Managing Conflicts Around Medical Futility

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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 - 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

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
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

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

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

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 are you 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.”

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

- 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

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

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### 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?”)
<table>
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<th>Trial Intervention Plan – Part 1</th>
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<td>• Present Trial Intervention Plan (with enthusiasm)</td>
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<td>• Present plan as an aggressive curative/restorative plan</td>
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<tr>
<td>– Continue interventions already in place (if appropriate)</td>
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<td>• Add Selected Interventions</td>
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<td>– Practical, feasible, trial duration (explain specific purpose &amp; goals)</td>
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<td>• Meet with family at the end of the trial period</td>
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<td>• Summarize the concrete trial goals</td>
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<td>– “As we discussed, we were hoping that we would achieve (ST goals).”</td>
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<tr>
<td>• Ask family for their assessment</td>
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<tr>
<td>– “How do you think she’s doing at this point? Have we achieved the goals you had been hoping for?”</td>
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<tr>
<td>• Check for Agreement</td>
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<td>• Schedule F/U meeting to evaluate outcome of trial</td>
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<tr>
<td>• NO OPEN-ENDED SOLICITATION!!!!!</td>
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<td>– (e.g., don’t ask, “What do you think we should do?”)</td>
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<td>• Present the “bad news,” clearly and compassionately</td>
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<td>– “I know you were hoping for (goals). I’m so sorry, but she’s just too sick to turn this around.”</td>
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<td>• Help families to shift their frame of reference</td>
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<td>– “Your wife is dying” “Let’s work together to help her be as comfortable as possible”</td>
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<td>Hospice &amp; Palliative Care</td>
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| • 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"  | • 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  |
| • 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  | • 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  |