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

Cases: Advanced Communication Role Plays

Overview

This section provides 7 role plays about disclosing to a parent the death of their child and 3 role plays about disclosing a medical error to a parent.

Learner Goals:

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Have insight into one's own reactions.
- Expose other learners to different styles of communicating in difficult situations.

Facilitator Goals:

- Create a safe environment for learners to practice generous listening.
- Review the ground rules prior to the first role play (see below).
- Faculty are facilitators, not teachers/lecturers. Simulated patients (SPs) are co-facilitators.
- These activities are learner-centered. The faculty member shapes the learning by playing "traffic cop". Many important points will not present themselves as teachable moments unless the facilitator asks the learner or group to reflect during a time out.
- Faculty help guide learners to the next skill level.
- Be sure to track the work of all players in the role play: i.e., learner or parent/actor

Rules of Role Plays:

- Offer each learner the opportunity to do a role play. The expectation is everyone will have the chance to participate.
- Vegas rules: What happens in the role plays is not discussed outside the sessions.
- Either the learner doing the role play or the facilitator may call for a "time-out" (see below); no one else is allowed to interrupt.
- The facilitator will identify which level of case the SP will do and introduce them to the group. The facilitator or a learner can read the case aloud, including the listed goals for learners.

Learner-called Time-Out

- Learner is stuck and calls a time out.
- Always go to the learner FIRST. Facilitator inquires: “What was going on that prompted you to call a time out?” Often the Learner will reply with a content-based answer: “I don’t know what to do now.” Sometimes they will disclose discomfort with the emotional content of the exercise.
- Facilitator involves the other Learners: “Before we address X’s concern, can you tell X what you appreciated about what s/he did that was successful?” Ask for specific skills, rather than “how do you think that went,” which can lead to unhelpful criticisms. After the fellow Learners have commented, it is legitimate for the faculty to add an observation that was not made by the class: “I noticed that X did this…” BUT try to avoid excessive teaching, many of the points will become apparent over time.
- Problem-solving the “stuckness”.
  - Facilitator to Learner: “What do you need to do to be able to get this interview back on track?”
  - Possible responses from the Learner:
    - They know what to do, explain their plan, and time back in to continue the role play.
    - They have an idea and request feedback from peers. Facilitator then invites the Learner to time-in to the role play.
    - They have no idea and request consultation from peers. After they have heard something useful, they time-in.
  - After the Learner gets back on track, the facilitator calls time out to end at a success point. Example, when a Learner missed the parent’s emotion, the facilitator helps her to label the parent’s feelings, and the parent and Learner re-connect, allowing the Learner to start forging the relationship.
- Facilitator asks Learner for feedback on how that worked
- Facilitator involves feedback from the SP
  - Facilitator invites the Learner to frame a question s/he would like to ask the SP. Encourage self-reflection: “what moment are you most curious about?” Question should be very specific. Avoid global questions such as “How did I do?”
  - Facilitator should model how to ask for feedback: “In the beginning I said your child was gone and you kept asking where. The second time I used the word died. Did the use of the word “died” help you understand what I was trying to tell you, without being too harsh?”

Facilitator-called time-out

- Facilitator can call a time out for a moment to comment on something well done, or to help when Learner is stuck (Learners often do not time-out even if they need help). “I am timing out for a moment” or “I’m timing out to comment on this last piece that you did.”
- Always go to the learner first. Facilitator: “How did that go for you? Are there any questions or issues you have?”
  - If yes, define them as explained in the Learner-called time-out and continue.
  - If not, ask the other Learners to comment on specific skills they saw the Learner use.
  - Then ask the Learner if s/he has a specific question for the SP.
- Facilitator can suggest that the Learner proceed with other portions of the role-play, such as informing about autopsy or obtaining additional information, if the Learner has successfully delivered the news and doesn’t know what else to do.

Role Plays: Working With Grief of Patients and Families

Case A: Death in the Delivery Room

You are called to a stat C-section at the community hospital. The OR nurse indicates to you that she has not been able to obtain a heart rate on the baby for 10 minutes. The mother had been having decelerations and she had told her OB that she felt like something "just wasn't right." Then the team could not find the heart rate. The baby is born grey-blue in color, apneic and has nuchal cord times 3. You begin NRP with the help of the fellow but never obtain a heart rate. The code is ended at 20 minutes. The mother had spinal anesthesia, is alert and asks you how the baby is when you come around the curtain to talk to her.

