

# A framework for conducting follow-up meetings with parents after a child's death in the pediatric intensive care unit\*

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**Objective:** To describe a framework to assist pediatric intensive care unit physicians in conducting follow-up meetings with parents after their child's death. Many childhood deaths occur in pediatric intensive care units. Parents of children who die in pediatric intensive care units often desire a follow-up meeting with the physician(s) who cared for their child.

**Data Sources:** Prior research conducted by the Collaborative Pediatric Critical Care Research Network on the experiences and perspectives of bereaved parents and pediatric intensive care unit physicians regarding the desirability, content, and conditions of follow-up meetings.

**Results:** The framework includes suggestions for inviting families to follow-up meetings (i.e., developing an institutional system, invitation timing, and format); preparing for the meeting (i.e., assessing family preferences; determining location, attendees,

and discussion topics; reviewing medical and psychosocial history); structure of the meeting (i.e., opening, closing, and developing a meeting agenda); communicating effectively during the meeting; and follow-up for both parents and physicians.

**Conclusion:** This framework is based on the experience and perspectives of bereaved parents and pediatric intensive care unit physicians. Future research should be conducted to determine the extent to which physician-parent follow-up meetings provide a benefit to parents, families, physicians, and other healthcare providers participating in these encounters. (*Pediatr Crit Care Med* 2011; 12:147–152)

**KEY WORDS:** parental bereavement; pediatric; guidelines for physician-parent follow-up visit; facilitating healthy bereavement; professional gratification; physician/staff burnout

Nearly 55,000 children die annually in the United States (1), affecting the health and welfare of many families. Regardless of the cause, the majority of these deaths occur in hospitals; many after admission to a pediatric intensive care unit (PICU) (2, 3). Bereavement care is an important aspect of pediatric end-of-life care (3), in part, because bereaved parents often seek information and emotional support from health professionals

who cared for their child (4–9). Bereaved parents may feel a particularly profound attachment to PICU physicians and staff because of the intensity of the PICU experience at the end of a child's life (10). PICU physicians and staff also have psychosocial needs after the death of a child under their care (11, 12) and are susceptible to stress-related syndromes, such as burnout and compassion fatigue related to the stress of caring for chronically ill and dying children (13–16). To address

these needs, clinicians, parents, and professional organizations have recommended that PICU physicians offer to meet with bereaved parents after the death of a child as part of routine care (7, 8, 10, 17–20).

One important barrier to follow-up meetings is physicians' discomfort and lack of training in discussing distressing information with patients and families (21–24). Literature exists to guide clinicians in communicating with families in a pediatric setting, and in particular, near the end of a child's life (7, 8, 25–28). A few reports (29–31) described pediatric specialists' experience in meeting with bereaved parents, but the recommendations may not be generalizable to a variety of settings and circumstances. A meaningful framework for follow-up meetings should be flexible enough to be widely applicable and informed by the values and preferences of those most likely to be active participants, in this case, bereaved parents and PICU physicians (32, 33). To develop a framework for conducting follow-up meetings with parents after a child's death in the PICU, we

## \*See also p. 221.

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conducted multisite research investigating the experiences and perspectives of bereaved parents and PICU physicians regarding the desirability, content, and conditions of follow-up meetings (17, 21, 26). This research was conducted at seven children's hospitals participating in the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network.

To gain the perspective of bereaved parents, we conducted qualitative telephone interviews with 56 parents of 48 children, who died in a Collaborative Pediatric Critical Care Research Network PICU 3–12 months earlier (17). Parents were asked open-ended questions about their desire to meet with their child's intensive care physician in the weeks or months after their child's death and about their preferences regarding timing, location, participants, and topics for such a meeting. Findings showed that many bereaved parents would like the opportunity to attend a follow-up meeting to discuss medical and emotional aspects of their child's illness and death and to give feedback on the care their child received, but few have been offered the opportunity.

Using similar methods, we elicited the perspective of PICU physicians through qualitative telephone interviews with 70 attendings and fellows practicing or training at a Collaborative Pediatric Critical Care Research Network site (21). Physicians were asked to respond to open-ended questions regarding their past experiences participating in follow-up meetings with bereaved parents, including the number, content, and conditions of the meetings, and perceived benefits to parents and to themselves. Physicians were also asked about how future follow-up meetings should ideally be conducted and potential barriers to meetings. Findings indicated that most physicians infrequently meet with bereaved parents after the death of a child under their care. Those physicians who have met with bereaved parents felt the meetings were beneficial to parents and to themselves and that inviting parents to follow-up meetings should be a part of future practice.

