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Pediatric intensive care unit family conferences: one mode of communication for discussing end-of-life care decisions

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Abstract

Objective—To examine clinicians' and parents' reflections on pediatric intensive care unit (PICU) family conferences (FCs) in the context of discussion about end-of-life care decision making.

Design—Retrospective qualitative study

Setting—A university-based hospital

Participants—Eighteen parents of children who died in the PICU and 48 PICU clinicians (physicians, nurses, social workers, child-life specialists, chaplains, and case managers).

Interventions—In depth, semi-structured focus groups and one-on-one interviews designed to explore experiences in end-of-life care decision making.

Measurements and Main Results—We identified comments about FCs in all clinician focus groups/interviews, except one individual nurse interview, and in 13 of the 18 parent interviews. Comments from parents were sparse compared to those from clinicians. Four topics emerged: purpose, structural aspects, challenges, and suggestions for improvement. We identified three purposes for FCs: communication between clinicians and parents; communication among clinicians; and support of families. Described structural aspects of FCs included: pre-conference planning, communication during conferences, and post-conference processing. Challenges noted involved communicating with parents during FCs such as: difficulties associated with having

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multiple services involved; balancing messages of hope and realism; using understandable language; and communicating with non-English speakers. Participants described additional challenges related to the logistics of organizing FCs. Suggestions focused on methods to improve communication in, organization of and preparation for FCs.

Conclusions—PICU clinicians in this study perceive FCs as having an important role in end-of-life care decision making. The paucity of data from parents, an important finding itself, limits our ability to comment on parents' perceptions of FCs. Prospective research of PICU FCs, with specific attention to parents' experiences and to all aspects of FCs, including pre and post-conference events, should seek to understand the role and impact of this mode of communication on end-of-life care decision making and to determine the need for improvement to FCs.

Keywords

Family conferences; qualitative research; pediatric intensive care unit; end-of-life care; communication; decision making

Introduction

Superior pediatric palliative care relies on good communication.(1–6) Of the approximately 235,000 children admitted annually to United States Pediatric Intensive Care Units (PICUs), almost 7,000 children will die.(7) Communication between hospital-based health care professionals and parents about dying critically ill children involves a range of challenges, including: relaying bad news; discussing prognosis; and making end-of-life care decisions, such as withdrawing or limiting life-sustaining treatment.(8, 9) Discussions between parents and clinicians regarding clinical decisions for patients often occur during family conferences (FCs), defined here as planned meetings that include parents of a PICU patient, other family or support individuals, and one or more members of the healthcare team.

The growing literature on family conferences (FCs) in intensive care units (ICUs) for adult patients is quite informative. One study described missed opportunities for clinicians to communicate better during FCs.(10) Other studies have shown that: clinicians' expressions of empathy and support correlated positively with family satisfaction(11, 12); information conveyed by clinicians varies, depending on clinician skill, subspecialty orientation, and other factors(13); and foreign language interpreters affect the quality of communication during FCs.(14) A randomized controlled trial involving critically ill adults suggested that standardized communication strategies for FCs may lessen families' bereavement burden.(15)

Despite the work on FCs in adult ICUs, the literature contains virtually nothing about PICU FCs.(16) Differences between the adult and pediatric experience demonstrate the need for this research. The potential death of a child often involves emotional influences different from those encountered with adults. Health care decisions for adults are based on input from advance directives or on “substituted judgment.”(17, 18) In pediatrics, decisions are generally based on the “best interest standard” because children often lack decision making capacity.(18) Adult ICUs generally have a relatively narrow disciplinary focus (e.g. surgical or neurological) giving clinicians a more homogeneous experience. PICU deaths occur in children with a wide range of medical problems (19, 20) requiring PICU physicians to manage varying medical issues during the dying process. Finally, deaths occur less frequently in PICUs;(7, 19–24) thus, pediatric intensivists may have less experience caring for dying patients.

