

EPEC

Education for Physicians on End-of-life Care

Participant's Handbook

Module 9

Medical Futility

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Abstract

Clear and unequivocal situations of medical futility are rare. More often than not the issue is conflict resolution. The physician may be pursuing unrealistic or unwanted plans. There may be difficulty for the proxy to perform his or her role. There may be misunderstandings over prognosis. There may be personal factors such as distrust or guilt, or there may be differences in values. Understanding the nature of the conflict may allow ready resolution. For intractable difficulties, a fair process for conflict resolution is recommended.

Key words

advance care planning, communication, due process, ethics committee, futility, goals of care, informed consent, interpersonal factors, misunderstanding, surrogate, value differences

Objectives

The objectives of this module are to be able to:

- list factors that might lead to futility situations
- understand how to identify common factors
- understand how to communicate and negotiate to resolve conflict directly
- understand the steps involved in fair processes to resolve intractable conflict

Clinical case on trigger tape

Seven days ago, 15-year-old Kevin Robinson was struck by a car while riding his bike and sustained major traumatic injuries. Now, despite maximally intensive therapy, Kevin has developed multi organ failure. He is currently receiving artificial ventilation and pressor support.

Introduction

There may be times in each physician's career when a patient or surrogate decision maker asks for therapy that the physician does not think is beneficial, or vice versa. In some hospitals, these situations, often called medical futility, are common reasons for ethics consultation.

Imagine a case involving a patient in a vegetative state, whose life is being supported mechanically, and whose family insists that "everything be done." How should physicians approach this type of situation? How might the physician better understand the reasons for the family's seemingly irrational request? Are there techniques that are useful for ensuring that both parties feel they have been supported and understood? In those rare

instances where a mutually acceptable resolution is not possible, how should the physician balance his or her own concerns with those of the patient and family, and those of the health care system? Ultimately, what is the physician's responsibility in providing futile care?

These cases tend to be frustrating and distressing. The health care team may feel that the family is being unreasonable, wasting scarce economic resources, and causing the patient to undergo increased pain and suffering prior to his/her ultimate demise. Physicians may at times respond by distancing themselves from the family, accusing family members of ulterior motives, or arguing that nonprofessionals should not be allowed to make "medical decisions." Meanwhile, the patient and/or family, already stressed by the realities of life-threatening illness, may feel isolated, misunderstood, or abandoned. Family members may react by suggesting that the health care team does not "care" about their loved one, or even by imputing financial, racial, or other prejudices to the team.

This module offers practical suggestions for preventing, minimizing, and resolving - conflicts between patients and physicians before relationships deteriorate to the point of irreparable damage. The module will not attempt to solve the debate about what constitutes medical futility. However, it will provide a rational framework to use when there is conflict about medical decisions.

Physicians and futility

This module will focus principally on the issues that arise when families want care that the physician and other professionals feel is futile. Less commonly acknowledged, but of equal importance, are those situations where the physician or other professional persists in recommending therapy that the patient or family does not think is beneficial, or where evidence does not support any benefit to the patient. This inclination to intervene may be out of a sense of needing to maintain hope, a personal belief that it is the professional's job to maintain life at all costs, or a need to avoid feeling failure or shame for not helping the patient. Physicians and caregivers, as well as patients and families, may need to feel that "everything possible" was done so that, after the death, they will feel no regret or guilt.

A fundamental question to ask is "Who are we doing this for?" The physician should be particularly careful to center care around the patient's values. After all, the patient's life and body are in question. Differences should be resolved in a manner that avoids showing disrespect for the professionals' expertise and knowledge yet fully respects the centrality of the patient.

The nature and limitation of futility definitions

Many definitions of medical futility have been proposed, based on a range of possible approaches. One definition proposes that futility exists when the treatment won't achieve the patient's intended goal. Others have defined a futile treatment as one that does not

serve a legitimate goal of medical practice. Some have advocated for a precise definition, suggesting that a treatment is futile when it is ineffective more than 99% of the time. Still others have indicated that treatment outside accepted community standards could be construed as futile.

