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Accounting for medical communication: Parents' perceptions of communicative roles and responsibilities in the pediatric intensive care unit

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Abstract

Through discourse analysis of transcribed interviews conducted over the phone with parents whose child died in the Pediatric Intensive Care Unit (PICU) (n = 51), this study uncovers parents' perceptions of clinicians' and their own communicative roles and responsibilities in the context of team-based care. We examine parents' descriptions and narratives of communicative experiences they had with PICU clinicians, focusing on how parents use accounts to evaluate the communicative behaviors they report (n = 47). Findings indicate that parental perceptions of communicative responsibilities are more nuanced than assumed in previous research: Parents identified their own responsibilities as participating as part of the team of care, gathering information, interacting with appropriate affect, and working to understand complex and uncertain medical information. Complementarily, parents identified clinician responsibilities as communicating professionally, providing medical information clearly, managing parents' hope responsibly, and communicating with appropriate affect. Through the accounts they provide, parents evaluate both parental and clinician role-responsibilities as fulfilled and unfulfilled. Clinicians' management of prognostic uncertainty and parents' struggles to understand that uncertainty emerged as key, complementary themes with practical implications for incorporating

parents into the PICU care team. The study also highlights insights retrospective interview data bring to the examination of medical communication.

Keywords

doctor-patient interaction; team communication; roles and responsibilities; parents' perceptions; end-of-life; bereavement; discourse analysis

'I was part of - I really was part of the team.' (44) 'The family's down there struggling and trying and working just as hard as anybody else.' (14)

1. Introduction

A robust body of research uses discourse analysis to investigate interaction within physician-patient encounters, most often from outpatient care (Atkinson 1995; Iedema 2005). Inpatient care, however, particularly acute care as in intensive care units, is often delivered within a multidisciplinary team-based model, which distributes care roles and related responsibilities across multiple members. For example, consider how team-based care is described for a PICU [Pediatric Intensive Care Unit]:

A team of 12 pediatric intensivists (pediatric intensive care specialists) lead a team of specialized pediatric critical care nurses, respiratory therapists, social workers, case managers, pharmacists, and child life specialists to provide multidisciplinary care while working side-by-side with families and providers. (Children's National Medical Center 2008)

The team described here consists of clinical personnel with specific roles and responsibilities, working in a vaguely specified 'side-by-side' relationship with family members of a pediatric patient; families' responsibilities are unspecified. However, it has been noted that in a traditional team-based model of PICU care, both clinicians and families have communication-related responsibilities, especially in the context of end-of-life care. The medical team has the responsibility for communication with families to keep them apprised of their child's course of care and to practice shared decision-making (IOM [Institute of Medicine] 2003, Ch. 4). Family members' chief responsibilities are to communicate information about their child (Strong and Davis 1977) as well as information about their goals and values in order to guide decision-making.

In addition to information, clinicians also provide - and families receive - support, which is often characterized as 'compassionate care'. Compassionate care is delivered through communication: the US Institute of Medicine report, *When Children Die*, emphasizes that 'families should have access to accurate information and excellent supportive care that offers physical, emotional, and spiritual comfort from the time of diagnosis through death and into bereavement' (IOM 2003: 20). This goal, however, is often unmet, as shown by the report's description of a continuum of end-of-life care and communication in PICUs:

[T]hese professionals [on the team] can at best help all involved to feel that they did everything to help, and that preventable suffering was indeed prevented. Other times, however, families' encounters with the health care system will leave them with painful memories of their child's unnecessary suffering, bitter recollections of careless and wounding words, and lifelong regrets about their own choices. In between these poles of medicine, families will often experience both excellent care and incompetence, attentiveness and neglect, and inconsistent communication of essential information. (IOM 2003: 104)

In this article, we examine parents' perceptions of good and poor medical communication with the team who cared for their child prior to his or her death in the PICU. Based on a discourse analysis of interview data from bereaved parents, we argue that parents hold complex perceptions of their roles and responsibilities in the course of their child's care: rather than a side-by-side relationship with no responsibilities beyond providing information, they envision their role as 'part of the team' (44), with specific responsibilities for good medical communication. The discourse analysis also revealed parents' nuanced perceptions of clinicians' communication roles and responsibilities.

