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Parental communication satisfaction with the clinical team in the paediatric cardiac ICU

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Abstract

Introduction Understanding parents' communication preferences and how parental and child characteristics impact satisfaction with communication is vital to mitigate communication challenges in the cardiac ICU. Methods This cross-sectional survey was conducted from January 2019 to March 2020 in a paediatric cardiac ICU with parents of patients admitted for at least two weeks. Family satisfaction with communication with the medical team was measured using the Communication Assessment Tool for Team settings. Clinical characteristics were collected via Epic, Pediatric Cardiac Critical Care Consortium local entry and Society for Thoracic Surgeons Congenital Heart Surgery Databases. Associations between communication score and parental mood, stress, perceptions of clinical care, and demographic characteristics along with patient demographic and clinical characteristics were examined. Multivariable ordinal models were conducted with characteristics significant in bivariate analysis. Results In total, 93 parents of 84 patients (86% of approached) completed surveys. Parents were 63% female and 70% White. Seventy per cent of patients were <6 months old at admission, 25% had an extracardiac abnormality, and 80% had a cardiac surgery this admission. Parents of children with higher presurgical risk of mortality scores (OR 2.875; 95%CI 1.076-7.678), presence of surgical complications (72 [63.0, 75.0] vs. 64 [95%CI 54.6, 73] (p = 0.0247)), and greater satisfaction with care in the ICU (r = 0.93922; p < 0.0001) had significantly higher communication scores. Conclusion These findings can prepare providers for scenarios with higher risk for communication challenges and demonstrate the need for further investigation into interventions that reduce parental anxiety and improve communication for patients with unexpected clinical trajectories

Parents of children with advanced heart disease experience severe distress, leading to depression, anxiety, and post-traumatic stress symptoms. All Making difficult decisions, the feeling of losing their parenting role, and the uncertainty of their child's prognosis are some of the major stressors that parents describe. Communication with critical care clinicians can significantly impact these experiences either worsening or mitigating them. Parents describe a need for emotional support and consistently report wanting honest and timely information on their child's condition. All of the support of the service of the support of the support of the service of the support of th

Importantly, communication challenges have themselves been cited as a significant source of stress for parents of children admitted to the cardiac ICU. ¹² Parents often feel that they receive insufficient and inconsistent information, leaving them unprepared for participating in the decision-making process, ^{11,13} and in some cases for their child's death.^{5,14} Long-stay parents, who usually become more familiar with the staff and their child's condition, also report poor communication to be a major source of conflict in the paediatric ICU. ¹⁵ These parents experience distress more consistently and have a more difficult time coping with their child's illness.^{7,16}

The negative impact of suboptimal communication on families underscores the importance of gaining a clearer understanding of parents' satisfaction with communication and how both parental and child characteristics may impact satisfaction with communication. However, literature on the lived experiences of families with team communication in the cardiac ICU is scarce. Without a better understanding of these factors, interventions that aim to optimise team communication with families during their child's cardiac ICU admission are less likely to successfully support parent's involvement in medical decision-making and promote long-term psychosocial well-being for families.

The current study aimed to assess a parental cohort's satisfaction with communication with the cardiac ICU clinical team and describe the parental and patient characteristics and a small number of system-level factors at the time to determine any associations that may exist between the two. Conceptual models about parental stress and how severity of illness results in different communication functions being more likely to result in satisfaction with communication and trust.¹⁹ We hypothesised that not only parental anxiety and depression would impact parental perception of communication but that the severity of illness of their child and clinical interventions like participation in a family meeting or the involvement of sub-specialty palliative care may be correlated with satisfaction with communication. We measured satisfaction of communication with the clinical team using the Communication Assessment Tool for Team setting^{20,21} and sought to examine how satisfaction was correlated with parental demographics, anxiety, depression, perceptions of clinical care, and their child's health status.

Materials and methods

Setting and design

This was a cross-sectional survey study of parents of cardiac ICU patients conducted from April of 2018 to March of 2020 in an urban children's hospital with 32 cardiac ICU beds.

