Pediatric Care

Caring for Pediatric Patients’ Families at the Child’s End of Life

Jodi E. Mullen, RN-BC, MS, CCRN, CCNS, ACCNS-P
Melissa R. Reynolds, RN, MSN, NE-BC
Jennifer S. Larson, LCSW, ACHP-SW

Nurses play an important role in supporting families who are faced with the critical illness and death of their child. Grieving families desire compassionate, sensitive care that respects their wishes and meets their needs. Families often wish to continue relationships and maintain lasting connections with hospital staff following their child’s death. A structured bereavement program that supports families both at the end of their child’s life and throughout their grief journey can meet this need. (Critical Care Nurse. 2015;35[6]:46-56)

The critical illness and death of a child are undoubtedly the most difficult experience any family faces, and nurses may find it difficult and uncomfortable to communicate with the family of a dying child. Some nurses feel anxiety related to the experience of death and are inadequately prepared to provide end-of-life care.

We begin by presenting a case that illustrates a family’s response when faced with such a life-altering event and the challenges nurses face in caring for and communicating with the family throughout the end-of-life experience. Next, we review practical strategies that nurses can use to communicate with patients’ families at the end of a child’s life. We also provide additional strategies to provide compassionate, sensitive care that respects a family’s wishes and attends to the needs of the family. Finally, we describe a bereavement program designed to facilitate lasting communication with the grieving family.

CE Continuing Education

This article has been designated for CE credit. A closed-book, multiple-choice examination follows this article, which tests your knowledge of the following objectives:

1. Describe the challenges nurses face in caring for and communicating with the family throughout the end-of-life experience
2. Discuss strategies to provide compassionate care that respects a family’s wishes and attends to the needs of the family throughout the end-of-life experience
3. Identify strategies that nurses can use to communicate with patients’ families at the end of a child’s life

©2015 American Association of Critical-Care Nurses doi: http://dx.doi.org/10.4037/ccn2015614
Needs of Parents of a Dying Child

Jamie’s case illustrates that despite a team’s best intentions, establishing open communication and mutual care goals with a distressed family may be difficult. However, perceptions of what parents have found helpful at the time of their child’s death have been explored.8-17 For example, 56 mothers and fathers whose child died in the PICU were asked what facets of care they found most helpful at the end of their child’s life.18 These parents appreciated staff who were accessible and caring, provided understandable explanations of their child’s condition, and recognized that details may need to be repeated for the information to be absorbed. Other themes detected in similar studies7,9-14,17-20 of bereaved parents indicate that the parents want to be involved in care decisions and to be offered the opportunity to parent their dying child as much as possible. Additionally, parents need to know that the staff are “experienced and competent” and have thoroughly explored all treatment options for the child.1,9 Some parents have stated an overwhelming need for compassionate, sensitive staff, and others have appreciated having members of the health care team maintain contact with the family after the child’s death.1,9,16,18-21

Strategies to Support Families During Illness and at the Time of Death

To provide physical, psychosocial, and spiritual care for grieving families, nurses need excellent communication skills and knowledge of appropriate interventions at the end of life.1,9,16,22,23 A nurse’s approach should draw from his or her individual experiences, compassion and sensitivity, and consideration of the family’s cultural norms and spiritual beliefs.8 Further nursing interventions are then adapted to the child’s age and developmental level, and as the situation progresses from diagnosis through the course of illness and treatment, whether acute or chronic, to continued support after the child’s death. Early integration of palliative care principles will maximize a family’s ability to manage end-of-life issues and will provide continued bereavement support after death.24,25

When communicating with the family of a dying child for the first time, nurses should establish rapport. Nurses should introduce themselves and their role in caring for the child and also learn family members’ names and the members’ relationship to the patient.9 Greeting formalities demonstrate courtesy and respect and provide an opportunity to assess any need for assistance in language interpretation.26-28 Non–English-speaking families may find information provided in English contradictory or
Calling the child by name and asking the family if the child has a nickname may invite the family to engage in further communication about the child. Addressing the family’s needs for facial tissues, food and drink, locating restrooms, and other necessary resources is another strategy to build rapport. Nurses can further establish a relationship with the family through inquiry and reflection. Asking open-ended questions such as “What can I do for you at this moment?” encourages family members to express what is immediately important to them. Variations of open-ended questions include “Can you tell me a little more about . . .” or “Help me to better understand . . .” Asking yes-no questions may be helpful during a crisis but otherwise could convey coldness or disinterest.

