



## Original Article

**Cite this article:** Samsel C, Reichman JR, Barreto JA, Brown DW, Hummel K, Sleeper LA, and Blume ED (2024) The experience of fathers of children hospitalised with advanced heart disease. *Cardiology in the Young* **34**: 1274–1278. doi: [10.1017/S1047951123004390](https://doi.org/10.1017/S1047951123004390)

Received: 24 May 2023  
Revised: 24 October 2023  
Accepted: 5 December 2023  
First published online: 10 January 2024


**Keywords:**

Fathers; CHD; children; palliative care; prognosis; parents

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**Abstract**

**Background:** There are little reported data on the perspectives of fathers caring for children with chronic conditions. Although survival of children with advanced heart disease has improved, long-term morbidity remains high. This study describes the experience and prognostic awareness of fathers of hospitalised children with advanced heart disease. **Methods:** Cross-sectional survey study of parents caring for children hospitalised with advanced heart disease admitted for  $\geq 7$  days over a one-year period. One parent per patient completed surveys, resulting in 27 father surveys. Data were analysed using descriptive methods. **Results:** Nearly all (96%) of the fathers reported understanding their child's prognosis "extremely well" or "well," and 59% felt they were "very prepared" for their child's medical problems. However, 58% of fathers wanted to know more about prognosis, and 22% thought their child's team knew something about prognosis that they did not. Forty-one per cent of fathers did not think that their child would have lifelong limitations, and 32% anticipated normal life expectancies. All 13 fathers who had a clinical discussion of what would happen if their child got sicker found this conversation helpful. Nearly half (43%) of the fathers receiving new prognostic information or changes to treatment course found it "somewhat" or "a little" confusing. **Conclusions:** Fathers report excellent understanding of their child's illness and a positive experience around expressing their hopes and fears. Despite this, there remain many opportunities to improve communication, prognostic awareness, and participation in informed decision-making of fathers of children hospitalised with advanced heart disease.

The paternal caregiver experience is not well understood<sup>1,2</sup> with few small studies<sup>3</sup> in pediatric populations, including neuro-oncology,<sup>4</sup> type 1 diabetes, and cardiac cohorts.<sup>6</sup> Understanding caregiver roles, contributions, and experiences of fathers of children with advanced heart disease (Figure 1) is critical to improving care for children and their families coping with and managing chronic paediatric illness.

The role that fathers play in the family unit and in support for their ill child is largely unknown in the clinical care setting and in the care of children with chronic medical conditions. Outcomes of children with heart disease have been improving due to significant medical advances. Despite these improvements, heart disease still serves as a leading factor in paediatric mortality, and long-term morbidity and burden of care remain high for children with advanced heart disease.<sup>7</sup> Our previous work has shown that parents and physicians caring for children with advanced heart disease differed in their perspectives regarding prognosis and disease burden, with parents less likely to expect limitations in physical activity, learning/behaviour, and life expectancy.<sup>7,8</sup> In addition, all parents rated communication with their child's care team as excellent, very good, or good, with more than half (56%) of parents reporting that they received conflicting information from their child's healthcare team.<sup>9</sup>

This study describes the father-reported experiences from a cohort of parents of children hospitalised with advanced heart disease.

**Materials and methods**

This is an analysis of 27 fathers who enrolled in our cross-sectional prospective survey study, as part of a cohort of 158 parents of hospitalised children with advanced heart disease.<sup>7</sup> Inclusion criteria into the study were one parent of a child hospitalised with advanced heart disease for more than 7 days, patient age between 30 days and 19 years, admitted between February 2018 and March 2019, and at a single large paediatric heart centre. Inclusion criteria for advanced heart disease diagnosis (Figure 1) included single ventricle heart disease, pulmonary vein stenosis, or pulmonary hypertension requiring therapy. In addition, any patient with CHD and

#### Definition of Advanced Heart Disease (AHD) in children

- 1.) Patients with single ventricle heart disease
- 2.) Patients with pulmonary vein stenosis
- 3.) Pts with pulmonary hypertension requiring therapy
- 4.) Patient with congenital heart disease and one of the following:
  - a. Length of stay > 30 days
  - b. Mechanical circulatory support
  - c. Mechanical ventilation > 14 days
  - d. ≥ 3 admissions in the past year

**Figure 1.** Definition of advanced heart disease.

any of the following were included: mechanical circulatory support, mechanical ventilation > 14 days, or ≥ 3 admissions in the past year. The study excluded parents who were unable to respond to the survey items in either English or Spanish.