In the majority of situations in which death is imminent, consensus is reached and life-sustaining interventions are not provided. Investigators in one large study found that less than 1% of patients whose prognosis for survival was less than 1% on their third hospital day who did not have a do-not-resuscitate (DNR) order in the medical record.

Most situations that arise are not straightforward issues of futility. Rather, they represent conflict about the relative value of treatments. Examples of medical interventions in which questions of relative value may be raised include:

- life-sustaining interventions for patients in a persistent vegetative state
- resuscitation efforts for the life-threateningly ill
- use of chemotherapy in patients with far advanced cancer
- use of antibiotics or artificial hydration for patients who are in advanced stages of the illness

Unequivocal cases of truly futile interventions are rare. A clear example would be an attempt to resuscitate a patient who is decapitated. In this situation, CPR would be futile according to all conceivable definitions.

More commonly, the concept of medical futility is invoked when there is a conflict over treatment and it is not clear how to reach resolution. In order to avoid conflict, some have argued that physicians should neither offer nor provide therapy that is unlikely to work, or will only result in a poor quality of life. To do otherwise, they believe, would be to violate professional integrity, offer false hope to patients and families, and inflict harm on patients without the possibility of benefit. Others would disagree, wondering why, in cases of disagreement, the physician's values should override patient and family values, especially when those values are religiously based. Many would point out the difficulty in differentiating "futile" therapy from "low-yield" therapy. Consequently, an increasing number of groups recommend defining futility on a case-by-case basis. Approaches are based on the need to find a fair process of resolution rather than a final definition of what is futile.

Conflict over treatment

Unresolved conflicts about treatment goals and specific therapies lead to increased misery for the patient, family, and health care professional. Yet, most conflicts about care can be resolved through a process of effective communication and discussion. It is part of the physician's role to try to understand and resolve any differences in perception about treatment. This responsibility can be challenging because it calls on important skills

involving communication, compassion, and empathy. In negotiating issues of perceived futility, it remains the physician's obligation to support the patient and family and try to relieve their suffering. The physician can use the principles for decision making based on informed consent, as well as prior advance care planning and the identified goals of care, to help achieve resolution (see Module 1: Advance Care Planning, and Module 7: Goals of Care).

Most disagreements about futile care are actually the result of misunderstandings or lack of attention to the family's or care team's emotional reaction to the patient's dying. Thus, the critical issue is to understand *why* there is disagreement. Typically, the conflict can be resolved in a manner that is respectful of the point of view of both the physician and the patient/family. Moreover, by concentrating on understanding points of view, one often can initiate interventions that help with bereavement.

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.

Surrogate selection

If the patient lacks capacity, the physician must rely on a surrogate. The surrogate should be the person whom the patient prefers. Look for documentation of advance directives—either statutory or advisory (see Module 1: Advance Care Planning). In the absence of an advance directive, some states have legislation laying out a hierarchy for surrogate decision makers. In cases of conflict, one may need to have a guardian named. It is useful to know the statutes under which you work. Blood relationship does not necessarily ensure the best surrogate. The following questions may help in finding who is the right surrogate: Has the patient stated a preference for the person he or she would want as a surrogate if the patient should become incompetent? Who is most likely to know what the patient would have wanted? Who is most likely to try to make a decision that reflects the patient's best interest? Does the surrogate have the cognitive ability to make decisions?

A rare but sometimes necessary question is, "Is the surrogate acting appropriately in the patient's interests?" If the physician believes that the surrogate is not doing so, it may be necessary to secure a different proxy. This usually involves going to court to appoint a guardian ad litem.

Misunderstanding of diagnosis/prognosis

Misunderstandings have a number of common causes. The physician should know how to assess and respond to misunderstandings.