Active listening is a strategy to encourage dialogue while validating that the story shared is important. Three skills critical to active listening are asking questions, paraphrasing responses, and acknowledging feelings. When words are appropriate, parents appreciate candid and honest information spoken in a gentle, caring tone. In a time of crisis, lay language that is succinct and slow in cadence is most easily understood.

Gordon et al interviewed bereaved parents whose child died in a PICU to determine the families’ perceptions of the communication they had with clinicians during the child’s hospitalization. A total of 72% of the parents criticized clinicians who did not fulfill the clinicians’ responsibility to communicate professionally, clearly, and with appropriate affect. Parents further described clinicians’ behavior as unprofessional when staff suggested the parents face the reality of their child’s situation. In another study on perspectives of palliative care and bereavement follow-up, 68% of family members indicated that someone from the health care team made a careless or insensitive remark. Family members may remember for years the pain and anger that result from insensitive communication. Table 1 gives statements to avoid and alternative examples of more compassionate end-of-life communication. Because each situation is different, nurses will need to determine responses that are appropriate for the circumstances.

<table>
<thead>
<tr>
<th>Statements to avoid</th>
<th>Rationale and recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>“How are you feeling?”</td>
<td>This question could be misconstrued as insensitive at a time when the family is obviously experiencing loss and emotional pain. Ask, “How may I best support you right now?”</td>
</tr>
<tr>
<td>“I know how you feel.” Or “I understand how you feel.”</td>
<td>An “I know” or “I understand” comment is less about how the bereaved feels and more about how the speaker feels. Dialogue may be encouraged by acknowledging the person’s unique experience: “I can only imagine how you are feeling right now.”</td>
</tr>
<tr>
<td>“You have other people to live for.” Or “Think of all the memories for which you have to be grateful.” Or “Count your blessings.”</td>
<td>At a time of unbearable loss, these statements seem dismissive and can create resentment. Well-intentioned advice minimizes the family’s pain and grief. Instead ask, “Are there family members or friends you would like me to help you contact?”</td>
</tr>
<tr>
<td>“You’re young. You can always have another child.” Or “It is good that you have other children.”</td>
<td>A bereaved family needs to be assured that their child’s life was unique and extraordinary, and worthy of remembering and celebrating. Listen for what the family says about the child to engage them in dialogue about their favorite memories or stories. Storytelling promotes coping.</td>
</tr>
<tr>
<td>“There is a reason for everything.” Or “It is God’s plan.”</td>
<td>For a grieving family, no reason in the world will be enough to justify their child’s death. Losing a child to death may elicit doubts of faith. Nurses should support the family’s spiritual worldview. For example, “What role does faith play in your life?”</td>
</tr>
<tr>
<td>“Time heals all wounds.”</td>
<td>This statement skips to the future and disregards the crisis of the present moment. Validate the family’s present feelings by saying, “This is tough, isn’t it?”</td>
</tr>
<tr>
<td>“Your child is in a better place.” Or “He/she is better off now.”</td>
<td>These statements may be perceived as diminishing the child’s value. Although some families may voice these expressions, nurses should refrain from euphemistic speech such as “passed away,” “deceased,” “gone to heaven,” or “in a better place.” Use concrete terminology such as “death,” “dying,” and “died.”</td>
</tr>
</tbody>
</table>

Table 1 Recommendations for end-of-life communication
express hope for miraculous healing, despite a clear understanding of their child's prognosis. Maintaining hope through adversity and loss is a dynamic process that often indicates adaptive coping.50,51 Nurses can acknowledge a family’s hope by sharing a commitment to the child's well-being with a wish-worry statement, rather than discounting the family’s feelings.26,39,48,52 For example, a nurse may say, “I also wish for Jamie to get better, but I worry that her condition is very serious.”

