Part C: Managing Emotions after Difficult Patient Care Experiences

Cases: After a Child Has Died

Case 1: 4 week old who died of SIDS

You are a third year pediatric resident. You have been on nights for the past 2 weeks, and prior to that you were on vacation, so it has been one month since you have been in continuity clinic. When you arrive, you find out that the mother of one of your patients left a message for you one week ago. You have known her since you started internship, as you first cared for her older child, and more recently she just had a baby. When you call her, she becomes tearful, and relays that her 4 week old infant died of SIDS about one week ago. You had seen the infant for his first newborn follow up visit just prior to going on vacation. Your mind races: did you talk to her about safe sleeping position…was there something you could have done to prevent this? You are shocked, but quickly have to pull yourself together, as you have a full panel of patients.

1. What do you say to this mother?

The first option is to convey to the family that you are sorry for their loss. You could say this using many different words or phrases. You can say, "I am so sorry to hear this. I am sorry for your loss." You could ask how other members of the family are doing. You should ask her what type of support that she has. You can offer to contact your clinic social worker for her. You should not say: I know how you must feel (unless you have lost a child yourself).

2. How do you start your work in clinic when you have just received this news?

You will likely need to a take a break prior to start seeing patients yourself. You may want to share what you have just heard with a colleague, or a preceptor. Sharing this news will help you to process it a bit more easily. If you spend a couple of minutes processing this devastating news, you may be able to go back to your busy clinic without feeling distracted for the entire day. If you feel that you are not able to work because of this news, you should discuss this with your faculty or your chief residents. They are here to support you through this. In addition, you could consider discussing your feelings and concerns with your faculty advisor, mentor, or colleagues.

3. Is there anything that you can do to help this mother with this loss?

You have already begun to help this mother with her loss. She reached out to you, as her pediatrician, and you have called her and talked with her. If you heard about the death prior to any services, you can ask the mother about the services, and attend the funeral or wake. You can send the parents a sympathy card. On the sympathy card, you can again express how sorry you about the family's loss.

You can offer any support that your clinic has—your social worker or pastoral care. You can connect the family to a parent support group. Studies have shown parents value support groups and they provide important support. Other options would be a follow up visit with you as the PCP, a home visit, or putting them in contact with bereavement groups, if available at your center.

4. What would you do to help you deal with your own emotions?

Different people deal with situations like this in different ways. For some residents, discussing the situation with others (including colleagues, chief residents, and faculty) may help them to deal with their emotions. The first step in dealing with emotions is to recognize them and reflect on why you feel that way. Sometimes this discussion, with other valued colleagues, will help one to identify if there was something different that could/should have done. Sometimes physicians feel guilt following the death of a patient, regardless of these alternatives.

In the case above, the resident feels guilt, a very common reaction after a death of a child. Reasons for guilt may include the concern that one "missed something", or did not provide the appropriate guidance, or the wish that one would have been more available for the mother at such a tragic time. Some people find journaling a helpful way to deal with death; others find meditation or exercise helpful. Finally, it would be appropriate to reach out to faculty mentors, the chief residents, program director, or the employee assistance program. Many physicians struggle with this problem; you are not alone.

Case 2: Nine month old girl who is declared dead in the ED

You are a first year pediatric resident working overnight in the pediatric ED. It is 6:00 am and you are looking forward to the end of your shift at 7:00 am. You receive a call from dispatch that a 9 month old female infant was found in her crib, blue and unresponsive. Her mother reports that the night prior she had a fever that she treated with ibuprofen, and when she went in to check on her this morning, she was unresponsive. Paramedics have intubated her and placed an IO for access. She was pulseless and has been undergoing CPR for the past 20 minutes. The infant arrives in the ED and you quickly take over chest compressions as your attending directs the code. Multiple doses of epinephrine are administered but no rhythm is established. After another 20 minutes the mother of the infant arrives in the room as you are doing chest compressions. The mother is distraught and screams at the team to "please not give up on my baby" and then collapses to the ground crying. Your attending updates her and tells her that the team has done everything they could but was not able to save her baby and that her baby has died.