We conducted a general study of PICU end-of-life care decision making. FCs unexpectedly emerged as a key topic from our initial analysis of data from this larger study. Given this

discovery, the lack of published information on FCs in PICUs, and the adult FC literature, we analyzed a subset of data from the larger study pertaining to FCs. This report describes clinicians' and parents' reflections on PICU FCs using that focused dataset.

Materials and Methods

Setting, Study Design, and Participants

The broader study seeks to use experiential information from key PICU stakeholders to describe 1) issues important in PICU end-of-life care decision making and 2) possible methods for improving the decision-making process for parents. We collected data from March 2007 to June 2009 at an academic children's hospital. Using purposeful sampling,(25) we conducted focus groups and semi-structured one-on-one interviews with bereaved parents of children who died in the PICU and with hospital-based health care professionals. All focus groups and interviews (hereafter "interviews" unless otherwise stated) were audio recorded. The hospital's institutional review board approved the study.

An initial set of parents provided pilot data. The hospital bereavement coordinator identified parents based on her perception of the parent's probable readiness to participate. Subsequently, we identified potential parent participants using the PICU database. We invited parents of children who died in the PICU to participate unless the parents were: 1) less than 18 years of age; 2) unable to communicate fluently in English; 3) parents of a child admitted with known or suspected non-accidental trauma; 4) parents of a child who died less than 6 months prior to the invitation; 5) parents of a child ≥ 8 years old; or 5) without available contact information. We focused on parents of younger children who rarely have the capacity to assent to treatment and participate in end-of-life decisions; thus we attempted to establish a degree of homogeneity regarding patient noninvolvement.

We sent letters to eligible parents explaining the study and asking them to mail in a form indicating their interest in study participation. We sent follow-up letters to parents who did not reply. Due to low parent response following the pilot phase, we modified recruitment as follows. We sent an initial letter explaining the study and asking parents to send in a "Decline Participation Form" or to call the principal investigator if they did not want further contact. We then made up to three attempts to contact parents by phone. If phone contact failed, we sent a second letter asking interested parents to request information by mail or return a written questionnaire. All parent participants were interviewed by one of two interviewers (KM or PB). Neither KM nor PB provided clinical care for the children whose parents were interviewed. Interviews took place at the parent's home or at the hospital.

We solicited study participation from PICU health care professionals (hereafter 'clinicians') by disseminating information via the PICU website, emails, regular meetings, and posters. As with the parents, the first clinician focus group, involving eight PICU bedside nurses, served as a pilot. Subsequently, we conducted separate focus groups with PICU attending physicians, PICU fellows, PICU advance practice nurses, PICU bedside nurses, chaplains, and social workers. One child-life specialist participated in the social workers' focus group. One case manager participated in the chaplain focus group. Because we initially had difficulty convening bedside nurse focus groups, we conducted two one-on-one interviews with bedside nurses prior to successfully convening three focus groups. One moderator (PB) conducted all clinician focus groups and interviews.

We developed our initial interview guides using information from published studies and discussions with experts in pediatric palliative care, sociology, parental bereavement, and parents of two children who died in the PICU. The guides addressed key decisions important to parents of dying children in the PICU and requested suggestions to improve parental

decision making. We asked parents to identify and discuss important decisions they faced as their child was dying in the PICU. We asked clinicians to identify all important end-of-life care decisions and subsequently focus on decisions to limit or withdraw life-sustaining therapies. The guides included questions on: the processes used in making decisions; the roles various individuals play in decision making; clinician-family communication; the influence of religion, faith or spirituality; and suggestions for improvements. We modified the interview guides based on ongoing data analysis, an iterative approach to data collection typical of qualitative research.(26) Our modifications included adjustments to concentrate on decision making rather than other aspects of patients' PICU experiences. We also added two questions for parents who did not spontaneously discuss involvement in a FC: "Did you have any meetings with the health care team as a group?" For those who replied affirmatively we asked, "How did the meeting(s) go?" For those who replied negatively we asked, "Might you have liked to meet with the health care team as a group?" We added these questions because clinicians frequently discussed FCs spontaneously, but parents introduced the topic less often.

