

Part B: Communicating with Families About Severe and Terminal Illness in Their Children

Discussion Guide: Communicating with Families about Severe and Terminal Illness in Their Children

Learning Objectives for this Section

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

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.

Relevant Milestones: PROF1, PROF6, ICS2.

Introduction

Bad news “any information likely to drastically and negatively alter the patient’s view of his or her future” (Buckman 2012).

- Discussing bad news requires advanced communication skills.
- It is difficult because we are not sure how we can be honest and not destroy hope; we are afraid of our own inadequacy and we are unprepared to manage emotions (our own and those of others).
- Learning these skills requires supervised practice, feedback and mentoring (Levetown, 2008).
- Advanced communication skills require learning and practicing specific techniques of communication, attention to one’s own emotional response and careful, empathic attention to the emotional responses of the children and families with whom we are communicating.
- Communicating in challenging situations requires a complex combination of skills.
 - o At the cognitive level, parents and patients need to know and understand what is going on, which requires task-related skills, such as asking questions and providing information.
 - o At the emotional/affective level, they also need to feel heard and understood, which requires of the provider relational behavior, such as reflecting feelings, showing respect, concern, compassion, using both verbal and non-verbal skills: gestures, posture, eye contact, silence.
 - o To relate to individuals with emotional skill the practitioner “needs to sense the sharing of suffering, ...be willing to be fully present, ...[and move] fluidly between a position as expert and as curious and respectful fellow human being. Self-awareness and reflective practice are central to compassionate communication”. (Browning, 2002).
 - o For effective communication, it is imperative to relate at both the intellectual and emotional levels.

Guidelines for Communicating Difficult News

Let's explore three approaches to the challenge of entering into and maintaining a difficult conversation with a family.

1. SPIKES (see slide set What is Bad News?)

Set-up: Consider privacy, who to include, sitting down, and building rapport. Some patients may begin to cry when they hear bad news. For this reason, it is best if there are tissues within reach even before starting the conversation. Having to leave to find some can be disruptive.

Perceive: What is your understanding of the situation?

Invite: Warning phase: "I am so sorry, but I need to share some bad news with you..."

Share Knowledge: Give knowledge and information using understandable language, give information in small pieces, and check in frequently.

Empathize: Empathy is "the projection of one's personality into the personality of another in order to understand the person better; the ability to share in another's emotions, thoughts, or feelings." (Webster)

Summarize and strategize with the patient/parents.

2. Ask – Tell – Ask (Back, 2005)

When deciding what and how much to share, a good place to begin is where the patient and/or family are in their understanding. Ask-Tell-Ask is a way of making sure that they understand what you say. (This is not to be used in situations of informing a parent of a child's death.)

Ask the patient/parent to describe their current understanding of the issue (e.g., Can you tell me what you understand of _____'s condition? What have the other doctors been telling you about the situation?).

Tell the patient/parent in straightforward language what you need to communicate – be it bad news, treatment options, etc. Do not give a long lecture or a lot of detail. Provide information in short segments. Avoid medical jargon.

Ask if the patient/parent understood what you just said. Consider asking them to repeat in their own words, or ask them with who they are going to share the news and what they are going to say to that person. Give them a chance to ask questions, so you can clarify.

Tell Me More: If you find that the parent is not following you, or if you are not following the parent/patient, invite them to tell you more. You could ask, "Please tell me more about what information you need at this point?" Or, "What does this information mean to you?"

As a follow-up for "Tell Me More," it may be appropriate to talk about the patient's and family's goals of care. Such a discussion may start with a statement such as, "Given what you now understand about the illness..."

- What worries or concerns you most about the illness?
- When you think about his illness, what is the best outcome? Worst outcome?
- What are your hopes? What else are you hoping for?
- What is most important to your child? And at this time?
- What brings your child joy? Pleasure? Comfort?

The discussion can then move to talking about the balance between continued survival vs. promotion of comfort. It may help parents to think about the benefits and burdens of each alternative, which can be introduced as whether we are doing things *to the child* or *for the child*.

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If the clinical scenario warrants it, the goals of care discussion may lead to conversations about resuscitation status. Having limits on resuscitation can be a protection from interventions that are likely to harm or unlikely to be of benefit. A “Do Not Resuscitate” (DNR) order can be thought of as an approach to refocusing active care, rather than “doing nothing.”

3. NURSE (Back, 2005)

During these challenging conversations we are likely to encounter strong emotions in our patients and families, as well as ourselves. The mnemonic NURSE offers a way to practice expressing openness and receptivity and more deeply exploring emotional responses.

Naming: Name the emotion to yourself as a way of paying attention to what is happening in the encounter. Consider saying the emotion name out loud to the patient or parent, but do not tell them what they are feeling. Rather than saying, “I can see you are angry about this,” consider “I wonder if you are feeling angry.” Or, stating, “Some people in this situation would be angry.”

