Working With Families of Suddenly and Critically Ill Children

Physician Experiences

Doris A. Bartel, MSN, RNC, CRNP; Arthur J. Engler, DNSc, RNC, CRNP; JoAnne E. Natale, MD, PhD; Vinita Misra, BA; Amy B. Lewin, PsyD; Jill G. Joseph, MD, PhD

Objective: To describe physicians' experiences in attempting to provide optimal care for families of children who suffer from sudden, acute life-threatening conditions (SALTC).

Design: To generate descriptive data in this exploratory study, we used qualitative methods including focus groups and in-depth interviews. Transcripts of focus groups and interviews were analyzed for content using standard phenomenologic analysis methods, which resulted in a participant-generated conceptual model of optimal care for families of children with SALTC.

Setting: The intensive care unit of an urban pediatric teaching hospital.

Participants: Twenty-two pediatric intensive care unit physicians, including residents, fellows, and attendings.

Intervention: None.

Main Outcome Measures: Each participating physi-

cian provided qualitative descriptions of experiences caring for families of children with SALTC.

Results: Physicians identified 4 components of optimal care for families: (1) providing timely, accurate information about their child; (2) maintaining privacy for confidential discussions and personal grieving; (3) giving adequate emotional support; and (4) granting family members the right to hold and comfort their dying child. Physicians also described barriers to, and facilitators of this optimal care.

Conclusions: Descriptive information provided in this exploratory study offers a complex model of optimal family care. Issues that affect the quality of care to families include those related to the context of providing care in a large teaching hospital, as well as subtleties of communication between parents and staff. Physicians' beliefs about optimal care of families in the pediatric intensive care unit revealed implications for both practice and training in pediatrics.

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HE WORK of caring for dying children and their families has been described as "heroic effort with compassion."1 For pediatric intensive care unit (PICU) physicians, compassionate care of children with lifethreatening conditions includes communication with and support of the child's family. Often, this includes working to develop the trust of parents, communicating with the family about the child's medical condition and treatment, and, at times, negotiating with the family about difficult end-of-life decisions. When children are hospitalized for a sudden, acute lifethreatening condition (SALTC), such as multiple trauma, burns, near-drowning, or meningitis, providing such support can be especially challenging. In this situation, the family members abruptly confront the crisis of the child's grave illness without time to prepare or adjust, and they are frequently overwhelmed. Communication with families in these instances may be problematic,²⁻⁴ and optimal support for a family's unspoken needs during the crisis may be difficult to discern or provide.^{5,6}

See also pages 1082 and 1154

Guidelines have been established for effective communication and decision making with families of patients in intensive care,⁷⁻¹² particularly in terms of how to break bad news.¹³⁻¹⁶ However, few data exist about the broader practices, experiences, and beliefs of physicians as they attempt to support parents who are coping with the crisis of a child hospitalized for SALTC. Studies performed in adult inten-

From the Children's National Medical Center, Washington, DC (Ms Bartel, Dr Engler, Ms Misra, and Drs Lewin and Joseph); and The Johns Hopkins Hospital, Baltimore, Md (Dr Natale).

PARTICIPANTS AND METHODS

DESIGN

The goal of this qualitative study was to describe physicians' experiences in caring for families of children with SALTC. Focus groups and individual in-depth interviews were conducted with physician-participants to explore their experiences, as well as their beliefs and perceptions of effective and appropriate care for these families. Such exploratory and descriptive methods were deemed essential to this early study of a complex topic involving the development of interpersonal relationships in the midst of a crisis. Since very few data exist on the communication and support of parents during the acute crisis of a child's hospitalization, qualitative methods were used to explore this phenomenon from the perspectives of the physicians working with families. The research protocol was approved by the institutional review board of the hospital in which the research was conducted.