Participants completed a short post-interview questionnaire about basic demographics. We continued data collection with parents until reaching data "saturation" based on the goals of the larger study.(25)

We include our pilot data (the first 8 parent interviews and one focus group with 6 bedside PICU nurses) in this analysis because: the data contain rich information which add to our understanding of PICU end-of-life care decision making; we made only minor modifications to the study design following the pilot (in addition to the interview guide changes noted above, we added an item on our questionnaire about Hispanic/Latino ethnicity); and we make no assumptions that our results are generalizable beyond the studied population.

Data Analysis

Audio recordings were professionally transcribed verbatim. A study team member reviewed the transcripts and removed personal identifiers. For more robust analysis, data were analyzed by a multidisciplinary group: a PICU attending; a social worker; a physician expert in palliative care; and a medical student. Using thematic analysis, two authors (PB and KM) conducted open coding (labeling of data based on ideas, concepts, patterns and properties identified) of the entire dataset.(25) From this coding, the category, "FC," emerged. Two authors (KM and AC) identified a subset of the data that included all comments related to FCs (as previously defined) and "care conferences," the local jargon for FCs.

Two authors (KM and AC) identified codes within the FC data set through separate transcript analysis and then defined and finalized the codes through iterative discussion. The transcripts were then reviewed and re-coded separately by the two authors using the agreed-on codes. The same authors compared their findings and arrived at the final categorization of the data through consensus. Further analysis revealed four major topics described in the data. Two other authors (PB and JF) reviewed the final coding for completeness and accuracy. We used ATLAS.ti Version 6.0.15 (ATLAS.ti GmbH, Berlin, Germany) for all coding. We applied a Fisher's Exact test and the Mann-Whitney U test to compare categorical and continuous variables respectively. We used SPSS version 12.0 (SPSS inc., Chicago, Illinois) for all quantitative analysis.

Results

For the pilot parent interviews we identified 15 patients from PICU deaths that occurred from 2003 – 2006. Thirty letters, one to each patient's parent, yielded eight individual interviews with the parents of six patients. For subsequent parent interviews, we reviewed

PICU deaths between February 2006 and January 2009. Forty-eight patients met our inclusion/exclusion criteria. Letters to 96 parents of these patients yielded 11 interviews with the parents of eight patients. Technical difficulties with the recording prohibited our analysis of one interview. We report results from the analysis of 18 parent interviews. We found no difference in sex (29% vs. 43% female, $p=0.37$), age (2.2 vs. 2.1 years, $p=0.81$), length of PICU stay (0.02 vs. 0.04 years, $p=0.21$), or length of hospital stay (0.03 vs. 0.05 years, $p=0.18$) between patients of parents interviewed vs. those not interviewed. We conducted nine focus groups and two nurse interviews involving a total of 48 clinicians. Tables 1, 2 and 3 give the demographic information of parent participants, the patients, and clinician participants, respectively.

We identified discussions of FCs in all clinician interviews, except one individual nurse interview. Mention of FCs occurred in 13 of the 18 parent interviews. The following four topics emerged from the data: purpose of FCs; structure of FCs; challenges to conducting effective FCs; and suggestions for improving FCs. We present the clinician and parent data separately for clarity. Tables 4 and 5 contain exemplary quotations from clinicians and parents respectively.

Clinician perspectives on FCs

Purpose—Clinicians described three broad purposes for FCs: communication between clinicians and parents; communication among clinicians; and support of families.

Clinicians most commonly indicated that FCs provide a means for coordinated communication between clinicians and parents. FCs provided an opportunity for clinicians to: inform parents of their child's status; convey information to parents from multiple services simultaneously; answer parents' questions; identify treatment options; and initiate discussions about future care. In the context of end-of-life care decision making, clinicians reported that conversations may address withdrawing or limiting life-sustaining therapies or introducing palliative care. Clinicians described using FCs to address non-medical issues important to end-of-life care such as “memory making” (obtaining photographs of the child and family, making hand and/or foot molds or prints, etc.) or funeral planning. FCs also give clinicians an opportunity to communicate to parents their personal feelings about the situation (i.e. empathy or sadness).