1. What could this intern say to the mother after the code is called?

This case is a bit different from the first case, in that the intern is present at the time of death, yet doesn't have a prior relationship with the mother. The mother is obviously incredibly upset, and the first thing that the intern can do is be there for this mother. He/she might not say anything for several minutes, just let her cry and remain present. This is hard to do, as parents may express/demonstrate intense emotions that are very uncomfortable for the person communicating the news, but to leave would only cause the intern to distance his/herself from the mother. It is important to become comfortable with the expression of emotions, and use the words, "I am so sorry, but your baby has died." Many people use the term "passed," but this term is not always clear. It is best to be direct when one tells a family member that their loved one has died, in order to avoid any misperceptions.

The intern should offer to call pastoral care or social work for this mother. Try to remain as present as possible with this mother. Even though the intern is likely to be upset as well, if he/she can stay present with the mother while getting someone from social work or pastoral care to help, this will mean a lot to the bereaved mom. As a provider, one can ask if there is anyone that she would like you to call on her behalf; family member, friend, or personal minister.

2. What are ways to honor this child at the time of death?

There are many ways to do this. The article, *The Code* from the NEJM, discusses a moment of silence at the time of the death. Other people honor the deceased person with a prayer. As the one running the code, one could ask the other participants to have a moment of silence for the life that was lost.

3. How do you think this situation made the intern feel?

In this situation, the intern is in his/her first year of training, and it may be the first time that she has had a patient die. She may feel a wide range of emotions: anger, guilt, fear, powerlessness, unfairness, personal vulnerability, sorrow, or burnout. All of these emotions are appropriate. It is also appropriate to have unexpected emotions when dealing with a situation like this one. As an intern, she may also wonder if enough was done to attempt to save this child. Could someone have done more?

4. What do you think could help the intern to deal with his/her emotions after this death occurred?

There are many different things that might help. Some residents find it helpful to talk with one of his/her colleagues, a senior resident, or the faculty member who was involved in this case. As a faculty member, it is important to help a resident debrief any time a patient dies. After dealing with an acute death, most residents will need to take a break from their work, at least for a few minutes. Some residents will find crying, journaling, exercise, meditation, or talking about the situation helpful.

Case 3: 15 year old male who is dying of medulloblastoma

You are a second year resident in the PICU. Your patient, John, is a 15 year-old male with a history of medulloblastoma, who completed initial chemotherapy and radiation and was in remission for 2 years. About 7 months ago, John was diagnosed with spinal metastases at which point he restarted chemotherapy. Three months ago, he had several brief admissions for worsening severe back pain and trouble walking, for which he was started on steroids. During these hospitalizations, he repeatedly expressed the recognition that he was dying, that the steroids were disturbing his mood and changing his personality, that he didn't want to spend any more of his life in the hospital, and that he strongly desired to retain the ability to walk. During this time, a palliative care consult was completed and goals of care were addressed.

John and the team drew up a list of activities that addressed his cultural and spiritual goals and the hobbies that he loved. The next day, he was offered palliative chemotherapy, which both he and his family accepted. Unfortunately, he was not able to complete the wish list of activities as his condition worsened. He was readmitted 6 weeks ago when he had altered mental status and was hospitalized with fungal sepsis, pneumonia, and a UTI. Since that time he has been in the PICU with a complicated course and prolonged need for mechanical ventilation. You have been caring for him during your entire PICU month, and during that time his mother expressed considerable guilt for choosing chemotherapy over completing his wish list. Last week he was weaned off of the ventilator, 3 days ago he was able to go home with hospice. You are on your last call in the PICU when you receive notice from the hospice nurse that he died peacefully at home surrounded by family.

