



Parent communication with care teams and preparation for family meetings in the paediatric cardiac ICU: a qualitative study

Original Article



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Abstract

Objective: The paediatric cardiac ICU presents unique challenges to optimal communication practices, which may impact participation in medical decision-making and long-term psychosocial outcomes for families. This study characterised parent perceptions of (1) team practices that impeded or facilitated communication and (2) preparation for family meetings with interprofessional care teams during extended cardiac ICU admissions. **Methods:** A purposive sample of parents of children admitted to the cardiac ICU was selected to participate in interviews about their communication experiences. Data were analysed using a grounded theory approach. **Results:** Twenty-three parents of 18 patients participated with an average length of stay of 55 days at the time of interview. Team practices that impeded communication included inaccurate/incomplete communication, inconsistent within team communication/coordination, and feeling overwhelmed by too many team members/questions. Team practices that facilitated communication included valuing parent preferences, provider continuity, explaining jargon, and eliciting questions. Preparation for family meetings included team practices, parental preferences, and experiences when learning about family meetings (including apprehension about meetings). Family meetings were described as valued opportunities to improve communication. **Conclusion:** Communication with medical teams represents a modifiable determinant of long-term outcomes for families of children in the cardiac ICU. When parents are included as valued members of their child's care team, they are more likely to feel a sense of control over their child's outcomes, even in the face of prognostic uncertainty. Family meetings represent an important opportunity to repair fractures in trust between families and care teams and overcome barriers to communication between parties.

The paediatric cardiac is a stressful environment for parents,¹ who are expected to make decisions about their child's care often under considerable uncertainty and time constraints.² Parents commonly experience anxiety, depression, and post-traumatic stress symptoms long after their child's admission.^{3,4} Parents' subjective experience of their child's critical care admission predicts long-term psychosocial outcomes for families.^{5,6} Communication from critical care providers is a key aspect of this subjective experience,⁷ and communication challenges have been cited as a significant source of stress for parents of children admitted to the cardiac ICU.⁸

High-quality communication is the foundation of shared medical decision-making and family-centred care,⁹ but the cardiac ICU presents unique challenges to communication practices that meet families' needs. Parents consistently report the need for honest, timely information about their child's condition, and prognosis in the cardiac ICU,¹⁰ however, providers may avoid difficult conversations due to misperceptions of parents' informational needs, personal discomfort, or inexperience.¹¹ A significant proportion of parents of children in the cardiac ICU report receiving conflicting information from providers and feel unprepared to participate in decision-making as a result.¹² Meetings between interprofessional care teams and families have the potential to address inconsistencies and misperceptions,¹³ but research indicates that physicians tend to dominate these conversations and miss opportunities to engage in dialogue with families.¹⁴

Structured interventions that improve team communication with families during cardiac ICU admissions are likely to support parents' involvement in medical decision-making and promote long-term psychosocial well-being for families;¹⁵ however, little is known about the lived experiences of families navigating team communication in the cardiac ICU.¹² Qualitative studies provide essential information about mechanisms of change from individuals most impacted by outcomes of interest.¹⁶ This qualitative study aimed to characterise parent perceptions of (1) aspects of team practices that impeded or facilitated

communication and (2) preparation for family meetings with interprofessional care teams during extended cardiac ICU admissions.

Materials and methods

Recruitment and procedures

This study followed the consolidated criteria for reporting qualitative research (COREQ) guidelines for qualitative research.¹⁷ A purposive sample of parent–child dyads were selected from the cardiac ICU at a large children’s hospital. Parents were eligible to participate in the interviews if their child had been admitted to the cardiac ICU for at least 7 days and if the medical team anticipated that the child would remain admitted to the cardiac ICU for at least another 7 days, or if the child had already been admitted for 14 days. Children needed to be under the age of 18 years and parents needed to be 18 years or older to participate. Parents were included in the sample if they were legal decision-makers, spoke English, and did not have cognitive impairments that would prevent them from being surrogate decision-makers. Parents were approached in person by study staff after eligibility was verified and interviews were conducted in person or over the phone. The primary interviewer for this study was a palliative care physician with training in bioethics and qualitative research methods (JW). The interviewer did not have a relationship with the parents prior to the interview. Interviews were conducted during a single session and pertained to parents’ perceptions of communication with their child’s care team, preparation for team meetings, and experiences with team meetings (e.g., “Did anyone prepare you for what to expect in the meeting” “What would have been helpful to know or do before the family meeting?” “Can you describe any challenges you may have had communicating with the cardiac ICU team about your child’s care?”). Interviews analysed for this study were conducted as part of a larger study aimed at developing a communication skills training programme for interprofessional teams in the paediatric cardiac ICU.¹⁸ All interviews were audio-recorded and professionally transcribed with identifying information removed prior to analysis. Interviews lasted on average 22 minutes, ranging from 9 to 35 minutes. Field notes were recorded during interviews but were not included in analysis.