Clinicians described FCs as opportunities for parents to convey important information about the family's needs or situation to clinicians. For example, parents may tell the clinicians about the influence of extended family and friends or religious/faith-based concerns. Such information may come directly from conversation during the FCs or indirectly, through identifying family members, friends, or religious advisors to include in the conference.

FCs provide a forum for clinician-clinician communication. Clinicians described how, outside of FCs, communication among various services can be suboptimal, resulting in multiple specialists communicating fragmented or sometimes contradictory information to parents. Participants indicated that FCs provide an organized forum for clinicians from different services to convene and share information and/or discuss care plans for their patients.

Finally, clinicians described how they use FCs to support the individual needs of parents and families. FCs provide a means for parents to discuss their child's illness with extended family members or friends. One person noted that FCs may help resolve conflict between parents who hold different views regarding their child's care. Some also explained how parents may feel supported by clinicians' acknowledgment that certain choices are made

based on what is appropriate for the child and not because there is an ethically or clinically “correct” decision.

Structural aspects of FCs—Clinicians described three key structural aspect of FCs: pre-conference planning, communication during conferences, and post-conference processing.

Clinicians noted a number of pre-conference events. First, someone identifies the need for a conference, often a nurse, chaplain, or social worker, but sometimes parents. Focus group participants commented that the frequency and occurrence of FCs suggested considerable variation in the situations which prompt FCs. Once clinicians agree on the need for a FC, someone must organize the conference and coordinate participation by clinicians, family members, and parent-support individuals. Some clinicians noted how an often-neglected aspect of planning is preparing the family for a conference, e.g. helping families understand the conference goals or what to expect during such meetings. Finally, clinicians may confer as a group prior to meeting with the family to plan what information to present and how.

In describing events during FCs, most clinicians noted that one person, typically a PICU attending physician or occasionally a PICU fellow physician, leads the meeting. Social workers, nurses and chaplains generally support parents by directing attention to parents' needs or by acting as parent advocates, e.g. asking questions that parents want answered or identifying issues of importance to the parents.

Clinicians noted that parents and clinicians frequently “process” conference events following the meetings. Many nurses said that parents often ask new or additional questions about or initiate discussions of care options with bedside nurses after the conferences. Nurses indicated that these bedside conversations sometimes occur with nurses who did not attend the conference. A number of participants described discussions among clinicians following FCs during which clinicians obtain feedback from one another regarding the meeting's outcomes.

Challenges—Clinicians described challenges to effective communication with parents during FCs. PICU clinicians frequently discussed difficulties associated with having multiple services present during the meetings, e.g. parents may receive conflicting information about or interpretations of the child's situation. While representatives from different services may meet prior to FCs, preconference gatherings do not happen consistently. Challenges also result from clinicians trying to balance messages of hope and realism, attempting to use nontechnical language (many noted the use of unclear or indirect language, especially when answering parents' questions), and using interpreters to communicate with non-English speaking parents.

Other major challenges related to the logistics of FCs. Scheduling difficulties occur because of conflicting commitments of clinicians, particularly those from different services, and parents. Bedside nurses described missing FCs because of their clinical responsibilities and noted that their absence impairs their ability to support and advocate for families during and after conferences. One person noted that in acute situations, when the patient's condition is changing rapidly, conducting a FC may not be feasible.

Suggestions for improvement—Clinicians suggested a number of strategies to improve communication between the conference “leaders” and parents. Suggestions included: asking parents to clarify their understanding of their child's condition in their own words; using direct, noneuphemistic language; including open expressions of emotions and caring; allowing periods of silence; and identifying a time-frame for decision making. A number of people felt additional training might help clinicians communicate more effectively.

Other suggestions pertained to organizing and preparing for FCs. One person suggested developing a standardized format for FCs; another thought there should be a team of individuals dedicated to and skilled in conducting FCs who may not necessarily be part of the patient's care team. Some people expressed a desire for more frequent and regular FCs beginning early in the child's PICU admission. Many participants supported pre-conference meetings among clinicians to clarify how to present information and unify, if possible, recommended goals and plans. Interviewees felt clinicians should maintain flexibility regarding parents' individual needs (e.g., when during the day or night to hold conferences and who should attend). Finally, bedside nurses unable to attend the conferences should receive detailed accounts of the discussions.

