

# EPEEC-O

Education in Palliative and End-of-life Care - Oncology

## **Participant's Handbook**

Module 12

**Conflict**

**Resolution**

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## Abstract

Conflict is inevitable in the practice of oncology. Clear and unequivocal situations of right and wrong are rare. There may be difficulty for the proxy in performing 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. The oncologist may be pursuing unrealistic or unwanted plans. A key skill is conflict resolution. Understanding the nature of the conflict is often a necessary condition for resolution. A 7-step protocol can be used to guide conflict resolution, including a fair process to resolve intractable difficulties.

## Key words

Futility, conflict, conflict resolution, communication, due process, values, goals of care, treatment priorities, informed consent, misunderstanding, interpersonal factors, surrogate, value differences, advance care planning, ethics committee

## Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Describe futility and factors that lead to conflict.
- Use a 7-step protocol to facilitate resolution of conflict.
- Recognize when the oncologist or cancer care team is the source of conflict.

## Clinical case on trigger tape

K.R. is a 15-year-old boy hospitalized in the ICU for sepsis and hemorrhage secondary to advanced chemotherapy for refractory leukemia. He has never been conscious since the hemorrhage. Despite maximally intensive therapy, he has developed multi-organ failure. He is currently receiving artificial ventilation and requires drugs to maintain his blood pressure. His mother, a single parent, is ‘unrealistic’ and wants ‘everything done.’ It is remotely possible that the patient may recover sufficiently to not need the ventilator.

## Introduction

There are times in every oncologist’s career when a patient, family member, or surrogate decision-maker (if the patient lacks decision-making capacity) asks for therapy that the oncologist does not think is beneficial, or vice versa. In some cancer centers, these situations, often called medical futility situations, are common reasons for calling an ethics consultation.

Imagine a case involving a patient with advanced cancer whose life is being supported by mechanical ventilation. Her/his family insists that ‘everything be done.’

- How should oncologists approach this type of situation?
- How might the oncologist 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 oncologist balance his or her own concerns with those of the patient and family, and those of the health care system?
- Ultimately, what is the oncologist's responsibility in providing futile care?

These requests for futile therapy tend to be frustrating and distressing for everyone who is involved. Members of the cancer care team may feel that the family is being unreasonable, wasting scarce economic resources, even causing the patient to undergo increased pain and suffering prior to his/her ultimate demise. In response/self defense, they may distance themselves from the patient and family, accuse them of ulterior motives, or argue that nonprofessionals should not be allowed to make 'medical decisions.'

The patient, family, or surrogate decision-makers, who are already stressed by the realities of the advanced cancer, then feel isolated, misunderstood, and/or abandoned. Some suggest that the cancer care team does not 'care' about their loved one, or they impute financial, racial, or other prejudices to the team.

This module focuses on the issues that arise when families want care that the oncologist and the cancer care team feel is futile. It provides a rational framework to use when there is conflict about medical decisions. It offers practical suggestions for preventing, minimizing, and resolving conflicts between patients and oncologists before relationships deteriorate to the point of irreparable damage. It does not attempt to solve the debate about what constitutes medical futility.

## **Futility**

There are many proposed definitions for 'medical futility,' including:

- Futility exists when a treatment won't achieve the patient's intended goal.<sup>1</sup>
- Treatment is futile when it is ineffective more than 99% of the time.<sup>2</sup>
- Futile treatment is one that does not serve a legitimate goal of medical practice.<sup>1</sup>
- Treatment could be construed as futile when it is outside accepted community standards.<sup>1</sup>

A prospective British study found that patients and families may have different definitions of 'futile treatment' when compared to oncologists.<sup>3</sup>

**Table 1: Medical benefit required to make hypothetical intensive chemotherapy treatments worthwhile**

Potential	Benefit required to make intensive chemotherapy worthwhile	
	Patient perspective	Oncologist perspective
A chance for cure	1%	50%
A chance to prolong life	12 months	24-60 months
A chance for relief of symptoms	10%	75%

This mismatch confirms the clinical observation that patients are sometimes willing to take extraordinary chances with the hope of improving survival.<sup>4</sup> It is consistent with the image that some patients are fighters at all cost when life and death are at stake (see EPEC-O Module 9: Negotiating Goals of Care). Nonetheless it can also be a member of the nursing, physician or other discipline within the oncology care team that feels uncomfortable about withholding intensive interventions that have little chance of serving the patient’s goals.