Participants

Parent-patient dyads were enrolled for patients who had already been admitted to the cardiac ICU for at least 2 weeks or had been admitted for at least 7 days with a projected stay of 2 weeks or greater at the time of enrollment. Legal guardians were eligible if they were >18 years old, if their child was under 18 years old, if they were English-speaking, and if they were the legal decision-maker for their child.

Data collection

Data from parents were obtained via a REDCap online survey. Patient characteristics were obtained via three data sources. The electronic medical record, Epic, provided information regarding palliative care consultation, whether they had been part of a planned family meeting initiated by the cardiac ICU to optimise communication with families for longer-stay patients (a meeting termed chronic care rounds), and data about do not resuscitate orders. The Society for Thoracic Surgeons Congenital Heart Surgery Database²² provided the STAT (The Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery) score measuring the risk for mortality associated with congenital heart surgery procedures. Scores range from 1 to 5 with higher scores being correlated with higher morbidity risk. Finally, the Pediatric Cardiac Critical Care Consortium local entry database registry²³ included hospital encounter reason (medical, preoperative, or post-operative), whether the patient had surgery during this admission, whether the cardiac surgery required cardiopulmonary bypass, whether there was a post-operative complication (including reoperation, open sternum, respiratory, infectious, and neurologic or gastrointestinal complications), whether the patient was ventilated at the time of the survey, whether the patient had an extracardiac abnormality or a chromosomal abnormality, cardiac ICU length of stay, health insurance type, hospital disposition, and major complication defined by Pediatric Cardiac Critical Care

Consortium. A proxy for child health status at the time of survey was created by cardiac intensivists as part of this study and was used to broadly differentiate patients across the spectrum of treatment options. The two factors included were vasoactive inotropic score and extracorporeal membrane oxygenation or ventricular assist device status and the four categories, including "good" if vasoactive inotrope score is zero and the patient was not on extracorporeal membrane oxygenation or ventricular assist device; "modest" if vasoactive inotrope score <=10 and no extracorporeal membrane oxygenation or ventricular assist device; "poor" if vasoactive inotrope score =11+ and no extracorporeal membrane oxygenation or ventricular assist device; and "worst" if vasoactive inotrope score =0 but required extracorporeal membrane oxygenation or ventricular assist device.

Survey measure

Parental survey included sections on parent-patient demographics (race, gender and ethnicity), parental characteristics (education level, income, partnered status, and who they make decisions about their child's care with), and the number of times their child had been hospitalised prior to this hospitalisation. Race was categorised as White, Black or Other, where "Other" was Asian, American Indian or Alaska Native, and Native Hawaiian or Pacific Islander or more than one race.

Based on conceptual models connecting parental anxiety, communication techniques, trust in physicians, severity of illness, and satisfaction with communications, 18,19 parents completed surveys with multiple measures. Parental satisfaction with communication used the Communication Assessment Tool for Teams,²⁰ a 15-item measure that measures patient/family perception of communication with the medical team and is adapted to team environments on a one to five scale with five being 'excellent' (range 0–75) (Cronbach's alpha in the present sample, $\alpha = 0.95$). Parental satisfaction with decision-making and care was measured using paediatric family satisfaction in the ICU,²⁴ a 24-item measure with five-point Likert scale responses with two subscales (care and decision-making) that is converted to a 100-point scale when scored ($\alpha = 0.97$). The survey also included the Trust in Physician Scale (TiPS),²⁵ a 11-item measure with fivepoint Likert responses (range 0-55) ($\alpha = 0.89$), and the Hospital Anxiety and Depression Scale, 26,27 a 14-item measure with fourpoint Likert scale measuring parental anxiety and depression in the prior week in separate subscales (range 0-21 for each subscale) (α = 0.91). Standard clinical cut-offs are used for both subscales and are categorised into normal (0-7), borderline (8-10), and elevated (11-21) scores. Finally, the Impact of Event Scale-Revised²⁸ measured parental traumatic stress in the prior 7 days with 22 items using a five-point Likert scale (range 0–88) (α = 0.93). For the scales Impact of Event Scale-Revised, Trust in Physician Scales, Hospital Anxiety and Depression Scale, Communication Assessment Tool for Teams, and Pediatric Family Satisfaction in the ICU, if <25% of each respondent's items were missing, we assigned the median value of the same respondent's non-missing items. No respondents had more than 25% missing data.