LEARNER

- In a timely and direct fashion, tell the mother the child has died.
- Address, in a non-defensive fashion, the mother's questions about what happened medically.
- Remain empathetic to the fact that the mother is angry/devastated at the situation, not necessarily at the Learner.
- Continue to be available and empathetic to the parent, even if the parent seems angry with the Learner.

ACTOR

You are devastated that your baby has died. You had a perfect pregnancy and were happily awaiting the birth of what you expected to be a healthy child. You had never really considered anything else. There were no indications prior to today that the fetus was not OK, all tests had been normal. You are very upset that the OB "didn't listen to you."

Faculty Guide: This is a case of an unexpected stillbirth. Skills required include direct, clear and empathic communication of the facts. In addition to being devastated by the death of her baby, the mother may be angry with the OB for not responding earlier to her concerns. The mother's emotional reaction may be extreme and the Learner needs to remain calm, not get defensive, and stay emotionally connected to the mother.

Learner Guide: This is a case of an unexpected stillbirth. Skills required include direct, clear and empathic communication of the facts. The mother's emotional reactive may vary and it is important for you to remain calm, not get defensive and stay emotionally connected to the mother.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Case B: School Bus Accident

This is your first night on a PICU rotation. A 5 year-old boy had been brought to the ED via ambulance after being hit by a car that was passing a school bus illegally. The boy had a picture in his hand he had drawn for his mother and was so excited when he saw her waiting for him; he jumped off the bus and crossed in front of an oncoming car that did not yield to the stop sign on the bus. He never regained consciousness but was not in arrest at the scene. EMS transported the patient to the ED where it was determined he had a head injury and as well as significant abdominal trauma., The child was taken for a CT scan and found to have a serious head injury and a splenic laceration. The child was brought to the OR where the spleen was removed and a CSF drain was placed to control his ICP. The child was stabilized and transferred to

the ICU. He was making gradual improvement over the next 5 days, but then developed complications that led to sepsis. During the first night of your PICU rotation, the child develops spiking ICPs and an arrhythmia. After much effort and multiple interventions, the child dies.

LEARNER

- In a timely and direct fashion, tell the mother the child has died.
- Address, in a non-defensive fashion, the mother's questions about what happened medically.
- Remain empathetic to the fact that the mother is angry/devastated at the situation, not necessarily at the Learner.
- Continue to be available and empathetic to the parent, even if the parent seems angry with the Learner.

ACTOR

For the first days in the ICU, the parent was very concerned about whether her child would live. However, the parent had been happy to see their child improving and were starting to think more about how he would be when this was all over. The parent doesn't understand what went "wrong" since it had seemed their child had been doing better.

The parent questions the doctor's abilities, and on some level blames the doctor for her son's death.

Faculty Guide: This previously healthy 5 year old dies in a pedestrian-motor vehicle accident after 5 days in the PICU, during which he had started to improve. The parents are devastated and angry. Skills required include direct, clear and empathic communication of the facts. The parent's emotional reaction may be extreme and the learner needs to remain calm, not get defensive and stay emotionally connected to the parent.

Learner Guide: This is a case of an unexpected death of a school aged child. The parents' emotional reactions may vary and you should try to remain calm, not get defensive and stay emotionally connected to the parent(s).

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Case C: SIDS

Mother and father present to ED after calling 911 when they found their 7-week-old infant limp, blue, and unresponsive after a morning nap. The mother and baby were napping together in the parents' bed because the infant had a cold. They had spoken to their doctor the previous day, but the infant had not been seen. There were no other medical problems and the infant had been doing well up to that point. The parents had last seen the infant alive 2 hours prior to her nap, at which time she had been fed her regular amount, but slightly slower than normal due to her congestion. The father found the infant with the mother when he went in to say goodbye for work. The infant was found face down in the parents' bed and there was no indication the mother had rolled over the baby or that covers had obstructed the infant's breathing. The parents call EMS, and they arrived 15 minutes later and began CPR, including chest compressions and intubation while en route to the hospital. It took about 15 minutes for EMS to arrive at the hospital. In the ED the code for continued for another 20 minutes when it was determined the infant could not be resuscitated and the infant was pronounced dead.