SAMPLE

The sample consisted of 22 physicians working in an urban pediatric teaching hospital in the Mid-Atlantic region of the United States. The demographic characteristics of the sample are displayed in the **Table**. Five attending pediatric intensivists, 5 pediatric critical care fellows, and 12 pediatric residents participated. Participants were volunteers who were invited to participate using purposive and theoretical sampling intended to capture the experiences of physicians at all levels of training. All physicians working in the unit during the study period were approached, and all agreed to participate. The sample size was consistent with standard qualitative samples, which are usually small in order to yield a rich description of the phenomenon rather than test specific hypotheses about a population of interest.²³

INSTRUMENT

A semistructured interview guide with open-ended questions was used in the focus groups and interviews. For example, the first 2 questions were (1) "Thinking back on your most recent experience with parents of a child who was admitted to the PICU unexpectedly, can you describe your experiences in working with the parents or family?" and (2) "In caring for children who are admitted to the PICU unexpectedly, what aspects of working with parents worked well or not so well?" The interview guide was reviewed after each interview. Questions that did not produce meaningful responses were deleted or modified, and questions examining new areas of concern raised by participants were added. A copy of the interview guide is available upon request.

PROCEDURE

Appointments were set at a time and place convenient for the participants. With the permission of the participants, audiotaped interviews and focus groups lasting 30 to 120 minutes were conducted, usually in conference rooms in the study hospital. Each participant was interviewed once or participated in one focus group. The 5 critical care fellows were interviewed in a focus group format because of the limited time they had available. The same questions posed in the individual interviews were used in the focus group. All interviews were transcribed verbatim and entered into *The Ethnograph Software* program²⁴ to facilitate data management and analysis.

DATA ANALYSIS

The investigators analyzed the tapes and transcripts using the standard qualitative methods described by Strauss and Corbin.²⁵ Each tape was transcribed and reviewed by the researchers. Then, each phrase and paragraph of the transcripts was examined thoroughly to identify and label the phenomenon being described. Each concept in the transcripts was labeled or "coded," and the codes were subjected to clarification, categorization, and/or differentiation. Similar codes were grouped together according to their "fit," and inclusive categories of these larger abstract concepts were developed. The content of the abstract categories and the relationship between the categories were then examined in a secondary analysis, which included further clarification, categorization, and/or differentiation. This process of examining the data and grouping and reexamining the categories resulted in a conceptual model of the phenomena. Each interview or focus group was coded after completion of data collection.

Several strategies employed in qualitative research were used to strengthen the credibility and reliability of the data.^{23,25} The investigators kept records of their "decision trail" in the development of the study, the choice of participants, and the coding and categorization decisions, which were discussed frequently. Each transcript was coded separately by 2 investigators (D.A.B. and V.M.); the coded transcripts were then reviewed for consistency between them. The coders discussed all inconsistencies, and came to a consensus on the final concepts. Two investigators (A.J.E. and J.G.J.) reviewed all the transcripts for consistency with coded themes and domains. All participants reviewed the results of the analysis for validity and truthfulness to their perspective. Nonparticipant pediatric intensive care physicians in another tertiary care PICU also reviewed the manuscript for credibility based on their own experiences.

sive care units with critically ill or dying patients found that family members need privacy and clear, accurate provision of information from consistent individuals caring for their relative. ¹⁷⁻¹⁹ Similarly, studies of parents with children in PICUs have identified 4 major family needs. First, parents need to be with their child in the unit. Second, they need frequent, accurate, and truthful information about the child's condition and prognosis. Third, parents want to know that the child is being treated for pain and is comfortable. ^{20,21} Finally, parents

often request a place to sleep near the PICU so that they are never far from their child. 22

Staff who work in the PICU can contribute to our understanding of their experiences in this unique environment, and can help identify factors that impede or facilitate effective care for parents. This study investigates the perceptions of PICU physicians working with families of children with SALTC and focuses on barriers and facilitators of appropriate and effective care for families. It is part of a larger work exploring the beliefs of nurses

and other PICU staff regarding effective care for parents of children with SALTC, as well as the perceptions of families of children with SALTC who are hospitalized in the PICU.