Conflict may arise primarily because of misunderstanding on the part of the patient, the patient's parents, or surrogate about diagnosis or prognosis. There are many sources of misunderstanding. For example, no one may have actually informed the parents or surrogate of the diagnosis or prognosis. Alternatively, the language used to inform the surrogate may not have been understandable. Including too much jargon and using a vocabulary that only has meaning to other health care professionals is common. Other health care professionals may have given the surrogate different or conflicting information. Health care professionals may have "hedged" regarding the patient's prognosis in the interests of not wanting to sound too pessimistic. In addition, the stressful environment, sleep deprivation, and emotional distress surrounding the situation may lead to a decrease in understanding. Finally, the patient, family, or surrogate may not be psychologically prepared to hear the bad news ("denial") or may lack the cognitive ability to understand the information. This is especially true when the dying patient is a child.

Misunderstanding: underlying causes

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.

Misunderstanding: how to assess

In order to assess misunderstanding, the physician must carefully listen to the patient's and family's or surrogate's view of things. Use good communication skills (see Module 2: Communicating Bad News). Get the setting right in order to have the discussion with the surrogate. Ask open-ended questions like:

- 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'?

Be sure to have a clear idea of what the surrogate (or patient, if competent) thinks of the situation before you begin to give information.

Misunderstanding: how to respond

Try to minimize the chaos caused by multiple caregivers and too much information. Choose one health care professional to serve as primary communicator. Give information

in small pieces and check for understanding frequently. Information can be given in multiple formats, both written and verbal. Be sure to use language that is appropriate to the educational level. You will need to provide adequate time for the discussions, knowing that frequent repetition may be required. Avoid the tendency to “hedge,” rationalizing that it may preserve hope. Unclear and vague communication only promotes misunderstanding. Encourage the decision maker to write down questions. Provide support. Above all, attend to the surrogate’s (or parents’) emotional state. Remember that denial is a normal psychological defense mechanism. It may be very helpful to involve other health care professionals. In the case of a dying child, it is imperative to involve child life or child psychology staff for the patient’s siblings.

Personal factors

There are multiple ways in which interpersonal issues can manifest themselves as a conflict over futility.

Distrust

Patients and families may make comments that suggest they do not trust the information they are being given. Because they may be trying to be polite and respectful, the clues may be subtle rather than overt. Comments about how other physicians were wrong, the previous hospital wasn’t very good, the patient’s previous physician was only interested in money, the nurses never answered the call lights or administered the wrong treatments, racial or ethnic prejudice was suspected, etc, should trigger the question: “Do they distrust us?”

It is often helpful to address this gently, but directly. Questions like the following might be helpful:

- 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.

Once established, it is then useful to explore the dimensions of the distrust. Ask patients and families to describe their issues fully. The process of active listening and eliciting concerns may go a long way to establishing trust. Give the clear message that the physician and team are interested and willing to hear about negative feelings, in order to facilitate repair of any problem and the building of trust.

After establishing that distrust is an issue, and after learning about its dimensions, the physician may pursue other avenues to strengthen trust. Emphasize what is being done for the patient. Offer to facilitate a second opinion or find other individuals whom the patient and family are more likely to trust. Make it clear that everyone wants the best care for the patient, and you want to work together with them to achieve that. Affirm that you want to share accurate and complete information based on mutual trust and respect.

Grief

Grief is a natural human response to loss. Conflict with the physician and the health care team over issues of futility may be an extension of anticipatory grief that is overwhelming. Comments like, “I can’t live without him,” or “What will I do when she dies?” are markers of overwhelming grief.

The physician and other members of the health care team can help the patient with grief. Social work, chaplaincy, nursing, and other disciplines can help the physician offer support. In making decisions, help the family distinguish between what the patient would want and what the family wants in response to their grief.

Guilt

A powerful motivator for human behavior is guilt. Guilt over relationship issues with the dying patient is often subtly present in decision-making discussions between physicians and patients/families. The archetypal, not-so-subtle situation is the arrival of the longestranged or distanced relative at the bedside saying, “You must do everything; you can’t let her die.”

Eliciting this dimension requires skillful interviewing and the willingness to assess the situation using a broad perspective (see Module 2: Communicating Bad News, and Module 3: Whole Person Assessment). It may help to include in this assessment the contributions and information gathered by other members of the team, such as nurses, social workers, and chaplains. Because guilt is sometimes associated with a sense of shame, families may not readily reveal this dimension to the physician whom they do not know well, may respect, and may fear. Consequently, the guilt may provoke conflicts about futility determination.

