

SGIM 2008 WORKSHOP WA02
CONFLICT OVER FUTILE CARE: THE WRATH OF MOM

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Link to all modules including Learning Module 7: Handling requests for therapies that you feel are futile. Copyright 2002.

The Conflict Over Futile Care: The Wrath of Mom

SGIM Annual Meeting 2008

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Objectives

- Define futility
- Better understand futility from perspective of patient, family, and clinician
- Apply at least one new strategy
- Locate resources

What is futility?

- One commonly used definition is that a futile intervention is one that
 - ◆ a) is unlikely to be of any benefit to a particular patient in a particular medical situation, and
 - ◆ b) will not achieve the patient's intended goals.
- The sticking point in all futility definitions is the concept of *benefit*, as the perception of benefit is highly subjective.
 - ◆ The public, policymakers, ethicists and the medical profession have been unable to agree on a clear, concise definition of futility that can be applied to all medical situations.

Most conflicts over futility* boil down to one of 2 situations

* Not due to inadequate communication

1. Values: life vs. quality-of-life

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

Most conflicts over futility boil down to one of 2 situations:

2. Differing Stages of Grief (Kübler-Ross)

- ◆ Denial, Anger, Bargaining, Sadness, Acceptance
- ◆ Everyone who cares about the patient experiences these stages
- ◆ Conflicts over futility arise when invested parties at different stages of acceptance *seek control*
- ◆ Conflicts over futility allow us to put off the difficult work of grief

Wrath of Mom: Small Group Round 1

Common Features of Cases

- Patients with multiple co-morbidities
- Communication issues – no information, language barrier, mixed messages, denial
- Family stressors
- Family dynamics – guilt, trust, secondary gain, miracles, own biases
- Value of life – quality vs. quantity
- **Conflicting perspective on goals**

1. Overtreatment

- Context changes as patient condition changes
- Therapy may no longer be appropriate
- Obligation to inform patients when overtreatment occurs
- Safety issue: can cause harm and suffering

2. Interdisciplinary Team

- One member may be able to make specific, meaningful connection
- Many heads are better than one, especially for creativity
- May diffuse the tension for individual members
- May promote stronger, unified message of multiple voices

3. Outside Advisor

- Look to clergy or cultural liaison or elder
- May provide different perspective or at least deeper understanding of differences

4. The Ethics Consult (and/or palliative care consult)

- Sense of a more objective outside opinion
- May use prior to entering the futility pathway
- May produce other options to address family concerns and needs
- Possibly preventive

5. Building Trust Between Physician and Family

- **Mistrust** often underlies conflicts over futility
- Focus on strengthening the **physician-family relationship**
 - ◆ **Stop trying to persuade** (twist arm, wring neck...)
 - ◆ **Keep Coming Back**
 - ◆ Rx: Tincture of Time, Repeated Brief Conversations
 - ◆ **Don't Talk - Listen**; Understand the family's views
 - ◆ **Look for areas of agreement**, some place to begin

6. Go for the Emotions

■ Listen for Emotions

■ **Actively ask** -- “This is such a hard time. I imagine how distressed you are. Can you tell me how you are doing?”

■ “NURSE” the Emotions

◆ Name -- “I see how upset you are.”

◆ Understand -- “I know this is not where you want your mom to end up. I see how difficult this must be for you.”

◆ Respect -- “I am really impressed by your caring and involvement.”

◆ Support -- “We will get through this together.”

◆ Explore -- “Tell me.”

6. Therapeutic Trials

- **IN MEDICINE:**
 - ◆ **There are no diagnoses; there are no treatments**
- **We only make provisional diagnoses and institute therapeutic trials.**
- **We follow and assess the clinical outcomes of a therapeutic trial, and change treatments according**

6. Therapeutic Trials: Withholding and Withdrawing

- We don't WITHDRAW treatment
 - ◆ We determine if the trial of treatment has achieved designated outcomes in the designated time
 - ◆ If not, a new treatment trial is instituted
- We TRY Aggressive Treatment initially, because we can stop/change the treatment when the trial of the treatment is judged to have failed.

Therapeutic Trials: Define Short Term Goals

- **Elicit Family's short term goals for the patient**
 - ◆ “What do you hope will happen over the next few days?”
- **Reach consensus on Operationalized Short Term Goals:**
 - SMART**
 - ◆ **Specific**
 - ◆ **Meaningful and Measurable**
 - ◆ **Active** (significant improvements in functioning)
 - ◆ **Realistic**
 - ◆ **Time/Trial Length clearly defined**
(e.g., awake communicating over the next week)
- **Confirm Consensus**
(e.g., “Does that sound OK?”)

