

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

Toolkit: Developing Skills in Interpersonal Communications

Learning Objectives of this Toolkit

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.

Slides are available to address the informational aspects of sharing bad news: e.g., what must be said and in what order to be most helpful to patients and at different ages and stages of disease.

This document is aimed at assisting residents to be more in tune with the emotional responses likely to be encountered in difficult physician-patient encounters and to walk through one possible approach to the steps involved in disclosure of medical errors.

The tool kit is designed to stimulate residents’ critical reflection for social-emotional learning through reflective questions applied to narrative cases. The questions may be used both for individual and group reflection and discussion, and to spark active learning (using the Discussion Guide and slide set, Sections B1 and B2). A few of the patient narratives are coupled with simple clinical mindfulness practice techniques, that are available for audio download or as You Tube videos to foster the development and practice of self-awareness, a key skill of mindful practice (Epstein, JAMA, 1999).

Simulated cases are provided (see Discussion Guide and Advanced Communication Role Plays) to implement practice and role play in a safe group setting with peers and a faculty facilitator. These tools will help residents learn to put the cognitive and emotional components together.

Introduction

Many of us have little experience with listening to patients’ powerful emotions. In fact, in the way we were raised, we may have been taught not to display our emotional reactions for fear of it being labeled “unacceptable”. We may lack models of how to hear expressions of deep emotional response to suffering.

One of the components of healthy listening to emotions is empathy. This is practiced by those trained in listening as a profession skill, e.g. psychotherapists, psychiatrists, or counselors. 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) The development of empathy has been associated with training in mindfulness, self, reflection and emotional skills in physicians and physicians in training (Burks, 2012)

Case Vignettes: Working With Grief of Patients and Family

Case 1: Giving a diagnosis of a potentially fatal disease whose prognosis will depend on unforeseen decisions down the road

Justin is an 11 year old boy who has had episodes of neutropenia and thrombocytopenia. You are a second year resident who sees him with your attending in the hematology/oncology clinic as the work up has been completed; i.e., after experts in the field have determined a diagnosis of CML. Since Justin is from a family of 9 children, the plan will involve seeking a bone marrow donor, hopefully from one of his siblings. The parents have been worried he may have cancer. Your task today is to inform the patient and his parents of his diagnosis, and to help them understand the importance of seeking a bone marrow donor from the family as the best chance of cure.

Reflection questions for this case:

- What feelings arise for you as you think about approaching this family? Is there anything you are afraid of? What about giving the news may bring on your anxiety?
- What would you like to know cognitively from your attending or from a literature review on the subject that might help you to feel prepared to handle questions from the family?
- Are you starting to feel sadness or anticipatory grief, and what are you thinking?
- Do you feel any unhealed pain from your own life, or feelings of loss of control, or anxiety about dealing with a possible bad outcome?
- As you listen to the brief mindfulness-based 3 minute breathing meditation, be open to any feelings arising in your own body as you take in this patient scenario, and mentally prepare yourself for talking with the family.

Support materials for the case:

The Three Minute Breathing Space: <http://cdn.franticworld.com/wp-content/uploads/2013/12/08-Three-Minute-Breathing-Space.mp3> free download (3 mins) from Franticworld.com developed by Mark Williams, Ph.D, Oxford University. Adapted from: Williams, Teasdale, Segal and Kabat-Zinn. *The Mindful Way Through Depression: Freeing Yourself From Chronic Unhappiness*, 2007.

Case 2: Sharing with the family that a child died despite efforts at repeated resuscitation

You are a third year resident on a PICU rotation. One of the patients on your service, Ebony, whose family is Ethiopian, has third degree heart block secondary to maternal lupus. This is the end of your month on service and you have taken care of Ebony for almost 3 weeks, including several times on call. You have grown quite fond of the parents, particularly the mother, who is constantly at her side and very appreciative of your care of her daughter. You are post-call today after a horrendous night of call. Ebony took a turn for the worse yesterday afternoon and you led 3 codes to keep her alive. After the team completes rounds, you stay to finish your only remaining note. The attending leads another code, but Ebony dies. You are not sure if you should join the attending to share the bad news. How might it benefit you and the family for you to be present? Is there anything you can share or convey that may impart a "healing balm" to their suffering? Review the support material below and then have a discussion as a group. How would you prepare to speak with the family, following advice from the article below?

