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PHYSICIANS' EXPERIENCES AND PERSPECTIVES REGARDING FOLLOW-UP MEETINGS WITH PARENTS AFTER A CHILD'S DEATH IN THE PEDIATRIC INTENSIVE CARE UNIT

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Abstract

Objective—Parents of children who die in the pediatric intensive care unit (PICU) often desire a follow-up meeting with the physicians who cared for their child. Our objective is to investigate critical care physicians' experiences and perspectives regarding follow-up meetings with parents after a child's death in the PICU.

Design—Semi-structured, audio-recorded telephone interviews.

Setting—Six clinical centers affiliated with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN).

Participants—Seventy critical care physicians (i.e., attendings and fellows) practicing or training at a CPCCRN clinical center between February 1, 2008 and June 30, 2008.

Measurements and Main Results—Twenty-three (33%) physicians reported never participating in a follow-up meeting with bereaved parents; 22 (31%) participated in 1-5; and 25 (36%) participated in more than 5. Of those with prior experience, 44 (94%) met with parents at the hospital and 40 (85%) met within 3 months of the death. Meeting content included discussing autopsy, parent questions, hospital course, cause of death, genetic risk, bereavement services, and legal or administrative issues; providing emotional support; and receiving parent feedback. Forty (85%) physicians perceived the meetings to be beneficial to families, and 35 (74%) to physicians. Barriers included time and scheduling, family and physician unwillingness, distance and transportation, language and cultural issues, parent anger, and lack of a system for meeting initiation and planning.

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Conclusions—Critical care physicians have a wide range of experience conducting follow-up meetings with bereaved parents. Although physicians perceive benefits to follow-up meetings, barriers exist that interfere with their implementation in clinical practice.

Keywords

bereavement; parent; critical care; communication; qualitative methods

INTRODUCTION

According to the Institute of Medicine's landmark report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Families*, bereavement care after a child's death is an important aspect of pediatric end-of-life care (1). Many childhood deaths in the U.S. occur in pediatric intensive care units (PICUs) (2). Studies conducted in this setting suggest that PICU staff are often a welcome source of support for bereaved parents and families (3-7). Such support may take many forms including condolence letters, phone calls, attendance at funerals or memorial services, and follow-up visits. Many families deeply appreciate such acts of kindness and commemoration by PICU staff, and are disappointed when these acts do not occur (4,6).

Parents whose children have died in a PICU often desire a follow-up meeting with the physician(s) who cared for their child during his or her final days (8). Parents report the need for information about their child's illness and death, the opportunity to provide feedback, and reassurance that the best decisions had been made for their child. Despite the importance bereaved parents ascribe to follow-up meetings with physicians, recent studies suggest that such meetings rarely take place (8,9). Many factors likely underlie the apparent discrepancy between parents' desire for follow-up meetings and their actual occurrence. Importantly, physicians at all career levels report their discomfort discussing death and bereavement-related issues with families (10). Physicians often describe a lack of communication training and inexperience as contributing to their discomfort (11).

A framework for conducting physician-parent follow-up meetings after a child's death in the PICU may provide useful guidance for physicians participating in this form of bereavement support. Such a framework must incorporate the perspectives of its major stakeholders (i.e., physicians and parents) (12-14). Frameworks developed without stakeholder perspectives may be based on erroneous assumptions and difficult to implement in clinical practice. In an effort to develop a meaningful framework, we previously conducted a study of parents' perspectives on the desirability, content and conditions of physician-parent follow-up meetings after a child's death in the PICU (8). In the current study, we investigated PICU physicians' experiences and perspectives regarding follow-up meetings with bereaved parents.

METHODS

Setting

The study was conducted across the six clinical centers (i.e., seven tertiary-care children's hospitals) affiliated with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) (15,16). The CPCCRN clinical centers are geographically diverse institutions. Each hospital has a multidisciplinary PICU, and a designated pediatric critical care faculty, fellowship program and staff.

Participants

Pediatric critical care medicine attending physicians and fellows practicing or training at a CPCCRN clinical center between February 1, 2008 and June 30, 2008 were eligible to participate. The CPCCRN principal investigator from each site was excluded. The study was approved by the Institutional Review Board at each site. Informed consent was obtained from all participants.

Recruitment

CPCCRN principal investigators compiled a list of eligible pediatric critical care attendings and fellows from their respective sites (n=131). Eligible physicians were individually contacted via a mailed letter from the principal investigator at Children's Hospital of Michigan (KM). The letter asked physicians to participate in a telephone interview about their experiences and perspectives regarding follow-up meetings with parents after a child's death in the PICU. Physicians were telephoned two weeks later by a research assistant who explained the details of the study and scheduled interviews.

