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## Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit

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### Abstract

**Objective**—Communicating bad news about a child's illness is a difficult task commonly faced by intensive care physicians. Greater understanding of parents' scope of experiences with bad news during their child's hospitalization will help physicians communicate more effectively. Our objective is to describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the pediatric intensive care unit (PICU).

**Design**—A secondary analysis of a qualitative interview study.

**Setting**—Six children's hospitals in the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network.

**Participants**—Fifty-six parents of 48 children who died in the PICU 3–12 months before the study.

**Interventions**—Parents participated in audio recorded semistructured telephone interviews. Interviews were analyzed using established qualitative methods.

**Measurements and Main Results**—Of the 56 parents interviewed, 40 (71%) wanted to provide feedback on the way information about their child's terminal illness and death was communicated by PICU physicians. The most common communication issue identified by parents was the physicians' availability and attentiveness to their informational needs. Other communication issues included honesty and comprehensiveness of information, affect with which information was provided, withholding of information, provision of false hope, complexity of vocabulary, pace of providing information, contradictory information, and physicians' body language.

**Conclusions**—The way bad news is discussed by physicians is extremely important to most parents. Parents want physicians to be accessible and to provide honest and complete information with a caring affect, using lay language, and at a pace in accordance with their ability to comprehend. Withholding prognostic information from parents often leads to false hopes and

feelings of anger, betrayal, and distrust. Future research is needed to investigate whether the way bad news is discussed influences psychological adjustment and family functioning among bereaved parents.

### Keywords

communication; critical care; physicians; parents; prognosis; death

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Things are just so unsettling that I think if you have an answer it's easier to deal with than not knowing.

—Bereaved parent, 2006

Communicating bad news to parents and families about a child's illness is a complex and difficult task. Bad news has been broadly defined as any information that is unanticipated and perceived as negative by the person receiving the news (1). For pediatric critical care physicians, communicating bad news often involves informing parents of a child's impending death (2). Many factors contribute to the difficulty encountered by physicians when discussing bad news (3, 4). Physicians may feel discomfort with the intense emotions displayed by parents in response to the news, such as sadness, anger, and blame. Physicians may feel guilty or inadequate regarding their inability to cure the child. When the child's illness is sudden, little opportunity may exist to establish relationships with parents before communicating bad news, thus making it hard to anticipate parents' informational and emotional needs. Prognostic uncertainty may lead to reluctance in providing information about outcomes. While bad news may be best provided in the forum of a family conference, such conferences are time-consuming and require advanced planning. Additionally, societal and family expectations that death is avoidable through advanced technology work against physicians' credibility when discussing the inevitability of a child's death, especially when trust has not been established.

Studies of physicians at all career levels, from incoming residents to attending staff, have described physicians' self-reported discomfort with communicating bad news, limited training, and need for more education in this area (5–10). Studies of parents and families of pediatric patients in both intensive and palliative care settings have described families' need for honest and complete information as well as their general dissatisfaction with the quality of physician communication near the time of their child's death (6, 11, 12). General guidelines for effective communication of bad news have been described (4, 13); however, such guidelines may not apply to all healthcare contexts (1). For example, in pediatric intensive care, the sharing of information about diagnosis, prognosis, treatment options, and complications is often compressed in time and may by necessity even occur in a single conversation.

We previously conducted a qualitative study regarding parents' perceptions of and experiences with physician-parent follow-up meetings after their child's death in the pediatric intensive care unit (PICU) (14). Most parents reported a desire to meet with the intensive care physician after their child's death in order to gain information and reassurance and to provide feedback about their PICU experience. Feedback that parents most often wanted to provide concerned physician-parent communication. Therefore, we undertook an in-depth analysis of the comments made by parents during our prior study regarding physician-parent communication at the end of their child's life. The objective of this study is to describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the PICU.

## MATERIALS AND METHODS

This study was conducted by the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) (15). The CPCCRN consists of six clinical centers and a data coordinating center. Details of the study methods are described elsewhere (14) and, briefly, here. The study was approved by the Institutional Review Board at each site. Informed consent was obtained from all participants.