LEARNER

- Tell the parent about the child's death in a timely and direct fashion.
- Display empathy.
- Explain why additional tests are required (skeletal survey, autopsy) in a non-accusatory and professional manner.
- Address any questions the parent may have about whether or not this was their fault.

ACTORS

The parent is waiting to hear how their baby is doing. They also feel very guilty because their doctor had given them information on BACK to Sleep and SIDS prevention, so they feel in some way responsible for the baby's death.

Faculty Guide: This is a case of sudden infant death in the context of a URI and co-sleeping. In addition to the skills of clear and empathic communication, the learner needs to recognize the potential for guilt and anger, and without conveying judgment, tell the family that non-accidental trauma has to be considered.

Learner Guide: This is a case of sudden infant death in which the parent(s) may feel guilty and angry; the parent(s) emotional reactions may vary.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

CASE D: Playground Accident

A 6-year old boy is brought to the ED via ambulance after being found unresponsive at home. The boy was at the playground with his father this evening when he fell from the monkey bars and hit his head. The child seemed stunned and a bit out-of-it for a few minutes, but then got up and seemed back to normal. His father was initially concerned, but the boy's return to normal reassured him that all was well. When they arrived home, the boy's mother asked how everything went at the park. His father replied that the boy had taken a little spill, but that he was ok. A short time later, the boy vomited a couple of times. He also complained that his head hurt, but his parents figured this was the beginning of a flu and sent him to get ready for bed. When they went up to check on the boy a short time later, they found him on the floor of his room, unconscious. The parents call 911. On route to the ED, CPR is started due to bradycardia. Upon arrival, the boy's pupils are noted to be fixed and dilated. During the resuscitation, you asked the parents if the boy had injured his head at all during the day. The mother is shocked when the father mentions the playground accident. After an extended resuscitation, the boy is pronounced dead.

LEARNER

- Tell the family the child has died in a timely and direct fashion.
- Address the parents' guilt about what happened.
- Remain empathetic to the family, despite the mother's obvious anger at her husband.
- Explain the need for an autopsy in a non-accusatory and professional manner.
- If time and skill level permit: ask about abuse.

ACTORS

Upon hearing that the child has died, the mother screams at her husband, “You killed our son!” She continues to yell things such as, “If you had told me about this…” “If we had gone to the doctor…” “If you weren’t so irresponsible…” The mother is really more sad than angry, and she calms down if the Learner remains empathic to her. The father feels tremendous guilt. He asks questions such as, “If I had brought him in earlier, could we have saved him?” “Was there anything else we could have done?” “Did you do absolutely everything you could?”

Faculty Guide: This is a case of traumatic brain injury, the seriousness of which is not recognized by the parent. In addition to the skills of clear and empathic communication, the Learner must recognize the potential for the father’s guilt, the mother’s anger toward her husband and consider the possibility of non-accidental trauma.

Learner Guide: This is a case of traumatic brain injury requiring clear and empathic communication. The parent(s) may feel both guilty and angry; the emotional responses may vary within and between the parents.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent’s emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Case E: ALL

An 8-year-old girl with a history of leukemia, which is no longer responsive to chemotherapy is brought by her parents to the ER for fever and lethargy. She had recently been receiving maximal doses of Morphine at home for refractory bone pain, and the family had decided during her last clinic visit not to escalate her care any further (specifically not to use any cardiac medications, bag-mask ventilation or intubation). She is assessed in the ER and found to be in septic shock. Despite appropriate antibiotic therapy and multiple fluid boluses, her blood pressure remains low. The family reiterates that their wish is for comfort measures only. The child is whimpering and complaining of pain, so she is given a dose of Morphine ordered by the Learner. In several minutes she ceases to breathe, and she is pronounced dead.

LEARNER

- Tell the family in a timely and direct manner that the child has died.
- Be available to listen to their feelings of ambivalence.
- Display skills of active and supportive listening in a non-judgmental fashion.