RESULTS

Physician-participants described their own experiences in trying to understand and meet the needs of families when a child is hospitalized for a SALTC. They also discussed the unit policies or staff practices that provide parental support and affect parent-staff collaboration in either a positive or negative way.

FAMILY NEEDS

The fundamental needs or basic rights of children with SALTC and their families identified by the participants are (1) providing timely, accurate information about the child's condition; (2) maintaining privacy to ensure confidentiality of the child's medical information and to provide an opportunity for personal grieving; (3) giving adequate psychosocial and emotional support; and (4) presenting family members with the option to hold and comfort a dying child in the last moments of life.

In the case of a child with a SALTC, physicians identified timely and accurate information about the child's condition as the family's primary need. All physicians described the priority of updating the family with factual information as quickly as possible after the child's arrival to the unit, and many described a family's need for further updates from physicians on a regular basis. One participant said:

If [the child] is very sick (in the high-risk group for dying) I think it's important that the family have a chance to sit in a separate conference room away from the bedside and meet with an attending or fellow every day. Unless it's clear the child is getting better, or things come to a conclusion, I try to meet with everybody once a day.

According to the participants, privacy is the second most important need of families. The physicians felt that families need a quiet, private space away from their child's bedside when discussing medical updates with staff. They saw privacy as important not only for reasons of confidentiality, but also for keeping distractions to a minimum during these discussions. One physician described the need for privacy in the following way:

A room for the families to be able to talk privately is extremely critical . . . somewhere where they can feel that they are safe and comforted. . . . A caring type of room seems absolutely necessary for the ICU.

Participants also stated that grieving families need to have a private place where they can express their feelings away from staff, other families, and their child in the unit. All physicians also considered the last moments of a child's life to be an intensely private moment for families, and all worked hard to provide this consideration to them.

Third, the physicians in the study indirectly articulated families' psychosocial, emotional, and spiritual needs by describing the critical role of the nurses and social

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Characteristic	No. of Participants
Educational level	
Attending pediatric intensivist	5
Critical care fellow	5
Pediatric resident	12
Race	
White	18
African American	3
Asian	1
Sex	
Women	14
Men	8
Total Sample Size	22

workers in providing this kind of support. Most participants mentioned the social bonds that nurses formed with families, and the kinds of personal information they learned about the child and the extended family:

The nurse learns about the family: do you have dogs? And they see the picture of the child growing up, and they learn the child's favorite song. [The child] becomes much more of a human being. The nurse knows the pet's name, they know the stuffed animal and the favorite song of the child.

Another said:

The nurses have this special role, I think, because they spend all their time at . . . the bedside. They spend all that time with the family. So the nurses really get to know the family and they usually bond. And I think the nurses, therefore, have a much more emotional attachment to the families.

The rapport that nurses develop with patients' families was particularly valued. However, it was also implicitly distinguished from the role physicians play by providing families with timely, truthful information, and by helping families make difficult end-of-life decisions.

Finally, many physicians spoke eloquently and passionately about the importance of providing dying children with comfort, when, in the last few moments of the patient's life, they believe aggressive medical therapy to be futile. They cited lessons learned from their own experience in pursuing medical interventions and cardio-pulmonary resuscitation (CPR) through to the last moments of a dying child's life. One physician said:

I think that the ICU staff usually wants the same thing. If the child's illness is very grave, and there is very little chance, then most of us (the medical staff) would rather have the family hold the child rather than do CPR. Most of us would rather not do CPR or push medications . . . because it's not going to make a difference . . . the more you do it, you just think, "if the kid is going to die, let them die."