Active listening may help modify the situation. Involvement of multiple team members over time is usually essential. Asking the family to come to internal resolution and work through 1 spokesperson can sometimes contain the effects of guilt within the family, protecting decisions for the patient. Negotiated time-limited trials may be helpful. (See Module 8: Sudden Illness.) Conflicted relationships are rarely resolved and resultant guilt is rarely eliminated. However, it remains the task of the physician and health care team to develop an understanding of the ir dimension. That understanding alone may illuminate behavior that previously seemed inexplicable.

Intrafamily issues

Health care decisions about a patient may be influenced by family dynamics. These conflicts may not be initially apparent to the physician, particularly if the physician does not see the entire family as a group. Evidence of disagreement within the family, in the context of conflicts over futility, may indicate intrafamily issues.

Social workers, who are trained in interviewing and in family systems, can be exceedingly helpful in both elucidating and managing intrafamily issues. A family meeting, where all parties get together to hear information and make decisions, can be an excellent way in which to both acknowledge intrafamily issues and come to a decision with which all can live.

Secondary gain

Occasionally, discussions regarding futility may be influenced by other implications of a patient's death. For example, income to the family or surrogate decision maker may be lost when the patient dies. The patient's death may also influence where the family member may live, or whether he/she will have access to savings or social status. Conversely, the decision maker may stand to benefit with the patient's death.

Physicians may be unaware of this dimension. Assessment by social workers may be very helpful in figuring out the social framework in which decisions are being made. Most often, resolution can be reached through sensitive discussions. However, ethics or legal consultation may be needed, particularly if it is apparent that the decision maker is not acting in the best interests of the patient.

Physician/nurse

Physicians and nurses bring their own personal feelings about dying and about the benefits and burdens of specific interventions to the case. 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.

Types of futility conflicts

People may differ over values in health care. What is futile to one may be worthwhile to another. Genuine value conflicts, ie, not based on misunderstandings, are typically of 2 types:

1. **Parties differ over goals.** For example, one party wishes to preserve life "at all costs" while the other party concludes that preserving life is not a worthwhile goal.
2. **Parties differ over benefit.** For example, one party wishes to pursue a therapy that is highly unlikely to achieve the agreed upon goal (ie, a "miracle") while the other party does not believe the chances of success are high enough to continue treatment.

Whichever the type of conflict, it may be important to explore the root of the value difference.

Difference in values

Some requests for therapies that others characterize as ineffective or futile are genuinely a reflection of differing values between the physician or system and the patient/family.

Religious beliefs

Many people have a firm religious foundation for their lives and the decisions they make. This may extend to decisions about medical treatments and life-sustaining therapies. Families may make religious references in relating their point of view.

It is useful to explore the religious dimension that patients or families use in decision making. Physicians may need to overcome the social convention of avoiding religious topics in order to have this discussion. Relying on chaplains, perhaps the family's own, to help discuss and elucidate the patient's or family's religious framework can be helpful.

An indication that the patient and family may rely on religious fatalism in facing serious illness is the phrase, "It's in the Lord's hands," in response to questions about preference and decision making. In such circumstances you may need more information on preferences. It is sometimes helpful to say something like, "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]?"

Physicians need to know their own disposition and must work to avoid imposing their views on the patient and family. Decisions that go against a physician's values should be avoided whenever possible by arranging for transfer ahead of time.

Miracles

Patients and families may express a belief in miracles. This may have a formal religious connotation or it may be less formalized. It is an expression of hope that a supernatural or paranormal force will intervene to change the course of events. Comments like, "Only God determines when someone dies," may be a clue.

Attending to concomitant emotion and grief is important. It may be helpful to discuss the situation in terms of what is in the physician's power to influence and what is not. Miracles are, by definition, rare and unpredictable. It may be helpful to express the same hope for a miracle that the family has, but introduce the concept of planning for what should be done if there isn't a miracle, so helping them 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." Such conversations need to be scrupulously attentive to accuracy and appropriateness. The inclusion of a chaplain or religious counselor may be essential.