Demographic and clinical variables of patients enrolled were collected by retrospective chart review. The study protocol and all survey instruments were reviewed and approved by the Boston Children's Hospital Institutional Review Board. The research team reviewed the electronic medical records of all potential patient participants to screen for eligibility and approached the patients' parents to discuss the study in person.

Only one parent per patient completed the survey, and 27 parents identified as fathers and 128 as mothers. Parents decided which caregiver completed the survey, and neither was pre-assigned to complete the survey by the research team. Corresponding patient medical records were reviewed. The overall cohort data have previously been reported.<sup>8</sup> Parents were surveyed using the questionnaire "The Survey about Caring for Children with Heart Disease." The survey instrument and overall methods have been previously published.<sup>8</sup> We analysed variables of father and patient characteristics from the medical record, father's understanding of prognosis from the survey, and father's experiences of healthcare communications from the survey. Finally, we compared those same variables between fathers and mothers.

Parents were administered the survey via iPad devices or paper surveys. Parent consent was obtained implicitly through the completion of surveys. Parents were enrolled consecutively. All iPad devices used were password-protected and encrypted.

#### Data management & statistics

All survey responses were recorded in Research Electronic Data Capture, a secure, password-protected database software.<sup>10,11</sup> The research team assigned each patient a unique study identification number. Only surveys with 50% or more of their questions completed were included in analysis. Survey questions used either a 3-point or 5-point Likert scale. Data from the surveys were analysed using descriptive methods.

A p-value of < 0.05 was considered statistically significant. Analyses were performed using SAS.

## Results

### Father and patients' characteristics

The median age of the fathers was 34 years (range 22–54) with nineteen fathers (70%) identifying as White, two (7%) as Asian, five (20%) as Hispanic/Latino, one (4%) as Black, and one (4%) as both White and Black. Eleven (42%) reported having a college

**Table 1.** Demographics of fathers and patients.

N = 27	Number (%) or median (IQR or range)
Father age (years) <sup>a</sup>	34 (Range: 22-54)
Race/Ethnicity—White	19 (70%)
Highest degree of education (n = 26) <sup>a,b</sup>	
• Less than high school	0 (0%)
• High school diploma	11 (42%)
• College degree	11 (42%)
• Graduate degree	4 (15%)
Married or living with partner <sup>b</sup>	20 (77%)
Child's age at time of enrolment (years)	2 (IQR: 0-4)
Child's gender—Female	11 (41%)
Length of time since diagnosis <sup>b</sup>	
• <6 months	9 (33%)
• 6 months to 1 year	2 (7%)
• >1 year	16 (59%)
LOS at time of survey (days)	Median (IQR): 11 (8-13)
Patient location at time of survey	
• Cardiac ICU	10 (37%)
• Cardiology Ward	17 (63%)
Surgery during the last month	18 (67%)
Diagnosis <sup>b</sup>	
CHD	11 (39%)
Cardiomyopathy	0 (0.0%)
Pulmonary hypertension	5 (19%)
Heart transplant recipient	1 (4%)
Single ventricle	10 (37%)

IQR = interquartile range; LOS = length of stay.

<sup>a</sup>These variables had missing values. Father age: 1 missing; Highest degree of education: 1 missing; Married or living with partner: 6 were not married or living with their partners. 1 was missing.

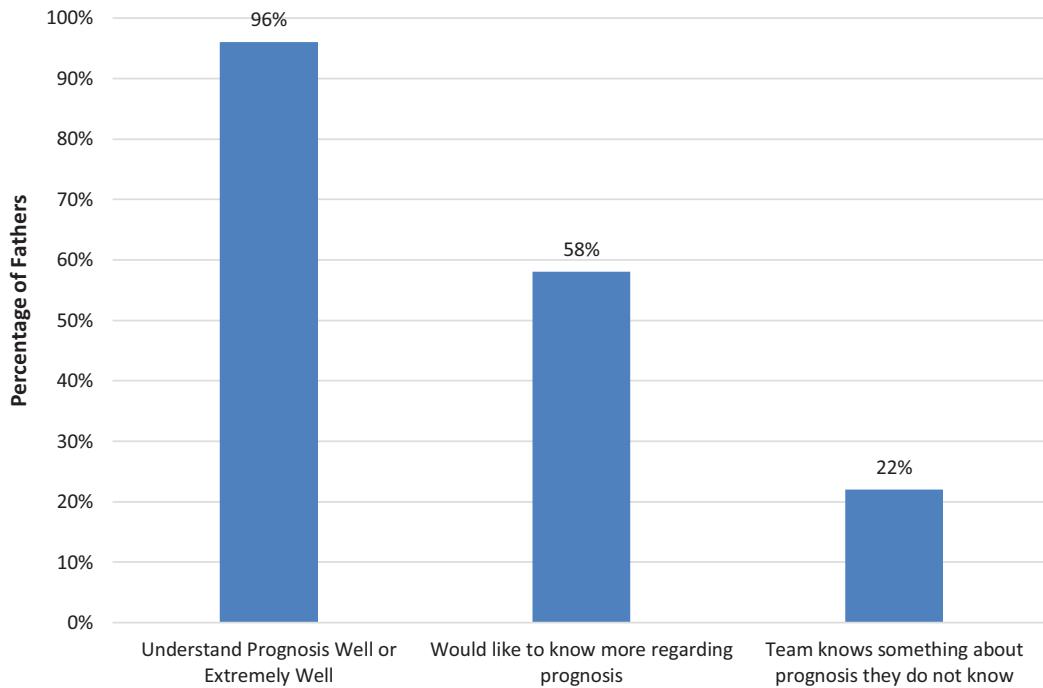
<sup>b</sup>Some percentages do not total to 100% due to rounding.