In what follows, we first present the theoretical framework, background, and methods of our study. We then present the findings of our analysis of parents' accounts for good and poor medical communication, and discuss these in terms of a more specific and complex role-responsibility framework than is usually assumed for communication between medical teams and families.

2. Theoretical framework

Our research emerges from a body of work on medical team communication focused primarily on communication within and across medical teams. Iedema (2005) calls the hospital a 'crowded clinical space', with intra- and inter-team-based communication taking place in formal and informal contexts, from team rounds to hallway talk (see also Atkinson, 1995).

Relatively few studies have explored team communication with patients and families, although medical anthropologists have described such communication. Anspach's (1993) ethnography of team-based care and communication in a neonatal ICU showed that medical teams made crucial clinical decisions and then presented them for parental assent, rather than engaging in shared decision-making. Cassell's (2005) ethnography of surgical ICUs similarly showed that end-of-life communication with families was initiated only after the attending physician determined that the withdrawal of life support was clinically responsible and ethically appropriate; Barton (2005, 2007) developed a discourse analysis of the jointly-constructed ethics of these end-of-life discussions. Maynard (2003) described family conferences at a clinic evaluating children for developmental disabilities, arguing that interaction was directed at moving parents toward the medical view of their child as learning disabled or cognitively impaired. Overall, these studies have revealed medical team members assuming primary responsibility for both communication and care, with parents providing information medical team members need to do so.

In this study, we adopt a role-responsibility framework for medical care and communication presented by Sarangi (in press). In this framework, roles are related to responsibilities in terms of sets of expectations for clinicians and lay patients/families (Hall *et al.* 2006). In medicine, these role-responsibility expectations were first described as a complementary structure by Parsons (1951). Patients occupy what Parsons calls the *sick role*; to do so legitimately, they must strive to get well, in part by cooperating with clinicians. As mentioned, traditionally parents' communicative responsibility is simply to provide clinicians with information.

In developing a role-responsibility framework for medical communication during the death of a child in an ICU, we examine how parents account for communicative behaviors they report as having occurred during their child's dying. We follow the social constructionist approach to accounts, as presented by Buttny (1993: 167), which starts from the position that 'human actions, social relations and states-of-affairs are not invariably self-explanatory, or may be seen by others as problematic, so actors may need to tell their version of events - to account for them'. In other words, people routinely use accounts to explain, justify, or

excuse their own (and sometimes others') actions. Our analysis of parental accounts uncovers parents' perceptions of what constitutes good and poor medical communication and their understanding of medical communication role-responsibilities.

Parents of children who died in the PICU of a hospital affiliated with the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) 3 to 12 months prior to the start of the study were eligible to participate. If parents agreed to participate, trained interviewers conducted a semi-structured audio-recorded telephone interview.¹ Parents were encouraged to elaborate on their experiences by the use of verbal prompts and appropriate pauses. Throughout the interviews, parents offered many spontaneous comments about their experiences during the PICU admission in which their child died, which became the data for our study.

We note at the outset that retrospective interview data is a contested source for a discourse analysis, in that interviews potentially create a context in which interviewees might feel compelled to provide socially appropriate answers (Cameron 2001). Also, parents who consented to an interview may not be representative of bereaved parents. Further, we note that the interview guidelines for the original study encouraged interviewers to prompt parents for elaborations of their answers. What effects these interview aspects may have had on parents is not easily known, but they stand as caveats to the representativeness and generalizability of our analysis and discussion. Despite possible shortcomings, the interview data provide a number of parents' accounts for medical communication during their child's course of care in the PICU, data that arguably reflect their perceptions on that communication.

3. Method

The present study analyzed data from 51 interviews with bereaved parents. Working primarily from written transcripts, CG and EB analyzed parents' accounts for medical communication behaviors, using QSR NVivo software to aid in data management. Drafts of the analysis were then sent to the larger research team for member verification (KM and SE), as suggested by Roberts and Sarangi (2005). KM also presented the analysis to members of the CPCCRN for additional feedback.