Statistical analyses

Parental and patient characteristics are reported via descriptive statistics. Communication Assessment Tool for Teams was analysed as a composite score (range of options from 15 to 75) and is reported with the most and least frequent individual items selected as 'excellent'. The scores of this measure are non-normally

distributed, so we present the comparative results as medians and interquartile ranges. To investigate the association between demographic and clinical variables and the satisfaction with communication (Communication Assessment Tool for Teams), bivariate associations are presented with the continuous version of the Communication Assessment Tool for Teams via Kruskal-Wallis and Wilcoxon rank sum tests where appropriate. Due to the non-normal distribution of the communication scores, we recoded the scores into quantiles and a multivariable ordinal model was conducted. This model included variables that were significant from bivariate relationships. Collinearity was assessed among the variables, and only non-colinear variables were included in the models. Variables with more clinical relevance in terms of parental stress and that were more distinct from other variables included were prioritised when selecting which variables to retain in the model. Analyses were conducted in SAS and Stata Version 17. Analysis had a predetermined significance of p-value equal to or less than 0.05 and power calculations demonstrated power of 0.8 to identify a correlation between anxiety and satisfaction with the expected enrolment of 120 parents.

Results

Participant characteristics

Parents

One hundred eighteen parents of 109 patients were screened as eligible; 10 parents were not approached because of the COVID-19 pandemic, which prohibited research personnel from recruiting in clinical spaces for several months. Ninety-three parents (86% of approached) of 84 patients completed surveys with nine patients having two parents complete surveys. Two-thirds of parents were female, and 70% were White (Table 1). A total of 83% reported making decisions for their child with another parent. Approximately 1/3 of parents demonstrated an elevated level of anxiety.

Patients

Seventy per cent of patients were <6 months old at admission, 46% were female, 61% were White, and 25% had an extracardiac abnormality (Table 1). Only 21% of patients had not been hospitalised previously. Over 80% had a cardiac surgery during this admission, with 70% of those patients having some kind of post-operative complication. The most common post-operative complications included arrhythmia requiring therapy (40%), sternum left open post-operatively (33%), and seizures (17%). Half of the patients had been discussed at the formal family meeting in the cardiac ICU, and 22% had a sub-specialty palliative care consult. The average length of stay among surveyed parents in the cardiac ICU was 45 days (SD 37.8), with 6% of patients dying during the hospitalisation. (Supplemental tables A and B)

Communication satisfaction scores

Figure 1 demonstrates the distribution of the communication satisfaction scores across all respondents [median 74, IQR(60–74)]. Individual items in the measure with the lowest per cent of excellent scores included: "Involved me in decisions as much as I wanted" (47.3%) and "Talked in terms I could understand" (47.3%) (Fig 2). Items with the highest per cent excellent scores included "Treated me with respect (physician)" (69.9%); "Gave me as much information as I wanted" (67.7%); and "Let me talk without interruptions" (65.5%).

Communication satisfaction scores and associated characteristics

Parents with elevated levels of anxiety were more likely to rate their communication satisfaction lower than parents with normal levels of anxiety (median 63.0 [IQR: 48.0, 72.0] versus median 73.0 [IQR: 65.0, 75.0]; p=0.0124) (Table 1). Parents were also more likely to rate communication satisfaction lower if they had higher levels of persistent stress symptoms on Impact of Event Scale-Revised (r=-0.24; p=0.0288), if their child had a lower risk of mortality via STAT score (p=0.0248) or if their child did not have a surgical complication (p=0.0247). The Communication Assessment Tool for Teams score was highly correlated with Trust in physician scores (r=0.49; p<0.001) and the Pediatric Family Satisfaction in the ICU scale (r=0.94; p<0.001).

There was no statistically significant correlation between Communication Assessment Tool for Teams scores and participation in the family meeting, sub-specialty palliative care consultation, or child health status.

