Project ECHO-PACA: Communication about impending death

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Goals

- Present a few challenging scenarios
- Discuss a specific clinical vignette
- Briefly discuss “SPIKES”, a conceptual framework for discussing any sensitive topic
- Present serious illness conversation guide
Most challenging aspects of end of life discussions

- Patient’s adult son asks “Please don’t tell my mother…”
- Patient who is near death says “I trust God will heal me. I will never give up.”
- “How long do I have?”
- “You mean you are just going to let him starve?!”
Patient Scenario

- 38 year old woman with progressive stage 4 cervical cancer no longer responding to chemotherapy
- Married with 3 children: 4, 7, and 11 years old
- Bedridden with liver failure and shortness of breath related to extensive lung metastases
- “I need to live for my children. My husband does not know how to cook or care for them, since he works as a truck driver and is gone frequently.”
The first step:
  take stock of our emotions

- What can we fix, and what is unfixable?
- Fix what can be fixed.
- Do not try to fix the unfixable.
- Accepting reality is not the same as admitting defeat.
- We can only do our best
- Presence and genuine empathy are therapeutic
• Setting
• Perception
• Invitation
• Knowledge
• Empathy
• Summary

SPIKES
Baile, The Oncologist 2000
The “Perception” part of the SPIKES paradigm

• Ask first (or ask-tell-ask):
  – “Where do you think you are in your illness now?”
  – “Tell me more….”
  – “What is most important to you now?”

• Whenever anyone asks a question that you do not know how to answer or “throws you a curveball”, ask for more information: “Tell me more about what you mean.”
“Ask-tell-ask” skill applied to the prognostic question

- “How long do I have doc?”
- “I will give you facts and figures in a moment if you want, but first tell me more why you ask this question. Help me answer the best way possible. What is on your mind?”
- Often people ultimately do not care about a time frame.
• If patient does want a time estimate, answer with ranges:
  – Hours to days
  – Days to weeks
  – Weeks to months

• Consider saying the following to set realistic expectations:
  – “We hope and pray for the longest and best possible life for your husband. However, as sick as he is, he could go suddenly at any time.”
  – Additional empathic response: “As difficult as it is to consider the worst, I think we should be prepared.”
NURSE
Empathic “Continuer” Phrases
Pollak, JCO 2007

- Name
- Understand
- Respect
- Support
- Explore
- Bonus: “I wish….”
Name the emotion

- “You seem sad. Tell me what’s going on.”
- “This must be incredibly frustrating for you.”
Understand the emotion

• “I don’t blame you for being anxious during radiation. That face mask would make anyone anxious.”

• “I don’t blame you for being mad. I would be too if I had to wait so long to see your doctor.”
Respect the emotion

• “I respect your religious faith. That is strong medicine.”

• “I respect your fighting spirit. You have fought your illness bravely.”

• “I respect the love between you and your family.”
Support the patient and family

- “No matter what happens, we will be here for you. We will do the best we can for you.”
• Check list approach
• Encourages patients to tell their “stories”
• Allows us to recommend a course of action rather than make an ultimatum.