The following framework (Table 1) is based on the parent and physician interview data gathered in our prior research. Thematic analyses of interview transcripts resulted in the identification of processes for initiating and conducting follow-up meetings and content areas for discussion

**Table 1.** Framework for physician-parent follow-up meetings

- 1) Extending the meeting invitation to bereaved parents
  - a) Develop a system for meeting invitation and follow-up
  - b) Extend the invitation in a variety of formats and at regular intervals during the first year
- 2) Preparing for the meeting
  - a) Assess family preferences for the meeting
    - i) Meeting location (e.g., hospital, telephone, other); meeting date/time
    - ii) Family attendees and guests (e.g., grandparents, pastor)
    - iii) Special family needs (e.g., translator)
    - iv) Discussion topics (e.g., specific parent questions)
  - b) Invite hospital attendees (e.g., bedside nurse, social worker, subspecialists, trainees)
  - c) Review medical record and psychosocial history; prepare the team
- 3) At the meeting
  - a) Meeting structure and content
    - i) Open the meeting: welcome family, express condolences, make introductions, give floor to parents to identify issues for discussion
    - ii) During the meeting: provide a balance of information, emotional support, opportunity for feedback
    - iii) Sample of discussion topics: chronology of events, cause of death, treatments provided, autopsy report, genetic risk, end-of-life decisions, ways to help others, bereavement support; family coping, reassurance, and referrals; feedback to hospital)
    - iv) Closing the meeting: summarize topics discussed, ask for further questions, provide referrals and documents, acknowledge sadness
  - b) Communicate effectively
    - i) Use lay terminology
    - ii) Adjust pace to parents' needs
    - iii) Refer specifically to child, rather than children in general
    - iv) Behaviors to avoid: blocking, lecturing, providing premature reassurance
    - v) Behaviors to cultivate: listen, use "ask-tell-ask," respond to emotions
- 4) Following the meeting
  - a) Send thank-you note and bereavement support materials
  - b) Follow up on any unfinished tasks identified at meeting
  - c) Debrief with hospital participants

deemed important by parents and/or physicians. These processes and content form the basis of the framework; the framework is also supplemented by relevant literature as referenced throughout the text. Although we have organized the framework in chronological steps, human interactions

are a dynamic, interactive communication process of mutual influence, and often unfold in highly complex and unpredictable ways (34). Therefore, the framework is not intended as a script to be followed, but instead as a general set of principles adaptable to the specific context of each family's circumstances.

## Framework for Physician-Parent Follow-Up Meetings

### *Extending the Meeting Invitation to Bereaved Parents*

**Systematic invitation and follow-up.** All parents whose child has died should be routinely invited to meet with the PICU physician who provided care near the end of the child's life. The process of inviting parents should not be left to individual physicians. Instead, an institutional system should be developed by a multidisciplinary group and managed by a bereavement service department (e.g., social work or pastoral care) (35). The purpose of this system will be to ensure that an initial invitation is extended to bereaved parents and repeated as appropriate, as well as to coordinate meeting arrangements if parents accept the invitation.

**Invitation timing and format.** To accommodate the diverse needs of bereaved parents, invitations should be extended in a variety of formats and at regular intervals during the first year after the death or until a family accepts or declines. The initial invitation should be extended as a family prepares to leave the hospital after the death. This invitation should be extended verbally and supported with written information, such as a business card or brochure, with specific information about whom to contact to arrange a meeting. The written information may be included with other information on bereavement support and services (31). This early invitation may be helpful for families that have pressing issues that they would like to discuss within the first few days after the death. For example, a parent may blame him- or herself for not being able to save the child; other family members may encourage a meeting with the physician to reassure the parent that he or she was not to blame for the death. On the other hand, families may not realize the need or feel a desire to meet with the physician for weeks or months after the death and may not remember receiving the initial invitation due to their emotional distress. Therefore, within a month, a second invitation

should be extended, along with a condolence card or personal phone call (5). Throughout the first year after the death, mailed letters, phone calls, or e-mails inviting parents to meet should be sent at intervals (e.g., quarterly), based on an individual family's circumstances, to remind parents that they can accept (or decline) the invitation whenever they feel the need or desire.