The physicians spoke of working with parents to help them come to the difficult decision to discontinue medical therapy or to not resuscitate the child in case of cardiorespiratory arrest. Physicians described these discussions as collaborative, but articulated their belief that families are the final arbiters of choice for end-of-life care. While the physicians would personally choose comfort care for the child over resuscitation measures, they consistently reported that they would always follow the decisions made by the parents.

The decision about how to handle the last few minutes or days are up to the family. But we certainly give them options. We say, "this is how it can be." Then the family decides how they're going to do it. It is guided by the family.

Experiences with parents who made the decision to discontinue therapy and hold their child in the last moments of life clearly resonated with the physicians. Physicians described these deaths as "peaceful" and "reverent." One physician put it this way:

The best scenario is when the family recognizes that [the child is going to die] and makes the last few minutes special. Just as an example, one family . . . decided that instead of pressing on with more medications and CPR, they just took her off the ventilator and played music she would enjoy, and mom got into bed with the child. [We] took off the tapes and tubes . . . and the dad sat in the chair next to them with his arm around both of them, and that's the way they spent the last 5 minutes.

BARRIERS AND FACILITATORS OF OPTIMAL CARE

The 4 family needs described earlier were the basis of the physicians' beliefs about barriers or facilitators of optimal care for families during the crisis of a child hospitalized with a SALTC. These barriers and facilitators fell into 2 broad categories: the contextual and the relational aspects of care. As defined here, *contextual aspects* are the conditions under which staff and family interactions occur. These conditions include both psychosocial and environmental concerns. *Relational aspects* include the personal skills and group strategies used by the PICU team to build trust, enhance communication, and provide support for the families of their patients.

Contextual Aspects

The contextual aspects of care were cited by many participants as critical to working with families. These include (1) the inevitable shock felt by families from the unexpected crisis, which in turn affects communication with physicians; (2) the physical structure and layout of the unit; (3) the time pressures inherent in caring for many critically ill children; and (4) issues of team care, and the difficulties involved in providing consistent information for families.

Shock. An abrupt change in a child's health leads many families to experience numbness or shock. Some participants acknowledged that staff may also need time to adjust to the unanticipated death of a child who was expected to survive. However, physicians most frequently commented on the denial common to parents whose child suffers a SALTC, and the "time lag" that occurs before the child's family is able to accept the reality of the situation:

When you have a dying patient on the unit, and you go out to the family to talk to them about the child's prognosis, almost inevitably, when you come back into the unit, the first question that somebody will ask you, usually the patient's nurse, is, 'do they get it?' A sense that the family at least understands the gravity of the situation and how they should be thinking in terms of planning for their own lives, even for the next couple of days. That's a reasonable question because a fair percentage of the time, they didn't [get it].

Another physician described the denial this way:

You can say . . . "she's getting maximal therapy. She's not getting any better. That really isn't looking well and we are going to have to start to think about what if she doesn't get better." And, to hear a parent say in response, "So, is she going to be healthy when she goes home?" You know that there's a huge chasm between [their] understanding and what we actually see.

The physicians in the study described trying to help families with the transition from having a healthy child to accepting the possibility of the child's death. They repeat information and try to be patient with parents. One physician emphasized the importance of giving families the time they need to adjust: "I've always had the conviction that families eventually come around, and everything works out. Just on a different time frame than the physicians and nurses."

Physical Facilities. The participants also stated that a unit that provides private spaces to both families and staff is enormously important in providing optimal care to families. This study was conducted in a unit like many PICUs, with semiopen rooms and beds surrounded only by privacy curtains. A small number of private rooms are available, generally for children requiring isolation. While this design has the advantage of keeping staff in direct and personal contact with the critically ill children at all times, it also creates an open space where any communication can be overheard by others. Units with open designs often have policies that require parents to leave during scheduled times for staff communication during the day (eg, during physician rounds or while nurses are changing shifts). Most physicians advocated more privacy and unlimited access for parents to their children. One physician said:

Most hospitals are concerned about the right of confidentiality, or preserving the right of one family's bad news so that medical news is not heard by the rest of the unit. I respect that. [Other] units have a physical layout where . . . you can close doors and [have] solid walls.

