


ORIGINAL RESEARCH

Parent and Physician Understanding of Prognosis in Hospitalized Children With Advanced Heart Disease

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BACKGROUND: The unpredictable trajectory of pediatric advanced heart disease makes prognostication difficult for physicians and informed decision-making challenging for families. This study evaluated parent and physician understanding of disease burden and prognosis in hospitalized children with advanced heart disease.

METHODS AND RESULTS: A longitudinal survey study of parents and physicians caring for patients with advanced heart disease age 30 days to 19 years admitted for ≥ 7 days was performed over a 1-year period ($n=160$ pairs). Percentage agreement and weighted kappa statistics were used to assess agreement. Median patient age was 1 year (interquartile range, 1–5), 39% had single-ventricle lesions, and 37% were in the cardiac intensive care unit. Although 92% of parents reported understanding their child's prognosis "extremely well" or "well," 28% of physicians thought parents understood the prognosis only "a little," "somewhat," or "not at all." Better parent-reported prognostic understanding was associated with greater preparedness for their child's medical problems (odds ratio, 4.7; 95% CI, 1.4–21.7, $P=0.02$). There was poor parent–physician agreement in assessing functional class, symptom burden, and likelihood of limitations in physical activity and learning/behavior; on average, parents were more optimistic. Many parents (47%) but few physicians (6%) expected the child to have normal life expectancy.

CONCLUSIONS: Parents and physicians caring for children with advanced heart disease differed in their perspectives regarding prognosis and disease burden. Physicians tended to underestimate the degree of parent-reported symptom burden. Parents were less likely to expect limitations in physical activity, learning/behavior, and life expectancy. Combined interventions involving patient-reported outcomes, parent education, and physician communication tools may be beneficial.

Key Words: communication ■ congenital heart disease ■ heart failure ■ pediatrics ■ prognosis ■ quality of life

Significant medical and surgical advances have resulted in a growing population of children surviving longer with advanced heart disease (AHD).^{1–3} Despite these improvements, the morbidity for this population remains high,^{4–8} and these children may face major neurodevelopmental challenges that affect quality of life.^{9,10} Studies to evaluate parent understanding of prognosis for children with AHD have been limited. However, prognostic awareness has been found to critically inform parental decision-making in the pediatric oncology population.^{11–13} Shared

decision-making between parents and physicians should ideally occur in the context of concordant understanding of the child's prognosis. Although the data are limited, previous studies have identified discrepancies between parent and physician expectations about prognosis,^{14,15} poor preparedness of pediatric cardiologists in predicting life expectancy,¹⁵ and significant variability in communication with families of children with heart disease.^{16–19}

The existing literature demonstrates a need for improvement in parent–physician communication,

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CLINICAL PERSPECTIVE

What Is New?

- This is the first study to evaluate and compare parent and physician understanding of disease burden and prognosis in hospitalized children with cardiac disease.
- Parents were less likely than physicians to expect limitations in physical activity, learning/behavior, and life expectancy.
- Physicians underestimate the degree of parent-reported symptom burden.

What Are the Clinical Implications?

- The present study identified gaps in communication between parents and physicians regarding key areas of disease status and prognosis.
- Combined interventions involving patient-reported outcomes, parent education, and physician communication tools may be beneficial in improving parent–physician shared understanding.

Nonstandard Abbreviations and Acronyms

AHD advanced heart disease

especially related to patient disease burden and prognosis. However, in order to inform the development of interventions to improve communication in this specific population, additional data are needed regarding how parents understand their child's disease and how this compares with physicians. The objective of this study was 2-fold: (1) to assess parental understanding of disease burden and prognosis; and (2) to evaluate agreement between parents and physicians regarding key aspects of disease burden and prognosis, including symptom burden, likelihood of future limitations in physical activity and learning, and life expectancy. We hypothesized that parents would tend to perceive greater symptom burden as compared with physicians, and would be less likely to expect limitations in future abilities and lifespan.

METHODS

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Study Design

This is a longitudinal survey study of parents and physicians caring for patients admitted with primary

cardiac diagnoses between March 2018 and March 2019 at a single large pediatric heart center. Patient characteristics including demographic and clinical variables were collected by retrospective chart review. The Boston Children's Hospital Institutional Review Board approved the study protocol and survey instrument.

Survey Development and Pilot Phase

The Survey about Caring for Children with Heart Disease (Table S1) was adapted from this group's original bereavement survey of parents of children who died of AHD,²⁰ which was implemented in a cross-sectional study of parents of children at 2 large pediatric cardiac centers. The original instrument was pretested to assess content, wording, response burden, cognitive validity, and willingness to participate. The Survey about Caring for Children with Heart Disease was further adapted following input from additional focus groups (including nurses, social workers, physicians, and child life specialists) as well as input from several parents of children with AHD. Questions were primarily closed ended and based on 4-point or 5-point Likert scales. The survey addressed the following domains: symptoms, quality of life, understanding of prognosis, quality of care, and communication. The survey and associated documents were also professionally translated into Spanish. All Spanish-speaking patients were approached with an in-person or video-based Spanish interpreter. The Survey about Caring for Children with Heart Disease Physician Survey (Table S2) was developed to include matched questions related to perceptions about patient quality of life, prognostication, and communication.

Participants

Eligible participants included parents and physicians of patients age ≥ 30 days and ≤ 19 years admitted for ≥ 7 days to the general cardiology ward or cardiac intensive care unit with a diagnosis of AHD, defined as the following: single ventricle physiology, pulmonary vein stenosis, pulmonary hypertension or any cardiac diagnosis plus 1 or more of the following: length of stay >30 days, mechanical circulatory support, mechanical ventilation >14 days, ≥ 3 admissions in past year, or listed for heart transplant (Table 1).³ Parents were excluded if they could not complete the survey in either English or Spanish.