Adjusted analysis of communication satisfaction scores and associated characteristics

Based on the preceding analysis, we constructed a multivariable ordinal model of the categorised Communication Assessment Tool for Teams scores as the outcome and elevated parental anxiety, risk of mortality score, and the parental stress Impact of Event score (Table 2). Of note, the model did not include surgical complications (due to collinearity with the STAT score) nor trust in physicians (due to collinearity with Impact of Event Scores). The model did include participation in the family meeting as this was the intervention of interest for the study. In this model, mortality risk scores were significantly related to Communication Assessment Tool scores, in that parents of patients with higher mortality scores also had higher communication scores (OR 2.88, 95% CI 1.076-7.678). Additionally, the relationship between parents with elevated anxiety and lower Communication Assessment Tool for Teams scores was borderline significant (p = 0.051).

Discussion

As clinical teams work to achieve better communication and decision support for families of children with serious illnesses, identifying clinical situations at high risk for communication challenges may prove helpful. In this single-centre, cross-sectional survey of parents of longer-stay cardiac ICU patients, we identified several parental and patient characteristics that were correlated – either positively or negatively – with their satisfaction with communication: parental anxiety, surgical risk of mortality, whether there was a post-surgical complication, and trust in physicians.

Let us consider each of these characteristics in turn. First, parents who experienced elevated levels of anxiety were less likely to be satisfied with their communication with the medical team. This is consistent with other findings^{6,12} and may contribute to a negative feedback loop of suboptimal communication exacerbating levels of anxiety, which may further hinder successful communication. Increased anxiety has long-term negative effects on family members' own health and their ability to successfully care for their children when they are discharged from the hospital.² Elevated levels of anxiety have been reported in almost all settings of parents of children with serious illness and should be

 Table 1. Parent demographics, mood, and perceptions of clinical care by CAT-T score and patient demographics and clinical characteristics by CAT-T score.

| Parent characteristics | Frequency n (%) | CAT-T overall score, median [IQR] | p value |
|---|-------------------------------------|---|---------|
| Parent gender | n = 93 | | |
| Male | 34 (36.56) | 72.5 [66.0, 74.0] | 0.0767 |
| Female | 59 (63.44) | 66.0 [54.6, 74.0] | |
| Parent race | n = 93 | | |
| White | 66 (70.97) | 69.5 [63.0, 74.0] | 0.8979 |
| Black or African American | 15 (16.13) | 71.0 [54.6, 74.0] | |
| Other | 12 (12.90) | 73.0 [35.5, 74.0] | |
| Parent Hispanic | n = 82 | | |
| Not Hispanic | 71 (76.34) | 70.0 [59.0, 74.0] | 0.2647 |
| Hispanic | 11 (11.83) | 74.0 [66.0, 75.0] | |
| Parent employment status | n = 93 | | |
| Employed full time | 63 (67.74) | 72.0 [63.0, 75.0] | 0.131 |
| Employed part-time | 7 (7.53) | 71.0 [40.0, 75.0] | |
| Unemployed | 23 (24.73) | 65.0 [57.0, 73.0] | |
| Parent relationship status | n = 93 | | |
| Single | 35 (37.63) | 70.0 [54.6, 75.0] | 0.946 |
| Married/Partnered | 58 (62.37) | 71.0 [63.0, 74.0] | |
| Who makes healthcare decision for your child? | n = 93 | | |
| I do | 15 (16.13) | 73.9 [63.0, 75.0] | 0.204 |
| I do with other parent | 78 (83.87) | 70.5 [59.0, 74.0] | |
| Total household income | n = 91 | | |
| < \$40,000 | 29 (31.18) | 72.0 [60.0, 75.0] | 0.8502 |
| \$40,001 to \$100,000 | 31 (33.33) | 68.0 [60.0, 75.0] | |
| More than \$100,000 | 31 (33.33) | 71.0 [63.0, 74.0] | |
| Parental anxiety | n = 93 | | |
| Normal | 48 (51.61) | 73.0 [65.0, 75.0] | 0.0124 |
| Borderline | 19 (20.43) | 68.0 [59.0, 74.0] | |
| Elevated | 26 (27.96) | 63.0 [48.0, 72.0] | |
| Parental depression | n = 92 | , | |
| Normal | 72 (77.42) | 72.0 [63.0, 74.5] | 0.129 |
| Borderline | 13 (13.98) | 68.0 [42.0, 71.0] | |
| Elevated | 7 (7.53) | 63.0 [33.0, 74.0] | |
| | Mean (SD), median, [IQR] | Correlation coef | |
| Parental impact of event (IES-R) (N = 84) | 43.67 (15.3), 38.5, [32.5, 51.0] | -0.23868 | 0.028 |
| | Mean (SD), median, [IQR] | Correlation coef | |
| Trust in physician (N = 90) | 35.54 (3.2), 36.0, [34.0, 37.0] | 0.49363 | <0.000 |
| Pediatric family satisfaction with care (PFS-ICU) | Mean (SD), median, [IQR] | Correlation coef | |
| Total score | 80.54 (19.8), 87.0, [72.8, 94.8] | 0.93922 | <0.000 |
| Care subscale | 81.79 (20.2), 90.4, [71.2, 96.4] | 0.90379 | <0.000 |