Early integration of palliative care resources can facilitate difficult dialogue between a dying child, the child’s family, and the treatment team.53,54 Use of age-appropriate advance planning guides such as My Wishes53 for school age children and Voicing My Choices: A Planning Guide for Adolescents and Young Adults54 might have given Jamie and her parents the opportunity to explore her wishes earlier in her illness, a situation that might have aided later communication. Jamie’s parents might have felt less distressed if they had a directive outlining what was important to Jamie and how she wished to be cared for by her family and the medical team. Nonverbal communication is a critical element in supporting grieving families.13,38 A nurse’s physical presence, body orientation, eye contact, facial expressions, and gentle touch can convey respectful acknowledgment of a family’s vulnerability, displacement, and coping. Attention to cultural norms is vital, as is sitting at eye level with the family.26,35 Examples of important nonverbal communication techniques are given in Table 2.

<table>
<thead>
<tr>
<th>Technique</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence</td>
<td>Presence is “the capacity to be fully there with a quality of attention and authenticity.”56 A nurse who is present is fully engaged in the moment and not distracted by personal bias or other obligations.37 Mindful body practices, including breathing deeply and exhaling slowly, may help nurses to cultivate “compassionate intention.”23</td>
</tr>
<tr>
<td>Body orientation</td>
<td>Maintaining an open stance with good posture demonstrates that the nurse is grounded, open, and not guarded. Arms, hands, and legs should be uncrossed and accessible. Standing diagonally to the side of someone is less confrontational than standing directly in front of the person.23 Be cognizant of the power differential created by who is standing up and who is sitting down. Many people, including children, may engage in conversation more openly if they are communicated with rather than “talked down to.”</td>
</tr>
<tr>
<td>Eye contact</td>
<td>Eye contact can demonstrate active listening.13,26 The nurse should take cues regarding comfort with eye contact from the family and from the person with whom the nurse is speaking. Be aware that in some cultures, direct eye contact can communicate disrespect. With children, however, eye contact does not necessarily equate to listening; a child may be listening intently without making eye contact.</td>
</tr>
<tr>
<td>Facial expression</td>
<td>Entire conversations can be communicated through facial expressions. A compassionate expression communicates sincerity when offering a condolence. A gentle smile may serve to acknowledge a memorable story about the deceased.</td>
</tr>
<tr>
<td>Touch</td>
<td>Observe cultural considerations and family norms. If appropriate, begin with a light touch on the forearm, elbow, or shoulder to gauge the family member’s responsiveness to touch and establish your physical accessibility. If the family member reaches out to the nurse, offering a hug or holding a hand may be a form of consolation. The nurse should ask permission before hugging children or spouses/partners.</td>
</tr>
</tbody>
</table>

Periods of silence may invite a family member to ask a difficult question or express strong emotion, thereby allowing the nurse to become more attuned to the family’s needs.2,31,32 Back et al58 caution that merely withholding speech, however, may generate an awkward silence rather than an enriching one. By focusing on an empathic sharing of the experience, clinicians can create moments of “compassionate silence” that convey mutual respect and understanding. To cultivate silence awareness, nurses can practice experiential exercises, such as deep breathing or mentally counting to 10 before responding.25,58

Strategies to optimize communication with families must include special consideration of a patient’s siblings, who are markedly affected by the critical illness and death of their brother or sister.19,30,59-61 In a study by Steele et al,60 siblings 8 to 17 years old who had a brother or sister die of cancer expressed their desire to be included in conversations and involved in the end-of-life experience.60 Youngblut et al61 sought parents’ perspectives of surviving siblings’ needs. The results indicated that siblings felt they did not have enough time to be with the dying child and/or say goodbye. Surviving siblings also expressed the desire to maintain
a connection with their deceased brother or sister. To honor siblings’ presence and unique contributions, nurses may explore with parents how to include siblings in meaningful ways. An important aspect is obtaining parental permission and respecting parental preferences about end-of-life communication while providing the siblings with honest, accurate information. Dialogue with siblings should be congruent with the siblings’ age and developmental level, and not euphemistic or metaphoric.