Parents were approached consecutively in person for potential enrollment. The survey was explained in detail and a study letter was provided. Trained research staff administered the surveys in person via iPads. The study iPads were password-protected, encrypted, and stored in a locked office. A link to the physician survey was then emailed to the provider who

Table 1. Study Inclusion Criteria

- Age ≥30 d and ≤19 y
- Admitted for ≥7 d to cardiology ward or cardiac intensive care unit
- At least 1 of the following:
 - Single ventricle physiology
 - Pulmonary vein stenosis
 - Pulmonary hypertension
 - Length of stay >30 d and any cardiac diagnosis
 - Mechanical circulatory support and any cardiac diagnosis
 - Mechanical ventilation >14 d and any cardiac diagnosis
 - >3 admissions in past year and any cardiac diagnosis
 - Listed for heart transplant

the parent identified as the person from whom they received most of their information about their child’s heart disease. Although parents most often identified a physician, in 4 cases they identified a nurse practitioner, who was included as “physician” in this study. Consent to participate in the study was assumed if a parent or physician chose to complete the survey. Both a parent and physician must have completed the survey in order for the patient to be included in the final study sample. Medical record review was performed by trained study team members utilizing a standardized algorithm. Cardiac diagnostic information was reviewed by the primary investigator (EDB). A response to at least 50% of survey questions was required in order to be included.

Data Management and Statistical Analysis

Survey responses were recorded in Research Electronic Data Capture (REDCap), a secure deidentified, password-protected database.²¹ Each patient was assigned a unique study number. Corresponding parent and physician surveys were coded accordingly. Autovalidations and queries were incorporated into the database. Research investigators then reviewed and verified the data for accuracy and completeness. Statistical analyses were performed using SAS version 9.4 (SAS Institute, Inc., Cary, NC). Associations were examined using the Fisher exact test, χ^2 test, and Mantel-Haenszel test for linear trend. Descriptive statistics of parents and physicians are reported separately as percentage of the total responding to specific questions. When parent–physician responses were compared, percentage agreement with exact 95% CIs was used to report concordance between parent and physician pairs. The percentage of parent–physician pairs with “major disagreement,” which was defined as having answers at opposite ends of the survey response scale, was also calculated. For questions that were administered as a 5-point Likert Scale, percentage agreement and major disagreement were analyzed using a collapsed 3-point Likert scale. Functional classification standard 4-point scales were analyzed in their original form. Weighted kappa statistics were also estimated to evaluate agreement between parents and

Table 2. Patient Demographic and Clinical Characteristics

Characteristic	N=160
Demographic	
Age at enrollment, y	
<2	87 (54%)
2–11	55 (34%)
>11	18 (11%)
Female	76 (48%)
Patient location	
Cardiology ward	101 (63%)
Cardiac intensive care unit	59 (37%)
Diagnosis	
Primary cardiac diagnosis	
Single ventricle lesion	63 (39%)
Other congenital heart disease	46 (29%)
Pulmonary hypertension	19 (12%)
Pulmonary vein stenosis	14 (9%)
Heart transplant recipient	9 (6%)
Cardiomyopathy	9 (6%)
Age at diagnosis	
Prenatal	105 (67%)
First week of life	35 (22%)
>6 mo of age	18 (11%)
Genetic syndrome present	36 (23%)
Burden of disease	
Catheterization and/or surgery during hospitalization	138 (86%)
Awaiting heart transplant	12 (8%)
Length of stay at enrollment, d	13 (9–31)
Total length of hospitalization in which survey occurred, d	35 (16–57)
Remained inpatient 1 mo after survey completion	45 (28%)
Death during hospitalization	10 (6%)
Days of hospitalization in past year	30 (13–47)

Displayed as n (%) or median (interquartile range).

physicians. Univariate logistic regression models were used to examine the association between patient characteristics and parent-reported outcomes. A *P* value of <0.05 was considered statistically significant.

RESULTS

Of the 178 parents approached for inclusion, 18 either declined to participate or did not complete at least 50% of the survey questions. A total of 160 parent–physician pairs were analyzed.

Patient Characteristics

Patient characteristics are summarized in Table 2. The median patient age at parent enrollment was 1 year (range, 30 days–19 years; interquartile range [IQR],

Table 3. Parent Characteristics

Characteristic	N=160
Age, y	34 (29–39)
Relationship to patient*	
Mother	130 (81%)
Father	27 (17%)
Race	
White	115 (72%)
Black	12 (8%)
Asian	7 (4%)
Other†/unknown	23 (14%)
Ethnicity, Hispanic/Latino	29 (19%)
Highest level of education	
Less than high school	8 (5%)
High school	49 (32%)
College	67 (44%)
Graduate school	30 (19%)
Married or living with partner	114 (75%)

Results displayed as n (%) or median (interquartile range).

*Two surveys were completed by both parents and 1 did not specify parental role.

†Participants wrote in Latino or Hispanic (14), Asian Indian (1), Middle Eastern (1), Brazilian (1), Spanish Spain (1), or did not specify (5).

1–5 years) with the majority of patients (54%) <2 years of age. Just over a third (37%) of patients were in the cardiac intensive care unit at the time of survey. Primary cardiac diagnoses included single ventricle lesions (39%), other congenital heart disease (29%), pulmonary hypertension (12%), pulmonary vein stenosis (9%), and cardiomyopathy/heart transplant (11%). Twenty-three percent of patients were known to have a genetic syndrome. Median length of stay at study enrollment was 13 days (range, 7–91; IQR 9–31 days) and almost all patients (86%) had undergone a cardiac surgery or catheterization during the survey hospitalization. The median total length of hospitalization in

Table 4. Physician Characteristics

Characteristic	N=50
Years in practice	19 (13–27)
Years in practice at study institution	11.5 (6–20)
Physician type	
Cardiologist	29 (58%)
General cardiology	9
Cardiac imaging	10
Heart failure/transplant	5
Interventional cardiology	2
Other	3
Cardiac intensivist	5 (10%)
Cardiac surgeon	6 (12%)
Other	10 (20%)

Results displayed as n (%) or median (interquartile range).

which the survey occurred was 35 days (range, 7–374; IQR, 16–57). Eight percent of patients were awaiting heart transplant at time of enrollment and 6% died during the survey hospitalization. Patients had a median of 30 days of hospitalization at the study institution in the past year.

Parent Characteristics

Parent characteristics are summarized in Table 3. Of the 160 parents, 81% were mothers, 63% had at least a college level education, 72% were White, and 19% identified as Hispanic/Latino.