Understanding: Validate the emotion you see, and use active listening to be sure you understand. Using compassionate silence can be useful here too. If you respond to emotion, use an accepting response. Do not immediately reassure or agree, just accept emotion without judgment, by saying, “I hear what you are saying.” Anger can be difficult. Within the medical setting, the majority of anger stems from fear. Fast Facts # 59 “Dealing with Anger” offers more information.

Respecting: Acknowledging and respecting emotion are ways to show empathy. You may use non-verbal cues such as facial expression, change in posture, or touch. Also consider empathic verbal responses like “this is so hard,” or offer praise for their coping skills. Different people respond to their own tears differently, and some will want tissues and others may not. Some will be calmed by a gentle touch to the shoulder or knee; others will not.

Supporting: Offer expressions of concern, show willingness to help, and acknowledge their efforts to cope.

Exploring: Invite them to elaborate emotions and concerns.

You may wish to view the brief you tube video by Dr. Stephen Liben at McGill Medical School Palliative Care program to prepare for the delivery of bad news and the skill of listening deeply: http://www.youtube.com/watch?v=KBrmMW9c8_g

Talking Directly to Children who are Dying

- In the situation of the dying child, parents often prefer to speak with the providers first. The role of the parent needs to be respected.
- There are many benefits to discussing death with the child and giving the child an active role in end of life decision making. Children who are offered the opportunity to discuss their impending death feel less isolated, they experience a greater sense of control and less anxiety, their long-term emotional and social adjustment is enhanced, and they are better able to participate in decisions.
- What happens when a child asks, “Am I going to die?” It is important to understand what the child is really asking. What is he or she really worried about; it may not be as anxiety-provoking (or as “deep”) as you think. The best response when anyone asks, “Am I going to die?” is “Tell me more” or “What’s on your mind?”
- It is important to have an awareness of the developmental understanding of death, yet recognize that life experience is a strong influence. More information on the child’s understanding of death can be found in Part A: Understanding Grief and Loss in Children.
- To generate reflection on the basis of sharing information about prognosis and potential death with the child, in addition to parents, you may wish to read the essay “Should parents speak with a dying child about impending death?” in NEJM 2004; 351:1251-1253.

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Six E's of Communication with Children Who are Dying (Beale, 2005)

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

Discussing End of Life Goal Setting with Families

The following table provides some suggestions about clear ways of talking to patients and families about end-of-life decisions, so you can avoid unintentionally sending them messages that are distressing or confusing. It was shared by Dr. Joanne Wolfe at Harvard Palliative Care program.

Palliative Care Communication Faux Pas – Examples			
Setting	Faux Pas	Unintended Message	Alternative
Discussion about defining goals of care	“What would you like us to do for you?”	Implies that the patient can choose from a menu of options.	Use open-ended questions to define treatment goals. “What’s most important to you?”
Discussion of disease-directed therapy	“We can use this chemotherapy agent or we can do nothing”	“If you don’t opt for chemotherapy, I won’t be your doctor anymore.”	“Whether or not we continue with cancer-directed therapy, I will continue to care for you and will do my best to help you feel comfortable.”
Discussion of disease-directed therapy	“He failed induction.”	It is the patient’s fault that remission was not achieved.	“Induction failed the patient.”
Discussion about resuscitation status	“Do Not Resuscitate Order”	“When used resuscitation is always successful.”	“Do Not Attempt Resuscitation Order.” “Limitation of Life-sustaining treatment order.” “Care orders for children with advanced illness.”
Discussion about resuscitation status	“As her father’s healthcare proxy, what would you like us to do for him? Bag mask ventilation? Intubation? Chest compressions? Cardioversion?” “Would you prefer that we pull back”? Or would you prefer that we withdraw care?”	Places the burden of responsibility entirely on the family member, which can at times be too difficult for her/him to bear. I will abandon your loved-one and let her suffer.	“As your father’s physician, I am so sorry to tell you that he is very ill and I am worried that he will not get better. Because his condition is not reversible, he will no longer benefit from intensive interventions such as being intubated....Rather what we can now hope for is that he feels as comfortable as possible for as long as possible. I would not recommend that he receive life-sustaining treatments. Instead I think it would be best if he receives all treatment necessary to assure his comfort and to allow him to be surrounded by his loved ones. Would you agree with this?”
Discussion about resuscitation status	“The patient/parents signed the DNAR	In most states, patients and family members DO NOT sign the DNAR order. Generally this is a physician order, signed by the MD. In stating that the “parents signed” the implication is that it was their order, again placing the burden of responsibility entirely on them.	“The parents agreed to our recommendation about the DNAR order.”

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Palliative Care Communication Faux Pas – Examples (continued)			
Setting	Faux Pas	Unintended Message	Alternative
Discussion about pain management	“We can best treat your pain by using narcotics.”	“And you will become a drug addict.”	“We can best treat your pain by using opioid medications...”
Discussions about withdrawal of support	“Discontinuing supplemental nutrition means starving the patient to death.”		“We’ve now entered a different phase of care for Tanya since she has suffered so much neurological injury. I am worried that she is dying and will not recover any quality of life. In this phase, we should ask ourselves, are we doing anything that is extending her suffering, rather than allowing her to die. For example, discontinuing fluids and nutrition may allow her to die sooner, without causing her to experience any discomfort.”
Palliative Care Consultant	“You should add gabapentin to the pain medication regimen”	In end-of-life situations there is a natural tendency to feel defensive about one’s actions as a medical provider.	“This patient is really well cared for...what do you think about adding gabapentin to his regimen?”