Physicians also commented on the need for a place where they could speak freely among themselves, both to discuss the care of the child and to use humor as a coping mechanism without being overheard by parents. In discussion of the physical space, many physicians articulated their desire to keep a respectful demeanor around the families:

A lot of the ICU staff use humor to get them through the day. Everyone has a dry, sometimes scathing sense of humor, and you make the most disturbing jokes about patients. If the families heard us talking, they would get the wrong idea—and yet, most of us do it because we have to. I'm constantly catching myself doing that in the middle of the unit with a nurse, not

realizing that we're surrounded by families. You can't be yourself or let your guard down.

Time Pressure. Time demands on PICU staff also influence optimal communication and collaboration with families. Several critically ill or injured children are admitted every day in the study PICU, often within a very short time span. The physicians described how important it is to take the time away from bedside care to provide anguished parents with information. However, the acuity of a child's condition and the intensity of required care often make spending time away from the child's bedside difficult, if not impossible. This demand limits their ability to meet with families to provide updates or answer questions. One participant described this concern as follows:

The thing that is unfortunate is that we [attendings] in the intensive care unit are often solo. There is one physician covering it, especially at night and on weekends when these things happen. So we let the families know what is happening, but then we go off to a STAT code in the ER, or on the floor, or a patient is crashing . . . so there is little time to spend with that family, unless that child starts crashing again.

Another participant noted:

When things are tight and stressful for the staff . . . the things that may fall by the wayside may include communication. . . . You are making certain that the life is spared, you shorten the amount of time you spend answering questions or in dealing with the family.

Because physicians are aware of the many demands on their time, they are concerned about the availability of other staff to work with families. Nurses and social workers are viewed by the physicians as playing a pivotal role in advocating for specific family concerns and values, and explaining medical information in a way that is more understandable. Therefore, they believe that adequate staffing of both nurses and social workers is very important. Several physicians noted that such support is especially critical during the evening and night shifts, when many families visit the unit, and when many new patients are admitted.

Team Care. The participants also described the large number and variety of staff participating in the care of a child. This includes PICU attending physicians, fellows, and residents, as well as residents, fellows, and attending physicians from other departments such as cardiology or surgery. One participant noted:

You have nursing aides, the unit clerk, the respiratory therapist, the nutritionist, the residents, the fellow, the ICU attending, the cardiology attending, the neurology attending, whoever is consulting on this patient, and there are always 3 or 4 consults going on at the same time. It is very difficult and frustrating . . . for the parents.

Many of the physicians spoke about the anxiety, confusion, or anger expressed by families when they believe that they are hearing contradictory information or advice from different staff members. One participant put it this way:

Some families . . . sort through the different layers of information very well, and other families just get totally confused and anxious because they're getting too much information and it's not all exactly the same.

Many families lack familiarity with the complex medical information being discussed, and are coping with their own shock and anxiety during this critical hospitalization. While acknowledging that these circumstances can contribute to families' confusion, many physicians stated that the large number of hospital personnel involved, and their different communication styles, contributes heavily to any difficulties.

Relational Aspects

The challenging work of communicating with families through a crisis requires physicians to develop specific skills, both collectively and individually. Participants spoke at length about the strategies they use to build relationships with families, and they went on to define these very specific techniques.

Team Strategies. Participants first discussed communication policies or strategies used by the entire unit, including "family meetings" and "identifying a spokesperson for the team." They described the family meeting as a structured event that could be requested by any member of the medical team or by the family. Everyone involved in the care of the family is invited. At this meeting, families are given medical updates, anticipated prognoses, and the opportunity to ask questions and clarify areas of uncertainty. During times of rapid changes in the health of the child, especially when a child is not doing well, family meetings are held frequently. It is often in the course of these family meetings that difficult decisions regarding limitations or withdrawal of care are made collaboratively:

The usual way is to provide the structure of a family meeting. And at that meeting, you bring into the room family members, minister, whoever is important to them, other family members, and all the managing docs and nurses and social service people, and sometimes the chaplain. So, as many of the involved parties are there, and then you talk. And you see what their perceptions are.