1. How do you think the palliative care consult helped John and family to deal with his terminal diagnosis?

The palliative care consult was helpful in several ways. It helped to deal with the spiritual needs of John and his family. It allowed the hospital providers to get to know John as a person, not only as a patient. And it allowed John to express his own goals for his care, knowing that he was dying, and for the family and staff to understand his goals.

2. What would you say to the mother when she expressed her guilt regarding choosing chemotherapy?

It is important to allow the mother to express this guilt, to listen to her, truly try to understand what she is expressing and then respond. There is not one single discussion that would work for every family. It could be important to remind her that John was involved in the discussion to choose palliative chemotherapy. At the time that choice was made, one of his main goals was to be able to maintain his ability to walk, and the palliative chemotherapy was intended to be one way to help him achieved this goal. It is also important to remind John's mother that when she made that decision, it was made with the best information that she had available at that time. When she participated in that decision, neither she nor any family or staff member could predict that he would end up intubated again so soon. It is also important to discuss with his mother that it is normal to feel a certain degree of guilt when dealing with the illness of a loved one.

3. Is there anything that you could do to support this family now that he has died?

The resident working with this family could send a sympathy card. In the card, the resident could share with the family what John meant to him/her. This expression will help the family to know that many of the hospital staff cared about him and he had touched their lives. The resident could also consider attending a memorial service. When a long-term patient like John dies, often members of the hospital staff will attend a memorial service or funeral. Hospital staff attendance helps the family to feel respected and it helps them to realize how important their child was to those who cared for him. Health care professionals who attend the services are sometimes asked to speak. Families also value that health care professionals demonstrate some emotion, such as tears in their eyes. Attending the funeral also allows the resident to grieve within a community who loved the child, and to learn more about the child in the context of his family.

If the resident does not feel comfortable to go on his/her own, he/she could reach out to other members of the health care team. After a patient dies, the physician could schedule a follow up meeting with the family. The timing of the meeting should meet the family's needs, but 1-3 months after the death of the patient is common. The later time frame is if you are awaiting autopsy results that can then be shared with the family. At this meeting, the physician can discuss how the family is coping as well as answer questions about John's death. It is important for the provider to review John's clinical course prior to this meeting, so he/she can answer questions.

4. What would you do to help deal with your own emotions?

A debriefing that is led by a faculty member or senior resident can help the resident to deal with his/her emotions. (See **Section C.5-7**). The debriefing could be done as a team, or individually, and may include faculty and staff from other disciplines.

Attending a memorial service or sending a sympathy card can help the resident start to find closure or at least begin to integrate the experience. It can provide support to the family, but in addition can allow the resident begin to identify and deal with his or her own emotions. Residents often use journaling to help them sort out their feelings. (See **Section C.1** and **D.1**). In addition, residents and faculty should have formal and informal discussions regarding how this experience might inform the residents' practice of medicine in the future.

Case 4: 9 month old girl with signs of non-accidental trauma

You are the intern on the inpatient ward team. Overnight a 9 month old girl was admitted with the chief complaint of right leg swelling. On evaluation in the ED, she was found to have a spiral fracture of her right femur. A subsequent skeletal survey also revealed several "bucket-handle" fractures of her long bones, two vertebral compression fractures and multiple rib fractures in various stages of healing. The infant also has bruising on her face and a hand-shaped bruise on her back. Your attending insists on a thorough evaluation for fragile bones as well as bleeding disorders. In your reading, you can find no other unifying diagnosis for the stereotypic bruising and fractures except for non-accidental trauma. You grow frustrated with the long, expensive work up and angry that the parents are still allowed to care for the child. During rounds, your frustration gets the best of you and you snap at your attending and the child abuse specialist, asking why all the testing and consultations are necessary in such a clear case of child abuse.

