APPROACHING ISSUES OF FUTILITY

Differential Diagnosis of Futility Situations

Approaching issues of futility from the point of view of resolving conflict will likely lead to resolution in the majority of cases. Among cases in which futility is claimed, most can be attributed to a problem in surrogate authority, a misunderstanding, or personal factors. Occasionally, there is a genuine value conflict, over either goals or the worth of a treatment.

Surrogates: Are We Talking to the Appropriate Decision-Maker?

Criteria for Surrogate Selection

- Patient's stated preference
  - Documentation in advance directives, statutory or advisory

- Legislated hierarchy for surrogate decision-makers
  - In absence of advance directive
  - Available in some states

- Questions to find a surrogate:
  - Who is most likely to know what the patient would have wanted?
  - Who is able to reflect the patient's best interest?
  - Does the surrogate have the cognitive ability to make decisions?

- Rare question, but sometimes necessary: "Is the surrogate acting appropriately in the patient's interest?"
  - If the physician believes that the surrogate is not doing so, it may be necessary to select a different proxy
  - Usually involves going to court to appoint a guardian-ad-litum

Misunderstanding of Diagnosis/Prognosis

Does the patient or surrogate understand the physician's view of the prognosis?

- **Underlying Causes:**
  - No information given on diagnosis or prognosis
  - Previous prognosis overly optimistic
  - Language not understandable (e.g., too much jargon)
  - Conflicting information from different health professionals
  - Stress, sleep deprivation, emotional distress decreased understanding
  - Not psychological prepared (e.g., denial)
  - Lack cognitive ability to understand

    Example…A frequent source of misunderstanding is the interpretation of the phrase "do everything". In medical jargon, it is frequently used to connote maximal medical attempts to save or prolong life, whether or not it is expected to be of benefit. Mistaken notions of legal requirements sometimes propel such use. In contrast, families may use the same phrase to communicate that they don't want their loved one to be abandoned or to die.

- **How to Assess:**
  - Listen carefully to patient's or family's view
  - Communication skills
    - Open-ended questions:
      - What do you understand about what is going on?
      - Tell me what you know so far about the situation for your child.
      - What's your understanding of your mother's condition?

        - What do you have in mind when you think about ‘doing everything’?
        - What do you expect to happen if we ‘do everything’?

- **How to Respond:**

    - Choose a primary communicator from health care team
        - Minimize chaos of multiple caregivers
        - Keep information manageable
    - Give information in small pieces
    - Information in multiple formats
        - Written
        - Verbal
    - Use understandable language
        - Appropriate to education level
    - Frequently assess understanding
    - Frequent repetition may be required
    - Do not hedge to "provide hope"--Unclear or vague communication promotes misunderstanding
    - Encourage writing down questions
    - Provide support
        - Attend to surrogate's emotional state
        - Denial is normal
    - Involve other health care professionals--If patient is a child, use child life or child psychology staff for patient's siblings

What Personal Factors May Influence Futility Situations?

- **Distrust**

    - Patients and families reluctant to suggest distrust
    - May be trying to be polite and respectful
    - Clues are in subtle comments
        - Other physicians were wrong
        - Previous hospital was not good, etc.
    - Assessing trust:
        - "What you’ve been through makes me wonder if it is hard for you to trust medical people now"
        - "From what you’ve said, I can imagine it might be difficult for you to trust us"
    - Restoring trust
        - Ask patient and family members to describe issues fully
        - Active listening and eliciting concerns
        - Clear message of interest and willingness to:
            - Hear negative feelings
            - Repair problems and establish trust
    - Strengthening trust
        - Emphasize what is being done for the patient
        - Offer to facilitate a second opinion, or find others whom the patient and family are more likely to trust
        - Clear message that everyone wants the best care for the patient
        - Affirm that you want to share accurate and complete information based on mutual trust and respect

- **Guilt**

    - Powerful motivator
    - Often subtle
    - Assessing guilt
        - Associated with shame, and families may not reveal this to the physician whom they do not know well, may respect and may fear
        - Use other sources of information, such as social workers, chaplains, and nurses

- Addressing guilt
  - Active listening
  - Involvement of multiple team members over time
  - Asking the family to come to internal resolution and work through one spokesperson
  - Conflicted relationships rarely resolved; resultant guilt rarely completely eliminated

- **Grief**

  - Natural human response to loss
  - Conflict over issues of futility may be extension of overwhelming anticipatory grief
  - Cues:
    - "I can't live without him"
    - "What will I do when she dies?"
  - Psychology, social work, chaplaincy, nursing, and other disciplines can help the physician offer support
  - Physician can help family distinguish between what the patient would want and what the family wants in response to their grief

- **Intrafamily Issues**

  - Family dynamics influence health care decisions
  - May not be initially apparent to the physician, particularly when the family is not seen together
  - Cues--family disagreement about treatment
  - Social workers, psychologists, psychiatrists, and other team members, trained in interviewing and family systems, can be helpful in both elucidating and managing intrafamily issues
  - A family meeting, where all parties get together to hear information and make decisions
    - Acknowledge intrafamily issues
    - Come to a decision with which all can live