Resilience in the Face of Grief and Loss:

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Reflection for this case:

One way to prepare oneself to be open to understand the sufferings of another who is deeply troubled is to re-connect with the alchemy of our own experiences of sorrow and trouble in our lives. This process takes developing an acceptance of our experience and letting go into the realization that when we experience loss, change has occurred and life will never be quite the same. We ourselves are different, perhaps having gained certain wisdom along the way. This connects us to appreciating the pain and suffering of others, and help them find the courage, humility, and trust in further goodness to come.

“We resonate with one another’s sorrows because we are interconnected. Being whole and simultaneously part of a larger whole, we can change the world simply by changing ourselves.”

(Jon Kabat-Zinn, Wherever You Go There You Are, p. 162)

Support materials for this case:

- “5-Items” loss exercise: Participants are provided with 5 slips of paper. They are told to write one thing that is very important to them on each piece of paper, and then fold the paper. Each participant then turns to the person next to them, and that neighbor takes away 3 of the slips of paper. Participants then look to see what they have lost, and what remains. Ask them to talk about how that “uncontrolled” loss felt.
- Journal exercise to connect with loss: bring to mind a memory of losing something or someone dear to you (a parent, grandparent, pet). What was it that you loved about the person or animal that you lost? What were your initial feelings in dealing with this tragedy? How did you learn to cope with it? Was there anything anyone did or said that made it easier to bear? Can you connect to the lessons learned of attachment and letting go; of grief and suffering, yet love and healing? Does this exercise help you to understand the acute pain of loss and the process of moving on after loss that may be experienced by those in your care as their physician?
- <http://www.docgurley.com/2008/01/19/how-to-break-bad-news>. You may want to have a resident read this aloud or have one resident summarize the steps on a dry erase board.
- Mindfulness of Body and Breathing exercise. This 8-minute exercise is available for free download from Franticworld.com. It is designed by Mark Williams, Ph.D from Oxford University to teach you how to de-stress, for example, after the imagined role play above. Notice feelings of stress and loss arising in your own body. Help to release these through this mindfulness meditation.

Case 3: Child takes a turn which is not anticipated by the family, but is one possible bad outcome of his disease and medical intervention

Justin (from case one) is in the hospital with fever and sepsis after a successful matched sibling bone marrow transplant. You, as his PCP from your resident continuity clinic, visit him and his father who is at his bedside. Before you enter the room, you speak to the resident on service who tells you the fever is coming down and the team is hopeful he will conquer the infection and be discharged. As you come in, the father takes your hand and begins to quietly let tears roll down his cheeks. What can you do and say to connect with him in his grief?

Reflection questions for this case:

When you see tears in someone close to you, what is your typical reaction?

Support materials for this case:

Review active listening tips from the following website <http://studygs.net/listening.htm>. Then carry out a role play for the remainder of the Case 3 script above.

One way to practice “being present” in the face of tears is to practice “mindful presence.” Here are 5 steps that I teach residents to help them remain attentive and connected in a setting of tears or unsettling emotion:

- 1. Be present.** Begin with your own breathing, notice it coming and going, notice your body and its position—sitting or standing—and its contact with the ground or chair.
- 2. Simplify your environment.** Notice any distracting sights and sounds. Consciously tune into allowing the emotion to enter the room. Turn off your pager. Close the door, draw near to your patient/family.
- 3. Consider silence.**
- 4. Notice body language** in both yourself and the family member.
- 5. Invite empathy**—an opening within yourself, in the chest—to listen deeply to the perspective of the person in front of you. Perhaps say to yourself, “I do not know what it is like to walk in your shoes, yet I care, and seek to understand this suffering.” We call this state of mind Mindful Presence.

Case 4: Sharing the news of a patient’s impending death—a change from a previous recent baseline.