3.1. Data collection

The data for the discourse analysis consisted of parents' narratives and descriptions of medical communication. Narratives include stretches of discourse that recount past events and include at least one 'temporal juncture' (Labov 1972); descriptions summarize past events without specific temporal juncture. We identified these narratives and descriptions by parents' use of reported speech (Coulmas 1986) within talk about a past medical encounter. We define reported speech broadly as the representation of previous communication in constructed dialogue (Tannen 2007).

¹This work was supported by cooperative agreements from the National Institute of Child Health and Human Development and the Department of Health and Human Services. Full details of this study, including a description of the ethical protocols for working with bereaved parents, were provided to the reviewers of this article and are published in Meert *et al.* (2007) and Meert *et al.* (2008). The original study found that the majority of parents ($n = 33/56$, 59%) would like to have a family conference regarding their child's death, partly to review information about the course of their child's care and death in the PICU and gain reassurance that their child had received the best care possible, but also to provide feedback about the experience (Meert *et al.* 2007). In a second study, Meert *et al.* (2008) conducted a qualitative content analysis of the data to describe parents' perspectives on clinician-parent communication during their child's time in the PICU. This study found that a significant majority of parents ($n = 40/56$, 71%) wanted to provide feedback on communication as part of a bereavement conference and identified seven communicative issues of interest to parents: the top three were the physicians' availability and attentiveness to parents' informational needs, honesty and comprehensiveness of the information provided, and affect of the clinician.

Reported speech is traditionally divided into two types: direct, where a speaker purportedly repeats a previous utterance word-for-word (quotation), and indirect, where the speaker reconstructs an utterance in his or her own words. Our data featured both types. For example, one parent, in remarking that some physicians were rude, used direct reported speech to provide an example: Somebody [one of the clinicians] would be like, ‘Well, I can’t answer that’ (3). Another used indirect reported speech to represent something a physician said: I mean he told me that [Kevin] was gonna pull through this (7). Speech can also be ‘reported’ in a more general way; parents did this in our data when they described extended courses of communication. For example, one parent described the communication at an autopsy meeting: She [the physician] explained in at least you know pretty decent detail why they did some of the things they did (32).

To identify narratives and descriptions of medical communication, we looked for reported speech, using a broad definition to include direct and indirect reporting of specific utterances as well as retrospective talk about larger communicative activities such as explaining, telling, giving information, answering, describing, and being informative in communicative settings such as meetings, conferences, and bedside or hallway communication.

3.2. Data analysis

These narratives and descriptions of medical communication were heavily evaluated (Labov 1972), both negatively and positively. Parents’ accounts for the medical communication they describe proved the most intriguing evaluative feature. As noted above, accounts serve many interactional functions, among them managing impressions and reinforcing social norms (Buttny 1993). In our data, parents used accounts to evaluate, both positively and negatively, specific aspects of communicative behavior - both of clinicians and of themselves. These accounts provide a means of uncovering parents’ perceptions of the distribution of communicative roles and responsibilities in the PICU.

The coding procedure was as follows: we first identified narratives and descriptions of medical communication by looking for reported speech in talk about prior medical encounters, finding one or more present in 44/51 (86%) interviews. We found a total of 129 narratives or descriptions of medical communication, each of which included one or more instances of reported speech. Within these narratives and descriptions, parents produced an account for communicative behavior about one-third of the time ($n = 47/129$, 36%).

The following excerpts illustrate descriptions of medical communication without and with an account for communicative behavior (italicized):²

²We use the following transcription conventions to present the examples:

incomplete utterance	–	we’re – we’re
intonation	.	falling intonation at utterance end
	?	rising intonation in question
	,	continuing intonation within utterance
direct reported speech	‘ ’	‘why are you doing that,’
deleted material	...	
edited material	[]	[Kevin]
accounts	<i>italicized</i>	<i>just because we’re – we’re older parents</i>

Interviewer back channels and other short utterances were eliminated in the examples.

(1a) I mean basically we talked to the doctor and everything while [Kurt] was in there and you know they pretty much - any questions that they had - we had - they explained it very well while we were actually in there. (51)

(1b) We were that way the whole time he was in the hospital, 'why are you doing that, what are you doing, what - what will that help, what side effects will there be.' We were probably you know more inquisitive than maybe the average parent and part of that just because we're - we're older parents. And, an uh, I mean I'm - I'll be 37 this year and my wife will be 31 and this was our first child and so we probably have a higher education level and a little more experience in life than a lot of the parents you all see there ... (2)

Although the description of clinicians answering questions in (1a) is positively evaluated (*very well*), it is not evaluated with an account. In the description of parents asking questions in (1b), the parent does provide an account (italicized) that explains the communicative behavior of asking many questions: these parents are *more inquisitive* than the average parent seen in the PICU due to their age, education level, and life experience.