**Supporting the Family After the Child’s Death**

Nurses may feel awkward and unsure about how to support a family once a child has died. A nurse can begin with a condolence, an acknowledgment of suffering. A condolence, when expressed with genuine emotion, can be a few simple, poignant words, such as “I am so sorry” or “I wish things were different.” In a study by Meyer et al, bereaved parents described the value of staff members’ genuine verbal and behavioral expressions of kindness and compassion. Crying or praying with a grieving family may be appropriate as well as healing for the family. However, during times of conflict or difficult decision making, nurses should respect the family unit and refrain from overidentification. A grieving family can also be comforted by hearing their child’s name and knowing that their child will be missed.

For many families, the death of their child may be the first time they have seen or touched a dead body. Family members should be offered the opportunity to view the body and, before doing so, should be prepared with a gentle, accurate description of what they will see and hear when they enter the room. Nurses should use sensitive explanations in lay language to describe the physical changes that occur in the body at or after death. Clarification at the bedside may also help alleviate apprehension about witnessing open eyelids, blood pooling with gravity, and expelled body fluids.

The shock of a child’s death, regardless of how anticipated, is often paralyzing to families, leaving them uncertain about what to do next. Nurses can create an environment conducive to grieving by minimizing distractions in and around the room, which will provide the family privacy and uninterrupted time to say goodbye. A sign on the patient’s door, such as a picture of a butterfly, may signify to hospital personnel the family’s need for privacy. When other family members are present, arrangements for additional seating, including a rocking chair for parents, may make the room more comfortable. Nurses can offer the family space to pray, sing, and talk to their child. Nurses can also propose opportunities for parents to hold or lie in bed with their child and to help with bathing and dressing, if the parents wish to do so. A group of parents and legal guardians whose child died in the PICU described the importance of having enough time with their deceased child and not feeling rushed. Family members also had a desire to grieve in the presence of their child’s body. Assuring the family that they may stay with their child as long as they wish, as permitted by hospital policy, shows compassion, as does offering to step outside the room but remain nearby.

Families may exhibit different expressions of mourning. Physical manifestations of great emotional pain, grief, and anger may create a sense of discomfort and disruption to others who are nearby. Wailing loudly and falling to the floor are normal expressions of mourning for some people. To de-escalate tension in or around the room, nurses can provide an appropriate space for such expression by closing the patient’s room door or guiding the grieving family members to a more private place. Alternatively, closing adjacent doors and strategically placing a staff member to route the flow of traffic away from the grieving family will afford the family members privacy.

Giving a family tangible mementos such as the child’s gown, blanket, bracelet, or toys is another way to convey that the child’s life was important. Feedback from bereaved parents has indicated that families often do not know it is appropriate to cut a lock of hair or take pictures until the possibility is suggested to them and have later regretted not doing so. Procedures for organ and tissue donation, involvement of a medical examiner, and handling the child’s body should be explained to the family with sensitivity, by using language that distinguishes between the human body and the child’s spirit. On occasion, families may request to transport the body themselves to the funeral home. This request may be honored, depending on hospital-specific policies and state requirements.

Asking open-ended questions such as “What can I do for you at this moment?” encourages family members to express what is immediately important to them.
When the family is ready to leave the hospital, verifying their safe transportation home shows concern and care. Accompanying the family to the hospital’s main entrance gives nurses the opportunity to respond to the family’s last requests and to identify any unmet needs that will require follow-up.

Ongoing Support and Lasting Communication

The prolonged effects of grief on a bereaved family may not be fully comprehended by others who have not experienced such a loss. Some religions and cultures call for a year of mourning. However, for many families, the mourning process may be much longer. Birthdays, important family events, and the anniversary of the child’s death are perpetual reminders of the family’s loss. Parents report fearing that their child will be forgotten and describe a marked need to maintain a connection with their child after the child’s death. Additionally, families report feeling lost or abandoned by health care providers after the child dies. Many parents have a need to continue a relationship with the hospital staff and perceive this relationship as an extension of caring and acknowledgment. The ongoing need for support following a child’s death is illustrated by the subsequent encounter with Jamie’s family.