Conversations About Medical Error

Disclosure of a medical error is a particularly challenging conversation requiring skillful communication, but it is clear that families want disclosure. They are entitled to know the details of incidents and their implications. Moreover, they are less likely to seek legal action if the physician is the one who informs them of the error. The primary objective in these conversations is to support the patient and maintain the healing relationship. Communication should be open, timely, and sustained. There are four essential steps in the disclosure of a medical error to a patient/family.

Tell the patient/family what happened. Leave the how and the why for later. Speculation and preliminary conclusions are interpreted by patients as definitive and early impressions are frequently contradicted by subsequent, careful analysis.

Take responsibility. The attending physician should take responsibility even when he/she did not actually make the mistake that caused the injury. This does not mean assuming sole culpability, but the patient/family needs to know that someone is in charge and will control the situation.

Apologize. Apology is an essential part of taking responsibility. The attending should apologize even if the error was made by someone else. That person should also apologize if possible.

Explain what will be done to avoid the same error in the future. Injured patients have a strong interest in seeing that no one else suffers. Knowing that something will be done to prevent the occurrence in the future helps them cope with pain or loss and may give a positive meaning to experience.

As with any challenging conversation requiring advanced communication skills, **clarity, directness and empathy** are of greatest importance. In this situation, the physician is also taking responsibility and apologizing. One’s own emotions and potential defensiveness need to be managed skillfully, along with the emotions of the patient/family.

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Skills to Practice

One way to learn advanced communication skills is to practice in structured role play scenarios. Several cases are provided in B4. Cases: Advanced Communication Role Plays, with further discussion in Section B3. Toolkit: Developing Skills in Interpersonal Communications. All of these cases are based on real patient encounters. You may also consider asking the learners for cases relevant to them or cases of which you are aware from your own training program or clinical practice. Each case offers trigger questions, skills development practice and appropriate application of knowledge content from Part B applied to handling the communication with the family in each unique situation. They address how to build empathy around potential feelings the family may be experiencing, and ways to connect on a human level with a shared understanding of the nature of the experience of loss and suffering. With the application of brief practices of mindfulness, the reader is invited to become aware of his/ her own emotional response arising before, during and after meeting with the family.

Certainly, dealing with the emotional reactions of a family can be difficult, especially angry emotions that are not commonly encountered in patient- physician interactions. Here are some suggestions about how to think about anger in the delivery of bad news and ways to observe it rather than react to it. **1.** Look for the source of anger: most anger stems from fear. Is there a perception of genuine insult? A personality conflict? **2.** Recognize the direction of the anger: Is this internal anger or guilt? Or is it external, directed at staff, the hospital, or God? **3.** Engage, but avoid enmeshment with the emotion. To gain further insight into ways to skillfully allow the expression of anger and redirect its energy, the reader is referred to a fact sheet on dealing with anger:

Wang-Cheng R. Fast Fact #59. *Dealing with Anger*, 2nd edition. 2009. End-of-Life/Palliative Education Resource Center (<https://www.capc.org/fast-facts/59-dealing-angry-dying-patient/>)

In addition to the narrative cases in Section B3. Toolkit: Developing Skills in Interpersonal Communications, there are ten cases which may be used for active role play or OSCEs in Section B4 Cases: Advanced Communication Role Plays. These scripted cases mainly involve communicating to a family about an unexpected death in a pediatric patient. These scenarios could be encountered in an ED, NICU or PICU settings. The last 3 cases repeat the medical errors cases contained in the Toolkit, to allow residents to practice communicating about errors to families with a faculty facilitator present.

Goals of structured role play:

Communication:

- a. In emotionally charged situations with children and families, residents will be able to practice advanced communication skills in a safe environment.
- b. Residents will have the opportunity to learn from the different communication skills and styles of their peers.

Managing emotion:

- a. Trainees will gain insight and understanding of emotion and the human response to emotion that will allow them to develop and manage human interaction (Milestones).
- b. With facilitation, trainees will become aware of their own emotional responses to these situations and reflect on what is challenging for them. Your group may consider using the narrative cases in the toolkit to help residents become aware of their own emotions in preparation for engaging in the role plays (see Section: **B4 Facilitator Guide: Advanced Communication Role Plays**).
- c. Trainees will use emotion to develop and maintain an effective empathic connection with families in these situations.

We hope that this Guide has been helpful in walking you through the content contained in **Part B Communicating with Families about Severe and Terminal Illness in Their Children**. Part B of the **Resilience in the Face of Grief and Loss Curriculum** is designed for either individual study or planning a systematic approach for teaching advanced communication skills in your particular training program.