

## 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 Baker's mother, step-father, and boyfriend, the medical situation and your recommendation that life support be withdrawn and that the patient receive continued palliative care.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 acknowledges that he has his own take on the situation and what he thinks his stepdaughter's wishes would be. It will take some effort to uncover that he believes Ms. A would not want to linger in her current state. This is not who she was or how she would want to live or die. However, he will defer to his wife's decision in the end.

“This is such a hard decision for my wife. We both love Ms. A so much. My wife just has a certain way she has to face this. I support my wife in her decision.”

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

**DEALING EFFECTIVELY WITH FUTILITY:  
ETHICS, COMMUNICATION, AND CONFLICT RESOLUTION**

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## **ONCOTALK**

<http://www.depts.washington.edu/oncotalk>

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

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# WA04 Dealing Effectively With Futility: Ethics, Communication, and Conflict Resolution

Ellen Coffey

Erik Fromme

Laura Morrison

Charles Schwartz

# Objectives

- Understand a physician's ethical and legal responsibilities to a patient in potentially futile care
- Review the psychology of futility from viewpoints of patient, family and physician
- Apply strategies for addressing demands for futile care
- Locate resources for further study

# It's Futile...

“if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for that patient...”

1991 American Thoracic Society

# Ethical and Legal Aspects

Dealing Effectively With Futility:  
Ethics, Communication, and Conflict  
Resolution

SGIM 2007

# In the Good Old Days...

- People died at home
  - Pneumonia was “the old man’s friend”
  - When someone stopped eating, that was it
  - Death was expected
- 
- And futility wasn’t an issue as it is now.

# Now...

- Medicare covers acute care, including ICU
- Improved diagnostics
- Improved technology
- Antibiotics
- Little attention to when technologies are not appropriate
  
- And futility issues

# Core Ethical Principles

- Beneficence

- ◆ Act in the best interests of the patient

# Core Ethical Principles

- Beneficence
- Non-maleficence
  - ◆ “Primum non nocere”

# Core Ethical Principles

- Beneficence
- Non-maleficence
- Patient Autonomy
  - ◆ Patient right to self-determination

# Core Ethical Principles

- Beneficence
- Non-maleficence
- Patient Autonomy
- Justice
  - ◆ “Do the right thing”

# Landmark Cases

- Karen Quinlan
- Nancy Cruzan
- Terri Schiavo

# Karen Quinlan - 1976

- Parents request stopping vent for pt in persistent vegetative state.
- Court stops MDs from forcing futile care
- Encourage living will legislation @ state level
- Encourage ethics committees

Annas, G.

N Eng J Med 2005;.352(16):1710-1715

# Nancy Cruzan 1990

- Feeding tube removal in PVS
- State: Need for clear and convincing evidence that pt would want
- US Supreme Court:
  - ◆ States can set evidentiary standard for surrogate
  - ◆ No legal difference between artificially delivered fluids/food, other medical interventions
- Growth of Durable Power/Health Care Agents

# Terri Schiavo 2005

- Persistent vegetative state, a family divided, and a national stage
- More people discussing, more living wills?

Annas G.

N Eng J Med 2005;.352(16):1710-1715

# Texas Advance Directives Act 1999 (Texas Futile Care Law)

- Signed by then Governor George W Bush
- Allows a health care facility to discontinue life-sustaining therapy against the wishes of a patient or guardian 10 days after written notification from the medical team that continuation of therapy is medically inappropriate
- Attending physician initiates process

# Texas Advance Directives Act

- Family gets 48 hr notice, written info on policy, can participate in ethics consult
- Ethics consult report in writing to family
- If not resolved, try to arrange transfer
- If no transfer in 10 days, hospital/MD may withhold or withdraw futile therapy
- Pt/surrogate may request extension

Fine R, Mayo T.

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# Texas Advance Directives Act

- 2-5 year data from 17 large hospitals
  - ◆ 2,922 Ethics Committee consults
  - ◆ 974 Ethics Committee consults for medical futility cases
  - ◆ 65 letters sent
  - ◆ 27 cases – treatment withdrawn
  - ◆ 22 cases – patient died receiving treatment and awaiting transfer

# Texas Advance Directives Act

## ■ Criticisms

- ◆ Waiting time too short
- ◆ No registry to keep track of cases
- ◆ May go against a patient's expressed wishes

## ■ Repeal Efforts – SB 439/HB 1094

- ◆ In process
- ◆ Much debate

# Oncotalk

- Developed by Anthony Back, Robert Arnold, Walter Baile, James Tulsky, Kelly Fryer-Edwards
- Communication learning modules for oncology fellows
- <http://www.oncotalk.info>

# Legal Decision Maker

- Patient's stated preference or durable power
- Hierarchy in your state
- Who would know what patient wanted?
- Who can reflect patient's best interest?
- Who has ability to make decisions?