#### *Preparing for the Meeting*

**Assessing family preferences.** When a family expresses interest in a follow-up meeting, the bereavement services department or the PICU physician should contact them to discuss their preferences regarding the time and date of the meeting; specific family needs (e.g., transportation, translator, babysitter); attendees from the family, community, and hospital; and location. Although most preferences can be accommodated, some may be unreasonable from the physician's perspective, such as the desire to engage physicians in legal issues, to hold a series of individual meetings with extended family members, or to have physicians travel long distances to meet the family. Unreasonable requests occur infrequently, but these examples illustrate the advantage of eliciting parents' preferences before the meeting and negotiating acceptable ways to address them.

**Location.** Most parents are willing to return to the hospital to meet with the physician (17). It is suggested that meetings be held in an office or conference room located away from the PICU (21, 31) unless a family specifically requests to revisit the site of their child's death or to visit the staff in the PICU. In cases in which parents are unable or unwilling to travel to the hospital, phone or video conferences may be arranged.

**Attendees.** A small, intimate meeting is usually preferable to both physicians and parents to facilitate the most effective exchange of information and emotional support. However, parents may request the presence of their other children, their parents, or other extended family members, and community members, such as their friends or pastor. In cases in which parents want to bring the deceased child's siblings to the meeting, it will be important to make arrangements ahead of time, for example with child life services, to address the varying developmental and psychosocial needs of siblings (7, 18). Similarly, in cases in which families desire the presence of several members of their extended family and community, ar-

rangements will need to be made for a larger room and possibly more staff to manage the needs of a large group.

**Discussion topics.** Prior research (17, 31) indicated that parents generally want to discuss the course of their child's illness and treatment, the last hours of their child's life, and genetic or other risks to their surviving children. Parents often want to provide feedback to the hospital regarding the care they received and to gain reassurance that both the family and the medical team made the most compassionate decisions regarding their child's care (17). To the extent possible, parents' expectations for topics to be discussed should be elicited before the meeting so that physicians can prepare accordingly. Based on these expectations, physicians may feel the need to read further about specific medical topics, gather additional documents, or invite medical or psychosocial consultants.

**Inviting hospital attendees.** Hospital participants may include nurses, bereavement care specialists, genetic counselors, primary care physicians, or consultants who were involved in the child's care. A small multidisciplinary group is ideal to address the varying medical and psychosocial needs of parents that are anticipated or emerge during the meeting. The meeting provides physicians and other hospital participants the opportunity to assess how the family is coping so that professional referrals can be made as necessary (18). Medical trainees should be included; these meetings are an exceptional opportunity to model interpersonal skills for trainees and to allow them to listen to the perspective of bereaved parents.

**Reviewing patient history and preparing the team.** Once parents' preferences have been elicited and arrangements have been made for the meeting, PICU physicians should prepare by gathering medical records and discussing the circumstances of the child's death with other healthcare providers who cared for the child. In cases where several physicians or hospital staff will attend the meeting, physicians may convene the group before meeting with the family. During this planning meeting, physicians and hospital staff can review the medical circumstances of the death and the psychosocial needs of the family in anticipation of the topics a family may want to discuss and referrals that may need to be made. Additionally, a meeting leader or spokesperson should be designated, thus reducing

the potential for confusion or conflict during the meeting. In many cases, the leader will be the PICU physician's, but this can vary depending on the PICU physician's experience and comfort level and the extent to which other specialists were involved in the child's care. Physicians may feel more comfortable leading the meeting if they mentally rehearse some aspects. It may also be important for physicians to acknowledge and reflect on feelings of sadness, anger, or guilt related to the death, either individually or as a group.