Data analysis

Data were analysed using constructivist grounded theory methods, including coding, memoing, and reflexivity.^{19,20} Transcripts were uploaded into Nvivo 12,²¹ and the study team developed a codebook through an iterative process. Transcripts were coded, and 20% were reviewed by at least two study members (HG, DH, and JW). Disagreements were discussed as a study team until consensus was reached.^{22,23} Excerpts from codes pertaining to team practices that impeded or facilitated communication and experiences with preparation for team meetings were then extracted and analysed for thematic content. This study was approved by the Children’s Hospital of Philadelphia Institutional Review Board.

Results

Sample characteristics

A total of 23 parents of 18 patients participated. Seventy-eight per cent of parents were mothers, and 61% of parents were White. Half

of the patients were under 1 month old at the time of admission and were admitted pre-operatively. The average length of stay of the patient was 55 days at the time of the interview, with a median length of stay of 43 days (range = 9–154). Additional parent demographics and child clinical characteristics are found in Table 1.

Study findings

Codes were grouped into the structure of Team Practices that Impeded Communication (four themes identified), Team Practices that Facilitated Communication (two themes, encompassing seven subthemes, identified), and Preparation for Family Meetings (three themes identified). Major themes and subthemes are found in Table 2, with representative quotes in Table 3.

Team Practices that Impeded Communication

Inaccurate/incomplete communication with families

Parents expressed frustration related to inaccurate and incomplete communication between the team and their families. One parent described that their child’s treatment was delayed when providers ordered an MRI as routine rather than urgent which delayed completion of the MRI without providing this information to the family. Another parent shared that team members did not provide sufficient explanation of their rationale for ordering certain tests, leaving the parent feeling that information was being concealed from them. In another instance, parents described the shock they experienced when a child’s room was moved without notification (Quote-1).

Inconsistent within team communication/coordination

Parents reported that communication was hindered by inconsistent or ineffective communication between team members. Parents reported feeling that they had to “play middleman” and negotiate provider inconsistencies, which contributed to significant stress and worry about delays in necessary care. Parents also frequently described the burden placed on them by the discontinuity of assigned bedside nurses, residents, attendings, and other care providers. Several parents described that individual providers would make consequential decisions about care (e.g., when to extubate), only for the next provider to reverse the decision during the following shift. One parent described the emotionally overwhelming experience of witnessing two attendings disagree on treatment decisions during rounds (Quote-2). Parents agreed that providers should resolve internal disagreements as a team before presenting options to parents.

Families ignored by the clinical team

Parents cited feeling ignored by team members as an additional barrier to communication. Specifically, parents wanted providers to acknowledge their *preferences* for care, *concerns* about changes in medical status, and the *urgency* of these concerns. Several parents described the experience of noticing a change in their child’s behaviour or physical appearance, and feeling that their concerns were dismissed by providers when vitals were otherwise stable. When these children then experienced changes in medical status (e.g., respiratory distress and infection), parents felt that their input could have prevented negative outcomes (Quote-3). Parents said these experiences forced them to become increasingly vigilant for signs of potential decline, and they felt that they could not rely on providers to be advocates for their child’s needs.

Table 1. Parent (n=23) and patient (n=18) demographics and clinical characteristics.