Interviews

Two investigators, a pediatric intensive care physician (KM) and a behavioral scientist with expertise in health communication (SE), developed a semi-structured interview guide to elicit physicians' experiences and perspectives about meeting with bereaved parents after a child's death in the PICU. Interviews were conducted over the telephone by a research assistant and were audio-recorded. The interview consisted of three sections. In the first section, physicians responded to open-ended questions regarding their past experiences participating in follow-up meetings with bereaved parents including the number, content and conditions of past follow-up meetings, and the perceived benefits gained by parents and themselves as a result of past meetings. In the second section, physicians responded to open-ended questions about how future follow-up meetings with bereaved parents should ideally be conducted, and perceived barriers to follow-up meetings. Lastly, physicians were asked to provide demographic information. Physicians selected their race and ethnicity from predefined lists to assess sample diversity. One of two investigators (KM, SE) listened to all interview recordings within 24 hours and provided feedback to the interviewer to maintain standardization and quality.

Data Analysis

Interviews were transcribed verbatim and imported into a qualitative software program (QSR N6, QSR International Pty Ltd., Doncaster, Australia) to facilitate analysis. Two investigators (KM, SE) used an iterative process to identify themes within physicians' responses to the interview questions. This process included independent reading of the transcripts to identify themes, comparison of themes between investigators, and re-reading of the transcripts and discussion to refine themes and reach consensus on their meaning. Analysis was ongoing during data collection, and interviews were conducted until saturation was reached (e.g., no new themes were emerging) (17). Numerical data were analyzed using a statistical software program (SPSS 13.0, Chicago, IL). Categorical data were described as absolute counts and percentages, and continuous data as medians and ranges.

RESULTS

One hundred thirty-one physicians were sent letters explaining the study; telephone contact was attempted for all. Seventy (53%) physicians were interviewed, one (1%) refused and 60 (46%) did not respond to initial attempts to contact them. Data collection was halted after 70 interviews because all CPCCRN sites were represented and saturation had been reached

(17). The number of physicians interviewed from each site ranged from 5-17. Characteristics of participants are shown in Supplemental Digital Content; Table 1.

Past Experience with Follow-up Meetings

Of the 70 physicians interviewed, 23 (33%) reported never participating in a follow-up meeting with bereaved parents, 22 (31%) participated in 1-5 follow-up meetings, and 25 (36%) participated in more than 5. A greater proportion of attendings than fellows had participated in follow-up meetings (33/40 (82%) vs. 14/30 (47%).)

Initiation, Location, Timing and Meeting Participants—Of the 47 physicians who had experience with follow-up meetings, 18 (38%) participated in at least one meeting that was initiated by parents, 17 (36%) by a physician, 9 (19%) by a social worker, and 13 (27%) by other hospital personnel. One physician stated, *“In this one instance which I just described, it was basically the family called. And in the other instances, it has been mostly us or the social worker arranging a meeting.”*

Forty-four (94%) physicians reported participating in follow-up meetings that were located at the hospital; mostly in private offices or conference rooms away from the PICU. Eight (17%) physicians participated in meetings conducted by telephone, and 2 (4%) participated in meetings held at a location outside of the hospital. One physician stated, *“I always give the families the option of doing that by phone or in-person. Sometimes it’s difficult for families to return to the hospital, and especially in the few months following the death.”*

Forty (85%) physicians reported participating in meetings that occurred within 3 months of the child’s death, 6 (13%) between 3 and 12 months of the death, and one (2%) after more than a year. Sixteen (34%) physicians reported meeting with parents when autopsy results became available. One physician stated, *“Usually it’s around the time that we’ve got post-mortem findings or some other information afterwards that might be of interest to the family.”*

All physicians reported the presence of at least one parent at follow-up meetings. Additionally, 13 (28%) reported the presence of grandparents, 6 (13%) the deceased child’s siblings, 5 (11%) parents’ friends or support persons, and 14 (30%) other extended family members. Twenty-eight (59%) physicians reported the presence of a social worker, 14 (30%) a subspecialist or primary care physician, 9 (19%) a nurse, 3 (6%) a chaplain, and 2 (4%) residents or medical students. Thirty-eight (81%) physicians described meetings led by a PICU physician, 4 (8%) a subspecialist, 4 (8%) a social worker, and 2 (4%) a parent. Three (6%) described meetings conducted without a leader. One physician stated, *“It wasn’t something like a, running the meeting. It was an open dialogue.”*

Content of the Meeting—Physicians described providing information and emotional support to parents during follow-up meetings, and receiving feedback about parents’ hospital experiences. Informational topics discussed included autopsy, parent questions, hospital course, cause of death, genetic risk, bereavement services, and legal or administrative issues (Supplemental Digital Content; Table 2). Emotional support included asking about family coping, providing reassurance, and expressing condolences (Supplemental Digital Content; Table 3). Parent feedback received by physicians included both expressions of gratitude and complaints.