Median parental age was 34 years (range, 17–56; IQR, 29–39). Seventy-five percent were married or living with partners.

Physician Characteristics

Physician characteristics are summarized in Table 4. The 50 participating physicians included cardiologists (58%), cardiac intensivists (10%), cardiac surgeons (12%), and other providers (20%). Cardiologist subspecialties included general cardiology (39%), cardiac imaging (34%), heart failure/transplant (17%), and interventional cardiology (7%). Physicians had a median of 19 years in practice (range, 2–44, IQR, 13–27).

Perceived Understanding of Prognosis

When asked how well they understood their child's prognosis (defined as “the likely course of your child's heart disease”), parents reported that they understood their child's prognosis “extremely well” (54%), “well” (38%), “somewhat” (8%), or “not at all” (<1%) (Figure 1). Parents of children who had undergone cardiac surgery before survey administration during the admission were significantly less likely to report understanding their child's prognosis compared with those who had not undergone cardiac surgery (83% versus 95% reported understanding prognosis “well” or “extremely well,” $P=0.016$). There were no other significant associations between patient characteristics and parent-reported understanding of prognosis.

Fifty-seven percent of parents reported worrying that their child will get sicker “a lot” or “all of the time.” Compared with physicians, parents more often reported that day-to-day management of their child's heart condition affected their ability to discuss prognosis “a great deal” or “a lot” (33% versus 14%). Twenty-eight percent of parents reported feeling that the care team knew something about the child's prognosis that they did not and 67% of parents answered “Yes” when asked if they would have liked to know more about their child's prognosis.

When asked how well they felt parents understood their child's prognosis, 72% of physicians selected

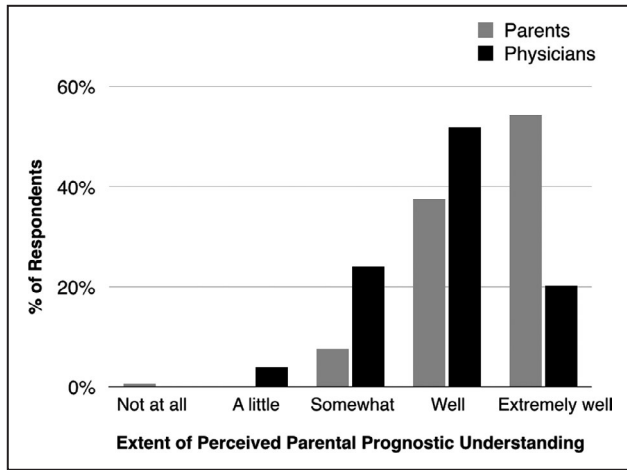


Figure 1. Parent and physician perception of parental prognostic understanding based on responses to: Parent: “How well do you feel that you understand the likely course of your child’s heart disease (ie, prognosis)?”; Physician: “How well do you think this patient’s family understands their child’s prognosis?”.

Although 92% of parents reported that they understood their child’s prognosis “extremely well” or “well,” 28% of physicians thought that parents understood the prognosis only “a little” or “somewhat.” No physicians selected “Not at all.”

“extremely well” or “well” (Figure 1). When asked to what extent their expectations for prognosis aligned with that of their child’s care team, 73% of parents felt that they aligned “a great deal” or “a lot.” Similarly, when physicians were asked, 71% felt that their expectations aligned “a great deal” or “a lot” with those of the parents.

When agreement with respect to understanding of prognosis was assessed between individual parent–physician pairs, 71.0% of pairs showed agreement (Table 5, Figure 2) and only 5 parents (3.2%, 95% CI, 1.1–7.4%) showed major disagreement with their physician counterparts. When there was disagreement, in general physicians underestimated the degree to which parents reported understanding their child’s prognosis.

To assess the individual components that make up prognostic awareness, parents and physicians were

asked a series of questions related to preparedness, perceived likelihood of future limitations, and life expectancy. To understand perceptions of baseline disease burden, parents and physicians were asked to describe the child’s current functional status and symptom burden.

Functional Status and Symptom Burden

Parents and physicians were asked to answer questions related to symptoms and perceived functional status of the child in the preceding week. In response to the question, “What describes your child’s current functional status?,” parents answered: I—no limitation (17%), II—slight limitation (43%), III—marked limitation (27%), and IV—unable to carry on any physical activity without discomfort (14%). Physicians classified the child’s functional status as I, II, III, or IV based on either the Modified Ross Heart Failure Class (≤ 8 years of age) or New York Heart Association Functional Classification (> 8 years of age): I (15%), II (45%), III (19%), and IV (21%). There was limited agreement (36.1%) between parents and physicians with regard to functional status (Table 5, Figure 2). Additionally, 6 parent–provider pairs demonstrated major disagreement (ie, 1 selected functional class I when the other selected class IV) (4.2%, 95% CI, 1.5–8.8). Parent/physician agreement with respect to functional status was higher in parents with education beyond high school compared with high school or less (43% versus 20% agreement, $P=0.006$). There was no association with parent age.

Participants were asked, “Overall, in the past week, to what degree do you feel your/the child is experiencing symptoms related to his/her heart condition?” Just over half of both parents and physicians (56% and 52%, respectively) selected “a great deal” or “a lot” of symptoms. However, there was limited agreement (45.0%) between individual parent–physician pairs regarding degree of symptom burden (Table 5, Figure 2). Moreover, 27 parent–physician pairs (18.1%, 95% CI, 12.2–25.3%) demonstrated major disagreement. When there was disagreement, in general physicians

Table 5. Parent–Physician Agreement in Key Survey Domains

Survey Domain	% Agreement	95% CI	κ	P Value
Parental understanding of prognosis	71.0	63.6–78.4	0.12*	0.035
Patient functional status	36.1	28.3–44.5	0.17	0.003
Patient symptom burden	45.0	36.8–55.3	0.13	0.051
Parental preparedness for child’s medical problems	51.0	43.4–59.8	0.14	0.017
Likelihood of limitations in physical activity	47.7	39.6–55.9	0.30	<0.001
Likelihood of limitations in learning/behavior	27.3	20.4–35.2	–0.15	0.013
Likelihood of needing lifelong interventions	77.9	70.5–84.2	0.70	<0.001
Patient life expectancy	41.3	33.0–50.0	0.24	<0.001
Patient inpatient status at 1 mo	61.3	51.2–70.9	0.45	<0.001

*Kappa statistic is unreliable (paradoxically low in presence of high agreement) when the distribution of responses is highly imbalanced.