1. How would you interact with this family given your suspicion of non-accidental trauma?

It is important to remain professional throughout every interaction with patients and families. In cases of non-accidental trauma, pediatricians often have strong feelings, but need to keep these in check so their feelings don't interfere with their ability to care for the patient. In cases of suspected child abuse, it is important to try to remain objective, and to continue to maintain rapport with the family. As physicians, it is not our job to judge nor to identify the perpetrator, but rather to assure the safety and medical care of the child. We are often wrong when we try to guess who may be the perpetrator. It is important to remember to NOT make assumptions. One of the parents may be another victim of domestic violence.

If the intern is able to maintain good rapport, it is possible that a family member will reveal information that could be important to this case. In addition, although the resident is convinced that this is non-accidental trauma, it is often very important to prove for legal purposes that there is no other explanation. Often these cases go to court, and when the physician is called to testify, it will be important to prove that these injuries are not caused by either osteogenesis imperfecta or bleeding disorders.

2. Do you think that anger changed the way that this intern approached the patient?

As a physician, it is common to be angry at the family. It is important to attempt to keep these feelings in check, so that they don't interfere with one's ability to care for the patient. The extensive workup that is being performed is important for a couple of reasons. The first is so that an infant is not wrongly removed from a parent, and the second is so if the cause of these injuries is non-accidental trauma, that this can proved, and the infant can be placed in a safe environment.

3. If you are the senior resident, how can you help your intern with this situation?

As a senior resident, it is important to discuss any emotionally charged situation with your intern. Often this will be the first time that the intern has had to deal with this type of situation. The senior resident will need to explain to the intern the reasons for the extensive workup. When the senior sees that the intern is having difficulty managing his/her emotions, it is important to discuss this with him/her in a safe environment outside of rounds.

Case 5: 4 year old, chronically ill child with sudden deterioration

Darius is a 4y/o boy who is an ex 24 week premature infant. He had a very complicated 8 month NICU course complicated by BPD, ROP, NEC (s/p bowel resection), and grade IV IVH. While in the NICU, he did not learn to feed, so he had a g-tube placed. Since discharge from the NICU, he has been diagnosed with spastic quadriplegia and epilepsy. He has significant developmental delay—he does not track, occasionally will smile, is unable to sit up on his own, only feeds through his g-tube. He has been admitted on a number of occasions in the past for worsening seizures, and more recently for aspiration pneumonias. You are the intern on the general pediatric wards, and are meeting Darius for the first time where he is admitted with influenza and pneumonia. You speak with his mother who replies that she stays home with him full time, as he requires 24 hours a day care. They have a nurse that comes in 40 hours per week, which helps, but since he has been home from the NICU, his mother quit her job, and the family has a hard time making ends meet. Darius has two older brothers, one who is 6 and another one who is 8, both of whom are in school. Throughout his hospital course, his family is almost always at the bedside.

Despite Tami-flu and broad spectrum antibiotics, during the first two days of this hospitalization, Darius has increasing oxygen requirements, and increasing work of breathing. You come into pre-round on Darius, and he is no longer able to maintain his saturations on the nasal cannula, so you begin a venti-mask, and transfer him to the PICU, where he requires intubation. In addition to increasing oxygen requirements, he becomes hypotensive, and requires several vasopressors. The PICU team works hard to resuscitate him, but unfortunately he dies on hospital day #4 of his pneumonia and sepsis.

1. As a physician, what are the emotions that one might feel with the death of Darius, a child who has been chronically ill?

Anytime a child dies, it can be incredibly hard for not only the parents, but also for the physician. Often many residents throughout the residency program have cared for these chronically ill children, and the death of one of them can have a huge effect on the whole program. Although a child is chronically ill, the death at this time was still not expected, which can be very difficult for the residents caring for this patient. In addition to sadness, the physician can also feel a sense of relief. The physician may see how much suffering the child has gone through. In addition, the physician may have a sense of how dedicated the family has been to this child, and what an impact this child has had on the life of the family. When a physician notices this relief, he/she may feel guilty for having a sense of relief.