ACTOR

Although they had anticipated being prepared for her death, they are stricken with grief to hear that it has happened. They are torn about whether they should have “fought harder” and escalated care near the end of her life or whether they had subjected her to too much pain and suffering during her chemotherapy that preceded her death.

Faculty Guide: This is a case of a child with leukemia whose parents have agreed on no heroic measures. Her death is not unexpected, but in addition to being grief-stricken, the parents may wonder if they gave up too quickly. In addition to the skills of clear and empathic communication, the Learner must recognize the potential for guilt.

Learner Guide: This is a case of a child with leukemia whose parents have agreed on no heroic measures. Her death is not unexpected, but the parents may feel grief and other emotions.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Case F: Choking episode

At 7 P.M. a two-year-old child was brought to the Children's Hospital emergency room by paramedics, apneic and without a heart rate. The child had been left in the care of a 13-year-old sister for 30 minutes while the grandmother delivered dinner to a sick neighbor. The children were having hotdogs for dinner, which the grandmother prepared before going to the neighbors. The sister said everyone was fine until she noticed the baby brother coughing on his hotdog. She tried to get him to cough it up and dialed 911 when he fell over and didn't seem to be breathing.

The paramedics arrived within 6-minutes; they were unable to dislodge the hotdog and attempted CPR. In the ER the child is cyanotic, pulseless and without spontaneous respirations. The hotdog is removed and the child is intubated. CPR is continued, but it is unsuccessful and the child is pronounced dead. Just then the grandmother arrives at the hospital. You are sent out to tell her about her grandson.

LEARNER

- Deliver the message of the child's death to the grandmother in a timely and direct fashion.
- Address the grandmother's feelings of guilt in causing this accident.
- Offer support to this grandmother with social services to help her and the other siblings in this time of need.
- If there is time and skill level: Ask about an autopsy.

ACTOR

She cries and tells you that she had taken her four grandchildren away from their mother's house (her daughter) one month ago when she found them in a deplorable state. The daughter's house was filthy, and over-run with insects. Dirty dishes were piled high in the kitchen. The children looked as though they had not been given baths for ages and were hungry. The daughter and her boyfriend were addicted to drugs and alcohol and no one seemed to be caring for the four children. The children were ages 2, 4, 5, and 13. The grandmother took the children home to care for them. The 2 oldest children were now going to school, and everyone seemed to be doing better. The mother had not made contact with them or the grandmother.

The grandmother had made dinner that night for an elderly neighbor who had just gotten out of the hospital and was gone for less than an hour. She expresses extreme guilt over leaving the house and blames herself for his death. She questions her own abilities to care for the rest of the children and "does not want to hurt them now too."

Faculty Guide: This is the case of an accidental death while the child was unsupervised by the guardian. In addition to clear and empathic communication, the Learner should be able to listen non-judgmentally to the grandmother's grief and guilt and allow her to reveal the important details about the social history.

Learner Guide: This is the case of an accidental death while the child was unsupervised by the guardian. Skills required include clear and empathic communication and the ability to listen non-judgmentally.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).
- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Case G: Infant in the PICU

This is your first night on a PICU rotation. A 7 month old female with trisomy 21, severe pulmonary hypertension, tracheostomy, duodenal atresia and complex congenital heart disease has been in the PICU for 7 months due to numerous surgeries, complications, and difficulty managing her pulmonary hypertension. She has had daily to weekly "death spells" as the ICU staff has begun to call them, which are severe pulmonary hypertensive crises that generally require sedation and paralysis to reverse. The staff has not been optimistic about her long term prognosis, but the parents have remained very optimistic. She has finally been moved to a ventilator that she can use at home and the family has been preparing for discharge. The family is ecstatic about the prospect of taking her home for the first time. The night before she is to leave, she has a severe pulmonary hypertensive crisis and then develops V tach. Despite resuscitation efforts, she dies. The family, who had been present for the entire admission, but when this occurs they had been taking items home to prepare for her arrival, and they return just as she is pronounced dead. An attempt was made to reach them, but the cell phone just rang. They are now waiting outside of the PICU doors to come back and see their child and have not been told of the arrest.