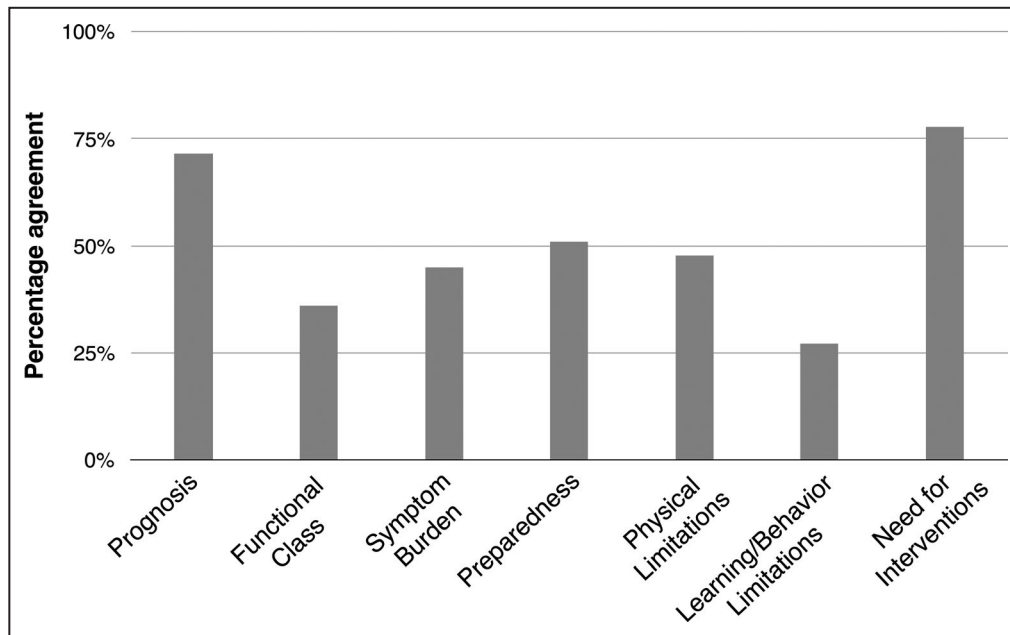


Figure 2. Percentage agreement between individual parent–provider pairs across survey domains.

For questions that were administered as a 5-point Likert Scale, percentage agreement was analyzed using a collapsed 3-point Likert scale. Functional class was analyzed in its original 4-point form. Parents and physicians demonstrated the most concordance with respect to parental understanding of prognosis and likelihood of need for cardiac interventions. The most limited agreement was observed with perception of functional class and likelihood of limitations in learning/behavior.

underestimated the degree of parent-reported symptom burden.

Parents who reported that their child had a functional class of III or IV were significantly more likely to report “a great deal” or “a lot” of symptom burden than parents whose child had a functional class of I or II (odds ratio [OR], 4.6; 95% CI, 2.2–9.5, $P < 0.001$). Seventy-six percent of parents who reported that their child had worse functional class (III-IV) perceived “a great deal” or “a lot” of symptoms, compared with 40% of parents of children who reported that their child had a functional class of I or II.

Preparedness

Parents were asked to describe how well prepared they felt for the medical problems their child was experiencing at the time of survey completion. Parents reported feeling “very” (56%), “somewhat” (35%), “a bit” (8%), and “not at all” (1%) prepared. When asked to describe how prepared they perceived the parents to be, physicians reported: “very” (40%), “somewhat” (48%), “a bit” (9%), and “not at all” (3%). There was moderate individual agreement (51.0%) between how prepared the parents reported feeling and how prepared the providers perceived the parents to be (Table 5, Figure 2). Moreover, 17 parents demonstrated major disagreement with physicians (11.1%, 95% CI,

6.6–17.2%). In general, when there was disagreement, parents tended to report feeling more prepared than physicians thought they were.

Better parent-reported prognostic understanding was associated with greater parent preparedness (“very prepared” versus all other categories) for the medical problems their child was experiencing (OR, 4.7; 95% CI, 1.4–21.7, $P = 0.02$). Fifty-nine percent of parents who reported understanding their child’s prognosis “extremely well” or “well” reported feeling “very prepared” for the medical problems their child was experiencing, compared with 23% of parents with lower levels of prognostic understanding. There were no significant associations between patient characteristics and parental preparedness.

Likelihood of Future Limitations

Parents and physicians were asked to describe their expectations for the child’s limitations in physical activity and learning/behavior and need for lifelong cardiac interventions. Parents and physicians reported that it was “very likely” for the child to have limitations in physical activity (34% of parents versus 63% of physicians), limitations in learning/behavior (36% of parents versus 63% of physicians), and need for lifelong interventions (50% of parents versus 65% of physicians). Individual parent–physician pairs were discordant with respect

to likelihood of limitations in physical activity (47.7% agreement) and learning/behavior (27.3% agreement) (Table 5, Figures 2 and 3). Parent–physician pairs demonstrated more concordance with respect to likelihood of needing lifelong interventions (77.9% agreement) (Table 5, Figures 2 and 3). In fact, this topic yielded the highest agreement between parents and physicians among all questions on the survey. Parent/physician agreement with respect to need for lifelong intervention was even higher in parents with education above high school compared with high school or less (87% versus 64% agreement, $P=0.002$). There was no association with parent age.

Life Expectancy

Parents and physicians were asked, “What is your current understanding of how long your child/this patient will live?” Many parents (46.6%) but few physicians (5.9%) expected their child/patient to have a normal life expectancy (Figure 4). Providers predicted survival of no more than “several years” for 39 subjects; for 22 (56%) of these, the parents expected a normal life span and/or survival into adulthood. There was discordance between individual parent–provider pairs (41.3% agreement, Table 5), with parents generally considering their child to have a longer life expectancy than the provider did.