We argue below that these accounts identified parents' and clinicians' communicative behavior as responsible or not responsible in a complex role-responsibility framework. We analyzed these accounts in terms of role - whether they evaluated the communicative behavior of self (parents) or other (clinicians): (1a), for example, evaluated clinicians (*the doctor, they*), while (1b) evaluated the parents themselves (*we*). We also coded what kinds of responsibility the accounts assume or assign: (1b) was coded as gathering information. We then coded whether that responsibility was represented as fulfilled or unfulfilled: (1b) was coded as fulfilled. The matrix of the coding is presented in Table 1, with example (1b) illustrated.

Each account occupies one of the four cells of Table 1. The frequencies from coding and the specific responsibilities named in the accounts are outlined in the next section.

4. Findings

We present our findings in three subsections: overall findings, parents using accounts to identify their own responsibilities in medical communication, and parents using accounts to indicate clinicians' responsibilities.

4.1. Overall findings

Within narratives and descriptions of medical communication, we found 47 accounts for communicative behaviors. As shown in Table 2, 22 (47%) accounts were parents evaluating their own communicative behavior; the remaining 25 (53%) evaluated the communicative behavior of clinicians, primarily physicians. Interestingly, parents accounted for their own responsibilities for medical communication almost as frequently as clinicians' (47% vs. 53%), indicating that they held themselves responsible for aspects of medical communication.

Also interesting to note is that parents saw communicative responsibilities, both their own and the clinicians', as fulfilled ($n = 16$, 34%) less often than they saw them as unfulfilled ($n = 31$, 66%). This may reflect the general association between accounts and matters that require explanations (Buttny 1993), but it also may reflect parents' perceptions that PICU communication needs improvement, perhaps underlying their reports in the larger study that they wished to attend a bereavement conference in part because they wanted to provide feedback to the PICU team (Meert *et al.* 2007, 2008).

Across the 22 accounts for parental communication, we found that parents described their specific communicative responsibilities in four categories:

- a. participating in the team ($n = 2$)
- b. gathering information by asking questions ($n = 7$)
- c. understanding the complexity and uncertainty of medical communication ($n = 10$)
- d. communicating with appropriate affect ($n = 3$)

Across the 25 accounts for clinicians' communication, parents described communicative responsibilities for clinicians in four related categories:

- a. communicating professionally in their roles as clinicians ($n = 6$)
- b. communicating medical information clearly ($n = 4$)
- c. managing parents' hope without creating false hope ($n = 9$)
- d. communicating with appropriate affect ($n = 6$)

These categories will be presented with examples below.

4.2. Parental roles and responsibilities

4.2.1 Participating in the team—Two parents in two accounts explicitly identified their role as a member of the team caring for their child in the PICU. Excerpt 2 shows one parent's account for the good medical communication that took place over the course of her daughter's care in the PICU:

(2) P: I was very much in contact with them [the doctors]. We - you know [were] very up on everything that was going on and I was part of - I really was part of the team. Which I felt was extremely helpful for me as a parent to really feel like I was participating in their team. I understood what was going on, I knew what she [the child] was going through ... (44)

For this parent, being *very much in contact* and *very up on everything* was related to her role as *part of the team*, allowing her to fulfill her responsibility of participating in what was going on, not only clinically (*up on everything that was going on*) but also empathetically (*what she was going through*).

A second parent gave an account for the poor communication that took place during his son's time in the PICU in which clinicians *shut the family out*, thereby preventing them from fulfilling the parents' responsibility to participate in the team, despite the fact that extended family members were down there struggling and trying and working just as hard as anybody else (14).

4.2.2. Gathering information by asking questions—An important responsibility parents held for themselves was to gather information from clinicians - to ask questions and to learn as much as possible about their child's course of care, including his/her dying. Five parents, in seven accounts, highlighted this responsibility, with four accounts describing parents' fulfilling their responsibility to ask questions, and three explaining their failure to do so.