## Prevalence

Unequivocal cases of truly futile interventions are rare, eg, an attempt to resuscitate a patient who is decapitated.<sup>3</sup> In the majority of situations in which death is imminent, consensus is reached and life-sustaining interventions are not provided. In one large study, on the third day of hospitalization, of patients whose prognosis for survival was < 1%, < 1% did not have a do-not-resuscitate (DNR) order in the medical record.<sup>5</sup>

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. Examples of medical interventions in which questions of relative value may be raised include:<sup>6,7,8,9,10</sup>

- Life-sustaining interventions for patients in a persistent vegetative state.
- Resuscitation efforts for the life-threateningly ill.
- Use of antibiotics, artificial hydration or chemotherapy in patients with very advanced cancer.

## Conflict

Conflict is *a disagreement between 2 or more parties who perceive a threat to their needs, interests or concerns*. It usually arises as a result of misunderstanding, differences in values, personal factors, or a problem with the surrogate decision-maker.

To minimize the risk of conflict, some have argued that oncologists 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 disagree. They wonder why the oncologist's values override patient and family values, especially when those values are religiously based. Many 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. With this approach, emphasis is placed on the need to find a fair process of resolution rather than a final definition of what is futile.

## Conflict over goals of care, treatment priorities

Unresolved conflicts about treatment goals and specific therapies can lead to misery for the patient, family, and health care professional. Yet, most conflicts about care can be resolved through a process of effective communication and negotiation. It is part of the oncologist'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 oncologist's obligation to support the patient and family and try to relieve their suffering. To this end, use the principles to guide effective communication (see EPEC-O Module 7: Communicating Effectively), negotiate goals of care and treatment priorities (see EPEC-O Module 9: Negotiating Goals of Care) and facilitate advance care planning (see EPEC-O Module 13: Advance Care Planning) to help resolve conflict.

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 oncologist and the patient/family. Moreover, by concentrating on understanding points of view, one often can initiate interventions that help with adjustment and/or bereavement.

## Root causes

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 misunderstanding, differences in values, personal factors or a problem with the surrogate decision-maker.

## Misunderstandings

### Diagnosis/prognosis

Conflict is frequently the result of misunderstanding on the part of the patient, family, or surrogate decision-maker about diagnosis or prognosis, because:

- No one informs the parent or surrogate of the diagnosis or prognosis.
- The language used to inform them is not understandable. This can happen when oncologists use jargon or technical terms that only have meaning to the cancer care team, or when the listener lacks the cognitive ability to understand the information.
- The patient or family members receive different or conflicting information
- The oncologist or members of the cancer care team ‘hedge’ regarding the patient’s prognosis in the interests of not wanting to sound too pessimistic.
- Stress, sleep deprivation, and/or emotional distress decrease the listeners’ comprehension.
- Patient or family members are not psychologically prepared to hear the bad news, eg, when they are in denial.

### ‘Do everything’

Misinterpretation of the phrase ‘do everything’ is another source of misunderstanding. In medical jargon this phrase 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 its use in this manner. In contrast, families may use the same phrase to communicate that they don’t want their loved one to be abandoned or to die. This difference in perspective can be the cause of considerable misunderstanding.

### Difference in values

Some requests for therapies that others characterize as ineffective or futile are genuinely a reflection of differing values between the patient/family/surrogate and the oncologist and/or the cancer care team. What is futile to one may be worthwhile to another. Genuine value conflicts, ie, not based on misunderstandings, are typically of two types of conflict:

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, i.e., a ‘miracle,’ while the other party does not believe the chances of success are high enough to continue treatment.<sup>11</sup>

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

Oncologists need to know their own disposition and work to avoid imposing their views on the patient, family or surrogate decision-maker. Whenever possible, anticipate decisions that go against the oncologist's values. If they are likely, arrange for transfer of the patient's care to someone else before the conflict arises.

**Religious beliefs:** Many people have a religious foundation for their lives and the decisions they make. That extends to decisions about medical treatments and life-sustaining therapies. When these are not recognized by the cancer care team, differences can lead to significant conflict.