- **Secondary Gain**

  - Other implications of a patient's death can influence futility situations
  - Examples:
    - Income to the family or surrogate decision-maker may be lost when the patient dies
    - Patient's death may influence where the family member may live
    - When patient dies, family members may lose access to savings or social status
    - Conversely, decision-maker may stand to benefit with the patient's death
  - Assessment by social workers to figuring out the social framework in which decisions are being made.
  - Resolution can be reached though sensitive discussions
  - Ethics or legal consultation may be needed--particularly if decision-maker is not acting in the best interests of the patient

- **Physician/Nurse Personal Feelings About Dying and the Benefits and Burdens of Interventions**

  - Examples:
    - Some push for interventions because of their belief that death is worse than any other state
    - Others push because they feel it is a failure in their care if they were to do otherwise
    - Still others have strong personal desires to avoid aggressive intervention and project this on the patient and family

How do Differences in Values Influence Futility Situations?

Religious

- Firm religious foundations may influence decisions about medical treatments and life-sustaining therapies
- Explore religious dimension that patients or families use in decision-making
- Physicians may need to overcome social conventions of avoiding religious topics to have this discussion

- Relying on chaplains, perhaps the family's own, can help with the discussion to elucidate the family's religious framework
- Assessing religious beliefs
  - Cues-- "It's in the Lord's hands"
  - Physician responses
    - What you say is important, and it helps me to understand how you feel about things
    - Can you help me to further understand what decisions would respect your belief about being in the Lord's hands?
    - For instance, if you were to be in ...[describe situation] would you feel I had decided right if I were to ...[describe situation]?
- Critical to know own values
  - To avoid imposing views on patient and family
  - If decision goes against physician's values, possible to arrange for transfer ahead of time

- **Miracles**

  - Belief in miracles
  - Formal religious connotation or less formal
  - Expression of hope that a supernatural or paranormal force will intervene to change the course of events
  - Clues-- "Only God determines when someone dies"
  - Physician responses
    - Attend to concomitant emotion and grief
    - Discuss situation in terms of what is in the physician's power to influence and what is not
    - Express the same hope for a miracle that the family has, but introduce concept of planning for what should be done if there isn't a miracle (hope for the best but plan for the worst)
    - It may also be appropriate to ask the patient or family if they have also considered that, "God might be calling him/her and we are preventing that from occurring?"
    - Scrupulously attend to accuracy and appropriateness in these conversations
    - Inclusion of a chaplain or religious counselor may be essential

- **Value of Life**

  - Cues:
    - "Life is worth preserving at all costs"
    - "Physicians shouldn't play God"
  - Issue may or may not be religiously based
  - Many physicians have used this justification for continuing therapies that conflict with patient and family wishes
  - Resolution
    - Helpful to focus on the patient's point of view
    - Useful to consider patient's expression of prior wishes in advance directives, either formally or informally

Due Process Approach to Futility Situations

This type of due process approach is strongly recommended by the AMA's Council on Ethical and Judicial Affairs, and should include the following steps:

- Earnest attempts in advance
  - Attempt to negotiate an understanding between patient, surrogate, and physician about what constitutes futile care in advance of actual conflict (See Module 8: Sudden Illness)
  - Can pre-empt conflict

- Joint decision-making
  - To the maximum extent possible, joint decision-making should occur between the patient (parents if the patient is a child) or surrogate and physician
  - Negotiate solutions to disagreements, if they arise, in order to reach a resolution satisfactory to all parties

    - Use the assistance of consultants as appropriate

- Negotiation of disagreements
    - If disagreements persist, suggest the participation of other consultants, colleagues, and/or a group, such as an institutional ethics committee
    - Additional resources may provide reasoned impartial assessment and evaluation of the conflict.
    - Value of ethics committees well described in the medical literature
    - The Joint Commission for Accreditation of Healthcare Institutions requires hospitals to have an ethics committee to aid its physicians, patients, and families to resolve difficult issues
    - The aim--provide maximum possible place for patient autonomy in the conduct of ethical medical practice

- Involvement of an institutional committee
    - If the institutional review supports the patient's position and the physician remains unpersuaded, transfer of care to another physician within the institution may be arranged

- Transfer of care to another physician
    - If the review supports the physician's position and the patient/surrogate remains unpersuaded, transfer to another institution can be carried out if both the transferring and receiving institutions agree
    - If transfer to another physician in another institution is not possible, the intervention need not be offered
    - However, there needs to be a diligent search for this option

- Transfer to another institution
    - This process does not solve the problem when no receiving institution can be found
    - The issue of cost of medical care, both to patients and families as well as to the institution and the health care system, is implicit in many of these steps

- If unable to transfer, the intervention need not be offered

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