#### *At the Meeting*

**Meeting structure.** Meetings typically last approximately 1 hr. The PICU physician (or other meeting leader) can open the meeting by briefly welcoming the family, acknowledging the sadness of the circumstances and expressing condolences, and making introductions. The floor should then be given to the parents so that they can express their thoughts and feelings and identify the issues they hope to discuss. For example, the physician might say, "I have some thoughts about what I'd like to go over with you today, but first I'd like to hear how you're doing and what you're hoping to discuss." A primary goal of the meeting is to provide parents an opportunity to talk through their thoughts and feelings, but they are likely to be distressed and therefore not particularly focused or organized. After parents have had an initial opportunity to express their thoughts and feelings and identify the issues they hope to discuss, the physician can summarize the goals of the meeting and make a transition to the specific topics requested by the family or by any other attendee. This type of meeting will help the family feel that their needs will be addressed and will also help the physician stay on track during a series of complex and emotional topics.

During the meeting, physicians should expect to cover a balance of medical, social, and emotional topics based on the needs of the parents. Although a great deal of information may need to be discussed, the physician should set a comfortable pace, allowing time for silence and processing of information and emotions (36). Physicians should make transitions between topics, encourage questions, and check occasionally to ensure parents are not feeling overwhelmed or confused. For example, a transition statement might be, "If you feel comfortable with what we've discussed about what



happened the night Ray died, I'd like to spend some time talking about the other questions that you have for me. Before we move on, do you have other questions? We can always come back to this topic if you think of other questions."

Closing the meeting can be awkward, in part, because the end of the meeting usually marks the end of the relationship, which may evoke feelings of sadness in the attendees. Physicians can signal the end of the meeting by summarizing the topics discussed, asking if there are further issues or questions, and providing professional referrals and copies of requested documents or instructions on how to obtain them (e.g., death certificate, autopsy report). These documents should ideally be provided to families who request them after discussing their contents during the follow-up meeting. Feelings of sadness can be acknowledged as part of the closing of the meeting, along with expressions of gratitude for the trust the family placed in the medical team and the opportunity to know the child and the family (29).

**Communicating effectively during the meeting.** Communicating effectively during these relatively brief meetings is complex, even in the best of circumstances, and requires physicians to address both the cognitive (i.e., to know and understand) and affective (i.e., to feel known and understood) needs of several individuals (7). Many parents want to understand very complex medical information about their child's illness and death; others want reassurance that everything was done by both the family and the hospital to prevent the child's death; still others are angry or upset about the care they received in the hospital at the end of their child's life. In their effort to address the family's needs or to manage their own discomfort in discussing distressing topics, physicians may find themselves engaging in behaviors that reduce the effectiveness of the meeting. Some simple suggestions for communicating effectively include using terminology that parents can understand, adjusting the pace to the needs of the parents, and tailoring the meeting to the specific family (26). Physicians should discuss the specific child's circumstances by using his or her name and referring to his or her medical condition, rather than talking about families in general or citing statistics. Back et al (37) suggested some communication behaviors to avoid and others to cultivate during difficult conversations. Behaviors to avoid include

blocking (i.e., failing to respond or redirecting the conversation when a parent raises a concern); lecturing (delivering a large amount of information without giving parents a chance to respond or ask questions); and providing reassurance prematurely (i.e., responding to a parents' concern with reassurance before exploring and understanding the concern). Behaviors to cultivate include "ask-tell-ask" and responding to emotions. In using "ask-tell-ask," physicians should begin a response to a parent's question or concern by first asking them to describe their current understanding of the issue, then crafting a response according to the parent's level of knowledge and emotional state, and finally, asking to see if the parents understood. For example, a parent might express the concern that his or her child was removed from the ventilator prematurely, without proper consideration of treatment alternatives. In response, the physician should avoid lecturing about how decisions to remove a child from a ventilator are made, or prematurely reassuring without responding to the concern (e.g., "Do not worry, our physicians are well qualified; you can be sure we made the best decision in your child's case.") Instead, the physician might say, "I'm glad you asked me about that decision, since it is always a difficult decision to have to make. What do you understand about how that decision was made for Lily?" This response gives the parents an opportunity to review their understanding of the medical and emotional circumstances surrounding the event and provides the physicians with a better understanding of the parents' perspectives. The physician can listen, agree or provide additional information to adjust parents' understanding of the event, and then ask the parents if they understand. Similarly, physicians can respond to parents' expression of emotions by making a statement that shows acceptance of the emotion, rather than judging, redirecting, or suggesting a different emotion. For example, if a parent says, "I just wish we had been able to do something for him," the physician should avoid saying, "It's time to accept it and move on." Instead, a response that validates and acknowledges the parents' emotion might be, "It's really hard to accept that there was nothing more we could do that would help him."