Prediction of Inpatient Status at 1 Month

Parents and physicians were also asked how likely they thought it was that their child/patient would still be in the hospital 1 month from the survey date. In general, both parents and providers more accurately predicted which children would be out of the hospital than they predicted who would still be in hospital. At 1 month from the survey date, 45 (28.1%) of the 160 patients were still in the hospital. Parents and physicians who selected that it would be “very likely” for the child to remain inpatient (28.1% and 28.7%, respectively) were correct in 40% and 60% of cases, respectively. Parents and physicians who selected “not likely” (46.3% and 50.5%) were correct in 78% and 94% of cases, respectively. There was 61.3% agreement between parent and physician pairs (Table 5). When there was disagreement, in general parents believed that their child would be out of the hospital earlier than the physician did.

DISCUSSION

This is the first study to assess understanding of disease burden and prognosis among parents and providers caring for children with AHD. Significant discrepancies emerged between parents and physicians with respect to assessment of disease burden. In addition, although parents report that they understand

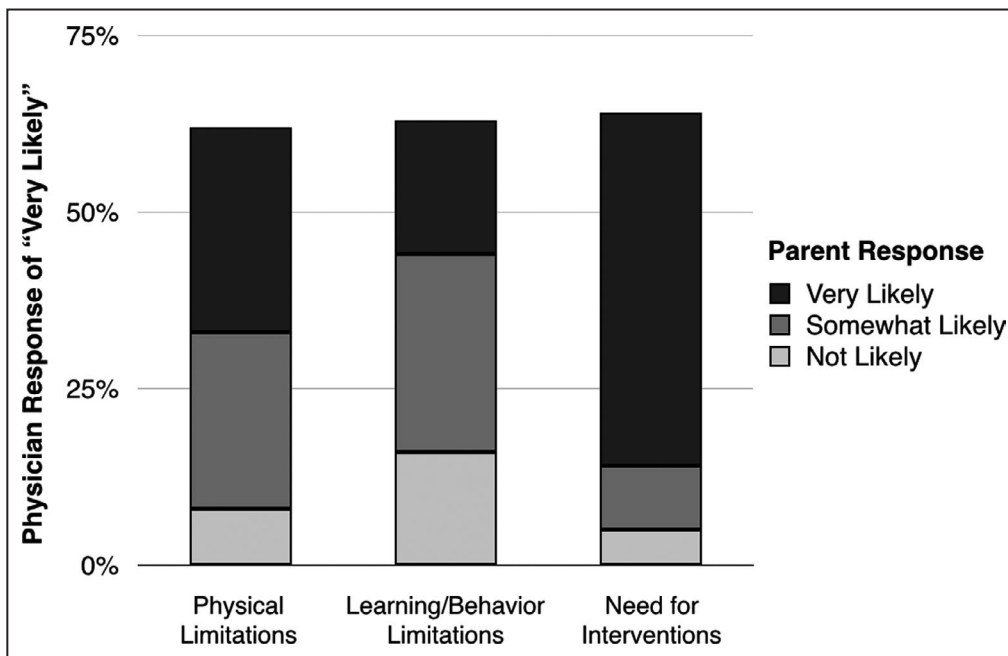


Figure 3. Parent and physician assessment of likelihood of limitations in physical activity and learning/behavior and likelihood of need for future cardiac interventions.

The y-axis is the percentages of physicians who selected “very likely” that the child would have limitations in physical activity and learning/behavior and “very likely” to need future interventions. Within each column is the percentage of parents of those patients who responded, “very likely,” “somewhat likely,” and “not at all likely” to the same questions. Compared with parents, physicians were more likely to expect limitations in physical activity and learning/behavior and more likely to expect that future interventions would be necessary.

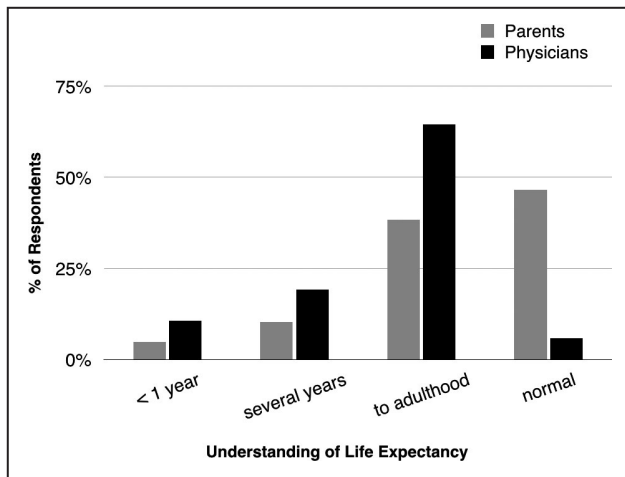


Figure 4. Parent and provider unpaired responses to the question “What is your current understanding of how long your child/this patient will live?”.

Many parents (47%) but few physicians (6%) expected their child/patient to have a normal life expectancy.

prognosis well, discrepancies exist between parents and physicians caring for children with AHD with respect to understanding the individual components of prognosis, including life expectancy and likelihood of future limitations.

Prognostication is difficult for physicians and families caring for children with AHD,^{3,14} in part because of the unpredictable disease trajectory,^{3,22} which often requires unanticipated intensive care unit stays²³ and frequent surgical or catheter-based interventions. A national survey of pediatric cardiologists revealed that the majority feel inadequately prepared to prognosticate life expectancy.¹⁵ Even when physicians do have an accurate understanding of prognosis, they may not effectively communicate this with the patient and family. Moreover, there is significant variability in communication with and counseling of families of children with heart disease with respect to diagnosis and prognosis.^{16–19} Additionally, pediatric cardiologists’ counseling approaches and overall demeanor have been shown to influence how parents perceive their child’s chance of survival and their request for a second opinion.¹⁶ Given this, open communication and shared understanding between parents and physicians is critical to help parents prepare for the likelihood of intermittent decompensations, functional limitations, and need for reintervention.