**Miracles:** Patients, families and surrogate decision-makers may believe in miracles. While their beliefs may have a formal religious connotation, they are more likely to be an expression of hope that a supernatural or paranormal force will intervene to change the course of the illness.

**Value of life:** Some people believe in life at all cost. These beliefs may or may not be religiously based. These 'fighters' need to know they tried everything possible. They may even choose to die receiving ventilatory support. Any suggestion that a possible therapy will not be beneficial leads to conflict.

## Personal factors

There are multiple ways that interpersonal issues can manifest as conflict.

**Distrust:** Comments from patients, families or surrogates may suggest that they do not trust the information they are being given. These comments may be subtle, particularly when they are being polite and respectful. Statements that might trigger the question, 'Do they distrust us?' include:

- The previous oncologist(s) was wrong.
- The last oncologist(s) was only interested in money.
- The previous hospital wasn't very good.
- The nurses never answered the call lights.
- The nurses administered the wrong treatments.
- They suspected racial or ethnic prejudice.

**Grief:** Grief is a natural human response to loss. Conflict may be an extension of anticipatory grief that is overwhelming. Comments like, 'I can't live without him!' or 'What will I do if she doesn't get better?' are markers of overwhelming grief.

**Guilt:** Guilt over relationship issues with the patient is a powerful motivator of human behavior. It can be a source of considerable conflict. It is often subtly present in decision-making discussions. When it is associated with a sense of shame, it may remain invisible to the cancer care team for a long time.



**Intra-family issues:** Health care decision making is frequently influenced by family dynamics. When there is a lack of communication or considerable conflict between family members, these can lead to significant conflict. These conflicts may not be initially apparent to the oncologist or the cancer care team, particularly if they don't see the family as a group.

An archetypal, not-so-subtle situation is the arrival of the long-estranged or distanced relative at the bedside saying something divergent from the prior plan for care. For instance, if the plan has been to cease curative attempts the distanced relative may say, "You must do everything; you can't give up." As frustrating as this may be to the care team's plans, avoid making assumptions about such family dynamics; each member of the family probably has an understandable background behind the position they have taken and little-informed opinions from the professional team are unlikely to help.

**Secondary gain:** Occasionally, discussions regarding futility are influenced by other implications of a patient's death that lead to a conflict of interest. For example:

- Income to a family member or surrogate decision maker may be lost when the patient dies.
- The patient's death may influence where the family member may live, or whether s/he will have access to savings or social status.
- Conversely, the decision-maker may stand to benefit financially from the patient's death if s/he is named in the patient's will.

## **Problem with surrogate decision-maker**

A problem in implementation of the surrogate's role can lead to requests for futile therapy and related conflicts when:

- There has been no advance planning and no surrogate appointed by the patient.
- The surrogate does not know the patient or her/his wishes well.
- There is a conflict of interest and the surrogates own biases / goals are guiding decision-making, not the patient's (with or without secondary gain).

## **A 7-step protocol to resolve conflict**

Conflict over goals of care and treatment priorities can be very difficult for everyone who is involved, particularly when there are significant differences between aspirations and what is medically likely or possible in advance of actual conflict. Attempt to negotiate an understanding between patient, family or surrogate decision-maker and oncologist about what constitutes futile care. This strategy can preempt conflict.

The first step to conflict resolution is open communication. As soon as conflict, or the possibility of future conflict, becomes apparent, organize a family meeting to discuss

everyone's understanding of the patient's situation, their hopes and expectations, etc. Simply giving patients and families the time they need to express themselves may be cathartic.

To have a greater chance of achieving a successful outcome, throughout the discussion use the following modification of the 6-step protocol, SPIKES, to guide effective communication (see EPEC-O Module 7: Communicating Effectively).<sup>12</sup>

## **SPIKES+**

**S**etting. Getting started.

**P**erception. What does the patient know?

**I**nvitation. How much does the patient want to know?

**K**nowledge. Sharing the information.

**E**motion. Responding to the patient and family feelings.

**S**ubsequent. Planning and follow-up.

+ **R**eview. Reassess and revise periodically

## **7-step protocol to resolve conflicts**

1. Create the right setting

2. Determine what is known

3. Explore hopes and expectations

4. Attempt to resolve the conflict

5. Respond to emotions

6. Make a plan and follow through

7. Review and revise periodically

## **Step 1: Create the right setting**

Start by getting the setting right. Ensure that everyone is present who needs to be, including the patient, family, surrogate decision-maker, oncologist and members of the cancer care team.