You are taking care of a teenage girl, Paige, who has had a heart transplant for cardiomyopathy secondary to a viral myocarditis. During rounds, the attending asks to speak to you since you are the resident assigned to the patient and are on call tonight. She shares with you that she is showing signs of overwhelming fungal sepsis secondary to her immunosuppression. It is not improving, despite maximal doses of amphotericin. She expects the patient is going to die during this hospitalization. She asks you to accompany her to give an update to the patient’s mother. She will discuss treatment options, which will include consideration of hospice care and adequate pain management. You have been off for the last couple of days and wonder what the mother understands of Paige’s condition. When the attending begins speaking, the mother becomes very angry, yelling and hostile. What can you do? How does it make you feel? What do you do to stay connected? In addition, after the discussion begins, the mother is adamant that she does not wish to include her teenage daughter (the patient) in this discussion. What is the rationale for disclosing information to children and teens about prognosis? When might it be appropriate to include the patient in the discussion? (Review slides on discussions with children about death.)

Support materials for this case:

- 1.** http://www.theonc.org/video.asp?section_id=1687&doc_id=253192
(A video of Duke Palliative care physician about use of Ask-Tell-Ask. (Viewing may require an id and password.)
- 2.** Review NURSE mnemonic from slide set or the Discussion Guide for ways to communicate through patient emotion.
- 3.** Review effective ways to handle anger in a clinical encounter (Fast Fact #59).
- 4.** Review slide set for ways to frame a discussion on goals of care.

Case Vignettes: Medical Error Disclosure

Note: These cases are repeated in Section B4: Cases: Advanced Communication Role Plays.

Case 1: No harm to the patient; resident is not directly responsible

It is late morning and you are on rounds with your team. Ryan, a 5yo boy with asthma, is admitted to the floor after waiting for a bed overnight in the ER. He arrives in the middle of rounds, so you go to see him quickly by yourself. You meet his mother, and check that Ryan is doing well on albuterol 5mg Q2h.

As you are walking away from the room, Ryan's nurse calls you over to a nearby computer. She tells you she was about to give Ryan his next dose of Q12h Orapred, and she was looking up the dose. She thought that the 80mg which was ordered seemed like a lot for Ryan's size, so she went back to the ER record to double-check things. She found that Ryan did get 80mg of Orapred in the ER, which was likely based on his recorded weight of 44kg. However, when he was re-weighed on the floor, his weight was found to be 20kg, which is the equivalent of 44 pounds. She feels that his weight was likely recorded as pounds instead of kg in the ER.

Now, you realize you should go in and tell Ryan's mother that her son got double the correct dose of Orapred. What do you need to know before you talk to her? Whom should you notify of the error? Is this an adverse event? What exactly qualifies as a medical error?

Support materials for this case

1. Review definition of medical error in Section B5: Appendix, "When Things Go Wrong" (<http://www.macoalition.org/documents/respondingToAdverseEvents.pdf>). The failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim. Medical errors include serious errors, minor errors, and near misses. (Note: A medical error may or may not cause harm. A medical error that does not cause harm does not result in an adverse event.)
2. In the same resource, review Appendix D Training for Communication for ways to communicate about what happened.

Case 2: No harm to patient; resident made the error

Nicole is an 8 year old on #2 of hospitalization for an exacerbation. She has remained on Q2 Albuterol overnight with no improvement, so the team decided to check a chest X-ray. When this was discussed with her mother on rounds, you talked about possibly starting antibiotics, depending on the results of the X-ray. The film just showed peri-bronchial thickening with no suggestion of pneumonia, so you decided to hold off on antibiotics.

Currently, it is about 4pm on the same day, and you are reviewing orders on your team's patients. Going through Nicole's chart, you notice that she received a dose of Zithromax today. You know that this was not the plan. When you look closer at the order, you realize that you must have ordered the Zithromax on Nicole by mistake; another asthmatic on the team was supposed to start antibiotics today. Even though the Zithromax that was given was the correct dose and she's not allergic to it, Nicole wasn't supposed to have gotten it at all. You now need to tell Nicole's mother that the Zithromax was given in error. What specifically should you tell her and how? Whom do you need to notify from the team and what do you need to document in the chart?

Support materials for this case:

Review Section X (pg25) in B5: Appendix "When Things Go Wrong" (<http://www.macoalition.org/documents/respondingToAdverseEvents.pdf>)

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Case 3: Harm to patient; resident made the error

It is Day #3 of hospitalization for Tyrone, a 7 year old with asthma. This morning the team felt that Tyrone would be able to wean from Q2 Albuterol nebs to Q3 Albuterol by MDI. You put the order in on rounds at about 9:30. Since Tyrone got his last Albuterol neb at 8, you ordered the MDI to start at 11.