Accounts for parental success in fulfilling this responsibility pointed to something specific about the parents' background ($n = 2$) or to their more general characteristics ($n = 2$). For instance, in (1b) above, a father accounts for the questioning he and his wife directed toward clinicians by explaining their background as older, educated, and experienced parents.

Similarly, a mother accounts for her information-seeking behavior by explaining her professional background as a nurse (34). In a more general example, a parent described asking questions of multiple members of the medical team caring for her child:

(3) P: ... because anytime I had a question I would ask anybody until I got to the right person to have the question answered. (54)

This mother accounts for her communicative behavior through her personal quality of persistence.

Parents who were unable to fulfill their responsibilities as information-seekers ($n = 3$) attributed their failure to the great stress and distress they experienced during the period of their child's treatment and death:

(4) P: I didn't know what else - what else to address. We were going through a really tough time here. I didn't - I was talked out about it and was interviewed so many times. I didn't want to talk to anyone else about it. (55)

Examples like this one illustrate the classic use and function of an account within a description or narrative of problematic conduct (Buttny 1993): the parents identify a responsibility they did not fulfill, and give an explanation/justification.

4.2.3 Understanding the complexity and uncertainty of medical

communication—Although parents see their responsibility to ask questions of medical team members as important, they did not stop at this responsibility alone. In the PICU, and especially in a death, a child's course of care can be complex and uncertain, which may result in insufficient or uncertain information being provided by clinicians. Eight parents constructed ten accounts for their own comprehension (or lack thereof) of the uncertainty and complexity inherent in medical communication. These accounts suggest that a primary parental role-responsibility is to (try to) understand medical communication.

Three parents indicated that they fulfilled this responsibility in four accounts. In (5), a parent provides an account for successful understanding as related to personal qualities:

(5) P: They answered you know everything that you know everything that I needed to know that I knew that they could answer. I'm a fairly logical person. And I understand that they don't necessarily have all the answers and a lot of times the answers that people do have are not the answers that I really want. (32)

In contrast to this parent who is rational and understands that physicians *don't necessarily have all the answers*, five parents in six accounts indicated that they failed to understand complex or uncertain information. For instance, one parent accounts for her lack of understanding by describing her emotional state during her child's course of care:

(6) P: ... when we had a little conference ... But, you know, when we watched the changes in her [the child's] body, um, and um, maybe we're just also very distraught. You know? Sometimes you can't even hear what's going on, either. I'm not quite sure how clear you are then, you know? (16)

This mother's account is similar to how parents explained their failure to fulfill the parental role of information-gatherers due to stress and distress (Excerpt 4).

Parents holding themselves responsible for understanding the complexity and uncertainty of medical communication is a more specific and nuanced responsibility than simply gathering information. Yet this was the responsibility most often identified by parents ($n = 10$), and the one that they reported most often as a responsibility they did not fulfill ($n = 6$).

4.2.4. Communicating with appropriate affect—Information is one important facet of interaction; affect, which encompasses ‘feelings, moods, dispositions, and attitudes’ (Ochs and Schieffelin 1989: 7), is another. In talking about their experiences with medical communication in the PICU, two parents in three accounts described volatile exchanges in which they exhibited inappropriate affect, and offered accounts for their behavior in terms of their stress and distress. For example, a mother who describes yelling at a physician explains in an account:

(7) P: I'm very sorry for the way I yelled at him. ... But yes I am sorry for the way I reacted but it was - I was in shock. (8)

In a similar but less volatile example, a father accounts for his rude behavior to a nurse by explaining that he was *a little upset* because she did not keep him informed about his child's situation.

4.2.5. Summary—As shown in Table 3, parents identified specific communicative responsibilities and accounted for their ability to fulfill or not fulfill them.

Parents assign multiple communicative responsibilities to their role, but they do not seem to feel that they were able to fulfill them well (13/22, 59%). In a moving finding, one kind of account for communicative behavior crossed all categories: in their explanations, parents took the blame for being unable to satisfy their role-responsibilities in medical communication because of the grievous distress of losing their child in the PICU.