Parent perspectives on FCs

Parents' comments about FCs were notably sparse compared to those from clinicians. While parents touched on the same four topics identified by clinicians, the depth of information was less. Of those parents asked directly about FCs, many could not remember any details. Some parents said that such a meeting did not happen because events occurred too quickly. Others described how communication with physicians typically occurred informally, especially during or directly after rounds.

From their limited discussion of FCs, parents described similar purposes for FCs: providing an opportunity for clinicians to communicate with one another; informing parents of the child's status; discussing treatment limitations; and describing the repercussions of any decisions made. One parent noted a discussion of organ donation. A few parents described the inclusion of extended family members in FCs.

No parents described pre-conference preparations. They simply described how they were brought into a room with several clinicians and a discussion of their child's situation followed. Nor did parents mention post-conference processing.

In terms of challenges, parents noted how physician time constraints limit organizing multidisciplinary conferences. Several parents said that the rapid evolution of clinical events prohibited organizing a formal meeting. When asked generally about helping families with end-of-life care decisions, one parent recommended that regularly scheduled conferences should occur with clinicians and parents. Another parent noted the importance of holding conversations about sensitive topics in a private room.

Discussion

Family conferences emerged as an important component of PICU end-of-life care decision making for interviewed clinicians. The importance of FCs for bereaved parents remains unclear because information about FCs from parents was notably sparse. Our findings suggest that clinicians value FCs as a forum for clinician-family and clinician-clinician communication and as an opportunity for clinicians to support families faced with tragic choices. We identified three important components of FCs; pre-conference planning, communication during conferences, and post-conference processing. Participants discussed important challenges associated with each of these components, including providing communication skillfully, coordinating communication among multiple subspecialists, and logistical difficulties convening conferences. Suggestions for improving FCs focused on conference planning and techniques for communicating effectively.

Despite the lack of data on PICU FCs, the growing literature on parental communication needs during end-of-life care in the PICU provides valuable insights and a context for our results. In similar studies involving interviews with bereaved parents of children who died in

a PICU, participants described: physicians' inability to give clear, direct information about the situation(27); how physicians often offered false hope(27); and the importance of honesty and completeness of communication.(28) In our study, clinicians noted how some people have difficulty communicating information directly and balancing hope and realism during FCs. Others have shown that parents received contradictory information from different physicians(27) and noted communication and care coordination as key priorities for parents.(28) Clinicians in our study also described the challenges associated with having multiple subspecialists involved in the care of one PICU patient, including the potential for confusing communication with parents and the need for better care coordination.

Regarding literature on communication specific to FCs, we turn to the adult ICU setting. A series of articles from a multi-center study of FCs at four hospitals in the Seattle-area indicate that clinicians often miss opportunities to listen and respond to families,(10) and illustrate the importance of clinicians' expressions of empathy and support.(11, 12) Our study also suggests, albeit indirectly, that silence may allow families to process information better; that clinicians may help by indicating to parents that the PICU staff will accept and support the parents' choices in most circumstances; and that clinicians' open expressions of emotion may assist parents.

From their study of FCs in adult ICUs, Curtis et al. have made suggestions for organizing family conferences. They emphasize the importance of preparing for conferences.(29) Our data underscore the potential value of pre-conference planning to help coordinate communication among multiple providers and from multiple providers to families.

Our results identify some aspects of FCs not addressed in the published literature. That clinicians often neglect to prepare families for FCs suggests that improving FCs may require addressing pre-conference behaviors. Similarly, clinicians described post-conference processing between nurses and families, a phenomenon not discussed in the literature. Attention to post-conference activities may be an important aspect of clinician-family communication in the PICU.