Benefits to Families and Physicians—Forty (85%) physicians perceived that the follow-up meetings in which they had participated were beneficial to families, 4 (8%) had mixed feelings, 2 (4%) perceived no family benefit, and one (2%) did not answer the question. Family benefits described by physicians included an opportunity to ask questions

and gain information, closure, reassurance, reconnection with staff, an opportunity to talk through feelings, professional referrals, an opportunity to provide feedback, and greater trust in the healthcare team (Supplemental Digital Content; Table 4).

Thirty-five (74%) physicians reported that follow-up meetings were beneficial to themselves, 5 (11%) reported mixed feelings, 4 (8%) reported no self benefit, and 3 (6%) did not answer the question. Physician benefits included a better understanding of parents' perspectives, an opportunity to increase skill and experience assisting families, reassurance, reconnection with families, closure, and professional gratification (Supplemental Digital Content; Table 5). Two physicians reporting no benefit to themselves felt that follow-up meetings allowed them to fulfill their professional obligations to parents.

Physician Perspectives on Future Meetings

All 70 physicians provided their perspectives on future follow-up meetings with bereaved parents. Sixty-three (90%) felt that follow-up meetings should be integrated into future practice and 7 (10%) had mixed feelings or were unsure. Explanations for why follow-up meetings should be a part of future practice included the various family and physician benefits described above. Reasons for having mixed feelings or being unsure included the physicians' desire to consider follow-up meetings on a "case-by-case" basis, and the need for emotional protection. One physician stated, *"If we keep meeting with families, it takes away one of our best ways of protecting ourselves which is putting the death aside after awhile and not going back to it."*

Initiation, Location, Timing and Meeting Participants—Physicians described many individuals who they felt would be appropriate for initiating follow-up meetings including physicians, social workers, chaplains, nurses and parents. Physicians expressed the need for a systematic process for inviting parents and arranging meetings, open-ended or repeated invitations, and an assessment of parents' preferences and expectations for the meeting beforehand. One physician stated, *"I personally would like to see it be more routine and automatic in the system rather than relying on me to initiate it."*

Fifty-nine (84%) physicians felt that follow-up meetings should ideally occur at the hospital; a common caveat was *"away from ICU."* Fifty-five (79%) felt that meetings should be initiated and/or conducted within 3 months of the child's death. Physicians expressed the need for flexibility in timing so as to meet when families are ready and autopsy results available. One physician stated, *"The time frame to me is arbitrary, it's more important to me when the family would want to meet."* Forty-seven (67%) felt that follow-up meetings would take an hour or more to conduct; a common caveat was to spend *"as much time as the family needs."*

Forty-seven (67%) physicians felt that family members attending the meeting should be based on parents' preferences. Physicians suggested that meeting size be kept to a small number of participants and that arrangements be made based on the number expected to attend. Fifty-five (79%) physicians felt that a social worker, chaplain or bereavement specialist should be present to provide psychosocial support. One physician stated, *"Make sure that they have appropriate spiritual and social support present to be able to explore if the family has other needs..."*

Content of the Meeting—Physicians described two broad topic areas as important for future meetings. First, they described the need to provide medical information including a review of past information available during the child's illness and new information available since the death. Second, they described the need to provide emotional support. Regarding specific topics, 20 (28%) suggested discussing whatever the family wants to discuss. One

physician stated, “*These meetings would be more for the therapy, health, assistance of the family so I would let them decide what the topics would be.*” Listening, encouraging and responding to questions, and eliciting and accepting feedback were frequently mentioned communication tasks.

Barriers to Follow-Up Meetings—Barriers to follow-up meetings included time and scheduling, family and physician unwillingness, distance and transportation, language and cultural issues, parent anger, and lack of a system for meeting initiation and planning (Supplemental Digital Content; Table 6). Logistical barriers were often viewed as a hindrance whereas personal barriers such as physician unwillingness were viewed as more prohibitive. Regarding logistical barriers, one physician stated, “*Usually those sorts of barriers can be overcome with a little bit of effort.*” Regarding personal barriers, another physician stated, “*If we as intensivists aren’t proactive and aren’t in favor of these...then it’s much less likely to happen.*”

DISCUSSION

Our findings indicate that PICU physicians have a wide range of experience participating in follow-up meetings with bereaved parents. As expected, attending physicians in our study had more experience than fellows; yet some attendings (18%) had never participated in a follow-up meeting at any time during their careers. In a recent web-based survey conducted among board certified physician members of the American Academy of Pediatrics (AAP) Section of Critical Care, 78% reported at least sometimes contacting families after a child’s death (9). Of these, most follow-up was passive (e.g., providing contact information or designating staff to follow-up) rather than active (e.g., physician-parent meetings), and 17% reported never meeting with bereaved families. Studies conducted among physicians caring for adult patients also show large variation in frequency and type of bereavement practices with follow-up family meetings occurring rarely (18,19).