Hold the meeting in a comfortable, private setting where confidentiality will be ensured.

Know the facts of the case. Have the medical record handy to refer to.

Allow adequate time for the discussions, knowing that frequent repetition may be required. To minimize interruptions, give pagers and mobile phones to someone from the team who is not present at the meeting.

## Step 2: Determine what is known

Start by clarifying the patient's, family's, or surrogate's understanding of the patient's diagnoses and prognosis. Try to glean an understanding of the root cause of the conflict. Understanding alone may illuminate behavior that previously seemed inexplicable. Ask open-ended questions like:

- What do you understand about what is going on?
- Tell me what you know 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'?

**Distrust:** Gently inquire about possible distrust:

- 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 you establish that there is distrust, explore the causes of the distrust further. Ask those present to describe their concerns fully. Active listening and carefully chosen questions to elicit concerns are likely to go a long way to establishing trust. Give a clear message that you are interested and willing to hear about negative feelings; that you hope to repair any problem and build trust.

**Grief:** Ask about loss. Assess the severity of the grief reactions, and the adaptive coping mechanisms (see EPEC-O Module 4: Loss, Grief, and Bereavement).

**Guilt:** Ask the patient, family, or surrogate, and members of the cancer care team about guilt. This requires skillful interviewing and the willingness to assess the situation using a broad perspective. It may help to include information gathered by other members of the cancer care team, eg, chaplains, nurses, social workers.

**Intra-family Issues:** Look for disagreement or conflicts within the family over goals of care or treatment priorities. These may indicate intra-family conflicts or dysfunction.

**Secondary gain:** Oncologists may be unaware of the role secondary gain is playing. Input by all members of the cancer care team, particularly the social workers, may be very helpful in figuring out the social framework in which decisions are being made.

**Religious beliefs:** Ask about the religious context that the patient, family or surrogate use to guide their decision making. A chaplain or the patient's own spiritual advisor may help to elucidate and understand the patient's and family's religious beliefs and how they impact decision-making.

An indication that the patient and family may rely on religious fatalism when facing serious illness is the phrase, 'It's in the Lord's hands,' in response to questions about preference and decision making.

**Miracles:** Comments like, 'Only God determines when someone dies,' may be a clue that the patient, family or surrogate believe in miracles. A chaplain or spiritual advisor may help to elucidate and understand their importance.

**Values:** Explore the patient's, family's or surrogate's values and their goals for life and care. Clues that people value life at all cost include comments like, 'life is worth preserving at all costs,' or 'oncologists shouldn't play God.'

### **Step 3: Explore hopes and expectations**

Before proceeding to give information and discuss conflict that may be present, be sure you have a clear understanding of what the patient, family or surrogate is hoping for and expecting from the cancer care team. When possible, explore expectations and hopes related to the cancer, symptoms or issues causing suffering, and their goals for work life, family, pleasure, and end-of-life care.

Start with a question like:

- Tell me what you are expecting in the future with this illness.

### **Step 4: Attempt to resolve the conflict**

To the maximum extent possible, facilitate joint decision-making between the patient, family or surrogate and oncologist. Negotiate solutions to disagreements, if they arise, in order to reach a resolution satisfactory to all parties. Use the assistance of consultants as appropriate.

Try to minimize the chaos caused by multiple caregivers and too much information.

Choose one member of the cancer care team to serve as primary communicator.

When communicating information, give a few facts at one time. Check for understanding frequently. Use language that is appropriate to the patient's/surrogate's educational level. Provide access to written resources, eg, brochures, internet resources.

For each possible treatment, communicate clearly about the potential for benefit, the risk of harm and the burden associated with it. 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 the facts and any questions.

**Distrust:** When distrust is an issue, pursue strategies to strengthen trust. Emphasize what is being done for the patient. Review the medical record, including the results of investigations. 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:** When grief is an issue, it will need to be addressed. Social workers, chaplains, nurses, and other members of the cancer care team can offer support. When making decisions, help the family distinguish between what the patient would want and what the family wants in response to their grief.