Most parents reported that they understood their child’s prognosis “well” or “extremely well.” This could reflect that parents do indeed have a reasonably good understanding of prognosis but that prognosis itself is uncertain. Moreover, two thirds of parents reported that they would like more information about their child’s prognosis. This is consistent with a prior study

demonstrating that parents of children with congenital heart disease would like to receive more education and counseling in the prenatal and newborn periods than cardiologists perceive is desired.¹⁷ Parents of children who had undergone cardiac surgery during the survey hospitalization reported significantly lower perceived understanding of prognosis. This may reflect that the day-to-day management of their child’s heart condition in the postoperative period makes it difficult to focus on long-term prognosis. This reinforces the importance of having prognostic conversations at times of stability before scheduled interventions or acute decompensations. Paired parent–physician agreement regarding parent understanding of prognosis was better than concordance found in other survey areas. However, given that discrepancies were found between the 2 groups with respect to the individual components that make up prognostic awareness, parent–physician agreement with respect to overall parent prognostic understanding may be a poor indicator of their actual agreement on the factors that contribute to a child’s long-term prognosis, life expectancy, and quality of life.

There was poor concordance between individual parent–physician pairs with respect to perception of disease burden. Physicians tended to underestimate the degree of parent-reported symptom burden. As survival for children with AHD has improved, there is greater focus on improving functional status and thereby quality of life. Children with cardiovascular disease have been demonstrated to have lower quality of life as compared with healthy children, and severity of cardiovascular disease tends to correspond with degree of limitation in quality of life.^{24,25} One study asked pediatric cardiac clinicians to review clinical summaries and predict health-related quality of life. They found poor agreement between individual clinicians as well as poor agreement between average clinician-predicted health-related quality of life scores and those reported by patients and parent-proxies.²⁶ Clinicians were generally noted to overestimate health-related quality of life compared with patients and parent-proxies, which is consistent with what we found in our study. Without patient-reported data in our current study, it was not possible to determine which group was more accurate in their assessment of disease burden. Studies from the pediatric oncology literature have demonstrated the feasibility and value of using patient-reported outcomes to assess health-related quality of life.^{27–29} A similar tool could be quite valuable if applied and studied in the pediatric cardiac population, especially if combined with parent and physician reports.

Parent preparedness for medical issues was also examined as a factor related to understanding of prognosis. We found that parents tended to report feeling more prepared than physicians thought they

were. Additionally, better parent-reported prognostic understanding was associated with greater parent preparedness (“very prepared” versus all other categories) for the medical problems their child was experiencing. This suggests that if we can improve parent understanding of prognosis, we can improve how prepared parents feel for the medical problems their child is facing. Compared with parents, physicians were more likely to perceive future limitations in all surveyed areas, including physical activity, learning/behavior, and need for lifelong cardiac-directed interventions. There was greatest agreement between the groups with respect to likelihood of needing interventions, which may reflect the focus on cardiac surgical and catheterization-based procedures in counseling of families, especially in the single-ventricle population where staged palliation is typically reviewed at time of prenatal diagnosis. Physicians may be more likely than parents to understand that frequent interventions will be associated with prolonged hospital stays and unforeseen complications, which may cause deconditioning and periods of missed school, thereby causing limitations in physical activity and learning/behavior.

Parents and physicians also demonstrated significant discordance with respect to life expectancy. Almost half of parents but only 6% of physicians expected the child to have a normal life expectancy. This discrepancy may reflect a greater focus during parent–physician interactions on more immediate issues related to patient care, rather than on long-term prognosis. Additionally, parents may be answering based on their hopes rather than true expectations. Data from future longitudinal studies would be useful to compare expected versus actual survival in this patient population. However, given that long-term survival data show significant limitations in life expectancy for many of the cardiac diagnoses included in this study,^{30–37} there already appears to be room for improvement in communication of this information to families.

To assess short-term prognostic accuracy, parents and physicians were asked how likely they thought it would be for the child to remain in the inpatient setting 1 month from the survey date. Physicians were more accurate than parents in their prediction. When there was disagreement, parents were more likely to predict discharge before 1 month. This suggests that physicians are either not communicating their assessment of anticipated hospitalization duration, not communicating their assessment in a way that parents can understand, or that parental optimism/hope influences parents’ prediction. A recent study in the pediatric oncology population demonstrated that parent prognostic accuracy was related to the way in which they value and receive prognostic information from physicians.³⁸ Most parents reported both “explicit” sources of prognostic

information (ie, formal conversations at diagnosis) and “implicit” sources (ie, “a general sense of how my child’s oncologist seems to feel my child is doing”) to be informative. However, those who valued implicit information demonstrated lower (more optimistic) prognostic accuracy. Given these findings, the authors suggested that physicians incorporate explicit factual information about prognosis into their ongoing conversations with parents to improve parent understanding and avoid overly optimistic parental expectations.

There are several limitations to the present study. The sample was limited to a single institution and consisted of predominantly English-speaking White or Hispanic mothers. The inclusion criteria focused on hospitalized children with AHD only, making the functional status and symptom burden results difficult to generalize to an outpatient cardiology population. Just over half of children included in the study were under 2 years of age, which may influence generalizability. However, patient age was not found to be significantly associated with any parent-reported outcomes. Additionally, the study institution is a major referral center and we recognize that some patients may have received prior cardiac treatment elsewhere. Parents who are able and motivated to seek treatment at a second institution may have different perspectives compared with those who remain at a local center. Moreover, parents may receive counseling and prognostic information from multiple providers, which could influence their understanding of prognosis. The study is also subject to the limitations inherent to parent- and physician-reported measures. Lastly, univariate logistic regression models were used to examine the association between patient characteristics and parent-reported outcomes and therefore potential confounders were not assessed.

CONCLUSIONS

This is the first study to assess prognostic understanding among parents and physicians of children with AHD. Overall, our results identify gaps in communication between parents and physicians regarding key areas of disease status and prognosis. Parents and physicians caring for children with AHD differed in their perspectives regarding prognosis and disease burden. Physicians tended to underestimate the degree of parent-reported symptom burden. Parents were less likely than physicians to expect limitations in physical activity, learning/behavior, and life expectancy. Better parent-reported prognostic understanding was associated with greater reported preparedness for their child’s medical problems. Combined interventions involving patient-reported outcomes, parent education, and physician communication tools may be beneficial.

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Disclosures

None.

Supplementary Material

Tables S1–S2

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SUPPLEMENTAL MATERIAL

Table S1. Survey About Caring for Children with Heart Disease – Parent.

