Resilience in the Face of Grief and Loss:
A Curriculum for Pediatric Residents and Fellows

Part B: Section B.2
WHAT TO DO WITH “BAD NEWS”
Learning Objectives

2.1 Use skill in sharing bad news, including disclosure of a life altering diagnosis, death of a patient, and occurrence of a medical error; specifically:

a. Answer the question “Am I going to die?” posed by a 4, 8 and 15 year old
b. Respond when a parent starts to cry in the middle of a conversation
c. Respond effectively when a parent exhibits anger
d. Be able to state, in under a minute, that a patient received a drug in error
Learning Objectives continued

2.2. Skillfully lead a discussion of end of life issues and goals of care (e.g., do not resuscitate measures) with a family whose child is severely or terminally ill.

2.3. Listen generously to the grief of patients and families.

2.4. Counsel parents about how to identify a child/teen who is experiencing complicated grief.

PART B. Communicating with Families about Severe and Terminal Illness in Their Children
What is bad news?

Any information likely to drastically and negatively alter the patient’s view of his or her future.

- Robert Buckman
What bad news have you delivered?
Examples of bad news in pediatrics

- Infant born with a deformity not known prenatally
- Child given an incorrect medication dose
- Child with clinical findings concerning for cancer
- Injured child brought to the ED who dies
- Teen who is unintentionally pregnant
- A delayed discharge or surgery
What is the scariest part of delivering bad news?
What makes bad news so bad?

- Fear of emotional response
- Sadness
- Helplessness
- Fear of blame
- Fear of death
- Lack of training
- Wanting to protect the child and family
Why learn to do it well?

- You will do it, more often than you realize.
- Powerful impact on how patients and families cope.
- It is rewarding when done well (and stressful when it is not).
- It is satisfying when done well (and satisfaction can minimize burnout).
Activity

Do it well—not perfectly

- Expertise in sharing bad news is *not* defined as doing it perfectly… rather it is getting it “right” most of the time.

- Requires:
  - Communication skills
  - Being comfortable managing emotions
The role of self-awareness and mindful practice in sharing bad news

- Self-awareness can assist practitioners in becoming more attentive to the presence of stress.
- Increased mindfulness is correlated with reduced burnout and total mood disturbance in physicians.
- Patient-centered qualities are correlated with increased mindfulness (Krasner, 2009).
Communication

“Words are, in my not-so-humble opinion, our most inexhaustible source of magic; capable of both inflicting injury, and remedying it.”

- Albus Dumbledore
  
  Harry Potter and the Deathly Hallows, Part B
Basics

- How to share bad news:
  - SPIKES
  - Ask – Tell – Ask

- Handling emotions:
  - NURSE
Spikes

- Set up (staging)
- Perception
- Invitation ("warning shot")
- Knowledge
- Empathy
- Summary and strategy

“Communication Skills in Clinical Practice Part 4”
http://www.youtube.com/watch?v=ftgNapAfV6Q

Set up and Staging

- Arrange for privacy
- Manage interruptions (e.g. pager, phone)
- Review the chart; clarify medical facts (for yourself)
- Involve others (e.g. other family members, nursing staff)
- Sit down (choose seats wisely)
- Introduce everyone
Which feels better?

Impact of Body Language
 Perception

- Always get information before you give information:
  - “What have the doctors told you…”
  - “What is your understanding of…”
Invitation

- Ask how the patient / family likes to receive information (i.e. the “big picture” or details)
- Ask if anyone else should be present
- Give a warning shot:
  - "Unfortunately the news is not what we had hoped for..." or
  - "I am sorry but I have some information which may be hard to hear..."
AVOID JARGON!

“Doctors sometimes use words that not everyone understands. Please stop me if I’m doing this.”

Avoid euphemisms

Give information in small pieces

Check understanding frequently
Empathy and Emotion

- Let them know you have connected with their emotions
  - Stop talking
  - Observe the emotion
  - Identify the emotion
  - Explore the reason for the emotion
  - (Use the NURSE mnemonic coming up)
Summary and Strategy

- Check overall understanding
- Recap goals
- Discuss the plan
- Probe for questions
- Document the discussion
Basics

- How to share bad news:
  - SPIKES
  - Ask – Tell – Ask
- Handling emotions:
  - NURSE
Ask – Tell – Ask

- Ask the patient / parent to describe their current understanding of the issue
- Tell the patient / parent in straightforward language what the “bad news” is about
- Ask the patient / parent to describe the information back to you
  - Ask what question they have, points they need clarified
  - Ask what it means to them
  - Ask how they may share this news with others

Sources of conflict

- Past experience of both you and the patient / parent
- Balance of truth-telling while maintaining hope
  - Physician wants to be candid, but wants to avoid hurting the patient / parent
  - Patient / Parent wants to hear the truth yet may be resistant to the content
- Cultural differences may mean differences in expected communication patterns
Anticipate reactions

- Be prepared for parental reactions, as well as your own
- Anticipate expressions of anger, sadness, guilt, relief
- Utilize NURSE mnemonic
- Never judge a reaction, nor assume you know why they are reacting a certain way
## NURSE Mnemonic