(Continued)

Table 1. (Continued)

| Parent characteristics | Frequency n (%) | CAT-T overall score, median [IQR] | p value |
|---------------------------|-------------------------------------|--|---------|
| Decision-making subscale | 78.78 (21.3), 82.5, [72.5, 95.0] | 0.90049 | <0.000 |
| Patient characteristics | Frequency n (%) | Parental CAT-T overall score, n, median [IQR] | p valu |
| Age at admission | n = 84 | | |
| <6 months | 60 (71.43) | n = 68 71.0 [62.0, 75.0] | 0.246 |
| 6-12 months | 4 (4.76) | dropped | |
| >12 | 20 (23.81) | n = 21 70.0 [59.0, 74.0] | |
| Child gender | n = 84 | | |
| Male | 45 (53.57) | n = 50 72.5 [60.0, 75.0] | 0.099 |
| Female | 39 (46.43) | n = 43 68.0 [59.0, 74.0] | |
| Child race | n = 84 | | |
| White | 52 (61.90) | n = 57 71.0 [63.0, 75.0] | 0.514 |
| Black or African American | 17 (20.24) | n = 18 71.5 [59.0, 74.0] | |
| Other | 15 (17.86) | n = 18 66.0 [51.0, 74.0] | |
| Child Hispanic | n = 84 | | |
| Not Hispanic | 70 (83.33) | n = 76 71.0 [60.5, 74.0] | 0.845 |
| Hispanic | 14 (16.67) | n = 17 68.0 [54.6, 74.0] | |
| Syndrome | n = 84 | | |
| No | 63 (75.00) | n = 71 71.0 [63.0, 74.0] | 0.496 |
| Yes | 21 (25.00) | n = 22 70.5 [54.6, 74.0] | |
| Surgery this admission | n = 84 | | |
| No | 14 (16.67) | n = 16 65.5 [58.0, 73.0] | 0.177 |
| Yes | 70 (83.33) | n = 77 71.0 [60.0, 75.0] | |
| STAT score | n = 84 | | |
| Not applicable | 22 (26.19) | n = 24 67.0 [59.0, 73.0] | 0.024 |
| Score 1-3 | 19 (22.62) | n = 23 65.0 [42.0, 74.0] | |
| Score 4-5 | 43 (51.19) | n = 46 73.0 [65.0, 75.0] | |
| Surgical complication | n = 84 | | |
| No | 24 (28.57) | n = 27 64.0 [54.6, 73.0] | 0.024 |
| Yes | 60 (71.43) | n = 66 72.0 [63.0, 75.0] | |
| | | | |

(Continued)