4.3. Professional roles and responsibilities

4.3.1. Communicating professionally in their roles as clinicians—Parents did not explicitly describe clinicians communicating in terms of roles as members of the PICU team; however, in their accounts they did point to clinicians' responsibility to communicate professionally. Five parents in six accounts described communicative behavior they identified as unprofessional. For example, one parent described a specific statement that she criticized in her account:

(8) P: ... [W]hy would the doctor tell me that if - if [Jamal] - if most parents - if most - if most - if most parents see their kids sink like that they'd have gone ahead and let them die. That's not professional for a doctor to say to a parent. (15)

In another example, a parent told a narrative of a request for organ donation and criticized the clinician's professionalism:

(9) P: I remember when he was telling us my son was brain dead in the same sentence he was asking us to donate his organs. *And I feel that was inappropriate at the time.* (8)

Both of these excerpts report memorable single utterances of clinicians' stepping out of their professional roles - moments of medical communication that may lead to 'bitter recollections of careless and wounding words' (IOM 2003: 104).

4.3.2. Communicating medical information clearly—As shown above, parents described their responsibility to gather information; in a related finding two parents in four accounts hold clinicians responsible for communicating medical information clearly. In two descriptions of her son's course of treatment and subsequent autopsy meeting, one mother accounts for clinicians' fulfilling this responsibility:

(10) P: I think that while we were there we had everything answered that we asked as best that they could really answer us. Um, I mean they quite literally did everything they possibly could to figure out what was wrong with our son. (34)

Like the parent in excerpt (1b), this mother indicates that she asked many questions and relates the communication to the clinicians' efforts in the care of her child (they quite literally did everything they possibly could to figure out what was wrong with our son) in their fulfillment of the responsibility to communicate clearly (*as best they could*).

In contrast, in one father's two accounts of the communication during his son's treatment, he points to clinicians' not communicating medical information clearly:

(11) P: That basically they overwhelm you, you know, with so many numbers and how many monitors are doing that and all that - that, you know. *And I think they just - I think they forget that you're not a doctor. You know, and that you really don't have any clue what they're talking about.* (14)

This father offers a reason for the poor medical communication in his account - physicians can forget that parents are not doctors - but when clinicians do not fulfill this responsibility, the result is that parents *don't have any clue what they're talking about*, not the goal for medical communication from either the parents' or the clinicians' perspectives.

4.3.3. Managing parents' hope without creating false hope—As shown above, parents held themselves responsible not only for gathering but also for understanding complex and uncertain medical information. A related responsibility parents assigned to clinicians, however, was management of the relation between complex and uncertain medical information and prognosis; put another way, parents held physicians responsible for managing hope, specifically by not creating false hope. Five parents offered eight accounts for managing hope.

Two parents in three accounts seemed to indicate that clinicians fulfilled, or at least may have tried to fulfill, their responsibility to manage hope. One parent, for example, described clinicians who *kind of ignored us a little bit*, which would seem to be problematic communicative behavior, but accounted for it in terms of clinicians not wanting to destroy the parents' last *glimmer* of hope:

(12) P: I mean when I asked questions, um, they were explaining things. But, you know, many times they came in during the day and, uh, there were things just - and then they walked out. And, kind of ignored us a little bit. And I realize now when I look back that - that the doctors realized certain things where we had still this glimmer of hope. And, um, but they had seen - have so much experience they do know and understands the signs. And, um, I don't know if they really wanted to tell us more about it. And, take this glimmer away. (16)

Another parent offered two accounts that expressed similar uncertainty as to the physician's seemingly problematic communication:

(13) P: And I don't know if he knew it or he just trying to help me out or what. I don't know. (7)

This parent expresses her uncertainty about the intent of the physician's communication, which may have been *trying to help me out*. These three accounts for managing hope were the most ambiguous accounts in the data: none of them offers an unqualified endorsement of the ways clinicians may have been managing parents' hope, but they do contrast significantly with accounts in which parents more unambiguously held clinicians responsible for creating and maintaining false hope.