2. What emotions do you believe that the family might have with the death of Darius?

The death of child, no matter how chronically ill, has a huge impact on the family. Although the family has dedicated most of the last four years of their life to Darius, he was an important family member who brought love and joy into their lives. The family will feel very sad for this loss. The family knows how much care Darius takes, but likely they were not prepared for his death. His death may come as a shock to the family. There may be some members of the family who see his death with a sense of relief, but often this is met with guilt. Some members may be to discuss the difficulty that caring for Darius has been for the family, but this may not be the case for all members.

3. Are there any discussions that could have occurred prior to this hospitalization that could have helped to prepare the family for Darius' death?

It could have been helpful to discuss with the family if they wanted to resuscitate Darius during an outpatient visit. Often it is very difficult to make these decisions very close to the time of death, and if this discussion occurred earlier, it could have prevented the ICU course, and could have had benefits for the family in the long run. In addition, it could have helped to have a palliative care team see Darius and his family prior to this hospitalization. The palliative care team often can help to clarify the goals of care for the family. See **Section A.7** and **A.9** for further information.

NOTE: The cases on the following pages are formatted for distribution to residents.

Cases: After a child has died

Case 1: 4 week old who died of SIDS

You are a third year pediatric resident. You have been on nights for the past 2 weeks, and prior to that you were on vacation, so it has been one month since you have been in continuity clinic. When you arrive, you find out that the mother of one of your patients left a message for you one week ago. You have known her since you started internship, as you first cared for her older child, and more recently she just had a baby. When you call her, she becomes tearful, and relays that her 4 week old infant died of SIDS about one week ago. You had seen the infant for his first newborn follow up visit just prior to going on vacation. Your mind races: did you talk to her about safe sleeping position…was there something you could have done to prevent this? You are shocked, but quickly have to pull yourself together, as you have a full panel of patients.

1. What do you say to this mother?

2. How do you start your work in clinic when you have just received this news?

3. Is there anything that you can do to help this mother with this loss?

4. What would you do to help you deal with your own emotions?

Case 2: Nine month old girl who is declared dead in the ED

You are a first year pediatric resident working overnight in the pediatric ED. It is 6:00 am and you are looking forward to the end of your shift at 7:00 am. You receive a call from dispatch that a 9 month old female infant was found in her crib, blue and unresponsive. Her mother reports that the night prior she had a fever that she treated with ibuprofen, and when she went in to check on her this morning, she was unresponsive. Paramedics have intubated her and placed an IO for access. She was pulseless and has been undergoing CPR for the past 20 minutes. The infant arrives in the ED and you quickly take over chest compressions as your attending directs the code. Multiple doses of epinephrine are administered but no rhythm is established. After another 20 minutes the mother of the infant arrives in the room as you are doing chest compressions. The mother is distraught and screams at the team to "please not give up on my baby" and then collapses to the ground crying. Your attending updates her and tells her that the team has done everything they could but was not able to save her baby and that her baby has died.

1. What could this intern say to the mother after the code is called?

2. What are ways to honor this child at the time of death?

3. How do you think this situation made the intern feel?

4. What do you think could help the intern to deal with his/her emotions after this death occurred?

Case 3: 15 year old male who is dying of medulloblastoma

You are a second year resident in the PICU. Your patient, John, is a 15 year-old male with a history of medulloblastoma, who completed initial chemotherapy and radiation and was in remission for 2 years. About 7 months ago, John was diagnosed with spinal metastases at which point he restarted chemotherapy. Three months ago, he had several brief admissions for worsening severe back pain and trouble walking for which he was started on steroids. During these hospitalizations, he repeatedly expressed the recognition that he was dying, that the steroids were disturbing his mood and changing his personality, that he didn't want to spend any more of his life in the hospital, and that he strongly desired to retain the ability to walk. During this time, a palliative care consult was completed and goals of care were addressed.