**Guilt:** When guilt is an issue, active listening may help modify the situation. Conflicted relationships are rarely resolved and resultant guilt is rarely eliminated. Involve multiple team members over time. Ask the family to come to consensus and work through 1 spokesperson. This can sometimes contain the effects of guilt within the family, protecting decisions for the patient.

**Intra-family issues:** When intra-family issues are present, social workers who are trained in interviewing and in family systems, can be exceedingly helpful at both elucidating and managing them. A family meeting, where all parties get together to hear information and make decisions, can be an excellent way in which to both acknowledge intra-family issues and come to a decision with which all can live.

**Secondary gain:** When secondary gain is an issue, resolution can usually be reached though sensitive discussions facilitated by a skilled social worker or chaplain. If a conflict of interest persists, 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.

**Religious beliefs:** When a family says something like ‘It is in the Lord’s hands,’ in response, 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 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]?’ If this type of approach is not enough, or perhaps whenever specific religious beliefs are influencing divergent decision-making, seek information and guidance from a chaplain and/or the patient’s, family’s or surrogate’s spiritual leader. They can often provide considerable insight into the beliefs. They may also help the patient, family or surrogate dispel myths or misinterpretation of particular teaching, eg, that you have to suffer pain in order to get to heaven/paradise.

**Miracles:** When belief in miracles is an issue, attend to concomitant emotion and grief. Discuss the situation in terms of what is in the oncologist’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 or the miracle turns out to be something other than the one they hoped for. Help them hope for the best and 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. They are often best facilitated by a chaplain or the patient's, family's, or surrogate's spiritual leader.

**Values:** When differences in values are an issue, it will be most helpful if the team focuses on the patient's point of view. If the patient lacks capacity, look for guidance in advance directives that may be formally written down, or statements previously made by the patient.

## **Step 5: Respond to emotions**

Throughout the process of discussing issues of futility and conflict, respond to the patient's, family's, or surrogate's emotional state. Provide ongoing support and reassurance that you will not abandon them.

In the face of conflict, anger or other emotions that may be aimed at the oncologist or members of the cancer care team, work together closely to identify projection and transference within team members. Be careful not to own responsibility for emotions that you did not create. Remember that:

- Denial is a normal psychological defense mechanism.
- Out of frustration, helplessness and hopelessness, people living with advanced cancer often aim their anger at the closest target – the cancer care team (and are subsequently even more distressed when they realized what they have done).

## **Step 6: Make a plan and follow through**

The process to resolve conflict will likely take time. Several family meetings may be needed to address all the issues and rebuild trust. Whenever possible, involve members of the cancer care team to assist you. Be patient. Focus on listening actively and providing reassurance and support.

Time-limited therapeutic trials with clear goals and outcomes to measure may help people realize that everything possible is being done. They can also provide more time and evidence to help the patient, family, or surrogate to realize the patient's situation and prognosis.

During each family meeting, follow the 6 steps outlined above. At the end of each meeting, make a plan and follow through. Attention to a careful process that identifies the root causes for the conflict and negotiates a plan of care based on articulated values and goals of care will most likely resolve any conflict.

## **When conflict persists**

When conflict persists, the cancer care team will need help to resolve differences between the patient, family, or surrogate decision-maker and the oncologist/cancer care team. Seek assistance from resources external to the patient's care team who may help guide

the process to resolve the conflict and/or may provide a reasoned, impartial assessment and evaluation of the conflict.

## **External facilitator**

An impartial facilitator may help to guide the process and break down some of the barriers. Choose someone who is:

- Skilled in the process of effective communication and decision-making.
- Knows medical language and approaches to care and conflict resolution.
- Has no preconceived bias about the case.
- Has no secondary gain.
- Is acceptable to everyone who will be present.

## **Second opinion**

If the patient, family, or surrogate, are open to a second opinion, suggest consultation with another oncologist. This can help to reinforce the information you have been providing and may address some of the root causes of the conflict.