<table>
<thead>
<tr>
<th>N</th>
<th>Name</th>
<th>I wonder if you are feeling angry. I see that you are frustrated. It seems like you are down today.</th>
</tr>
</thead>
<tbody>
<tr>
<td>U</td>
<td>Understand</td>
<td>It is hard to imagine what you are going through. This is a lot to be dealing with.</td>
</tr>
<tr>
<td>R</td>
<td>Respect</td>
<td>I see how strongly you’ve been advocating for her. You are good, loving parents.</td>
</tr>
<tr>
<td>S</td>
<td>Support</td>
<td>I want you to know that I am here for you. We are available for you as questions come up.</td>
</tr>
<tr>
<td>E</td>
<td>Explore</td>
<td>Tell me more about what you are thinking. How are you doing today?</td>
</tr>
</tbody>
</table>

Tears

- Tears are common when hearing bad news
- Have tissues available
  - Demonstrates you know this is emotional
  - Gives the person ‘permission’ to cry
Anger

- Look for the source of anger
  - A majority of anger stems from fear
  - Other sources: genuine insult; personality

- Recognize the direction of the anger
  - Is this internal anger or guilt?
  - Is it external – toward staff, the hospital, God

- Engage, but avoid enmeshment with the emotion

Wang-Cheng. EPERC Fast Fact #59
Putting it together

- Here is how one pediatric palliative care physician frames the issues we’ve just talked about:
  
  http://www.youtube.com/watch?v=KBrmMW9c8_g
After the bad news disclosure

- Encourage parents to spend time with their child
- Determine how to disclose to the child*
- Offer to call other family members or supports
- Be available for questions
- Arrange a plan for follow-up

* See Part A: Understanding Grief and Loss in Children
Misguided objections to disclosure to the pediatric patient

- Fear of inducing anxiety
- Perception that children cannot comprehend the whole truth
- Perception that some children do not wish to know the truth
Benefits of disclosure to the pediatric patient

- Decreases isolation and feelings of abandonment
- Creates more control and less anxiety
- Enhances long-term emotional and social adjustment
- Allows for better participation in decisions
- Keeps kids from being deprived of the opportunity to make their deaths meaningful

Kushnick HL. *Virtual Mentor* 2010;12:573-577
Disclosure to the pediatric patient

- Parents prefer to speak with the providers first
  - Make a plan to disclose
  - Young *Pediatrics* 2011

- Autonomy without the exclusion of parents
  - Respect for the role of the parent
  - An active role in end of life decision making

- “Straight talk” about diagnosis, treatment, prognosis

- Planned follow-up and ongoing discussion
Pointers for discussing disclosure

- Disclosure is a process
- Establish a culture of openness
- Partner with parents to find hope & solutions
- Inform parents that you will not lie
- Discuss benefits & harms of disclosure
- Engage in a dialogue about the “process”
- Explore family fears about disclosure
- Involve team members & family supporters
- Explore what the child already knows
- Employ nonverbal means as needed

Friebert S. Virtual Mentor. 2010;12:522-529
Tell the children...

Because children know when they are dying and can sense the extraordinary stress of their parents and doctors when death is imminent, they may feel tremendous isolation if they are not given permission to talk openly about their illness and impending death.

6 E’s of communication with children who are dying

- **Establish** agreement with parents and children concerning open communication
- **Engage** the child at an opportune time
- **Explore** what the child already knows and wants to know
- **Explain** medical information according to the child’s age and needs
- **Empathize** with the child’s emotional reaction
- **Encourage** by reassuring him/her that you will listen and be supportive

Additional reference:
Activity

Respond to the essay “Should parents speak with a dying child about impending death?” in NEJM 2004; 351:1251-1253

Respond to the essay “At the end of a child’s life, parents at a loss for words” ABC News March 5, 2012
Activity

Answer the question “Am I going to die?” posed by a 4, 8, and 15 year old

http://www.bcchildrens.ca/KidsTeensFam/A-ZPamphlets/G-HPamphlets.htm#Griefandloss
A way to find out more… ask about goals of care

- What is your understanding of the illness?
- Given that, what are your hopes? What else?
- What concerns you most about his illness? What concerns you most right now?
- What’s most important for your child?
- What is the best and the worst that might happen?
How does uncertainty impact bad news?
Uncertainty

- Acknowledge uncertainty
  - This illness can act in different ways

- Admit what you don’t know
  - Medicine only knows so much at this time
Some “dos”

- Be humble, yet competent
- Give honest information
- Acknowledge uncertainty
- Include children in developmentally-appropriate discussions when available *
- Balance emotions and cognitive needs
- Negotiate treatment decisions based on goals of care and family values
- Practice your communication skills

* See Part A: Understanding Grief and Loss in Children
Some “don’ts”

- Give conflicting or vague information
- Use euphemisms
- Speak directly to a child about their illness without permission
- Present treatment options as a choice between life or death
- Give unrealistic hopes about treatments (including resuscitation)
- Assume that not wanting to die is the same as “wanting everything done”
Putting it into practice with role play*

- Guided reflective patient narratives
- Simulated patients

* See Sections B3 and B4
References

- Kushnick HL. Trusting them with the truth - disclosure and the good death for children with terminal illness. *Virtual Mentor* 2010;12:573-577