

Part C: Managing Emotions after Difficult Patient Care Experiences

Discussion Guide: The Physician's Role When a Child Dies

Learning Objectives for this Section

3.3 Describe the important steps to take after the death of a child, including saying good-bye to a patient, demonstrating good timing of future contact with the family, such as a follow-up meeting; attending a memorial service; and/or sending a note to the grieving family, in addition to initiating self-care.

Relevant Milestones: ICS1

The Physician's Role

1) Supporting the family

Just as parents who have experienced the death of a child may feel inadequacy, guilt, or a lack of control, so may the child's health care provider. To effectively help a family grieve for their loss, one needs to understand the stages of grieving (see **Part A, Sections A.1-2**) as well as the developmental stages of grieving in sibling survivors (**Sections A.3-4**).

What is a health care provider's role at the time of death? Several aspects of this role can produce anxiety for health care providers. How does one pronounce a patient dead? What does one say to family members? It may be easier if the clinician knows the patient and family, because this relationship makes it easier to connect with them emotionally. Conversely, it might be easier if the clinician does not know the patient and family, since lack of a strong relationship allows for sympathy without an overwhelming emotional response. Consider what might be your response if you have known the patient and family? What might be your response to the family if you are meeting them for the first time?

When a child has died, a health care provider may choose to honor that person in a personally meaningful way. Examples include a moment of silence, holding the child, touching the child, saying a prayer. A personal act or ritual can be a way to say good-bye to a patient, and a way of honoring or recognizing his/her life. Such a ritual may also help us to keep in touch with our humanity. Some academic and community hospitals have an annual or semi-annual event recognizing all of the patients who have died, where a provider may choose to say something about a patient for whom he or she cared. How else might one accomplish this goal? Consider reading "The Code" by Treadway.

2) What to say

One of the more difficult tasks of our profession is talking with a family after a child has died. One needs to be able to anticipate the family's response, which may be anger, denial, sadness, pain, or disbelief. You also need to be aware of how you may react to the family's reaction. It might be guilt, fear, anger, frustration, sympathy or in some cases when there has been a prolonged illness, relief. It is important to be aware of your reactions, so you do not allow them to interfere with the family's experience. Read "I Wish You Knew" by Wills and Wills. See also **Section A.1-4**.

It is important to sit with family members. Plan to spend some time with them. One should be direct but sensitive. Inform the parents and family of what has occurred in an understandable, compassionate manner. Sharing this information with the family may avoid feelings of isolation and abandonment. Console the family, listen to them, answer questions, and be aware of possible support resources available for them. Remain present.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

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Listening to the parents can be especially difficult when the health care provider is experiencing anxiety about what questions the parents will ask, what blame they may assign, what emotions they will manifest, or questions about what more the health care team might have done to prevent this death.

If the parents are not present when the child has died, they should be informed as soon as possible. Whether or not to notify them of the death over the phone is a controversial topic. One should be candid, speak to both parents at the same time if at all possible and inform them that the child's status has worsened and they should come to the hospital. If the parents ask if their child has died, one needs to be honest. One can continue the conversation over the phone or wait until they arrive at the hospital.

A physician needs to be aware of any religious, spiritual or cultural traditions of the family that might affect their grieving (see **Section A. 9-11**), and use this knowledge when comforting a family. Stuart Matlin's book, *How to be the Perfect Stranger, the Essential Religious Etiquette Handbook*, offers a helpful discussion of different religions and customs.

This chart is taken from the article, "When a Child Dies" which includes a chart of Dos and Don'ts when talking to parents. Part of this chart is reproduced below.

Dos and Don'ts when talking to parents after their child has died	
DO	DON'T
Be available	Let your own sense of helplessness keep you from reaching out to bereaved parents
Let your genuine concern and caring show	Avoid them because you are uncomfortable
Say you are sorry	Say you know how they feel—unless you have lost a child yourself, you probably don't

Residents can learn a lot about this difficult subject from videos, role-playing, or stories. They might observe a scenario and then participate in role-play. For example, one scenario might be a physician informing parents that their seven-year-old child was brought to the ED via ambulance, after being hit by a car while riding his bike. The ED team worked on resuscitating the child for thirty minutes and was unsuccessful. The child has died. You are the physician responsible for talking with the family. What do you say?

When caring for patients who are dying or have died, physicians will experience many emotions. Questions that commonly arise are:

- What are appropriate emotions and how does one balance one's emotions and maintain one's professionalism?
- What are considered professionally appropriate emotions?

3) Dealing with your own feelings

A health care provider may have feelings of anger, guilt, fear, powerlessness, unfairness, personal vulnerability, sorrow or burnout. The death of a child may be especially difficult for those clinicians whose orientation is toward new, growing, developing life and optimizing a patient's health and well being.

Often, health care providers may think it is inappropriate to consider their own emotions. They may fear that their colleagues consider them weak. Yet, to have an emotional response when a patient dies is testimony to our humanity. (4) Scenarios or videos will be helpful here. The clinician's perspective and biases may differ from those of the patient and family. It is helpful to identify those differences and recognize how they may influence the experience for the patient, family and physician. Many parents have mentioned that they were touched when a health care provider had tears in their eyes when sharing bad news. The parents felt respected yet also felt that the health care provider had truly cared about their child.