At 1:30, your intern comes to tell you that Tyrone's having a lot of trouble breathing. When you check on Tyrone, he's breathing in the 40s and has sub- and intercostal retractions, as well as tracheal tugging. His O2 sat is 91%. You order a stat Albuterol neb, which only helps a little, so you order two more back-to-back treatments of Albuterol 5mg. You review the orders and realize that your intern did order the Albuterol MDI, but forgot to order a respiratory consult. Now Tyrone hasn't gotten any Albuterol for almost 6 hours, and you realize that he might need to go to the PICU for continuous Albuterol if the next two treatments don't help.

In the middle of the second treatment, Tyrone's mother returns from a couple of hours away from the hospital. Is it best to talk to Tyrone's mother now or should you wait to disclose this error later? Who should be present at the meeting? Where would be an appropriate place to share what happened? How can you give feedback to the intern and offer support for possible feelings of guilt and inadequacy? Are there supports available at your institution for counseling? How should you involve the attending? How about documentation- what needs to go in the chart? What level of error is this? What about case 1 and 2?

Support materials for this case:

1. Review Section VIII Initial Response to the Event (p. 22) (<http://www.macoalition.org/documents/respondingToAdverseEvents.pdf>) and Section XI Reporting (p26).
2. Before going into speak to the family, Review 4 steps to disclosing medical errors summarized in B.1 Discussion Guide: Communicating with Families about Severe and Terminal Illness in Their Children.
3. Rehearse the model language in Section B5. Appendix "When Things Go Wrong", The Words for Communicating with the Patient (p. 27)

Reflection questions for cases:

1. Who is responsible for the error?
2. What level of error is this (serious, minor, near-miss)
3. What must be done to stabilize the patient?
4. What information should be shared with the family? Who should be present?
5. What must be done to inform the team?
6. What must be documented in the chart?

Debrief with learners about who made the error- reflect together to allow each mistake to serve as a learning opportunity, and lead to individual and system-wide change to catch future errors

Remember the 4 simple steps of informing the patient and family: Tell what happened. Take responsibility. Apologize. Tell what will be done to prevent future events.

Finding What You Didn't Lose

by John Fox

*When someone deeply listens to you
It is like holding out a dented cup
You've had since childhood
And watching it fill up with cold, fresh water.
When it balances on top of the brim,
You are understood.
When it overflows and touches your skin,
You are loved.
When someone deeply listens to you,
The room where you stay
Starts a new life
And the place where you wrote
Your first poem
Begins to flow in your mind's eye.
It is as if gold has been discovered!
When someone deeply listens to you,
Your bare feet are on the earth
And a beloved land that seemed distant
Is now at home within you.*

Appendix

Bulleted Learning Points for Case Vignettes: Grief of Patients and Families

Case 1

- Inform family of diagnosis of cancer
- Discuss Bone Marrow transplant as potential goal of care

Possible discussion themes: the range of feelings which may arise in delivering bad news. How can awareness of what is coming up for us inform our delivery to the family and help us remain *connected* rather than distant from them?

Case 2

- Sharing that a child died despite repeated efforts of resuscitation
- Reflect on the value of a resident who cared for the child being part of the delivery of the news.
- Preparation: tune into one's own experiences with loss to build understanding of the parents' potential feelings (loss exercise and journal exercise).
- Body and breathing exercise: may use 8 min recording or design own
- Review steps to delivering bad news article, slides

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Case 3

- What to do and say when tears arise in the father of the patient from case 1? Building comfort with spontaneous emotion.
- Potential discussion points: how does each of us normally react to tears?
- Do a role play of the case vignette
- Review short video about steps to active listening
- Concept of mindful presence using the breath, body position and listening to create space for the difficulty to be held by being present

Case 4

- Change in prognosis and goals of care; anger erupting in a parent; whether to include teen in discussion of goals of care
- Resources: Ask-Tell-Ask video clip; NURSE mnemonic
- Anger fast fact sheet; framing discussion on goals of care

Bulleted Learning Points for Case Vignettes: Medical Error Disclosure

Case 1

- Informing parent of error in medication dosage. Discuss definitions of adverse events. Discuss what to share, by whom and with whom.

Case 2

- Inform parent of error in medication given to wrong patient

Case 3

- Documentation, informing family, and feedback delivery to learners involved in an adverse event.