Therapeutic Trials: Define Trial Interventions

- **Present Trial Intervention Plan** (with enthusiasm, optimism):
 - ◆ **Continue interventions** already in place. (Present these as an aggressive curative/restorative plan, not an old, stale, holding action, done instead of “real treatment.”)
(e.g., “I want us to continue to aggressively treat her (specific illness(es) illness over the next week, to see if we can help her to become awake and alert, and able to communicate with both of us.”).
 - ◆ **Add Selected Interventions** -- practical, feasible, only for duration of trial.
(e.g., “In addition, I would like to give her a trial of dialysis, to see if that helps her to recuperate over the next week.”)
- **Check for Agreement** (encourage agreement; be open to disagreement and willing to discuss it, including explaining why treatment suggestions are inappropriate, when necessary.)
(e.g., “How does that sound to you?”)
- **Schedule F/U meeting** to evaluate outcome of treatment trial
- **NOTE: NO OPEN-ENDED SOLICITATION**
(e.g., don’t ask, “What do you think we should do?”)

Evaluating the Trial Outcome

Meet with family at the end of the trial period

- **Summarize the concrete trial goals**

“As we discussed, we were hoping that we would achieve (short term goals).”

- **Ask family for their assessment**

“How do you think she’s doing at this point? Have we achieved the goals you had been hoping for?”

- **Present the “bad news,”** clearly and compassionately,

“I know you were hoping for (goals). I’m so sorry, but she’s just too sick to turn this around.”

- **Help families to shift their frame of reference: “Your mother is dying”**

“Let’s work together to help her be as comfortable as possible”

Working Together at EOL

- ◆ **Close Monitoring for Distress**

“As we discussed, I will watch her very closely for distress. Please tell me if she looks at all uncomfortable to you.”

- ◆ **Adding palliative interventions**

“As we discussed, I’m going to increase her pain medications, so that she is as comfortable as possible.”

- ◆ **Stopping over-treatment, withdrawing ineffective interventions**

“As, we discussed, I am going to be slowly stopping the medications for her blood pressure. At this point in her illness, the medications are doing more harm than good.”

- ◆ **Define new therapeutic trial period, e.g**

“I’d like to meet with you tomorrow, so that we can talk about how things are going.”

7. Shifting the Burden of Responsibility

- **Burden of EOL Decision-making:**
 - ◆ very painful burden for families
 - ◆ Families stumble, become paralyzed
- **The Burden should be shifted:**
 - ◆ **To the Patient**
 - ◆ inferring her goals, wishes
 - ◆ **To the Physician**
 - ◆ designing and instituting the treatment plan consonant with patient's goals, wishes

The Patient Decides, The Physician Treats

- **Reframing the Family's Role: "Substituted Judgment"**

"I can see how hard this is for you. You are trying to do the right things for her. But you are taking on more than you should. She and I should be carrying most of the weight."

- **The Patient Decides:**

"I want to work with you, so that we can try to figure out what medical care she would want now. Even though she can't speak directly, it's really up to her, and not something you should have to struggle with."

Patient's Values and Goals

- Understanding who the patient is:
 - ◆ “What’s she like as a person?”
 - ◆ “What’s important to her?”
 - ◆ “What does she do that means the most to her?”
 - ◆ “What does she hope to accomplish in the future?”

Inferring Patient's Wishes

■ Identifying Previously Stated Wishes

- ◆ “Did she ever discuss what she would want if she were to become desperately ill?” **COMMONLY, NO**
- ◆ **“When a family member was critically ill or died:**
 - What did she say about the medical care she witnessed?
 - What did she say she would want in similar situation?”

■ Inferring Current Wishes

(from long experience, knowledge of patient's values, life goals, and previously stated wishes (formal, informal))

- ◆ **“ If I could speak with her right now,** what do you think she would say about her current situation?
- ◆ “Would she want to live like this? Would she want (specifics, e.g., life on a respirator, unconscious, unable to speak with you?
- ◆ **“What would she tell us to do now?”** (specifically)

Physician States Patient's Inferred Wishes

Summarize your understanding of pt's values, goals, inferred wishes:

“Thank you so much. I think I understand her much better now.”

- ◆ She is a (characteristics) person”
- ◆ “The most important things for her are (activities/capabilities, core future goals)”
- ◆ **“She wouldn't have wanted...”**
 - ◆ (current functional life circumstances)
 - ◆ (suffering, pain, other symptoms)
 - ◆ (current treatment: invasive interventions, life support)

Patient Decides, Physician Treats, Families Agree

- **Physician takes full responsibility for the treatment plan.**
Family should not have to decide/articulate plans

“I’m her doctor, and it’s my responsibility to understand her wishes, and to give her the care that she wants, if she could tell us directly.”

 - ◆ “I will be...”
 - ◆ (specify interventions being added)
 - ◆ (specify interventions being withdrawn)
 - ◆ “I believe that this is the care she would want. OK?”
- **Family tacitly agrees, and has the opportunity to disagree**

Final Thought: Our Burden

- **We, feel the emotional burden of decisional responsibility, just like patients' families**
 - ◆ **Most dramatically in care of patients without families (“the elder alone”), where we become de facto family**
- **Clinical Inertia may set in**
 - ◆ **This month's team may punt to the next**
 - ◆ **The new team may start all over again**
 - ◆ **institutional amnesia**
 - ◆ **decisional burden**
- **Medical Team may need the support of the consult team**
 - ◆ **Periodic follow up meetings**
 - ◆ **Acknowledging emotional burden**
 - ◆ **Helping the team to carry out the medical decisions**

Wrath of Mom: Small Group Round 2

Please Complete Your
Evaluations

Thank you!!!