Patient and parent characteristics	Frequency N (%)
Reason for cardiac ICU admission	
Medical condition	5 (28)
Pre-operative cardiothoracic surgery	9 (50)
Post-operative cardiothoracic surgery	2 (11)
Post-cardiac catheterisation	2 (11)
Child primary cardiac diagnosis	
Hypoplastic left heart syndrome	8 (44)
Other critical congenital heart disease	8 (44)
Cardiomyopathy	2 (11)
Child cardiac ICU average stay at time of interview in days (SD)	55 (46.8)
Child's age at admission (months)	
< 1	9 (50)
1-5	3 (17)
6-12	2 (11)
> 12	4 (22)
Family meeting while in cardiac ICU	
Yes	14 (78)
No	4 (22)
Relationship to child*	
Mother	18 (78)
Father	4 (17)
Legal guardian	1 (4)
Parent's race/ethnicity*	
White	14 (61)
Black	3 (13)
Hispanic	3 (13)
Other	1 (4)

Overwhelmed by too many team members/questions

Several parents reported that these gaps in communication were exacerbated by the number of team members involved in their child's care (Quote-4). One parent said that providers spent more time repeating *who* they were than *what* they were doing for their son.

Team Practices that Facilitated Communication Parental preferences for communication

Parents consistently wanted timely, regular, transparent updates about their child's medical status. Parents also wanted an understanding of the long-term outlook for hospital care, with real-time updates to this plan as needed (Quote-5). Transparency was supported by providers who communicated the thought process behind their decision-making. One parent described feeling less like a "bystander" and more confident about their child's care when they understood the rationale behind provider decision-making.

Parents frequently described wanting to know all available information (Quote-6), "whether it's good, bad, or in between."

Multiple parents stated that they did not want information "sugar-coated" and did not want providers to attempt to minimise the impact of potentially difficult news. Parents preferred to feel prepared and not be "blindsided" by a negative outcome. One parent said that they felt well supported when an attending shared difficult news and then offered emotional support, rather than attempting to present a falsely positive outlook. Another parent dyad felt frustrated when team members repeatedly warned them of the "ups and downs" of their child's treatment course, without specifically describing what those "downs" might be. In contrast to feeling *ignored*, as described above, parents felt that communication was facilitated by feeling *heard* and being treated as a valued member of the team (Quote-7). Parents also felt that an identified continuity clinician would help to address gaps and delays in communication (Quote-8).

Beneficial team communication behaviours

One specific team practice that facilitated communication was explaining medical jargon. Parents preferred that providers anticipate that parents may not understand medical terminology and proactively clarify, rather than relying on parents to identify their own misunderstandings (Quote-9). Parents appreciated when explanations were reworded several different ways to increase information uptake. Parents also preferred that providers elicit parent questions and remember to follow up on unanswered questions during subsequent meetings (Quotes-10 and 11). Beyond the content of communication, parents valued providers who took extra time to listen to parent concerns and provide information, separate from rounds. Communication between parents and providers was facilitated when providers expressed care for parents' well-being and for parents' communication preferences (Quote 12).

Preparation for Family Meetings

Team practices for preparation, parental preferences for preparation, and experiences when learning about the family meeting

Parents spoke highly of family meetings as an opportunity to reconcile inconsistencies in communication and allow parents to feel like valued members of their child's care team. Common practices for family meeting preparation included providing information to parents about who would attend the meeting, including names and roles in their child's care, the general structure of the meeting, and the general content to be discussed (Quote-14). Parents liked knowing that this would be an opportunity to discuss "the big picture" of their child's treatment course and wanted to be told to prepare questions ahead of time (Quote-15). Parents also wanted to know explicitly whether new information about their child's condition would be provided or not, so they could prepare to receive potentially difficult news. Some parents expressed apprehension about team meetings and would have appreciated reassurance ahead of time about the meeting content (Quotes-16 and 17).

Discussion

Communication with medical teams represents a critical and modifiable determinant of long-term outcomes for families of children admitted to the cardiac ICU. Despite this, studies aimed at improving engagement in medical decision-making and coping with potentially traumatic events during cardiac ICU admissions tend to focus on parent behaviours, with few studies intervening

Table 2. Themes and subthemes identified from the qualitative data.