When communication with a family becomes difficult, a common unit strategy is to delegate a particular person to be a spokesperson, either for the family or for the medical team. Once this individual is designated, all communication between family and staff is channeled through that person to reduce confusion and the possibility for miscommunication:

You identify a spokesperson from the medical team. It's successful because it minimizes trouble. If you have a family that is so distrustful that they are creating anxiety for themselves, by contrasting words (hearing different things from different staff members), then it's better that you identify a communicator.

Individual Communication Style. Physicians described their own style of communicating accurate information in ways that families would understand and trust. Implicit in these descriptions was a respect for the families. In particular, they focused on "giving bad news" well. Discussions of giving bad news included thoughtful commentary on essential social and communication skills that helped to set a tone of mutual respect:

I've developed a style where I introduce myself again, shake hands, I think that's real important, start off by kind of giving an overall summary statement, ask if the parents have the questions first

Some physicians also mentioned the importance of respecting families' body language, and being careful about their own body language when conversing with parents about a child's medical condition or prognosis:

Like, if you were sitting there leaning back, legs crossed when the family is talking, it shows that you're not very interested.

Some physicians also mentioned pacing the tempo of the "bad news," and remaining silent at key moments as ways of respecting parental reactions and supporting families who are overwhelmed:

[The social worker taught me] about eye contact, using medical jargon or not... the timing — how rushed the conversation went. She taught me how to set the tempo to automatically give a few seconds of silent time after certain phrases or after delivering a prognosis. The best thing she taught me was how to interact with family through their silent communication of what they're ready for.

Choosing Appropriate Language. The physicians stressed the importance of choosing appropriate wording to explain complex medical updates in ways that families can understand:

I'll try to find out what their level of understanding is first. Then I bring them up to date and use terminology appropriate to their level. I'll keep it simple. I'll say, 'breathing tube' instead of intubation. I do a lot of visual stuff. Show them simple things, like how the tube goes in the mouth.

Physicians with more extensive experience in the intensive care setting also described using analogies to aid in families' understanding of the complexity of a critical illness:

I use a forest fire analogy with sepsis and infection: there's a little campfire, which is the infection, and we have antibiotics to try to put that out, but there's a whole forest that's on fire and we have to think about that, too. We have to begin to contain that, and reduce the size of the fire. I think that parents like that analogy . . . it helps with the whole explosion of critical illness and trauma and containing things.

Many of the attending physicians and ICU fellows used foreshadowing techniques to help families prepare for the worst. One physician described giving "a grim scenario but with compassion at the same time and in stages, [depending] on how much the family can take." Another said:

I stage the delivery of bad news. If I know with 100% certainty that the kid is going to die, it will be 50% with the first discussion, then 70%. [But] not literally . . . where you kind of prepare them in increments.

The residents reported struggling with their wording when conveying uncertain or poor prognoses to families. One participant noted:

The attending sat me down and said, "you need to be able to tell the families. You can tell them they are 'critical' but they don't understand what that means. You have to use the word 'dead' or 'death' or 'dying.'"

Most attending physicians, and fellows with more experience in hopeless situations, were more likely to be blunt with bad news:

Don't give false hope because you're too uncomfortable with . . . information . . . that you're giving. If you really can't bear the thought that some children die, then you might translate that into being unable to say [to a parent], "this is a non-survivable situation."