SGIM Case

Alice Baker is a 50 year old, widowed patient with a many-year history of alcoholism, resulting in cirrhosis of the liver and hepatic failure. Her husband, also an alcoholic, died 10 years ago of cirrhosis. She has no children. Ms. Baker has not remarried; she has been living with her boyfriend for the past 5 years. You admitted her to the Medical Intensive Care Unit with sepsis and acute renal failure requiring hemodialysis 3 weeks ago. She is only minimally responsive and no longer capable of making decisions. Ms. Baker developed pneumonia and required intubation and mechanical ventilation for respiratory failure. She currently requires moderate sedation for severe agitation. She also now has a coagulopathy with upper GI bleeding and oozing around the oropharynx, requiring intermittent blood products, and has been on and off pressors.

Ms. Baker does not have an advance directive. Her legally authorized surrogate decision maker is her mother, a widow who has been remarried for 30 years to Ms. Baker's stepfather. Ms. Baker's mother has consistently approved of all interventions to try to save or prolong her daughter's life. As her clinical condition has deteriorated and the ICU staff have become more pessimistic, Ms. Baker's mother has become increasingly strident in demanding that any and all care be given to extend her daughter's life.

Instructions for the role play:

1. Select participants for each of the following roles. Each participant should read his or her role only.
 - a. ICU Physician
 - b. Primary Care Physician
 - c. Mother
 - d. Step-Father
 - e. Boyfriend
2. Additional participants can act as a facilitator or observer (body language, emotional content, use of language (avoidance/collusion/vague language, etc.).
3. The ICU physician has convened a family meeting to discuss goals of care with the family (as the patient is unconscious). **The ICU physician should take the lead in starting off the family meeting.**

Roles

ICU Physician:

You've been taking care of Ms. Baker for most of the last 3 weeks, watching her clinically deteriorate with increasing evidence of multi-system organ failure. In your clinical judgment, her multi-system organ failure is irreversible and she is terminally ill. You have explained to Ms. Baker's mother, step-father, and boyfriend, the medical situation and your recommendation that life support be withdrawn and that the patient receive continued palliative care. You also suggest a DNR status. Personally, you are frustrated because you feel that the patient's mother's demand that you 'do everything' is unreasonable. You believe that the patient's medical care is futile and a source of suffering.

"An important part of our job is to let you know when our medical interventions are no longer helping. Unfortunately, we have reached this point with Ms. Baker. All of us involved in her care feel we are now causing her harm and suffering. She is only getting worse."

Primary Care Physician:

You've been taking care of Ms. Baker on and off for the past 3 years for her liver disease. Her attendance in clinic has been spotty, and you've never had the opportunity to discuss an advance directive because she always has a crisis of one kind or another to deal with. Based on her lack of attention to her own health and ambivalence towards healthcare, you find it hard to believe that she would want 'everything' done.

"I have seen Ms. Baker over time. Though she and I never had a chance to discuss her exact wishes in this situation, my sense is she would not want to live this way indefinitely."

Patient's Mother:

72 year old woman – objects strenuously to the physician recommendations for withdrawal of life sustaining treatment, questioning the clinical judgment. She wants all life support continued and also wants full resuscitation. She states she is hopeful for a miraculous recovery and believes that by keeping her alive as long as her daughter is alive a miracle is possible. She has a strong Christian faith with an emphasis on the healing power of God and also a sense of guilt over her daughter's alcoholism.

"It's important to me that we continue to do everything for my daughter. It would be wrong to give up and I still hope for her to get better."

Patient's Step-Father:

70 year old man – has known the patient for over 30 years. He shares his wife's faith and shares that he has also been praying a lot. He acknowledges that Mr. A is very sick. However, he's determined to be optimistic and wants to provide all support necessary to allow her to get better when the opportunity arises.

“This is such a hard time for us. We both love Ms. A so much. We should continue on with all the treatments to give her a chance.”

Patient's Boyfriend:

55 year old man – seems to understand the seriousness of the situation. Disagrees with the patient's mother, saying Ms. A would not want to be kept on machines indefinitely without hope for improvement. She specifically told him when a friend died on a ventilator after a car accident a few years ago that she would never want life support if her liver got that bad. He has nothing to gain in this situation other than to see his loved one die with less suffering. He has known Ms. A's mother and stepfather but has spent little time with them.

“I know my darling would never want this. We talked about it once. I wish I could stop this torture by making the decision myself. I don't know if her mother can do this.”

Suggested schedule:

- 0-10 minutes: Ask audience what they are hoping to address and get out of this workshop (Erik)
- 10-30 minutes: Presentation on Ethics/Legal matters (Ellen/Laura)
- 30-45 minutes: Set up the roleplay and present 3 strategies: therapeutic trial, taking on the burden of responsibility, and building trust (Charlie)
- 45-75 minutes: Small group role plays
- 75-90 minutes: Discussion and evaluations