	Major theme	Subtheme
Team practices that impeded communication	<p>Inaccurate/incomplete communication with families: Parents feeling that the team/clinicians were providing inaccurate or incomplete communication to the family.</p> <p>Inconsistent within team communication/coordination: Parents feeling that the team was not on the same page and were not communicating well with each other.</p> <p>Families ignored by the clinical team: Parents feeling that clinicians are ignoring them or dismissing their concerns regarding their child's care.</p> <p>Overwhelmed by too many team members/questions: Families overwhelmed by the number of different clinicians involved in their child's care, and the number of questions they were asked.</p>	
Team practices that facilitated communication	<p>Parental communication preferences: The things parents had or wanted that they believed would facilitate communication for them.</p> <p>Beneficial team communication behaviours: Practices that the team engaged in that parents believe facilitated communication.</p>	<p>Transparency and in the loop: Transparency refers to "all the information" being given and in the loop refers to the "frequency of information" that families get.</p> <p>Want to know everything: Families expressed that they want to know everything, the good and the bad, and not have overly optimistic information only. They want to feel prepared for all that can happen.</p> <p>Family feeling heard (voice included): Parents felt that it was beneficial when their voice was heard by the clinical team.</p> <p>Continuity person: Having a constant point person to help navigate their child's care.</p> <p>Jargon explained: Having medical jargon explained or having someone communicate in 'plain English.'</p> <p>Eliciting parental questions and following up on unanswered questions: Team members proactively checking in regarding parental questions and following up with answers if they didn't know the answer right away.</p> <p>Team support: How the team supported families emotionally or socially during the meeting or throughout the meeting planning process.</p>
Preparation for family meetings	<p>Team practices for preparation: The ways in which the team prepared families to have a family meeting.</p> <p>Parental preferences for preparation: Ways in which the family would have liked to be prepared, including preparation that was missing.</p> <p>Experiences when learning about the family meeting: How the family/parent felt when they were told they would be having a meeting.</p>	

with medical teams and their communication to families. The current study characterised the experience of communicating with providers in the cardiac ICU and preparing for family meetings with cardiac critical care teams to inform future interventions. We heard from parents that when teams incorporated parental preferences into communication practices, parents felt a greater sense of control, which alleviated emotional distress related to the uncertainty of their child's admission. Inconsistent and incomplete communication contributed to frustration, shock, and worry; however, family meetings emerged as a valued opportunity to address these barriers and to optimise patient care while supporting family well-being.

This study identified several experiences of team practices that impeded communication and increased emotional distress for families, namely communication described as inconsistent within team members or incomplete when delivered to families.

Inconsistent communication burdened parents, contributing to stress as parents took on the role of mediating team member disagreements. Incomplete communication left parents feeling that information was concealed from them, which eroded trust in medical providers. Feeling ignored by team members comprised an additional barrier. When parents felt that their preferences for care, concerns about medical status, and the urgency of these concerns were ignored by team members, they experienced heightened vigilance to changes in their child's appearance and behaviour that might indicate decline. Our findings are in line with past studies which demonstrate that receiving conflicting information from too many providers leads to poorer communication and decreased parent preparedness for medical decision-making,^{12,24} and that the heightened vigilance reported by parents of children with advanced heart disease portends the later development of post-traumatic stress symptoms for parents.²⁵ Our study contributes

Table 3. Representative quotes.