COMMENT

Any discussion of these results must begin with a frank acknowledgement of their limitations. Little is known about the practice of pediatrics in the intense context of treating children who are suddenly critically ill and may be dying. We therefore chose to begin with a modest and qualitative approach to this understudied but important issue. These methods more closely resemble anthropologic research than randomized clinical trials, and may be unfamiliar or even suspect to many pediatricians. Furthermore, the sample was drawn from a single institution and the number of participants, although relatively large for a study of this sort, is modest for those concerned with statistical power and significance testing. We do not present our findings as being generally true for all hospitals providing critical care for children. On the contrary, we view them as giving "voice" to the otherwise unshared experience of one group of pediatricians, or as an initial "mapping" of unfamiliar territory. Their value lies not in their generalizability but in their power to stimulate thoughtful consideration and to inform the conduct of future research. For this group of investigators, the results described raised several important issues that may be relevant both for those directly involved in the care of critically ill children and more generally for all pediatricians.

First, it is apparent that physicians at all levels of experience recognize the importance of their psychosocial and interpersonal skills in dealing with families. They reflected on techniques such as pacing disclosure of prognosis, use of body language, and methods for matching their language to the family. They wanted to be sensitive to needs of families as well as the pressures of their work, and they demonstrated remarkably consistent empathy. In an era of emphasis on efficiency, and concerns about the effects of such pressures, this provides a reassuring reminder that our profession continues to focus on the interpersonal art of medicine as well. It also raises questions about whether there is sufficient formal and explicit recognition of this skill set in our publications, our training, and our system of incentives. Physicians are given explicit didactic training in technical skills. Perhaps we should be providing similarly structured training in psychosocial and communication skills, rather than expecting trainees to learn such complex skills simply through observation.

The second point is related to the first. It is encouraging that some medical schools and residencies are now offering training in "breaking bad news." Such skills are clearly essential and these efforts commendable. Nonetheless, our participants were explicitly aware of the broader contextual issues, such as the need for optimally designed space and more weekend staff, that affected their ability to work with families. It would be unfortunate if communication with families became a narrowly defined technical skill, and we were not willing to aggressively advocate for work environments that best serve the needs of those families.

Third, woven into the observations of the physicians we interviewed was a consistent awareness of the toll imposed by working with critically ill children and with families in crisis. It was also apparent that this was most distressing to the relatively inexperienced residents, although the concern was general. In our opinion this reflects the reality that empathy paradoxically presents both the opportunity for building strong relationships, and the hazard of becoming overwhelmed. Given what is known about the short-term and longterm psychological sequelae of stress, might we do a better job in supporting pediatricians as they learn to develop adaptive responses to the often difficult demands of work, here exemplified in its most extreme form? In environments where demands are particularly intense, how can our colleagues in consultation-liaison psychiatry or in social work support us individually and collectively in maintaining the required balance? Perhaps a reasonable starting point would be recognizing this issue, and moving beyond crisis intervention for the rare pediatrician who is truly distressed to support for the majority who are coping well.

Fourth, these results remind us of the value of teams in caring for patients. Nurses, in particular, are appreciated as often being more informed about patients and their families, and as having more developed relationships with them. Incorporating the team perspective into decision-making and communication would likely improve our ability to respond accurately and effectively to the needs of families.

Finally, it seems important to consider what participants did not say. It was particularly noteworthy that they expressed few reservations about their own skills, and never discussed the issues of race and class in their work with families. Both these omissions likely reflect the difficulties of the topic rather than their lack of importance. Surely, any pediatrician can recall painfully incompetent moments with families: the slip of the tongue, the irritation unwillingly conveyed, the confused response to a question. Similarly, most of us are aware that our patients often come with expectations and experiences immensely different from our own, and that these differences can adversely affect our work with them. In order to build greater competence in interpersonal skills, it is necessary to realistically recognize the problems that exist. Both of these topics are difficult. As professionals, we select and train for success rather than failure. As a society, discussions of race and class are often constrained and painful, but we do fail at times, and racial and class differences can be difficult. While we cannot advocate for some specific and facile solution, we do urge a greater attention to these potentially problematic issues in the training and practice of pediatrics.