Where is this survey being administered?

- Cardiac ICU
- Cardiology ward
- Other _____

As part of this initiative, there is a doctor survey as well. Can you tell us who at Boston Children's Hospital you consider to be your child's heart doctor? _____

How long have you known about your child's heart problem?

- <1 month
- 1 to 6 months
- 6 months to 1 year
- >1 year

At what age was your child diagnosed with a heart problem?

- Before he/she was born
- In the first week of life
- At age _____

Has your child ever been treated at a hospital other than Boston Children's Hospital for his/her heart condition?

- YES, Where? _____
- NO

YOUR CHILD'S MEDICAL ISSUES

We would first like to ask you about some of the medical problems your child may be experiencing.

In the past week, how well prepared have you been for the medical problems your child is experiencing?

- Very prepared
- Somewhat prepared
- A bit prepared
- Not at all prepared

How has your child been obtaining nutrition in the past week?

- Eats by mouth
- By feeding tube
- Eats by mouth and feeding tube
- Nutrition through IV
- Not receiving nutrition
- Other _____

Which of the following services, if any, have contributed towards improvement in your child's quality of life in the past week? *Check all that apply.*

- Child life specialist
- Hospital school teacher
- Psychology/Psychiatry
- Social work
- Spiritual advisor/Chaplain
- Palliative care/PACT team clinician
- Other (please describe: _____)

What best describes your child's current functional status (i.e. symptoms and activity level)?

- No limitation of physical activity
- Slight limitation of physical activity
- Marked limitation of physical activity
- Unable to carry on any physical activity without discomfort

In the past week, to what degree do you feel your child is experiencing symptoms related to his/her heart condition?

- A great deal
- A lot
- Somewhat

- A little
- Not at all

In the last week, has your child experienced any of the following symptoms?

	Yes	No
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>

If yes, how much did your child suffer from each symptom?

	A great deal	A lot	Somewhat	A little	Not at all
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past week, has your child received treatment or interventions specifically for this symptom?

	Yes	No
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>

If yes, how well did the treatment work in decreasing these symptoms?

	Successfully	Somewhat successfully	Not successfully
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, to what extent do you feel that your child's medical team has asked about his/her symptoms over the past week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, to what extent do you feel that your child's medical team has addressed his or her symptoms over the past week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Which of the following describes the amount of suffering your child had from his/her symptoms in the last week? Would you say he/she suffered:

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Please add any additional information regarding your child's symptoms: _____

RECENT TREATMENTS OR INTERVENTIONS

Overall, which of the following describes the amount of suffering you perceive your child is experiencing as a result of treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount you feel that your child is benefitting as a result of treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

In the last month, did your child undergo cardiac catheterization?

- Yes
- No

Which of the following describes the amount of suffering you perceive your child is experiencing as a result of undergoing cardiac catheterization?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing cardiac catheterization for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from undergoing cardiac catheterization? _____

In the last month, did your child undergo cardiac surgery?

- Yes
- No

Which of the following describes the amount of suffering you perceive your child is experiencing as a result of undergoing cardiac surgery?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing cardiac surgery for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from undergoing cardiac surgery? _____

In the past month, did your child undergo any non-cardiac procedure?

- Yes (What type? _____)
- No

Which of the following describes the amount of suffering you perceive your child has experienced as a result of undergoing this non-cardiac procedure?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing this non-cardiac procedure for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from this non-cardiac procedure? _____

PROGNOSIS AND GOALS OF CURRENT CARE

You will now be asked some questions regarding your current goals and expectations for your child. We ask that you base your answers on how you feel that your child is doing at this point in time, based on all of the information you have today.

How would you describe the quality of care delivered by your child's care team during the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

How well do you feel that you understand the likely course of your child's heart disease (i.e. prognosis)?

- Extremely well
- Well
- Somewhat
- A little bit
- Not well at all

How likely do you think it will be that your child's heart condition will require lifelong interventions or treatment?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for your child to have limitations in physical activity (such as difficulties exercising), compared with what you would expect if your child did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for your child to have limitations in learning, development, and behavior (such as difficulty with schoolwork), compared with what you would expect if your child did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How often do you worry that your child will get sicker?

- Never
- A little
- Sometimes
- A lot
- All the time

I am unsure if my child is getting better or worse.

- Strongly disagree
- Disagree
- Undecided
- Agree
- Strongly agree

Have you ever had a conversation with your child's healthcare team that included discussion on what would happen if your child got sicker?

- Yes
- No

Was this conversation helpful?

- Yes
- No
- Not applicable

Comments: _____

What is your current understanding of how long your child will live?

- Days to weeks
- Weeks to months
- Months to 1 year
- Several years
- Into adulthood
- Normal life expectancy

Comments: _____

To what extent does the day to day management of your child's heart condition make it challenging to talk about long-term issues such as prognosis?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

How likely do you think it is that your child will still be in Boston Children's Hospital one month from now?

- Very likely
- Somewhat likely
- Not likely

YOUR CHILD'S CARE TEAM & DELIVERY OF NEWS

During the past month, has your child's medical provider had a conversation with you during which he/she specifically delivered new information regarding your child's prognosis or course of treatment?

- Yes
- No

Would you please share some details of what was discussed during this conversation? _____

To what extent did you feel this discussion was open and honest?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

To what extent did you feel this discussion was confusing?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

During this discussion, were you able to express your hopes?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

If so, were your hopes adequately addressed?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Were you able to express your worries?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

If so, were your worries adequately addressed?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Did you need to make a decision about your child's medical care following receipt of this new information?

- Yes
- No
- Not applicable

To what extent did you feel prepared to make this decision?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

To what extent did you feel supported in making this decision?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Is there anything else you would like to add regarding how news was given to you and your family? _____

During the last month, how often did you receive conflicting information from different health professionals?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

Please add any additional comments: _____

How do you feel about the number of different people who give you information regarding your child's heart condition during the past month? Would you say the number of people is:

- Too many
- Just enough
- Not enough

How often were you the one to tell health professionals the medical details of your child's condition because they didn't seem to know during the past month?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

To what extent do you feel that your expectations for your child's prognosis are the same as the expectations of your child's care team?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Have you ever felt that your child's care team knows something about your child's overall prognosis that you might not know?