## **Ethics committee**

If conflict persists in spite of all these efforts, suggest a consultation with the institution's ethics committee. The Joint Commission for Accreditation of Healthcare Institutions requires hospitals to have an ethics committee to assist its oncologists, patients, and families to resolve difficult issues. They help ensure maximum possible patient autonomy in the conduct of ethical medical practice.

If, after review of the case, the committee supports the patient's position and the oncologist remains unpersuaded, transfer care of the patient to another oncologist within the institution.

If the review supports the oncologist's position and the patient/surrogate remains unpersuaded, transfer care of the patient to another institution if the patient, family, or surrogate and the transferring and receiving institutions agree. If transfer to an oncologist in another institution is not possible, the care team will need to continue to work with the patient, family, or surrogate to find a mutually acceptable solution.

## **Step 7: Review and revise periodically.**

As with so many matters of communication, and illness management in general, things can change rapidly and progress can slip backward easily. Continuous reevaluation allows pro-active management to minimize adverse developments. Touch base with all relevant family members and care team members on a regular basis, as part of the daily

or more frequent attention paid to the patient's care. Constant weaving in of this part of care allows for efficiency and saves potentially great amounts of time and effort by preempting further conflict.

## When the care team is the source of conflict

Oncologists and other members of the cancer care team bring their own personal feelings about cancer care and benefits and burdens of specific interventions to every 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.

Less commonly acknowledged, but of equal importance, are those situations where the oncologist persists in recommending therapy when the patient or family does not think it is beneficial, or evidence does not support any benefit to the patient.

This inclination to provide 'futile therapy' may be out of a desire 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. Oncologists and other members of the cancer care team, 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.

At all times, it is helpful for the oncologist to ask, 'Who are we doing this for?' Center care on the patient's values and goals for care. After all, it is the patient's life and body that are in jeopardy, not the oncologist's. To minimize the risk of conflict, maintain an open and ongoing process to listen to the patient, family and surrogate, share information carefully, facilitate their decision-making and support their choices. Strive to resolve differences in a manner that avoids showing disrespect for the professionals' expertise and knowledge yet fully respects the centrality of the patient.

## 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 oncologist or institution if necessary. Rarely, if no oncologist 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. Oncologists and other members of the cancer care team may seek to provide futile therapies just as patients and families may want them.

## Nature and limitation of futility definitions

3. Most disagreements about futile care are the result of misunderstandings or lack of attention to the family's (or oncologist's) emotional reaction to the patient's dying.

## Differential diagnosis of futility situations

4. Does the patient/surrogate understand the diagnosis and the oncologist's view of prognosis?
5. Are there personal factors?
6. 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
7. Failure to acknowledge and explore cultural and religious values, beliefs, and practices may exacerbate or prolong conflict and disagreement.
8. Differentiate "futile" therapy from "low-yield" therapy during discussions.
9. Are we talking to the appropriate decision maker?

## Due process approach

10. Negotiate an understanding in advance of conflict.
11. Use joint decision making.
12. Suggest participation of others, eg, a facilitator, other consultants, an ethics committee
13. Transfer care to another oncologist.
14. Transfer care to another institution.

## Pearls

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

## 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.

## References

- <sup>1</sup> Goold SD, Williams B, Arnold RM. Conflicts regarding decisions to limit treatment: a differential diagnosis. *JAMA*. 2000 Feb 16;283(7):909-14. [PMID: 10685716](#). [Full Text](#).

A "differential diagnosis" of conflicts, distinguishing and describing the characteristics of families, physicians, and organizations and society that contribute to the "etiology" of the situation, as well as strategies for "diagnosing" the dominant factors, is described. As a medical model, the differential diagnosis can be a useful tool to help physicians understand and manage conflicts about end-of-life care.

- <sup>2</sup> Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: response to critiques. *Ann Intern Med*. 1996 Oct 15;125(8):669-74. [PMID: 8849152](#). [Full Text](#).

A patient benefit-centered definition of medical futility that included both quantitative and qualitative components was proposed. The authors distinguished between an effect of a treatment that is limited to some part of a patient's body and a benefit that improves the patient as a whole. The quantitative portion stipulated that physicians should regard a treatment as futile if empirical data show that the treatment has less than a 1 in 100 chance of benefiting the patient. The qualitative portion stipulated that if a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, physicians should consider the treatment futile. In this paper, the authors clarify and modify the original proposal and respond to criticisms.