Physicians’ experiences and perspectives regarding the content and conditions of follow-up meetings were generally consistent with those of bereaved parents reported in our prior research (8). For example, most parents who reported wanting a follow-up meeting with the PICU physician were willing to meet at the hospital. Parents wanted information about the course of their child’s illness and death, treatments received, autopsy results and genetic risks to siblings; reassurance that the right decisions had been made; and the opportunity to voice complaints and express gratitude. However, there were some differences between the perspectives of physicians and bereaved parents. For example, parents sought advice on how to use their experiences to help other families. Most complaints voiced by parents in our prior research concerned ineffective communication during the child’s PICU stay; a problem rarely mentioned by PICU physicians. Another difference noted between physicians and parents was in the choice of professionals attending the follow-up meetings. Whereas physicians emphasized the attendance of a social worker, chaplain or other bereavement specialist to provide psychosocial support, parents often desired the presence of their child’s bedside nurse (8). Research suggests that nurses are viewed by families as more emotionally supportive than other healthcare providers (3,20). Physicians’ experiences and perspectives in this study were similar to the reported experiences of other physicians who have conducted physician-parent meetings after a child’s death (21,22). However, other physicians have also mentioned screening for pathological grief reactions.

Most physicians in our study felt that follow-up meetings were beneficial to parents and physicians. In the survey conducted within the AAP section of Critical Care (9), 76% of study participants reported that follow-up meetings were helpful to families and 47% to physicians. Our results provide insight into the nature of the benefits attributed to follow-up

meetings. For families, physicians perceive that follow-up meetings provide a forum for getting questions answered, closure, reassurance and reconnection with health care providers. The salience of these processes is underscored by studies that show families often feel abandoned by physicians when a loved one dies (23,24). Nonabandonment has been defined by Quill and Cassel as an “open-ended, long-term, caring commitment to joint problem solving” (25). One aspect of nonabandonment previously identified by families is the need for closure of the family-physician relationship after a death (23). Similarly, benefits of follow-up meetings for physicians included closure, reassurance and reconnection. Some physicians, however, expressed the need to avoid the bereaved as a form of self protection. Physicians are susceptible to stress-related syndromes such as burnout and compassion fatigue (26,27). Burnout is related to stresses arising from the work environment whereas compassion fatigue is related to caring for people who have experienced traumatic events. The extent to which follow-up meetings promote professional growth and satisfaction or burnout and compassion fatigue is a question for further study.

Perceived barriers to follow-up meetings were often logistical such as lack of time during busy clinical days, conflicting schedules, the need for some parents to travel long distances, lack of transportation or other resources, and the need for translators for non-English speaking parents. Physicians in our study suggested that a systematic hospital process for meeting initiation and planning would allow follow-up meetings to be integrated more easily into clinical practice. For example, having a designated social worker to contact parents, assess parents’ preferences, schedule time, place and meeting participants, and obtain records was suggested. In other studies, physicians have also expressed the need for logistical help contacting families for bereavement follow-up (18,19). Intra- and inter-personal barriers included physician and family unwillingness, and parent anger. Physician unwillingness was often described by physicians in our study in terms of emotional discomfort, and only rarely in terms of concern about potential legal ramifications or reimbursement issues. Physicians perceived that some families may not want a follow-up meeting due to their reluctance to revisit the place and events associated with their child’s death. Physicians also felt some families may be angry or distrustful of the medical team due to their child’s poor outcome.

Limitations of this study include the small sample size and number of participating clinical sites. Differences in physicians’ views based on demographics, career level or extent of experience with follow-up meetings could not be evaluated because of the small sample size. Strengths include the qualitative design and use of open-ended questions which allowed physicians to discuss personal experiences and perspectives rather than choose or rank responses from predefined lists. Strengths also include the geographic diversity of participants and sites.

We have described critical care physicians’ experiences and perspectives regarding follow-up meetings with bereaved parents. These findings, along with bereaved parents’ experiences and perspectives described in our previous research (8), provide a background for designing a framework to guide physicians in conducting follow-up meetings with families after a child’s death in the PICU. Physicians and parents identify similar topics for discussion at follow-up meetings and describe the importance of including social workers, chaplains, nurses, and extended family and community members as meeting participants. A framework that incorporates the views of physician and parent stakeholders may be a useful tool for those willing to engage in this form of bereavement support. Once such a framework is developed, the effect of physician-parent follow-up meetings on family bereavement outcomes and physician satisfaction will need to be evaluated.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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