Three parents in six accounts held clinicians directly responsible for creating or maintaining false hope as the death of their child approached:

(14a) P: They seen it [child's death] coming and I could tell by their actions after the fact that they seen it coming and it's - it seems like they led us on for a little, little longer than they should. (45)

(14b) P: And how much was I supposed to take when I sit there and I'm thinking that all my hope is you're telling me that OK she's gonna be OK. And that's all I'm hearing and I know that, I don't know if that's their job. 'Cause I would have much better they told me her chances were slim or her chances was nil or something. But she's not gonna be OK. And I got mad at them because they told me she was gonna be OK if she wasn't. (24)

One final example of an account for a clinician not fulfilling the responsibility to manage hope without creating false hope is expressed in terms of what the parent would like clinicians to know about balancing hope and realism, both in care and communication:

(15) P: Remember when you're on that floor there's kids they can't help. (53)

4.3.4. Communicating with appropriate affect—Finally, five parents used six accounts to assign physicians' responsibility for communicating with appropriate affect ($n = 6$). Parents saw appropriate affect in terms of clinicians' view of their child as more than simply a patient or a routine clinical case. When clinicians make this view clear, as one mother explains, they provide *something to hold on to*:

(16) P: I remember the day that they called me and tell me that my baby had a stroke and I was so mad, I was mad at the world. ... And she [the doctor] said '[Donna]? How can you think that having your child and getting to know her, see what she look like' ... And that was kind of something to hold on to ... She first saw a baby before she saw Down's syndrome. (30)

Parents criticized clinicians who failed to fulfill their responsibility of viewing their patient as a child:

(17) P: Um, just the way he presented the information in such a cold matter of fact tone. Without any real consideration for what he was really talking about. It was like he didn't have a concept that he was talking about a human being. (20)

When parents detected that their physician was thinking of their child solely as a patient, they held that physician responsible for failing to communicate with appropriate affect.

4.3.5. Summary—As shown in Table 4, parents identified specific communicative responsibilities for clinicians and accounted for when they were fulfilled or unfulfilled.

Parents criticized clinicians who did not fulfill their responsibilities of communicating professionally and clearly; they also criticized clinicians who created false hope or who communicated with an inappropriate affect. Although the majority of accounts were critical ($n = 18, 72\%$), perhaps again reflecting the association between accounts and problematic behavior, the responsibilities parents assign to clinicians comprise a nuanced set: parents hold clinicians responsible not only for information but also for the implications of their communication of that information, particularly in terms of the hope parents have for the life of their child. Interestingly, as parents pointed to their own stress and distress as impeding their ability to fulfill their own responsibilities to understand the medical information they received during their child's course of care in the PICU, they also acknowledged that physicians sometimes do not fulfill their responsibilities for similar reasons, particularly with respect to managing hope. As one parent empathetically said in describing end-of-life communication: It's difficult for doctors to talk to parents; They feel distressed (16).

5. Discussion

In descriptions of team-based care in the PICU, an ideal is that ‘parents are part of the care team’ (IOM 2003: 7). What this means in the ‘crowded clinical space’ (Iedema 2005) of the hospital, however, is not always clear. We have argued here that parents identify medical communication as a shared role-responsibility of team-based medical care that incorporates parents as part of the team, and not in a superficial way.

Our analysis showed that parents hold complex role-responsibility expectations for good medical communication, both for clinicians and for themselves. These role-responsibility expectations come in four related sets:

- a. if parents are to be *part of the team*, then clinicians are to communicate with them professionally;
- b. if parents are to fulfill their responsibility to gather information by asking questions, then clinicians are to communicate medical information clearly;
- c. if parents are to work to understand complex and uncertain medical information, then clinicians are to manage their hope responsibly by not creating false hope;
- d. if parents are to communicate with appropriate affect despite the stress and distress of losing their child, then clinicians are to communicate with appropriate affect by respecting the patient/child as a person.

In the context of the extensive research literature on medical communication, it is not surprising to find that medical communication is to be professional (a), comprehensive and comprehensible (b), and appropriate to the emotional context of the death of a child (d) (IOM 2003, Ch. 4).