LEARNER

- Tell the family in a timely and direct manner that the child has died.
- Be available to listen to their feelings.
- Display skills of active and supportive listening.
- Offer autopsy to investigate further why the child died.

ACTOR

You are irate that you were not notified and feel that they should have continued CPR until you returned. You feel a lot of guilt about leaving your child and feel like this never would have happened if you had been here. The mother and father were both in their 40s when the child was born and feel like the Trisomy 21 was their fault.

Facilitator Guide: This is a case of a 7-month old with trisomy 21 who dies just when her parents are about to take her home for the first time. They have retained great optimism about their baby, despite her numerous near-death experiences. In addition to the skills of clear and empathic communication, the Learner must deal with their severe disappointment and resulting anger, as well as with potential feelings of guilt because they were not present for the child's death.

Learner Guide: This is a case of a 7-month old with trisomy 21 who dies just when her parents are about to take her home for the first time. Skills required include clear and empathic communication. Parents may display a range of emotions.

- Practice Generous Listening: communication skills that help to build therapeutic alliances with parents and patients, even in emotionally charged situations.
- Recognize the parent's emotion and be empathic: Remember NURSE (Name, Understand, Respect, Support, Explore).

- Remain supportive regardless of family response. Silence can be powerful tool.
- Try to stay aware of your own emotional responses.

Role Plays: Disclosing Medical Error

These cases provide an opportunity for Learners to practice disclosing to the parent an error in the care of his/her child. Disclosing an error is a difficult experience that many of them have probably already had, but they might have never received guidance about how best to do it. At the beginning of the session, please go quickly over the four things we know that patients want to hear when an error is disclosed to them, as well as the NURSE mnemonic for responding to emotion. It might even be helpful to write these on the board so that all can refer back to them during the session.

The 4 things patients want to hear when an error is disclosed:

1. An explicit statement that an error occurred.
2. A statement of responsibility on the part of the physician.
3. An apology.
4. A description of how recurrences will be prevented.

The NURSE mnemonic for responding to emotions:

- Name the emotion; “I know that this must be really scary for you.”
- Understand the other’s situation/perspective; “I can’t imagine how hard this must be.”
- Respect; “I can tell that you’ve done a really great job taking care of your son’s asthma.”
- Support the other person; “I will be here all day and will come by later in case you have any other questions.”
- Explore the other’s experience/feelings; “Do you have any more questions for me now?”

Background on the cases

For this session, there are 3 cases that increase in emotional intensity, from an error made by someone else that will likely cause little harm, to a serious error made by the person disclosing it.

Medical Error Case A is a case of an error in dosing of medication due to incorrect recording of patient’s weight. The Learner disclosing did not make the error, it was a different Learner who saw the child in the ED. There is no harm to the patient.

Medical Error Case B is a case of an error in giving a medication to the wrong patient. The Learner disclosing is the one who made the error. There is no harm to the patient.

Medical Error Case C is a case of an error of omission: the order for a medication was not given. The error resulted in deterioration in respiratory status. The Learner who made the error needs to disclose both the error and the resulting deterioration.

Medical Error Case A:

It is late morning and you are on rounds with your team. Ryan, a 5yo asthmatic, 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 must go in and tell Ryan's mother that her son got double the correct dose of Orapred.

Medical Error Case B

It is late morning and you are on rounds with your team. Nicole, an 8yo asthmatic, is admitted to the floor after waiting for a bed overnight in the ER. She arrives in the middle of rounds, so you go to see her quickly by yourself. You meet her mother, and check that Nicole is doing well on albuterol 5mg Q2h.

It is now day #2 of Nicole's hospitalization. Since she has remained on Q2 Albuterol with no improvement, 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 peribronchial 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 he'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.

Medical Error Case C

It is late morning and you are on rounds with your team. Tyrone, a 7yo asthmatic, 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 Tyrone is doing well on albuterol 5mg Q2h.

It is Day #3 of Tyrone's admission. 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 intracostal 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 you did order the Albuterol MDI, but you 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. You have asked to talk with her outside the room, because you need to explain what has happened.