- Yes (Describe: _____)
- No

Would you like to know more about your child's prognosis?

- Yes
- No

Overall, how adequate has communication between you and your child's care team been during the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

What have you found to be the most effective way for you to receive information from the care team about your child's heart condition?

- Attending bedside rounds
- Scheduled formal family meetings
- Informal bedside conversations/updates

When making decisions regarding your child's care, which of the listed caregiver's opinion do you regard as the most important in guiding these decisions? Please choose only ONE answer.

- Your child's primary cardiologist
- Intensive Care Unit physician
- Cardiac Surgeon
- Family member
- Pediatrician
- Other _____

What other sources do you use to obtain information about your child's heart condition? Check all that apply.

- Talking with other parents of children with heart disease via social media
- Talking with other parents of children with heart disease in person
- Talking with other parents of children with heart disease over the phone
- Searching the internet (Which websites? _____)
- Reading books

CURRENT PARENT SOCIO-DEMOGRAPHIC CHARACTERISTICS

We would now like to ask you some information about yourself. This information will remain confidential.

What is your relationship with the patient?

- Mother
- Father

What year were you born? _____

Choose the response that most nearly describes the highest degree you obtained:

- Less than high school
- High school diploma or equivalent (GED)
- College degree
- Graduate degree

Which of the following groups best describes your racial background?

- American Indian / Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other (please specify): _____

Which group best describes your ethnic background?

- Hispanic or Latino
- Not Hispanic or Latino

Please describe your marital status

- Not Married
- Married or living with partner

Earlier studies by our group have shown that many families experience financial stress during their child's hospitalization. Information about finances from families like yours will help us be sure that finances do not impact a child's experience during treatment.

Survey responses will be kept confidential and not shared with your treatment team. No information will be presented in any way that would permit identification of your family or child.

Please answer these questions thinking about the 6 months before your child's current hospitalization.

In the last 6 months, was there a time when you were not able to pay the rent or mortgage on time because of financial difficulties?

- Yes
- No

How many people are currently living in your household, including yourself? _____

How many bedrooms are in your home? _____

“Within the past 6 months we worried whether our food would run out before we got money to buy more.”

- Often true
- Sometimes true
- Never true
- Don't know or refused

“The food that we bought just didn't last, and we didn't have the money to get more.”

- Often true
- Sometimes true
- Never true
- Don't know or refused

Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), etc. Please give your best estimate: _____

Please provide your zip code prior to your child's hospitalization: _____

During your child's hospitalization, have you been able to stay locally?

- Yes
- No

If yes, where are you staying? (select all that apply)

- In a local hotel
- With local relatives
- In Patient Family Housing
- At bedside
- A sleep space
- Other, please describe: _____
- Not applicable

If no, is it because? (select all that apply)

- Live close enough
- Local hotels are too expensive
- Affordable options through hospital resources are not available
- Work
- Commitments at home
- Other, please describe: _____
- Not applicable

Table S2. Survey About Caring for Children with Heart Disease – Physician.

SYMPTOMS AND QUALITY OF LIFE

If this patient is currently < 8 years of age, what best describes the patient's current functional status according to the Modified Ross Heart Failure Classification for Children?

- Class I: Asymptomatic
- Class II: Mild tachypnea or diaphoresis with feeding (infants) or mild dyspnea on exertion (older children)
- Class III: marked tachypnea or diaphoresis with feeding (infants) or marked dyspnea on exertion (older children) or prolonged feeding times with growth failure
- Class IV: Symptoms such as tachypnea, retractions, grunting, or diaphoresis at rest

If this patient is currently >8 years of age, what best describes the patient's current functional status according to the New York Heart Association Classification?

- Class I: No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or shortness of breath.
- Class II: Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, shortness of breath.
- Class III: Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
- Class IV: Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

In the past week, to what extent is this patient experiencing symptoms attributable to his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, to what extent do you feel that the team has addressed this patient's symptoms in the last week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Which of the following describes the amount of suffering you perceive the patient is experiencing as a result of his/her symptoms in the last week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount of suffering you perceive the patient is experiencing as a result of receiving treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount that you feel the patient is benefitting as a result of receiving treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

GOALS OF CURRENT CARE AND PROGNOSIS

In the past week, how well prepared do you feel that this patient's parents have been for the medical problems their child is experiencing?

- Very prepared
- Somewhat prepared
- A bit prepared
- Not at all prepared

How well do you think this patient's family understands their child's prognosis?

- Extremely well
- Well
- Somewhat
- A little bit
- Not well at all

How likely do you think it is for this patient's heart condition to require lifelong interventions or treatment?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for this patient to have limitations in physical activity (such as difficulties exercising), compared with what you would expect if this patient did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for this patient to have limitations in learning, development, and behavior (such as difficulty with schoolwork), compared with what you would expect if this patient did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

Have you ever had a conversation with this patient's family that included discussion on what would happen if their child got sicker?

- Yes
- No

Was this conversation helpful?

- Yes
- No

What is your current understanding of how long the patient will live?

- Days to weeks
- Weeks to months
- Months to 1 year
- Several years
- Into adulthood
- Normal life expectancy

What makes this question difficult to answer? _____

Would you be surprised if this child died within the next year?

- Yes
- No

How likely do you think it is that this patient will still be at Boston Children's Hospital one month from now?

- Very likely
- Somewhat likely
- Not likely

COMMUNICATION & DELIVERY OF NEWS

To what extent does the day to day management of this patient's heart condition make it challenging to talk about long-term issues such as prognosis?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

During the last month, how often do you think the family received conflicting information from different health professionals?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

To what extent do you feel that your expectations for this patient's prognosis are the same as the expectations of the patient's family?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, how adequate do you feel the team's communication with this family has been in the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

What have you found to be the most effective way for this family to receive information from the care team about their child's heart condition?

- Attending bedside rounds
- Scheduled formal family meetings
- Informal bedside conversations/updates

Do you think that participating in this study has changed the way that you communicate with this family?

- A great deal
- A lot
- Somewhat
- A little
- Not at all