We suggest that clinicians' frequent discussions of FCs may demonstrate the value they place on formal meetings for making end-of-life care decisions. In our study, parents discussed FCs less often and in less detail than clinicians. While parents may value FCs less than clinicians, we cannot conclude that based on our findings. Perhaps conversations during FCs did not influence decision making for the parents we interviewed or perhaps the interviewed parents did not differentiate formal FCs from other end-of-life care discussions they had with clinicians. Other possibilities include: recall bias--we interviewed parents nearly two years after the death of their child, on average; selection bias--we may have inadvertently identified a group of parents for whom few FCs took place or involvement in FCs may have influenced some parents not to participate in our study; and study design--more parents might have commented on FCs if all were asked directly about such meetings.

Other impacts of our study design merit discussion. The data come from a larger study to identify key factors in end-of-life care decision making for children who died in the PICU. As a result, we cannot comment on the experience of parents whose children did not die and the impact of FCs on decisions resulting in maintaining life support for surviving children. Our data are not amenable to comparing experiences of families who had FCs versus those that did not. Our focus on comments about FCs does not allow us to explore other modes of communication in the PICU, such as informal bedside care discussions. Despite limitations, our findings indicate that FCs may constitute a potentially crucial communication modality in the PICU. Addressing these limitations requires a prospective study to evaluate PICU FCs and their role amidst other modes of communication.

We acknowledge other study limitations. Some investigators (KM and JF) could have recognized comments from clinicians because of ongoing working relationships. We offset this potential bias by having two non-clinician investigators (AC and PB) involved in the data analysis. Our overall response rate (14 of 63, 22%) was small, but is similar to that of related studies.(27, 30) The parents interviewed included only English-speakers and mainly well-educated, White, Christian individuals. While the predominance of White participants may be partially explained by the patient population at the study hospital (20% of patients are not White or Hispanic), we can only speculate on the lack of participation from parents in lower-socioeconomic groups (e.g. time constraints or inaccurate contact information). Finally, we acknowledge that our results are not generalizable because we used a qualitative approach, excluded children over seven years old, and collected data at one institution. Prospective, real-time study of PICU FCs may improve response rates (as seen in other studies)(31), inclusion of people from varied ethnic and socioeconomic backgrounds, and generalizability.

Conclusions

Our data suggest that PICU clinicians perceive FCs as important for end-of-life care decision making. The paucity of data from parents limits the extent to which we can comment on parents' perceptions of FCs. Prospective research of PICU FCs, with specific attention to parents' experiences and to all aspects of FCs, including pre- and post-conference events, is needed to understand the role and impact of this mode of communication in the PICU and to determine the need for improvement to FCs.

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Table 1

Parent Demographics (n = 18)

Characteristic		n (%)
Sex	Female	11 (61)
	Male	7 (39)
Age	Mean (sd)	35 (6.6)
	Median	34
	Range	19 – 47
Marital Status	Married	16 (89)
	Never Married	1 (6)
	Partnered, not married	1 (6)
Education	College 1 – 3 years	5 (28)
	College Graduate	4 (22)
	Graduate School	8 (50)
	Missing	1 (6)
Religion	Protestant	4 (22)
	Catholic	8 (44)
	Jewish	2 (11)
	Spiritual ^a	1 (6)
	Other	3 (17)
Race	Asian	1 (6)
	Black	1 (6)
	White	16 (89)
Ethnicity	Hispanic/Latino	1 (6)
	Not Hispanic/Latino	10 (56)
	Missing data ^b	7 (39)
Income ^c	≤ 49,999	4 (22)
	50,000 – 74,999	1 (6)
	75,000 – 99,999	4 (22)
	≥ 100,000	9 (50)
Years after child's death	Mean (sd)	1.9 (0.83)
	Median	1.8
	Range	0.62 – 3

Abbreviations: sd, standard deviation

^aNot affiliated with an organized group

^bThis item not included on 7 post-interview questionnaires.