Theme or subtheme	Quote
Inaccurate/incomplete communication with families	<ul style="list-style-type: none"> “We’ve been here three weeks. And multiple times, they have moved him and not told us. We show up and the bed’s empty. And we immediately freak out. We’re like, ‘what the hell is going on?’ ‘Oh, I’m sorry. We forgot to tell you.’ They moved him two pods down. It’s like, what the hell? And it happened again. And then it happened again . . . and there was a couple times where he had a bad night and we weren’t here, obviously, like 2:00 o’clock in the morning. And then the next morning we show up and we hear all these horrid things we would have showed up for.”
Inconsistent within team communication/ coordination	<ul style="list-style-type: none"> “One time in the very beginning when he was on ECMO, before transplant, right in rounds there was two physicians in rounds for one reason or another, two attendings, and they completely disagreed and it was kind of hard to follow because I didn’t know either one of them really at that point and I didn’t have oh, well, I trust this one more than the other, kind of experience and it was a little overwhelming.”
Families ignored by the clinical team	<ul style="list-style-type: none"> “I feel like a lot of time . . . when she was first out of surgery . . . we were over in the cardiac ICU and she was off her medication and they were moving her to the stepdown unit. I said for like three days straight that my daughter was not acting the way she normally does. She was hitting and kicking nurses. She was angry and that was not my child. And I brought this up numerous times and I just kept getting told, ‘oh, this is normal 3-year old behaviour. She’s just a 3-year old,’ this and that. And I knew it wasn’t that. And then when we came over to the CCU, we were only over here for about eight hours before they had to transfer us back because they found out she did in fact have something wrong and had an infection and had to get completely reopened again”
Overwhelmed by too many team members/ questions	<ul style="list-style-type: none"> “I think it’s hard because you have so many doctors. Like, I mean, he has a cardiac physician and then like a general physician and you have the surgeons and then you have the doctors who are in the cardiac ICU, like the rounds doctors. And then, of course, there’s the numerous doctors who come by for studies. That would probably feel like we had like, I don’t know, ten plus doctors. And keeping track of everybody is quite challenging.”
Transparency and in the loop	<ul style="list-style-type: none"> “So we basically did a whole restart on [communication]. But, I mean, it was helpful to hear, like, we expect it to be three weeks doing these medications and two weeks to do this and blah, blah, blah. That was helpful because parents want timelines. Like, sitting here every day, not knowing, like, okay. Well, am I going to be discharged next week? Like, we like dates. We like timeframes.”
Want to know everything	<ul style="list-style-type: none"> “I don’t think it’s everyone’s approach. I just feel like the questions I ask are very direct, so, kind of, they have to give me a direct answer. For example, I asked – he was on ECMO, so I had asked them if you can code on ECMO – because you think ECMO’s doing all the work and they’re fine – but no, that’s not the truth. So to hear – I mean, somebody could sit there and say, oh, well, it’s not very likely or this – no, but I said can you code on ECMO, and that’s a yes or no question.”
Continuity person	<ul style="list-style-type: none"> “And I think having to keep explaining that to doctors, I think what would make that type of communication better is to know that I have one point person who is following him throughout I think is really the only critique I could make or criticism I could make of the communication there. I appreciate having a team approach because when you get lots of different ideas, but sometimes you have to limit how many times you experiment with a kid.”
Family feeling heard (voice included)	<ul style="list-style-type: none"> “I’ve always felt, like, when I do speak up that I am included as part of the team, that the doctors do listen to me, and that they’re willing to take it into consideration. And even today, I spoke up about something that we’ve been going - it’s happened multiple times and the doctor listened and said,,, “Okay. We’re going to do what mom suggested”, and I felt like I wasn’t just another – like, I was kind of a valuable input in his care is the way that I was treated, and I really appreciated that.”
Jargon explained	<ul style="list-style-type: none"> “We had one nurse at kind of a critical time who we really trusted and had good communication with. And she would – my wife is very medically savvy. She’s a doctor, veterinarian, and so she understands all of the talk. I don’t. I’m an attorney, so I have a different background. And the nurse would like just break it down to like medicine for dummies for me.”
Eliciting parental questions and following up with unanswered questions	<ul style="list-style-type: none"> “Oh, everyone answered questions really well. I feel like in general any time we ever had a question it was answered very quickly either by the nurse or if the nurse didn’t know, she would get a doctor and the doctor would handle it.” “I think after they come talk – if they’re talking about a procedure or a diagnostic tool, I feel like they are very good at asking, do you have any questions? Are you sure? Is there anything else you need to know or you want to know?”
Team support	<ul style="list-style-type: none"> “They just told me that if I ever needed to step away and leave the room for a little bit, there’s always somebody I could talk to. I could get them to sit with my son - that I could take care of myself, as well. I can’t just worry about him.”
Team practices for preparation	<ul style="list-style-type: none"> “. . . telling us that [the family meeting] was just to update us, make sure that we’re all on the same page, and be able to answer any questions and have the entire team there so that it was - we were sure to get the entire picture of what was going on, what was found, and what our plans were going forward, and to answer any questions. So it’s pretty much what they told us and then we found out [what we were actually] discussing when we were there in the meeting itself.”