- <sup>3</sup> Council on Ethical and Judicial Affairs. Medical futility in end-of-life care. In: *Council on Ethical and Judicial Affairs Reports on End-of-Life Care*. Chicago, IL: American Medical Association; 1998:46-51. ISBN: 0899709621

- <sup>4</sup> Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: "it was just out of the question". *JAMA*. 2005 Mar 16;293(11):1374-81. [PMID: 15769971](#). [Full Text](#).

Physicians often assume that conflict is undesirable and destructive, yet conflict handled well can be productive, and the clarity that results can lead to clearer decision making and greater family, patient, and clinician satisfaction.

- <sup>5</sup> Halevy A, Brody B. A multi-institution collaborative policy on medical futility. *JAMA*. 1996 Aug 21;276(7):571-4. [PMID: 8709410](#).

This article reports on the creation of a multi-institution futility policy in the greater Houston area that is based on a new approach to dealing with these problematic cases.

- <sup>6</sup> Hudson T. Are futile-care policies the answer? Providers struggle with decisions for patients near the end of life. *Hosp Health Netw*. 1994 Feb 20;68(4):26-30, 32. [PMID: 8305945](#). [Full Text](#).

Clinicians and ethicists are working to develop effective guidelines on futile care, but even reaching for definitions presents daunting challenges. When is patient care futile? Who decides? What are the legal, operational and health care resource utilization issues involved? An examination of the range of issues. And a look at the maturing hospice field.

- <sup>7</sup> Teno JM, Murphy D, Lynn J, Tosteson A, Desbiens N, et al. Prognosis-based futility guidelines: does anyone win? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc*. 1994 Nov;42(11):1202-7. [PMID: 7963209](#).

The impact of prognosis-based futility guidelines on survival and hospital length of stay in a cohort of seriously ill adults is examined. The number of days of hospitalization that would not be used if, on the third study day, life-sustaining treatment had been stopped or not initiated for subjects with estimated 2-month survival probability of  $\leq 1\%$  is calculated. Of 4301 patients, 2.7% had an estimated chance of 2-month survival of  $\leq 1\%$ . All but one of these subjects died within 6 months. Almost 86% died within 5 days of prognosis. By forgoing or withdrawing life-sustaining treatment in accord with a strict 1% futility guideline, 199 of 1,688 hospital days (10.8%) would be forgone prospectively. Implementation of a strict, prognosis-based futility on the third day of a serious illness would result in modest savings.

- <sup>8</sup> Tomlinson T, Brody H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med*. 1988 Jan 7;318(1):43-6. [PMID: 3336383](#).

- <sup>9</sup> Truog R, Brett A, Frader J. Sounding board: the problem with futility. *N Engl J Med*. 1992 Jun 4;326(23):1560-4. [PMID: 1285741](#).

- <sup>10</sup> Youngner S. Futility: saying no is not enough. *J Am Geriatr Soc*. 1994 Aug;42(8):887-9. [PMID: 8046202](#).

The concept of medical futility, its applications and implications for clinical behavior are discussed. The author concludes that the concept of futility may provide a much needed corrective expert on health care, but will better fulfill its promise if those applying it also give attention to the social, psychological, and institutional problems that fostered demands for futile care in the first place.

- <sup>11</sup> Slevin ML, Stubbs L, Plant HJ, Wilson P, Gregory WM, Armes PJ, Downer SM. Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ*. 1990 Jun 2;300(6737):1458-60. [PMID: 2379006](#).

To compare responses of patients with cancer with those of a matched control group, cancer specialists, general practitioners, and cancer nurses in assessing personal cost-benefit of chemotherapy, a prospective study of consecutively recruited patients with cancer and other groups were evaluated by questionnaire. Respondents to the questionnaire included patients, controls, medical oncologists, radiotherapists, general practitioners, and cancer nurses. Patients with cancer were more likely to opt for radical treatment with minimal chance of benefit than people who do not have cancer, including medical and nursing professionals.

- <sup>12</sup> Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-11. [PMID: 10964998](#). [Full Text](#).

A protocol for disclosing unfavorable information-"breaking bad news"-to cancer patients about their illness is described.