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Reprints: Jill G. Joseph, MD, PhD, Center For Health Services and Clinical Research, Children's National Medical Center, 111 Michigan Ave NW, Washington, DC 20010.

REFERENCES

- Todres ID, Armstrong A, Lally P, Cassem EH. Negotiating end of life issues. New Horiz. 1998;6:374-382.
- Shiminski-Maher T. Physician-patient-parent communication problems. Pediatr Neurosurg. 1993;19:104-108.
- Groves JE, Beresin EV. Difficult patients, difficult families. New Horiz. 1998;6: 331-343.
- Waller DA, Todres ID, Cassem NH, Anderton A. Coping with poor prognosis in the pediatric intensive care unit. AJDC. 1979;133:1121-1125.
- Saines JC. Phenomenon of sudden death: part I. Accid Emerg Nurs. 1997;5:164-171.
- Granger CE, George C, Shelly MP. The management of bereavement on intensive care units. *Intensive Care Med.* 1995;21:429-436.
- Todres ID, Earle M, Jellinek MS. Enhancing communication: The physician and family in the pediatric intensive care unit. Pediatr Clin North Am. 1994;41:1395-1404.
- Harrison H. The principles of family-centered neonatal care. *Pediatrics*. 1993; 82:643-650.
- Stark J, Thape J. Decision making in neonatal intensive care units: a collaboration of parents, physicians and nurses. AWHONNS Clin Issues Perinat Womens Health Nurs. 1993;4:589-595.
- Todres ID. Communication between physician, patient and family in the pediatric intensive care unit. Crit Care Med. 1993;21(suppl 9):383-385.
- Vincent JL. Communication in the ICU. Intensive Care Med. 1997;23:1093-1098.
- Stern, HP. Communication, decision making and perception of nursing roles in pediatric intensive care unit. Crit Care Nurs Q. 1991:14:56-68.
- Vaida VU, Greenberg LW, Patel KM, Strauss LH, Pollack MM. Teaching physicians how to break bad news: a one-day workshop using standardized parents. Arch Pediatr Adolesc Med. 1999;153:419-422.
- Greenberg LW, Jewett LS, Gluck RS, et al. Giving information for a life threatening diagnosis. AJDC. 1984;138:649-653.
- Sharp MC, Strauss RP, Lorch SC. Communicating bad medical news: parents experiences and preferences. J Pediatr. 1992;121:539-546.
- Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. JAMA. 1996;276:496-502.
- Johnson D, Wilson M, Cavanaugh B, Bryden C, Gudmundson D, Moodley O. Measuring the ability to meet family needs in an intensive care unit. Crit Care Med. 1998:26:266-271.
- Fraser S, Atkins J. Survivors' recollections of helpful and unhelpful emergency nurse activities surrounding sudden death of a loved one. *J Emerg Nurs*. 1990; 16:13-16.
- Malacrida R, Bettelini CM, Degrate A, et al. Reasons for dissatisfaction: a survey of relatives of intensive care patients who died. Crit Care Med. 1998;26:1187-1193.
- Fisher MD. Identified needs of parents in a pediatric intensive care unit. Crit Care Nurse. 1994;14:82-90.
- Vincent JL, Alexander JG, Money B, Patterson MS. How parents describe caring behaviors of nurses in pediatric intensive care. MCN Am J Matern Child Nurs. 1996;21:197-201.
- Kasper JW, Nyamathi AM. Parents of children in the pediatric intensive care unit: what are their needs? Heart Lung. 1988;17:574-581.
- Lincoln Y, Guba E. Naturalistic Inquiry. Beverly Hills, Calif: Sage Publications; 1985.
- The Ethnograph Software: A Program for the Analysis of Text Based Data [computer program]. Version 5.0. Thousand Oaks, Calif: Sage Publications; 1998.
- Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park, Calif: Sage Publications; 1990.