Table 1. (Continued)

| Parent characteristics | Frequency n (%) | CAT-T overall score, median [IQR] | p value |
|---|--------------------|--------------------------------------|---------|
| Child health status (VIS score and ECMO/VAD status) | n = 55 | | |
| Good | 11 (13.10) | n = 11 74.0 [64.0, 74.0] | 0.3857 |
| Modest | 30 (35.71) | n = 30 69.0 [60.0, 73.0] | |
| Poor | 5 (5.95) | n = 5 72.0 [71.0, 75.0] | |
| Worst | 9 (10.71) | n = 9 72.0 [65.0, 73.9] | |
| Major complication | n = 84 | | |
| No | 45 (53.57) | n = 50 70.5 [59.0, 74.0] | 0.6623 |
| Yes | 39 (46.43) | n = 43 71.0 [60.0, 75.0] | |
| Discussed at chronic care rounds | n = 84 | | |
| No | 41 (48.81) | n = 45 68.0 [59.0, 74.0] | 0.2275 |
| Yes | 43 (51.19) | n = 48 71.5 [60.5, 75.0] | |
| Palliative care consultation | n = 84 | | |
| No | 65 (77.38) | n = 74 68.5 [59.0, 74.0] | 0.197 |
| Yes | 19 (22.62) | n = 19 73.0 [65.0, 75.0] | |

*When cell size was <5, the distribution is not shown.

expected.^{29,30} Thus, the extent to which better communication can reduce anxiety and traumatic stress for families is an important area of further investigation.

Second, trust or the lack thereof. Other research has identified historical and contemporary distrust in the healthcare system by minoritised communities and corresponding dissatisfaction with communication.³¹ However, our study did not find statistically significant differences in satisfaction by race or ethnicity of the parent or children in our study. Similar findings were reported with no differences between Latino and White families in the paediatric ICU at an institution with a substantial Latino population.³² Recent work demonstrated that mistrust in medical providers, perceived discrimination, and less communication with providers³³ were better predictors of differences between adults who described feeling more versus less prepared for their serious illness. Experiences of discrimination may be pervasive in minoritised races, but not uniform, and therefore, they are a better predictor of partnership with the healthcare team than race itself. Additionally, some of the described differences in satisfaction could be modifiable through improved communication between the healthcare team and families. Our study demonstrated a strong correlation between trust in physicians and satisfaction with communication. For patients and families who have less trust in the clinical team, this offers the possibility that family-centred communication, which addresses a parents' concerns, may be a way to rebuild trust or to develop it from the beginning.

Third, the patient's risk of surgical mortality. Counterintuitively, parents of children with lower risk mortality scores and no post-surgical complications experienced lower levels of satisfaction with communication than parents of children with higher risk mortality scores and who had suffered surgical complications. One potential explanation for this finding is that patients admitted for low-risk procedures or who do not have postsurgical complications would be expected to be discharged from the cardiac ICU relatively quickly. Given that the parents surveyed were only included if they were expected to be hospitalised for at least 2 weeks with an average stay of over a month, these parents may be less satisfied with explanations for why there was a deviation from the expected trajectory of a relatively quick recovery. The medical team may have more uncertainty as to the reason for the prolongation of the hospitalisation in cases with unexpected, prolonged stays. And, if this uncertainty leads to inconsistent communication about the reasons for the prolongation, it is understandable that parents may experience increasing frustration and dissatisfaction.¹⁸

Interestingly, the composite score intended to be a proxy for the severity of illness of the patient was not correlated with satisfaction of communication. In other models of parental medical trauma,³⁴ there are data supporting the fact that parental perception of illness may be more correlated with parental distress than objective measures of illness. Strikingly, families of adult patients were more satisfied with their loved ones' ICU experience if their loved one

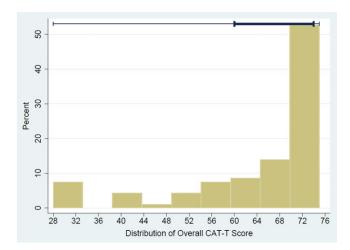


Figure 1. Distribution of overall CAT-T scores.

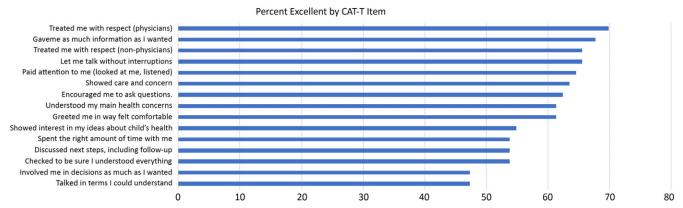


Figure 2. CAT-T items listed by per cent excellent ratings.

died rather than survived. This phenomenon seems attributed to an increased satisfaction with the types of communication that can occur when there is a serious illness, inclusion in decision-making and support for the family.³⁵ This finding helps reassure clinicians that families evaluate the quality of communication independently of their child's health status and that the impact of optimal communication for families, even if their child is not doing well clinically, is important.