#### *After the Meeting*

**Parents.** Within a week of the follow-up meeting, a thank-you note should

be sent to parents, along with bereavement support materials or other information. Also, if a particular medical or psychosocial need has been identified during the meeting, follow-up should be undertaken. For example, bereaved parents are known to be at increased risk for developing complicated grief (38); referrals for psychosocial intervention may reduce the likelihood of adverse consequences (39).

**Physicians.** Physician participants, including medical trainees and potentially other hospital staff, should convene to debrief the meeting together as soon as possible to take advantage of the benefits gained by meeting with parents. Physicians report their perception that meeting with parents benefits them by providing the following (21):

- A better understanding of parents' perspectives;
- An opportunity to increase skill and experience to assist future families under their care;
- A chance to reconnect with families and find out how they are coping;
- An opportunity to reach closure regarding the child's death;
- Professional gratification.

Although these benefits may seem trivial at first glance, they may serve to counteract burnout and compassion fatigue in PICU physicians (13, 14).

In several prior studies (40–43), physicians from diverse specialties and with various levels of training have reported that talking with colleagues is a preferred method for coping after a patient's death. Similarly, research (44) on medical students' experiences with patients' deaths found that talking with others was the most common coping strategy reported. Medical students most often described discussing a patient's death with other students and having little opportunity to talk with faculty physicians. The lack of discussion with faculty left students feeling frustrated and angry and that their educational needs were unmet.

Bereavement debriefings have been recommended to allow clinical teams to discuss their thoughts and experiences regarding a patient's death and to critique the quality of care provided (7, 10, 29, 45). Trainees attending follow-up and debriefing meetings should ideally be those who participated in the patient's care; however, changing rotations and call schedules may not permit their presence. Because the trainee's role in fol-

low-up and debriefing meetings is primarily educational, trainees assigned to the rotation at the time of the follow-up meeting should be encouraged to observe and debrief with staff. Specific recommendations for the format of debriefing meetings are limited, but, for example, Rushton et al (46) reported on the format of bereavement debriefings held regularly in response to a child's death in a children's hospital. The meetings included standard open-ended questions, such as "What will you remember most about this child and family?" "What was the most difficult aspect of this case?" and "What was the most satisfying aspect of this case?" This model may be adapted to debrief follow-up meetings with trainees by including questions such as:

- What did you learn from this family's experience?
- What kinds of needs did you detect and were they met?
- What surprised you most about the parents' questions during the follow-up meeting?
- What suggestions do you have for 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 what improvements can we make?
- How do you think we can translate what we learned today into future practice?

In addition to debriefing, other personal, professional, and organizational strategies to help physicians and trainees recognize and manage their grief have been described elsewhere (16, 47).

This framework for conducting follow-up meetings is limited by the lack of testing of the framework's efficacy in improving outcomes for bereaved parents and families. Future research should pilot test the framework for feasibility of implementation in clinical practice. Also, larger-scale longitudinal evaluation of the framework should assess its potential benefits and harms on bereaved parents' health and family functioning, as well as PICU physicians' professional growth and satisfaction. Although bereavement may lead to poor mental and physical health for some individuals, most bereaved people eventually adjust to their loss. Research suggests that routine psychosocial intervention is of little benefit if provided simply because individuals are bereaved;

rather, intervention should be reserved for individuals at risk (48). Bereaved parents, however, are increasingly recognized as a high-risk group for poor health outcomes (38, 49, 50). Open invitations to follow-up meetings will provide bereaved parents who feel the need for additional information and support from their child's physician with the opportunity to obtain it. However, it is important to recognize that the potential for harm from follow-up meetings exists and must be carefully monitored by clinicians and examined in future research.

## CONCLUSIONS

We describe a framework to assist physicians in conducting follow-up meetings with bereaved parents after the death of a child in the PICU. The framework is primarily based on the experiences and perspectives of bereaved parents and PICU physicians and, therefore, may be adaptable to a wide variety of settings and family circumstances. These meetings have been recommended by parents, clinicians, and professional societies as having the potential to facilitate healthy bereavement among parents (7, 8, 10, 17–20). The meetings may also provide professional gratification for physicians and other clinicians and reduce burnout and compassion fatigue associated with working in the PICU (13, 14).

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