^cTotal household income

Table 2

Patient Demographics (n = 13)

Characteristic		n (%)
Sex	Female	5 (39)
	Male	8 (62)
Age at death (years)	Mean (sd)	1.9 (2.2)
	Median	0.53
	Range	0.06 – 6.5
Limitations of medical therapies identified ^a	Yes	12 (92)
	No	1 (8)
PICU length of stay (days)	Mean (sd)	8.7 (11)
	Median	3
	Range	0 – 38
Cause of death	Neoplasm	7 (53)
	Heart disease ^b	3 (23)
	Bowel perforation	1 (8)
	Sepsis	1 (8)
	Trauma	1 (8)

Abbreviations: PICU, pediatric intensive care unit; sd, standard deviation

^a Includes patients for whom life-sustaining therapies were withdrawn and/or there was a “do not resuscitate” order in the chart.

^b Includes two patients who underwent surgery for congenital heart disease and one patient with an arrhythmia.

Table 3

Clinician Demographics (n = 48)

Characteristic		n (%)
Position	Attending Physician	7 (15)
	Chaplain	4 (8)
	Child-Life specialist	1 (2)
	Fellow Physician	6 (13)
	Nurse (bedside)	20 (42)
	Nurse (PNP)	3 (6)
	Social Worker	6 (13)
	Case Manager	1 (2)
Years in current field	Mean (sd)	8.8 (8.6)
	Median	5
	Range	0.33 – 33
	Missing	6
Sex	Female	35 (73)
	Male	8 (17)
	Missing	5 (10)
Age	Mean (sd)	37 (10.4)
	Median	35
	Range	22 – 68
	Missing	5
Marital Status	Married	17 (35)
	Widowed	1 (2)
	Divorced	1 (2)
	Never Married	21 (44)
	Partnered	2 (4)
	Missing	6 (13)
Religion	Protestant	7 (15)
	Catholic	19 (40)
	Jewish	4 (8)
	Spiritual	5 (10)
	Other	4 (8)
	Not religious	4 (8)
	Missing	5 (10)
Race	Asian	2 (4)
	Black	1 (2)
	Native Hawaiian/Pacific Islander	1 (2)
	White	36 (75)

Characteristic		n (%)
	Other ^b	1 (2)
	Missing	7 (15)
Ethnicity	Hispanic/Latino	1 (2)
	Not Hispanic/Latino	37 (77)
	Missing ^c	10 (21)

Abbreviations: PNP, pediatric nurse practitioner; sd, standard deviation

^aNot affiliated with an organized group

^bSelf-identified as “Indian”