Of note, interventions intended to improve communication with families and to provide decision support, like the planned family meeting and sub-specialty palliative care involvement, did not impact the satisfaction with communication to a statistically significant degree (although parents exposed to either of these interventions did have higher mean communication satisfaction scores but the differences were small). Family meetings are recommended by professional guidelines (with limited evidence) for all patients in the ICU and hope to improve the family's satisfaction with communication. 10 This study adds further evidence that conducting a single meeting with little standardisation or structure may not achieve this intended goal. The statistical non-significance of the impact of sub-specialty palliative care involvement may be the result of how this impact was measured. We obtained medical record data for whether an order for palliative care consultation existed but did not assess the extent of the team's involvement in care. This may have limited the impact of palliative care given some patients receive frequent visits

from the sub-specialty team while others may only meet once or twice depending on the family's wishes and goals for the patient.

Limitations to this study include the recall bias of the parents who may have had a variety of communication experiences over the course of their hospitalisation. Given we only measured these factors at one point in time, we were not able to determine whether anxiety preceded decreased satisfaction with communication or vice versa. Additionally, we limited our sample to legal guardians who were English-speaking, which made it possible we missed important information regarding differences in satisfaction for families with emerging English proficiency. The study was conducted entirely prior to the COVID-19 pandemic, raising questions for its generalisability to the current COVID-19 era. We also were unable to enrol as many subjects as we were initially planning to enrol due to COVID-19; however, we were able to reach near significance with our expected predictor of satisfaction, parental anxiety.

The limitations of this work highlight the need for future research, which more granularly characterises the quantity and quality of communication between clinicians and families, not only of English-speaking families but also families with emerging English proficiency. Additionally, research is needed that would test a standardised approach for family meetings, which incorporate recommendations in best practices for shared decision-making to determine if optimised family meetings have a bigger impact on parental experience than the suboptimal

Table 2. Adjusted likelihood of increase in communication satisfaction (CAT-T score).

| Characteristics | OR | p value | 95% CI | |
|--------------------------|------|---------|--------|-------|
| Anxiety | | | | |
| Normal | | | | |
| Borderline | 0.54 | 0.247 | 0.191 | 1.532 |
| Elevated | 0.31 | 0.051 | 0.094 | 1.004 |
| | | | | |
| Risk of mortality (STAT) | | | | |
| N/A | 1.01 | 0.984 | 0.350 | 2.918 |
| Score 1–3 | ref | | | |
| Score 4–5 | 2.88 | 0.035 | 1.076 | 7.678 |
| | | | | |
| Parental stress (IER-S) | 1.00 | 0.960 | 0.969 | 1.034 |
| | | | | |
| Chronic care rounds | 1.53 | 0.271 | 0.718 | 3.250 |

Legend: An ordinal logistic regression model was used to investigate the relationship between parent and patient characteristics and CAT-T scores. Continuous CAT-T scores were transformed into quantiles with score ranges 28–60, 61–71, 72–74, and 75.

meetings that frequently occur.³⁶ While navigator-type interventions, which provide coaching and communication support to parents, have been less successful in the paediatric ICU,³⁷ they have been helpful in adult ICU settings³⁸ and may warrant testing in the paediatric cardiac ICU as well. Additionally, further work to reduce parental anxiety and depression are warranted with enhanced support from psychologists and others trained in parental mental health.

In conclusion, parental satisfaction with communication with the clinical team is associated with specific patient and parent characteristics that can be useful in identifying families who may be at highest risk for negative outcomes. Interventions designed to better support communication with families can also identify other associated factors that may need to be addressed to better support parental decision-making.

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Competing interests. None of the authors report any conflicts of interest.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (the Common Law) and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the Institutional Review Board of the Children's Hospital of Philadelphia.

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