### Participants

Parents (i.e., legal guardians) of children who died in the PICU of a CPCCRN clinical center 3–12 months before the start of the study were eligible to participate. Medical records of the deceased children were reviewed to obtain the parents' names, contact information, and primary language (16). Parents who did not speak English or Spanish were excluded. Parents were contacted sequentially beginning with those whose child died 12 months earlier. Initial contact occurred via a mailed letter that requested parents' participation in a research interview. To respect parents' privacy, the initial contact letter included a local telephone number or declination postcard that enabled parents to refuse further contact by the investigators. If further contact was not refused, a research coordinator telephoned parents to explain the details of the study, request research participation, and schedule interviews. Parents were categorized as a "refusal to participate" if the parent returned the declination postcard, told the research coordinator that he or she did not want to participate, or initially agreed to participate but failed to keep the interview appointment without prior cancellation and without returning the research coordinator's call. Parents were categorized as "unable to contact" if the initial letter was returned with no forwarding address or if the parent could not be reached by telephone. Hospital bereavement support services were available to all parents regardless of their participation in the research.

### Interviews

Semistructured audio recorded telephone interviews were conducted between January 19, 2006, and May 22, 2006, by research coordinators from the clinical center where the child died. Research coordinators were trained to conduct interviews using didactics, modeling, role-playing, and verification of skills. Each audio recording was monitored by one of two investigators (KM or SE) who provided feedback to the interviewer to ensure quality and consistency across sites. Parents were asked about their desire to meet with their child's intensive care physician after their child's death and about the preferred timing, location, participants, and topics for such a meeting. Throughout the interviews, parents offered many spontaneous comments about their experiences during the PICU admission in which their child died. Parents were encouraged to elaborate on their experiences by the use of verbal prompts and appropriate pauses. Parents were not specifically asked to respond to questions about physician-parent communication; all comments made by parents regarding communication were spontaneous. The interview question that prompted most spontaneous disclosures regarding physician-parent communication was as follows: "What are some of the things that you would want to talk about with the intensive care doctor?" Parents also provided demographic information.

### Qualitative Analysis

A secondary analysis of the interviews was performed for the current study (14). Two investigators, a pediatric intensive care physician (KM) and a behavioral scientist (SE) performed the analysis. The behavioral scientist is bilingual; the physician analyzed the Spanish interviews with the assistance of a translator. The two investigators listened to each interview independent of each other and wrote detailed notes on parents' responses to the interview questions. Parents' responses to select open-ended questions were transcribed

verbatim. The two investigators compared their notes for accuracy and generated a combined data set. Discrepancies between investigators were resolved by listening to the audio recording together and reaching consensus. The data set consisting of notes and transcripts was entered into a qualitative analysis software program (QSR N6) (17) to facilitate data management and analysis. The two investigators used an iterative process to identify physician-parent communication issues discussed by parents. This process included independent reading of the data set to identify (i.e., code) communication issues; comparison of identified codes between investigators; and rereading of the data set and discussion to refine codes and reach consensus on their meaning (18). Sample quotes were used to demonstrate each of the communication issues identified by parents.

### Quantitative Analysis

Demographic data were analyzed using a statistical software program (SPSS 13.0) (19). Categorical data are expressed as absolute counts and percentages and compared using Fisher's exact tests. Continuous data are expressed as medians and ranges and compared using independent Student's *t*-tests.

## RESULTS

Contact letters were sent to parents of 161 deceased children. Fifty-six parents of 48 children were interviewed, parents of 33 children refused to be interviewed, and parents of 79 could not be contacted by telephone. One parent agreed to be interviewed but the recording device malfunctioned and the interview was lost. Of the 56 parents interviewed, 37 (66%) were mothers, 17 (30%) were fathers, and 2 (4%) were other female legal guardians; 42 (75%) were white, 7 (13%) black, 2 (4%) Asian, 1 (2%) American Indian, and 4 (7%) of unknown race; 47 (84%) were non-Hispanic and 9 (16%) of Hispanic ethnicity; and median age was 36 yrs (range, 22–57 yrs). Of the 48 deceased children, 26 (54%) were boy, and median age at time of death was 1.6 yrs (0–20 yrs). Twenty-eight (59%) children died from a chronic condition; 16 (33%) from a sudden, unexpected illness; and 4 (8%) from a lethal congenital anomaly; 29 (60%) died after life support had been limited or withdrawn.