^cThis item not included on 6 post-interview questionnaires

Table 4

Example quotes from clinicians

Topic	Quote
Purpose	
Communication between clinicians and parents	<p>“because the child is involved with lots of different services, not just the PICU team, but many other specialties. And so, they [the parents] want to know what everybody's saying.”(Chaplain)</p> <p>“To clarify, just specifically on treatment...typically it can happen in a care conference.” (Social worker)</p> <p>“at a care conference today, that very situation in that the, the idea of having the photographer come in once they decide to withdraw care” (Chaplain)</p> <p>“...to say we don't have the answer on this, ... this is a terribly sad situation and -- it allows the family to glimpse our own vulnerability.”(Chaplain)</p>
Communication among clinicians	<p>“It's usually not until we facilitate a care conference...and make everyone sit down together and, and give sort of a united picture.” (Nurse)</p> <p>“and the doctors themselves sometimes need to talk among themselves that you're passing on the same information.”(Nurse)</p>
Supporting families	<p>“when we're talking about withdrawal and we're having care conferences about that, that they always acknowledge that there is no right or wrong decision in this.”(Chaplain)</p> <p>“He said to mom, she was Spanish-speaking and we had an interpreter but he said, ‘Everyone in this room cares about your son.’”(Nurse)</p> <p>“when you do have a family that wants ten family members to come into the care conference or, to be a part because they're all a part of the decision-making.”(Chaplain)</p>
Structural Aspects	
Pre-Conference	<p>“Actually what I like to do is to do a pre meeting. So the first ten minutes you don't have the parents in the room and we actually script what we're going to do and how we're going to do it...” (Physician)</p> <p>“I had to sort of explain what a care conference was and that's a horrible, it was a horrible situation to be in 'cause you're saying well you know bring family members, bring whoever you need, in this case it was a Rabbi, but there needs to be some type of connection between we did this, this and this. This is the prognosis, we need to sit down and talk about future plans as opposed to well we're going to have a meeting tomorrow about what we're going to do.” (Nurse)</p>
During Conference	<p>“...sitting down in the room with us and having a discussion with a lot of different people present, but the majority of the time it [is] the fellow or attending doing the talking.” (Fellow Physician)</p> <p>“But I'm here sitting next to this family cause I know them well and maybe they're not good at asking questions and I can ask a question that they need to hear the answer to, so being part of those talks.” (Social Worker)</p>
After Conference	<p>“We have talked around the table and the feedback afterwards was one or the other of us was so much more pessimistic.” (Physician)</p> <p>“You know, you go to the care conference, you come back to the room and you ask the parents, ‘Okay. How are you guys doing?’” (Nurse)</p>
Challenges	
Communication	<p>“We sort of hint around these things and we use words that are unclear and families get the gist that you're telling them it's not going well. But the tendency as human beings then is to throw out some obscure, hopeful thing at the end which kind of muddies the waters again.” (Social Worker)</p>
Organization	<p>“I hate how, okay a care conference may happen but I can't go because, like you said, I have to take care of this critically ill kid. But I need to know what happened in there, how the parents feel and what they said. You know, what decisions were really made.”(Nurse)</p> <p>“You know, we're so busy right now and to try to get a group of doctors together, sit in a room for ten, fifteen minutes is just very difficult”(Nurse)</p>
Suggestions	
Communication	<p>“And then just being silent and letting the parents respond, talk, say what they need to say.” (Chaplain)</p>

Topic	Quote
	<p>“Really lay it down, `cause some of these families aren't here for rounds in the morning and they don't understand half the stuff they're talking about in rounds.”(Nurse)</p> <p>“Like there's [sic] certain people who clearly have heard this in their training and so they also know the grace of shutting up and saying your child's condition is worsening. We don't expect your child to survive.”(Social Worker)</p>
Organization	<p>“I think with the physicians and the services they should start the conference without the parents in the room and talk with each other. Have a mini conference....I think that would definitely help and lessen some of the confusion and differences of opinion.” (Nurse)</p> <p>“I think getting everyone together in the first twenty-four hours of [a] patient coming in, if they're really sick or acute and just sort of giving them all the information in a -- at the same time, in the same place. Would be better -- is better than bits and pieces here and there...” (Nurse)</p> <p>“Or a standardized care conference format or, you know, some checklist that everyone, all the players go over beforehand.” (Social Worker)</p>

Table 5

Example quotes from parents

Topic	Quote
Purpose	<p>“You know we were brought into a conference room and you know several people came in and, and they talked you know about you know how the morning would progress and we called our parents so they could make their way down and we weren't going to take him off of anything until they came down.”</p> <p>“And the doctors were there. There was like a big -- that big room with the table. Everybody was sitting around the table kind of -- and she let me ask. Like, I, because I said -- because I was back and forth. Like one minute I want to donate, and the next minute I'm like, no this is not, you know,”</p>
Structural Aspects	<p>“Yeah, we sat in like a conference room where she was kind of the head of the table, and then there were three people on each side of then my husband and I....She was basically the only one that spoke. I think you know the rest of them were just kind of waiting in the wings for whatever we decide you know.”</p>
Challenges	<p>“maybe it's even like `hey P1, listen can we set up a meeting with you and me and your eye specialist?’ You know I know it's difficult. I know it's hard. I know but you know I think that you know for these doctors, I know they're busy, I know they're always doing something maybe they need to be less busy.”</p>
Suggestions	<p>“Well I was just going to say right now, throw in that it would be really nice for the doctors to be able to pull you outside of that space into a separate room, like this. It's, you know, there's just too many other things going on with bells and whistles and noises and monitors to be able to give full attention.”</p>