Of particular importance, however, is (c). That parents hold themselves responsible for understanding the complexities and uncertainties of medical information is a more specific and nuanced perspective on medical communication, a responsibility beyond the commonly assumed perception of parents as primarily information providers and gatherers. It is, essentially, a responsibility to try to understand prognostic uncertainty. For clinicians, prognostic uncertainty accompanies most complex courses of care; it is an essential perspective underlying clinical reasoning and decision-making. Prognostic uncertainty, however, is not as well-known as part of medical care outside of the profession, and clinicians have identified communicating hope for prognosis, especially at the end-of-life setting, as a particularly vexed type of medical communication, fraught with clinical, ethical, and emotional issues (Christakis 1999). As shown in Tables 3 and 4, parents in this study identified their responsibility to understand the complexities and uncertainties of medical information more often than any other category ($n = 10$), and they similarly mentioned clinicians’ responsibility to manage hope appropriately ($n = 9$) more often than any other category. Parents also saw these responsibilities most often as unfulfilled by themselves ($n = 6$) and by clinicians ($n = 6$). These findings suggest that clinicians may need to explain the nature of prognostic uncertainty to parents as the basis for balancing hope and realism. Parents’ understanding of prognostic uncertainty is, perhaps, the means to preclude false hope, both in clinician communication and parent understanding. In other words, clinicians should describe to parents, as clearly as possible, the course of the child’s clinical care, including the reasons for and implications of tests and procedures. As a result, parents may have a better understanding of physicians’ uncertainty as well as their own.

The move to team-based care has been important and successful in improving medical care, including end-of-life care in the PICU, and the move to incorporate parents as part of the team has begun, both in communication and in decision-making (IOM 2003). We have

argued here that parents' perceptions of their roles *as part of the team* (44) encompass specific responsibilities for good medical communication, including the responsibility to understand the complexities and uncertainties of clinical care, even when the course of care leads to the death of their child. We end by suggesting that compassionate care is more effective when team-based care is structured so that parents can enact their role and consider their deeply-held responsibilities fulfilled in answer to the primary question concerning the death of a child: *Were we good parents?* (11).

6. Conclusion

As with any exploratory research, this study has several limitations. First, the sample may not be representative of all parents who have lost a child in the PICU. Second, the data base for the discourse analysis was relatively small: the total number of accounts was 47, which means that the communicative responsibilities parents identified may not be comprehensive. Third, while the findings and discussion were reviewed by clinicians (KM and other members of the CPCCRN), they were not reviewed by parents due to the design of the larger study, which was sensitive to the burden of bereaved parents.

Our findings, however, do point to interesting questions for future research. First is the question of whether physicians perceive a role-responsibility framework similar to the one we described for parents. An interview study with PICU physicians is now being conducted to investigate this. Second, this study points to the need for more in-depth linguistic analysis of communicating about prognosis, perhaps by analyzing communicative events that surround prognosis, such as PICU team meetings with parents. Third, for discourse analysts investigating medical communication, this study suggests that retrospective narratives and descriptions are important sources of information, particularly when evaluative features are considered. We looked at accounts as just one evaluative feature explaining perceptions of medical communication; it would be interesting to widen the analysis to explore others, such as embedded adjectives (e.g., *I felt like he was really callous at the time*) and qualifiers (e.g., *we were pretty much kept pretty updated on everything that was going on*). Finally, this study points to the importance of looking at the details and complexities of medical communication in acute care settings using multiple sources of data, including interviews, which were shown to reveal parents' insightful and nuanced perceptions on their own and their clinicians' responsibilities for medical communication.

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Table 1

Account coding

	Fulfilled Responsibility	Unfulfilled Responsibility
Parent	(extract 1b)	
Clinician		

Table 2

Overall findings

	Fulfilled Responsibility	Unfulfilled Responsibility	Total
Parent	9	13	22 (47%)
Clinician	7	18	25 (53%)
Total	16 (34%)	31 (66%)	47 (100%)

Table 3

Parental responsibilities

	Fulfilled	Unfulfilled	Total
Participating on the team	1	1	
Gathering information	4	3	7
Understanding complexity and uncertainty	4	6	10
Communicating with appropriate affect	0	3	3
Total	9 (41%)	13 (59%)	22 (100%)

Table 4

Professional responsibilities

	Fulfilled	Unfulfilled	Total
Communicating professionally	0	6	6
Communicating clearly	2	2	4
Managing hope	3	6	9
Communicating with appropriate affect	2	4	6
Total	7 (28%)	18 (72%)	25 (100%)