Forty (71%) of the parents interviewed wanted to provide feedback regarding the way information about their child's terminal illness and death was communicated by the physicians caring for their child in the PICU. The percentage of parents at each site providing feedback about physician-parent communication ranged from 50% to 100%. Parents who provided feedback about physician-parent communication were similar to those who did not in gender (female 26 of 40 vs. 13 of 16,  $p = .3$ ), race (white 29 of 40 vs. 13 of 16,  $p = .7$ ), ethnicity (Hispanic 6 of 40 vs. 3 of 16,  $p = .7$ ), and age ( $35.9 \pm 8.8$  yrs vs.  $36.8 \pm 9.6$  yrs,  $p = .8$ ). Communication issues identified by parents included the following: a) physician availability and attentiveness; b) honesty and comprehensiveness of information; c) affect with which information was provided; d) withholding of information; e) provision of false hope, f) complexity of vocabulary; g) pace of providing information; h) contradictory information; and i) physicians' body language. The communication issues and their descriptions are presented in order of decreasing frequency of mention by parents (Table 1). Quotations are italicized in the text for clarity and labeled with the parent's study number in brackets.

### Availability

The communication issue mentioned most often by parents was physician availability. Parents wanted physicians to be "*accessible*" [20] and "*attentive*" [38] to their informational needs. Parents expressed the desire to meet with physicians "*a multitude of times*" [56] and to "*get information along the way*" [2]. Parents reported that their comprehension was

enhanced when physicians took the time to sit with them during conversations. As one parent explained, *“Actually the doctors were pretty informative. They sat down and talked to us a lot”* [45].

Some parents perceived an unwillingness of physicians to discuss their child’s care unless specific requests were made. One parent said, *“And they see you there and nobody come and talk to you until you request to talk to them”* [30]. The lack of attention by physicians often precipitated resentment and anger. The same parent explained, *“I was upset and I wanted to talk with the doctor. And he ignored me, ignored me, ignored me until I got the social worker”* [30]. Even when physicians were physically present, parents often felt excluded from conversations. One parent described her experience as follows,

*“Often doctors would come in and they would communicate with each other in our presence. ...I often felt very uncomfortable when they were communicating in a quiet way about procedures they were planning or wanted to implement and some of those procedures were not really well explained, especially not privately outside the room. ...Many times they came in during the day and there were things done. And then they walked out, kind of ignored us a little bit”* [16].

### Honesty and Comprehensiveness

Parents wanted complete information presented in a candid, straightforward manner. Parents expressed appreciation for physicians who *“explained everything”* [19, 35, 37, 40, 44, 53] were *“straight up forward”* [50] and *“honest”* [3]. Providing complete and candid information helped parents to trust the physicians caring for their child. As one parent said, *“I understood what was going on. I knew what she was going through. I really had a strong trust for the doctors on that team ... they explained everything I needed to know”* [44]. Communicating an honest prognosis helped parents to make decisions in their child’s best interest. One parent explained, *“I told them, you just let me know when it’s that time. You guys know if there’s nothing else you can do. I just don’t want her to bear the pain. If she’s suffering, I would just rather make the decision to let her go. And you know, they did”* [43].

Knowledge of the physician’s formulated prognosis also allowed parents to prepare themselves to some degree for their child’s death. One parent described, *“They explained everything to us, and that was really good. They told us exactly what was coming and what to expect, and that was really helpful in preparing ourselves psychologically”* [35].

### Affect

Parents emphasized that complete and candid information must be expressed with a caring emotional tone. Parents described a caring tone as *“compassionate”* [9, 19, 37], *“kind”* [16, 20], *“consoling”* [29], and *“supportive”* [50]. One parent described the physicians’ warm display of emotion at the time of her child’s death:

*“I remember after we had our quiet time with S- after she passed, the doctors were all outside the door. And they were very kind and some of the young doctors were in tears. And it was very moving to see all these emotions because they had watched her fight for days”* [16].