Value of life

When this type of conflict occurs, it may be expressed by comments such as “life is worth preserving at all costs,” or “physicians shouldn’t play God.” This issue may or may not be religiously based. Some physicians have used this justification for continuing therapies that conflict with patient and family wishes.

To help resolve this conflict, it may be helpful to focus on the patient’s point of view and the patient’s expression of prior wishes in advance directives, either formally or informally.

A due process approach to futility situations

The foregoing discussion was meant to help the physician understand the nature of situations that may lead to conflict over medical treatment between the physician and patient/family. It is also a framework for preventing and resolving conflict. This process often leads to obvious and acceptable solutions. But this is not always so.

If conflict persists we suggest a process whereby that conflict might be resolved. Many institutions and communities have policies related to the provision of futile care that employ a step-by-step process of communication and problem solving to help resolve differences between the physician and the patient/family. This type of due process approach may include the following steps:

1. 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). This step can preempt conflict.
2. To the maximum extent possible, joint decision making should occur between the patient 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. Much of the preceding text is meant to provide a basis for this negotiation.
3. If disagreements persist, suggest the participation of other consultants, colleagues, and/or a group, such as an institutional ethics committee. These additional resources may provide a reasoned impartial assessment and evaluation of the conflict. The value of ethics committees has been 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 is to provide the maximum possible place for patient autonomy in the conduct of ethical medical practice.
4. 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.

5. 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 a physician in another institution is not possible, the intervention need not be offered. However, there needs to be a diligent search for this option.
6. 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.

Plenary 2: Legal Issues discusses some of the legal issues related to futility.

Summary

Situations involving true medical futility are rare. More often than not, the question of futility comes up when there is distress with consequent miscommunication and conflict. Sources of conflict may be identified as follows. The proxy may not be performing the role well. There may be misunderstandings over prognosis. There may be personal factors such as distrust or guilt. Or there may be differences in values. For intractable difficulties a fair process for conflict resolution is recommended. This process should include, if at all possible, prior discussion as to what constitutes futility, joint decision making with the patient/proxy and other parties, involvement of a consultant and/or ethics committee, and transfer of care to another physician or institution if necessary. Rarely, if no physician or institution can be found to provide the intervention, it may be necessary to withdraw or withhold what the patient/proxy or family has requested.

Key take-home points

1. Most so-called futility situations are not straightforward. Persistent conflicts usually represent conflict about the relative value of treatments.
2. Physicians and health care providers may seek futile therapies just as patients and families may.

Nature and limitation of futility definitions

3. Disagreements about futile care may be the result of misunderstandings or lack of attention to the family's emotional reaction to the patient's dying. Thus, it is critical to understand why there is disagreement.
4. Most disagreements about futile care are the result of misunderstandings or lack of attention to the family's (or physician's) emotional reaction to the patient's dying.

Differential diagnosis of futility situations

5. Are we talking to the appropriate decision maker?
6. Does the patient/surrogate understand the physician's view of prognosis?
7. Are there personal factors?
8. Are there genuine value conflicts (ie, not based on misunderstandings)? They are typically of 2 types:
 - a. parties differ over goals
 - b. parties differ over treatment benefit
9. Failure to acknowledge and explore cultural and religious values, beliefs, and practices may exacerbate or prolong conflict and disagreement.
10. Differentiate "futile" therapy from "low-yield" therapy during discussions.

Due process approach

11. Negotiate an understanding in advance of conflict.
12. Use joint decision making.
13. Suggest participation of others.
14. Transfer care to another physician.
15. Transfer care to another institution.

Pearls

1. Clarify the overall goals of care.
2. Never use the phrase "do everything."

Potential pitfalls

1. Hiding behind information. Facts alone won't help deal with emotions.
2. Defensive medicine. Mistaken notions of legal requirements often drive poor judgment.
3. Mistrust. Patients and families may not trust the information they are being given.
4. Missing a diagnosis of anticipatory grief. Reactions may be the result of anticipatory grief or guilt.
5. Using anecdotes to make decisions.
6. Projection. Be careful not to let your personal values interfere with decision making.

Resources

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