APPROPRIATE care for the patient

Negotiating with Patient & Family

- Elicit family's (and patient's) ST Goals for the patient
  - "What do you hope will happen over the next few days?
- Reach consensus on Operationalized ST Goals

Therapeutic Trials

- We TRY Aggressive Treatment initially, knowing we can stop/change the treatment if and when the treatment is judged to have failed

Negotiating with Patient & Family

- SMART
  - Specific
  - Meaningful and Measurable
  - Active (significant improvements in functioning)
  - Realistic
  - Time/Trial Length clearly defined
    - e.g., awake, alert, interactive within the next week
- Confirm Consensus (e.g., "Does that sound reasonable?")

Trial Intervention Plan – Part 1

- Present Trial Intervention Plan (with enthusiasm)
- Present plan as an aggressive curative/restorative plan
  - Continue interventions already in place (if appropriate)
- Add Selected Interventions
  - Practical, feasible, trial duration (explain specific purpose & goals)

Trial Intervention Plan – Part 2

- Meet with family at the end of the trial period
- Summarize the concrete trial goals
  - "As we discussed, we were hoping that we would achieve (ST goals)."
- Ask family for their assessment
  - "How do you think she's doing at this point? Have we achieved the goals you had been hoping for?"

Trial Intervention Plan – Part 1

- Check for Agreement
- Schedule F/U meeting to evaluate outcome of trial
- NO OPEN-ENDED SOLICITATION!!!!!
  - (e.g., don't ask, "What do you think we should do?")

Trial Intervention Plan – Part 2

- Present the "bad news," clearly and compassionately
  - "I know you were hoping for (goals). I'm so sorry, but she's just too sick to turn this around."
- Help families to shift their frame of reference
  - "Your wife is dying" "Let's work together to help her be as comfortable as possible"

Hospice & Palliative Care

- Can be a positive, high-quality alternative
- Focus on what can be done
  - Does not preclude all Life-Prolonging Therapy
  - "Gently Supportive Treatment" may be appropriate
- Focus on "whole patient"

Conclusions

- Medical Futility is and will remain a challenge and source distress for HCPs as well as families and patients
- Often reflects a disconnect between benefits & burdens
- Often indicates a conflict of VALUES or a difference in STAGES OF GRIEF of those involved
  - Often reflects a fight for CONTROL

Hospice & Palliative Care

- Present as changing the goal of treatment rather than "discontinuing care"
  - Focus on benefits and burdens of treatment
- Attend to language – be VERY careful what you say
- Resources for processing and support

Conclusions

- Focus on building trust and attending to emotions
  - Allow TIME for processing and grieving
- Utilize Therapeutic Trials – Be EXPLICIT
- Emphasize the positive aspects of PC and Hospice