In contrast, some parents described the pain encountered when honest information was expressed with a callous emotional tone. Parents described a callous tone as *“cold”* [20] and causing the parent to *“feel more like a number”* [35]. One parent described the insensitive way that a physician informed him of his child’s fatal diagnosis,

*“He came across very cold almost like he was trying to impress the residents that he was with. That was a horrible incident especially for my wife, well for me too.”*

*Just the way he presented the information in such a matter-of-fact tone. Without any real consideration for what he was really talking about. It's like he did not have a concept that he was talking about a human being" [20].*

### **Withholding Information and Providing False Hope**

Parents often felt that physicians withheld information, especially concerning their child's prognosis. Parents described a sense that physicians were "*beating around the bush*" [45]. Parents also described that withholding their child's prognosis kept them "*in the blind*" [8] and made them feel "*led on*" [45] when they "*deserved to know*" [45] and "*wished someone would have told*" [55]. Some parents considered the possibility that physicians intentionally withheld prognostic information as a way of protecting parents' optimism and reducing their suffering. As one parent explained,

*"I would like to know why, when there were so many physical signs that led us to believe that it was a very, very serious situation, why didn't they say that? One time, during a conference, I asked the doctor directly if it was serious, and that was the only time he said 'yes.' ... And I realize now when I look back that the doctors realized certain things where we had still this glimmer of hope. But they had seen and had so much experience. They do know and understand the signs and I don't know if they really wanted to tell us about it, and take that glimmer away. I truly do not know" [16].*

Regarding communication of an overly optimistic prognosis, another parent said, "*I wonder why he told me that, maybe it's because he was just trying to help me out*" [7].

Other parents felt a sense of betrayal when prognostic information was withheld. One parent said, "*I don't think it's fair to family members. I think the family members need to know. If they say this kid's not gonna make it, or whatever, they need to tell the family that. The family deserves to know that rather than being led on. It's easier to prepare. We went for a long time thinking, it's possible he's gonna get better, until like a week prior to his passing. ... When did you realize my baby was gonna pass? Why didn't you tell me then?" [45].*

For some parents, the false hope created by withholding prognostic information led to anger and a lack of trust. One parent explained her emotional reaction, "*I did not realize, and nobody had told me that my son was dead on arrival at the hospital. So I was in the dark on the truth of the matter. So I had a lot of anger*" [8]. Another parent described her challenge to her child's physician, "*Doctor, you might have children just like anybody else. Would you want somebody to give you false hope or tell you, 'OK, your child is gonna be fine,' and you know she's not?" [24].*

### **Vocabulary and Pace**

Several parents commented on the complexity of language used by physicians when communicating about their child's condition. Parents wanted information provided in "*layman's terms*" [20, 24] or "*English terms*" [14] rather than "*doctor talk*" [32]. One parent described her inability to understand the treatment that was planned for her child,

*"I kept asking, 'What is this? What are you telling me you are going to do for her?' They gave me answers in medical terminology. This is what I kept getting, and I'm like, 'Could you explain that?' No one really explained it to my satisfaction because I did not and still do not understand. And I would like to understand it in layman's terms. It was what you were gonna do for her" [24].*

Additionally, parents wanted information provided at a rate in accordance with their ability to comprehend. Parents advised that when giving bad news, physicians might need to let

parents “*chew on it for a little while*” [8] and allow “*time to set in*” [8] because “*you can only take so much information at once*” [13]. When information was provided too quickly, some parents perceived the communication as callous. One parent said, “*And I remember when he was telling us our son was brain dead and in the same sentence he’s asking us to donate his organs*” [8]. Excessive use of medical terms and too rapid rate of communication caused some parents to feel overwhelmed. One parent explained, “*There got to a point in our hospital stay when a certain doctor came in and I couldn’t tell you a word he said. I know he was there, I couldn’t tell you a word he said*” [49]. Parents’ desire for paced information may need to be balanced with their need for full disclosure of information about their child.

### Contradictory Information

Some parents expressed stress and frustration with receiving contradictory information from different physicians caring for their child. One parent described the conflicting prognoses provided by two intensive care physicians rotating on and off service with the following words,

*“He took care of our son Sunday through Thursday and kept telling us that our son would come off his respirator just fine. On Thursday when he left we got a new doctor who straight up told us, ‘There’s no way, he’s not coming off the ventilator ever.’ And we made a decision to let our son go that we never would have made if this other doctor hadn’t stepped in. We’d have taken our son off the respirator expecting him to breathe on his own and he would have died just like he did when we knew that that was gonna happen. We would have gone through that alone without our family there”* [2].