John and the team drew up a list of activities that addressed his cultural and spiritual goals and the hobbies that he loved. The next day, he was offered palliative chemotherapy, which both he and his family accepted. Unfortunately, he was not able to complete the wish list of activities as his condition worsened. He was readmitted 6 weeks ago when he had altered mental status and was hospitalized with fungal sepsis, pneumonia, and a UTI. Since that time he has been in the PICU with a complicated course and prolonged need for mechanical ventilation. You have been caring for him during your entire PICU month, and during that time his mother expressed considerable guilt for choosing chemotherapy over completing his wish list. Last week he was weaned off of the ventilator, 3 days ago he was able to go home with hospice. You are on your last call in the PICU when you receive notice from the hospice nurse that he died peacefully at home surrounded by family.

1. How do you think the palliative care consult helped John and family to deal with his terminal diagnosis?

2. What would you say to the mother when she expressed her guilt regarding choosing chemotherapy?

3. Is there anything that you could do to support this family now that he has died?

4. What would you do to help deal with your own emotions?

Case 4: 9 month old girl with signs of non-accidental trauma

You are the intern on the inpatient ward team. Overnight a 9 month old girl was admitted with the chief complaint of right leg swelling. On evaluation in the ED, she was found to have a spiral fracture of her right femur. A subsequent skeletal survey also revealed several "bucket-handle" fractures of her long bones, two vertebral compression fractures and multiple rib fractures in various stages of healing. The infant also has bruising on her face and a hand-shaped bruise on her back. Your attending insists on a thorough evaluation for fragile bones as well as bleeding disorders. In your reading, you can find no other unifying diagnosis for the stereotypic bruising and fractures except for non-accidental trauma. You grow frustrated with the long, expensive work up and angry that the parents are still allowed to care for the child. During rounds, your frustration gets the best of you and you snap at your attending and the child abuse specialist, asking why all the testing and consultations are necessary in such a clear case of child abuse.

1. How would you interact with this family given your suspicion of non-accidental trauma?

2. Do you think that anger changed the way that this intern approached the patient?

3. If you are the senior resident, how can you help your intern with this situation?

Case 5: 4 year old, chronically ill child with sudden deterioration

Darius is a 4y/o boy who is an ex 24 week premature infant. He had a very complicated 8 month NICU course complicated by BPD, ROP, NEC (s/p bowel resection), and grade IV IVH. While in the NICU, he did not learn to po feed, so he had a g-tube placed. Since discharge from the NICU, he has been diagnosed with spastic quadriplegia and epilepsy. He has significant developmental delay: he does not track, occasionally will smile, is unable to sit independently, only feeds through his g-tube. He has been admitted on a number of occasions in the past for worsening seizures, and more recently for aspiration pneumonias. You are the intern on the general pediatric wards, and are meeting Darius for the first time where he is admitted for influenza and pneumonia. You speak with his mother who replies that she stays home with him full time, as he requires care 24 hours a day. They have a nurse who comes in 40 hours a week, which helps, but since he has been home from the NICU, his mother quit her job, and the family has a hard time making ends meet. Darius has two older brothers, one who is 6yo and the other 8yo, both of whom are in school. Throughout his hospital course, his family is almost always at the bedside.

Despite Tamiflu and broad spectrum antibiotics, during the first two days of this hospitalization, Darius has increasing oxygen requirements, and increasing work of breathing. You come in to pre-round on Darius, and he is no longer able to maintain his saturations on the nasal cannula, so you begin a venti-mask and transfer him to the PICU, where he requires intubation. In addition to increasing oxygen requirements, he becomes hypotensive, and requires several vasopressors. The PICU team works hard to resuscitate him, but unfortunately he dies on hospital day #4 of his pneumonia and sepsis.

1. As a physician, what are the emotions that one might feel with the death of Darius, a child who has been chronically ill?

2. What emotions do you believe the family might have with the death of Darius?

3. Are there any discussions that could have occurred prior to this hospitalization that could have helped to prepare the family for Darius' death?