Saying good-bye to a patient can be healing for the physician. In addition to using the personal rituals discussed above, physicians may choose to attend the memorial service or send a card to the family. In a sympathy card, you might mention your experience with the patient, the meaning it had for you, and what you will remember about the child. You might also express your sorrow for the family. The family will appreciate the thought of a card and one's presence at a service. Attending a service has several potential effects: it demonstrates respect for the patient and family, may strengthen the relationship with the family, allows the physician to see the patient and parents in context of family, and may help physician integrate the experience and begin to find closure. (See also **Section A**)

4) Follow-up Meeting with Family

A follow-up meeting with the family should be arranged at least a month after the child has died. They will have had an opportunity to process some of what happened and be better able to ask questions they forgot to ask at the time of death. One study found that the most important aspect of this meeting is to provide information to the parents. Because of the intense emotions surrounding the time of a child's death, the family may not have understood all of the information given to them at the time. Most parents want information on their child's treatment and cause of death. Reviewing the sequence of events leading up to a child's death may help the parents make sense of what happened. The type of emotional support the parents want from the physician is the reassurance that the right decisions were made and that nothing else would have changed their child's outcome. Grief counseling can be offered by referral to social workers or chaplains.

In preparation for this meeting, it is important for the physician to review the facts of the case and understand all that happened. If needed, a specialist should be present to help answer complex questions. One may want to limit the number of family members present, since the health care provider will be addressing not only questions, but also the family's emotions. This will be an opportunity to answer questions, review the autopsy results and check in with the family. Some parents may not want to meet after a child has died, but the family should be given the opportunity to decline.

During the meeting or during any difficult conversation, using the "ask-tell-ask" method can be very effective (see **Sections B.1-2**). When the parent asks a question, the health care professional can ask "what is their understanding of the situation", and then share his or her understanding. (When a parent asks a question about a decision, the health care provider might say something such as, "That is always a difficult decision to make. What is your understanding as to why that decision was made?") This gives the family the opportunity to review their understanding of what occurred, and the clinician can reply with a review of the health care team's perspective. The health care professional then should ask if the family understands. It is important in these conversations to validate a parent's emotions, rather than judging or suggesting different emotions.

How to Use the Curricular Tools in Section

1) Section C.8, “Discussion: The Physician’s Role When a Child Dies,” is a basic source of information for a curriculum preparing physicians-in-training to deal with families of patients who have died, and manage their own personal reactions. It includes approaches to honoring a patient who has died, talking with the family, and dealing with one’s own emotions.

2) Section C.9, “When a Patient Dies: Physician Self Care,” is a slide set that can be used for a workshop for faculty, residents and fellows (potentially medical students, as well). Use it in concert with Section C.8, which provides background information. Begin the workshop by reading “I Wish You Knew,” an article written by two parents of a child who died at nine months of age due to complications of pulmonary hypoplasia. The workshop can include topics and discussions about family reactions; being aware of the stages of grief; the influence of religion, spirituality and culture; and the physician’s awareness of personal biases and perspectives that will influence the patient, family’s and physician’s experience. It will be helpful to include discussions on balancing personal emotions while maintaining one’s professionalism. The slides also discuss the value of remaining engaged with the patient and family, being able to say “good-bye” to the patient, attending a memorial service, sending a sympathy card, and arranging a meeting with the family one month later.

3) Section C.10, “Cases: After a child has died” provides cases interwoven with suggested readings for experiential learning by the residents. These can be integrated into the workshop, or used as reflection and discussion activities in other settings.

4) Additional experiential activities that could be used are bereavement debriefing meetings for the health care team. Debriefings are discussed in detail in Sections C.5-8. They can help with understanding of a family’s reaction, provide an opportunity to improve one’s skill in dealing with end-of-life issues, may offer closure after a child’s death, and may prevent compassion fatigue and burnout. Dr. Eggly has listed several questions that might be asked during a debriefing, such as:

- What will you remember most about this child?
- What was the most difficult aspect of this case?
- What was the most satisfying aspect of this case?
- What did you learn from this family’s experience?
- What surprised you the most about the parents’ questions during the follow-up meeting? What suggestions do you have about ways to respond to these questions?
- How did the family’s emotional concerns make you feel? How will you manage these feelings now and in the future?
- What did we do well and how can we make improvements? How do you think we can translate what we learned today into future practice?

5) Relevant Competency Domain: *Interpersonal and Communication Skills. Competency 1. Communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds.*

For this competency, one goal is to progress from using a template or scripts to being able to develop a trusting relationship with the patient and family and communicate effectively over a wide range of difficult situations. Another goal is to “demonstrate insight and understanding into emotions and human response to emotion that allows one to appropriately develop and manage human interactions.” This construct, which is rooted in the concept of emotional intelligence, is comprised of developing one’s ability to perceive, use, understand and manage emotions of oneself and others. These abilities are believed to be independent of one’s intelligence and personality and can be improved upon throughout one’s career.

6) Part C Annotated Bibliography should be useful to both instructors and residents.