Another parent advised, “*I think the doctors need to talk to one another. I think that is a very important thing to do*” [25].

### Body Language

In addition to the content and style of physicians’ speech, parents commented on physicians’ nonverbal behaviors when giving bad news. Physicians’ body language led some parents to suspect the physicians were “*guilty*” [15] or had “*done something*” [15].

One parent described the physician’s lack of eye contact, “*I wanted to ask the doctor, after he came out and talked to me after her procedure, why didn’t he look me in my face, he kept his head down to the ground talking to me. Then when he lift his head up he turned the other way but he never looked me in my eyes. What went wrong?*” [22].

## DISCUSSION

The majority of parents interviewed wanted to provide feedback on the quality of physician-parent interactions near the time of their child’s death in the PICU. Our findings show that parents want physicians to be accessible and to provide honest and complete information with a caring tone, using lay language, and at a pace in accordance with their ability to comprehend. Ignoring parents or withholding prognostic information from them may lead to false hope and a sense of anger, betrayal, and distrust among parents. A central tenet of physician-parent communication is that parents need information to make treatment decisions for their child. Parents of critically ill children are often faced with serious decisions, including whether life support for their child should be initiated, continued, limited, or withdrawn (20, 21). Effective physician-parent communication is necessary to impart information, improve understanding, reduce conflicts, and implement a management plan that is in the best interest of the child. Understanding parents’ perspectives of their

communication experiences can help physicians communicate with greater sensitivity and confidence and reduce physicians' discomfort with and avoidance of difficult conversations. Our findings can also be used to tailor existing guidelines for the effective communication of bad news in the PICU setting.

Published communication guidelines assume that the interactions between physicians, patients, and families occur in a linear fashion with information regarding diagnosis, prognosis, treatment, and complications discussed sequentially (1, 4, 13). Guidelines also suggest that each interaction is composed of three chronologic phases. First, physicians must prepare for the interaction in which bad news will be given. Strategies for preparing include ensuring adequate time and a private space and eliciting from the patient or family members their current knowledge of the patient's condition. Second, physicians must disclose the information. Strategies for adequate disclosure include using lay language, providing discrete pieces of information, allowing the patient or family members to set the pace, and probing to assess their comprehension. Third, physicians must allow time for and respond to the patient or family members' emotions, answer questions, summarize the information provided, and identify what will happen next.

While these guidelines provide a useful framework for discussing bad news with patients and families, they need to be adapted to the PICU setting. The assumption that bad news unfolds in a lengthy chronologic process may not apply in the PICU, where illnesses are life-threatening and events occur rapidly. Despite this added complexity, our findings suggest that parents want full disclosure of information at a pace in accordance with their ability to comprehend. This seeming contradiction might best be resolved by keeping parents informed through frequent, short conversations with the physician or their designee. For example, while cardiopulmonary resuscitation is being performed on a child, physicians might break away to meet family members, send a designee to provide frequent updates and emotional support, or allow parents to be present at the bedside. These approaches may prevent the feelings of isolation, abandonment, and distrust that were reported by parents in this study. Additionally, frequent updates may prevent physicians from having to provide a complex cluster of bad news all at once. Often, news of a child's death must be coupled with a request for organ donation or autopsy. In such cases, our findings suggest that physicians should provide empathic support and at least a few moments for parents to grasp the bad news before such requests are made.

Parents in this study stressed that they wanted an honest and comprehensive disclosure of the physician's formulated prognosis and wanted it provided in a caring tone. Much research exists on formulating and disclosing prognoses at the end of life, especially in the field of oncology (1, 22–28). Research suggests that while formulating a prognosis can be difficult, equally difficult is communicating that prognosis to the patient and family. A recent meta-analysis concluded that physicians consistently overestimate survival of adult cancer patients (24). In another study, physicians reported that they would not communicate any survival estimate to their adult cancer patients or would communicate an estimate different from the one they formulated almost two thirds of the time (27). In pediatric oncology, Wolfe et al. (28) reported a >3-month gap between the time the physician recognized the child had no realistic chance of cure and the time the parents recognized the same. The authors suggested that the reason for this gap may be two-fold; physicians may not communicate clearly, and parents may not fully acknowledge their child's prognosis even when told. In pediatric critical care, similar physician and parent factors are likely to underlie parents' awareness and understanding of their child's expected outcomes. Nevertheless, parents' understanding of prognosis is extremely important to facilitate informed treatment decisions for their child.