# Family Perceptions – Misunderstanding?

- No information
- Language
- Conflicting info
- Told to be hopeful
- Stressed out
- Denial

# Family Dynamics

- Guilt
- Trust
- Secondary gain
- Hoping for a miracle
  
- Check your own bias

# Next Steps...

- Devise care plan, discuss with decision maker and stakeholders
- Consider ethics consult

# Pearls

- Know views before trying to convince
- Assume good intent
- Can you help the family?
- Empathy builds trust
  - ◆ “I wish things were different”

# Pitfalls

- Trying to convince someone that a decision is unreasonable or just wrong
- Asking the family what they want to do
- Ignoring emotion

# **DEALING EFFECTIVELY WITH FUTILITY: 3 STRATEGIES FOR CONFLICT RESOLUTION**

**Charles E. Schwartz, MD**

**Erik K. Fromme, MD**

**Ellen Coffey, MD**

**Laura J. Morrison, MD**

# Building Trust Between Physician and Family

- Mistrust often underlies conflicts over futility
- Conflicts over futility breed mistrust
- When all else fails, focus on building trust
  - ◆ Don't try to get your points across
  - ◆ Try to understand their point as fully as you can
  - ◆ Look for areas where you can agree

# Building Trust: The 4 things

- Show up
  - ◆ Don't expect change overnight -- keep seeing the patient, even though it's painful
- Pay attention
  - ◆ Create the opportunity for you to listen to them
- Tell the truth, without judgment or blame
  - ◆ When you are asked for your opinion
- Don't be attached to the outcome
  - ◆ You are not in control (would you really want to be?)
  - ◆ Remember the serenity prayer

Angeles Ariens, PhD

# Building Trust: Helpful Phrases

- Ask, Tell, Ask
- Tell me more
- Respond to emotions: NURSE
  - ◆ 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 want you
  - ◆ Support -- “I will come
  - ◆ Explore -- “Tell me

Robert C. Smith (1991)

James Tulsky (2004)

# Conducting a Therapeutic Trial: Collaborating with the Family

- Find out what the family's goals are for the patient

“What are you hoping will happen?”

“More specifically, what do you hope will happen over the next few days?”

- ◆ Operationalize the goals -- potentially achievable in days, concrete, measurable (e.g., hemodynamic stability off pressors)

- Discuss what interventions the family feels will achieve the goals

“What specific treatments would help us try to achieve (short term goal)?”

- ◆ Interventions already in place
- ◆ Additional interventions -- selected from a practical, feasible set that you present (e.g., no heart transplant)

# The Therapeutic Trial: Collaborating on the Plan

- Collaboratively design a therapeutic trial
  - ◆ Repeatedly emphasize that you are talking about what you should “TRY”
  - ◆ This is not “The Patient’s Treatment” -- immutably writ in stone
  - ◆ It’s a “trial” -- with defined parameters --
    - ◆ defined interventions
    - ◆ desired outcomes
    - ◆ defined trial period
    - ◆ outcome evaluation
    - ◆ A new therapeutic plan based on outcomes
      - Clearly and Directly present the Palliative Plan that will be appropriate if (when) the therapeutic trial fails
        - Adding palliative interventions, e.g., more aggressive pain management, pastoral care, getting other family informed and involved
        - Withdrawing futile curative intervention, e.g., pressors

# Therapeutic Trial: Evaluating the Outcome

- Meet with family at the end of the trial period they had agreed to
- Summarize the concrete goals they had hoped would be achieved, e.g.,  
“As we discussed, we were hoping that we would achieve (short term goals).”
- Ask family for their assessment, e.g.  
“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, e.g.,  
“I know how much you were hoping for (goals). I’m so sorry, but she’s just too sick to turn this around.”

# Therapeutic Trial: Instituting a New Plan

Discuss a new therapeutic plan, e.g.,

“In fairness to her, we need to focus on doing things that help her to be comfortable during this final time. We shouldn’t be doing uncomfortable things that aren’t helping her.”

- ◆ Close Monitoring of Distress, e.g.,

“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, e.g.,

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

- ◆ Withdrawing curative interventions, e.g.,

“As, we discussed, I am going to be slowly stopping the medications for her blood pressure.”

- ◆ 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.”

# Shifting the Burden of Responsibility

- **Decision-making at End-of-Life is very painful for families**
- **Families stumble, under the weight of this burden**
- **Some of the Burden should be shifted:**
  - ◆ **To the Patient -- inferring her wishes**
  - ◆ **To the Physician -- providing support, clarifying patient goals and wishes, designing and instituting the plans appropriate to goals and wishes**

# Shifting the Burden of Responsibility From the Family

## ■ Reframing the Family's Role:

**“I can see how hard this is for you, how hard 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 a lot 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.”**

### ◆ The Physician Treats

# Shifting the Burden of Responsibility To the Patient: 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?”**

# Shifting the Burden of Responsibility to the Patient: Inferred Wishes

## ■ **Inferring the Patient's Wishes:**

**“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 (be specific, e.g., to live having to be on a respirator, be unconscious and not able to be with family)?”**
- ◆ **“What would she tell us to do now?” (be specific)**

# Shifting the Burden of Responsibility To the Physician: Understanding the Patient

- **Summarizing your understanding of the patient'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)**

# Shifting the Burden of Responsibility To the Physician: Treating the Patient

- **Taking Responsibility for the plan**

- “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)

- **Physician, not Family Plans Treatment. Family tacitly agrees, but has the opportunity to disagree**

- ◆ “I believe that this is the care she would want. OK?”