Nurses can initiate steps to help a family establish lasting communication and redefine the family’s roles after the child’s death. This understanding led to the development of a multidisciplinary bereavement committee at University of Florida Health, Shands Children’s Hospital, Gainesville, Florida, and the creation of the Life Journey Bereavement Program.

The Life Journey Bereavement Program, supported by funds from the Children’s Miracle Network Hospitals, initially provides end-of-life support to families by assisting them with the preservation of final gifts at the time of their child’s death. Examples include molds of the child’s hand or foot or both (Figure 1) made by the staff and placed in a memory box along with a lock of hair, a blanket donated by volunteers, and any other meaningful items identified by the family. If death is anticipated and the family is comfortable, these activities can be done before the death occurs. These gifts of kindness serve as tangible evidence of the child’s presence in the family’s life.

Hospitalized children who have died are identified in a weekly report generated from the hospital information system. The hospital’s bereavement committee, composed of representatives from nursing, child life, guest services, pastoral care, and social work services, also identifies patients with whom committee members have established relationships who have died outside the hospital. After a family profile (Figure 2) is completed by the social worker most familiar with the family, the family is enrolled in the Life Journey Bereavement Program. During the next 13 months, guest services specialists

CASE STUDY, Part 2

A year after Jamie died, her father contacted the hospital gift shop manager with the request to send balloons to the patients currently in the PICU in memory of his daughter. The gift shop manager contacted the PICU nurse manager about the unusual request and asked for guidance on a response. Recognizing the father’s name, the nurse manager elected to contact him to discuss his wishes. Jamie’s father asked whether specific nurses and doctors involved in her care still worked in the PICU and if they ever mentioned his daughter. It became readily apparent that the parents were struggling with their grief and desperately wanted to know that the nursing and medical staff remembered their daughter. After a very poignant conversation, the father offered to send balloons to all the patients with “get well” wishes, and a bouquet to the staff in Jamie’s memory. The parents have continued the tradition of sending the balloons every year on the anniversary of Jamie’s death.
prepare packets of bereavement literature according to the family’s profile. These packets address the grief experiences of various family members, including mothers, fathers, grandparents, and siblings. Letters with corresponding materials are sent to the families on a monthly basis for the first 4 months and then every other month, until the first anniversary of the child’s death. Special holiday and the first anniversary letters are included (Figure 3). Each letter contains a paragraph about how to contact the patient and family resources department at the hospital for additional support and instructions if the family chooses not to participate in the program.

Families enrolled in the Life Journey Bereavement Program are invited to an annual remembrance service

**Figure 2** Family profile.

Abbreviations: DOB, date of birth; DOD, date of death; PICU, pediatric intensive care unit.

Courtesy University of Florida Health, Shands Children’s Hospital, Gainesville, Florida.
to celebrate the lives of their children. This service provides families an opportunity to share their grief with others who have experienced the same kind of loss and to reconnect with the staff members who cared for their child, a need that has been repeatedly identified in the literature.8,10,12,19,21,66 The service includes music, poetry, sharing memories, art projects sponsored by the Arts in Medicine program, and release of live butterflies to honor the memory of the children.

The importance of the Life Journey Bereavement Program was perhaps best exemplified by the experience of a sibling who attended a recent remembrance service. When he opened the glassine envelope containing the butterfly (Figure 4), it gently moved its wings but made no attempt to fly away. At the prompting of a nurse, the child whispered a special message to his deceased sister. At that moment, the butterfly took flight, as if to carry the message to its intended recipient.

**Summary**

The needs of families faced with the death of their child present challenges to pediatric nurses who may feel unprepared to deliver compassionate and sensitive care at the end of life. The practical strategies outlined in this article may enable nurses to confidently communicate with the child’s family during the dying process and after the child’s death, while providing a profound and meaningful experience for the family. A bereavement program that supports the hospital staff’s connection with the family after the child’s death attends to the family’s grief journey and acknowledges the value of their child’s life and unique legacy. CCN

*A butterfly lights beside us like a sunbeam. And for a brief moment, its glory and beauty belong to our world. But then it flies on again, and though we wish it could have stayed, we feel so lucky to have seen it.*

—Author Unknown
References