Foundational to this study was the researchers' desire to report the parents' own versions of their communication experiences and to accept them as valid in their own right. The findings represent the parents' versions of reality based on their perceptions and lived experiences rather than absolute truths judged by external means. Undoubtedly, the physicians involved in these interactions have their own views, as do the researchers generating this report and its readers. As well-meaning physicians, it may be difficult for us to accept that the parents participating in this study were "telling the truth" about the negative aspects of their interactions with physicians. However, by acknowledging that parents' perceptions may be different from our own, we can begin to discover ways to modify our behaviors in order to communicate with parents more effectively. Caution must be taken with this approach, however, because parents' perceptions and desires expressed after their child's death, as in this study, may or may not relate to their actual needs at the time of the death. Parents are often angry after their child's death; anger and blame directed at others may be a form of unresolved grief.

Similarly, parents' desire for prognostic information should not be construed to mean that physicians should make hasty judgments about a child's expected outcome. In the scenario described previously, in which a parent perceived that two physicians rotating on and off service provided her with different prognoses and recommendations regarding withdrawal of life support for her child, it is unknown which physicians' assessment was most correct. What can be learned from the scenario is that the breakdown in communication between physicians and the way that information was subsequently provided to the parent eroded her sense of confidence that her child had received optimal care. Sixty percent of the children who died in this study had life support limited or withdrawn. Presumably, the physicians caring for these children had in-depth conversations with parents about their child's expected duration and quality of life before such decisions were made.

Limitations of this study include the large number of parents who could not be contacted and the predominance of mothers among participants. Parents were not specifically asked to provide feedback on communication with the PICU physician. Reliance on parents' spontaneous disclosures rather than solicited responses to explicit interview questions may bias the study findings because the views of parents who did not volunteer such disclosures are not known. The percentage of parents commenting on communication issues varied by site; this may reflect differences in interviewer style and degree of probing parents' responses. This study includes only bereaved parents; it is plausible that the views of parents who are not bereaved may be different. Future research will need to include in-depth interviews on this topic to gain more insights from parents followed by large-scale surveys to assess the extent to which the results of this study are generalizable. This study also does not address the important issue of communicating bad news to pediatric patients or their siblings. Strengths of this study include the multicenter design, racial and ethnic diversity of participants, and the open-ended interview format that allowed the spontaneous discussion of communication issues.

## CONCLUSION

Greater understanding of parents' perceptions of their communication experiences will help critical care physicians to communicate bad news more effectively. Because bad news is always a subjective appraisal by the person receiving the news, the findings of this study should be considered in all physician-parent interactions in which information is discussed. Recommendations to improve physician-parent communication in the PICU include frequent contacts to update parents as information becomes available, increased attention to conversational tone and affect, honest disclosure of formulated prognoses, avoidance of medical jargon, and encouragement of parental questions. Future research should investigate

whether the way bad news is discussed influences parents' decision making regarding their child's treatment plans, as well as parents' short-and long-term psychological adjustment and family functioning after their child's death.

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**Table 1**

## Communication issues discussed by parents

<b>Communication issue<sup>a</sup></b>	<b>Description</b>
Availability	Physician accessibility and attentiveness
Honesty and comprehensiveness	Candid, straightforward information that is complete and without major omissions
Affect	Emotional tone of the communication
Caring	Kind, compassionate
Callous	Insensitive, cold
Withholding information	Omitting information
False hope	Overly optimistic information in order to maintain a positive outlook
Vocabulary	Complexity of language
Lay language	Use of nonmedical terms
Medical jargon	Excessive use of medical terms
Pace	Rate of providing information
Appropriate	Rate in accordance with parent's ability to comprehend
Excessive	Rate exceeding parent's ability to comprehend
Contradictory information	Conflicting information from two or more physicians
Body language	Eye contact and other nonverbal behaviors

<sup>a</sup>Communication issues are listed in order of decreasing frequency of mention by parents.