(Continued)

Table 3. (Continued)

Theme or subtheme	Quote
Parental preferences for preparation	<ul style="list-style-type: none"> • “Maybe to say [do you] have any specific questions that maybe you have thought of during the day or just the overall stay that maybe I wasn't comfortable speaking [about] at the bedside – things like that.”
Experiences when learning about the family meeting	<ul style="list-style-type: none"> • “I guess hindsight's 20/20, right? I was so anxious, because I thought I was going to get bombarded with something that maybe I didn't know – so they were going to kind of just put me in a room and – so morbid – but give me bad news.” • “We just – well, having the name of chronic team kind of made us a little nervous, so I feel like more of an explanation would have been nice. I mean, they calmed our nerves saying, like, it's nothing to be worried about, but just being part of a team that's called the chronic team made us a little eerie of the situation. It didn't sound good to us. We thought, like, something was wrong with our daughter.”

additional insight into the mechanisms through which these barriers to communication may contribute to long-term stress for families, which should be validated in future prospective studies of communication in the cardiac ICU.

In agreement with past studies,²⁶ we found that key facilitators of communication included timely, regular, transparent updates regarding medical status and treatment, as well as communication practices that supported parents in understanding the information provided to them. It is known that these communication practices support parents' desire to play an active role in their child's care¹ and to fulfil their parental role even when they cannot provide hands-on care.²⁷ Our findings additionally underscore the impact of these facilitators on parental emotional well-being. When parents' communication preferences are honoured by their child's medical team, parents feel less like “bystanders” and experience a sense of control that may decrease the likelihood that, if potentially traumatic events do occur, they are experienced with shock and helplessness. Care teams should assume a collaborative stance in conversations with parents, treating them as valued team members who benefit from the provision of honest information and who provide essential information about their child's medical status and needs in return.

For families in our study who participated in family meetings, these were viewed as opportunities to address potential barriers to care by reconciling inconsistencies, clarifying miscommunications, and allowing parents to feel like valued members of their child's care team. For children in the cardiac ICU, whose prognosis is often uncertain and unpredictable,²⁸ past research indicates that parent and physician prognostic concordance may be particularly low, contributing to parent difficulty participating in decision-making²⁹ and highlighting the particular need for family meetings. This study is the first to characterise parental experiences of preparation for family meetings in the cardiac ICU and found that parents often were told who would be involved, the general structure and content of meetings, and to prepare any questions they have for the team prior to meetings. Parents additionally would have preferred to be informed about the purpose of the meeting. For some parents, the uncertainty associated with attending a new and unfamiliar type of meeting elicited worry, and parents preferred that a member of the team meet with them ahead of time to let them know whether new information about their child would be discussed.

While this study provides valuable information for teams caring for children in the cardiac ICU, several limitations should be noted. Study data were collected from a single site and therefore may not generalise to children's hospitals in other regions or countries, particularly when cultural approaches to communication may differ. Relatedly, participants in the current study were exclusively English-speaking. Thus, future research should aim to understand

cultural variations in communication preferences in cardiac ICU settings to further personalise and individualise care. While this study highlights themes likely relevant to other critical care settings, all patients in the current study were receiving care for a primary cardiac diagnosis, and most patients in the study were under 5 years old. Additional research is needed to understand team communication practices in neonatal and paediatric ICU settings where diagnoses and treatment courses may be more diverse. Particularly in the case of paediatric ICUs, where patients may be older and more able to participate in decision-making, studies should elicit experiences of communication from patients themselves. Future research should design and test interventions that aim to optimise communication and preparation for family meetings based on the barriers and needs identified in the current study. Interventions that target medical team communication practices in critical care settings are likely to support psychosocial well-being for families long after discharge.

Conclusion

This study identified that inconsistent and incomplete communication as well as team practices that ignore parental concerns and preferences further increase emotional distress for families who are already experiencing helplessness and fear due to the unpredictable and uncertain nature of their child's critical cardiac illness.³² When parents are treated as valued members of the care team and provided with timely, regular, transparent updates, they are less likely to feel blindsided by unexpected events and more likely to feel a sense of control over their child's outcomes, even in the face of prognostic uncertainty. Family meetings represent a critical opportunity to repair fractures in trust between families and care teams and to optimise communication between parties.

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