degree, and 11 (42%) reported high school diploma as their highest degree of education. Almost three-quarters of the fathers (20/26, 77%) reported being married or living with a partner. (see Table)

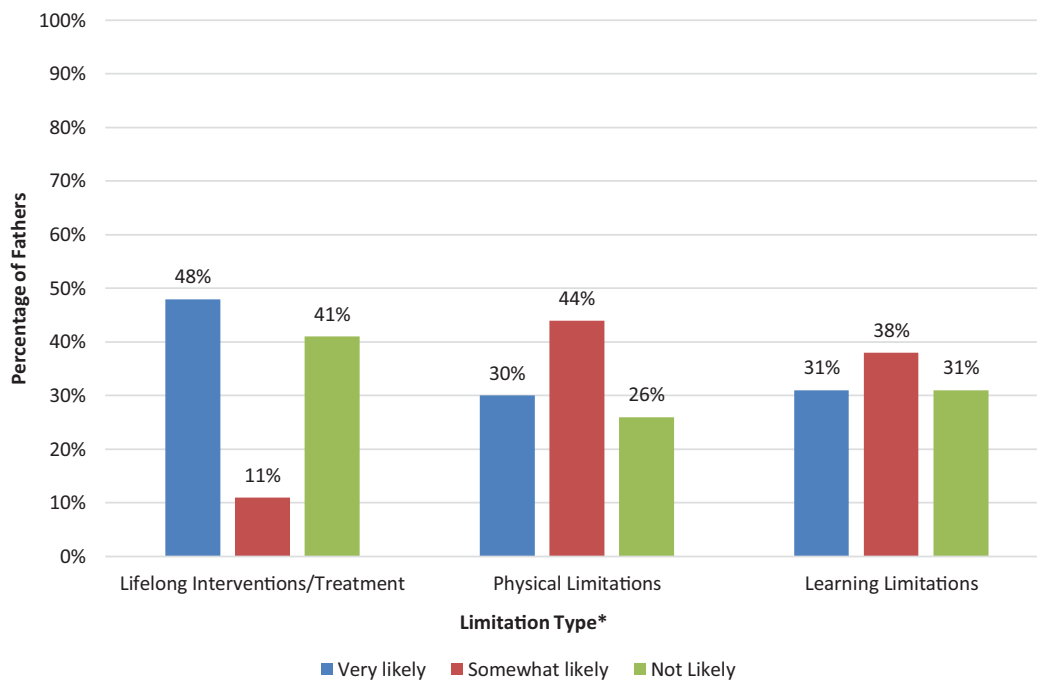
Patient characteristics are summarised in Table 1. The median patient age was 2 years (range 0–20) and 41% were male. Slightly over one-third (10/27, or 37%) of patients were in the cardiac intensive care unit at the time of the survey, and the remaining 17 patients were in the cardiology ward. The median length of stay in the hospital for all patients was 11 days, with an interquartile range of 5 days. The majority of patients had undergone cardiac catheterisation (63%) or surgery (67%) in the last month. Primary cardiac diagnoses included 10/27 (37%) patients with single ventricle lesions, 5/27 (19%) patients with pulmonary hypertension, and one heart transplant recipient (1/27, or 4%).

### Fathers' understanding of prognosis

More than one-half of fathers (16/27, 59%) reported they had known about the diagnosis for over one year, with three fathers



**Figure 2.** Fathers' report of their understanding of prognosis.



**Figure 3.** Specific components to prognostic understanding: fathers were asked: “when compared to a child without heart disease, how likely do you think it will be that your child’s heart condition will require or result in *a*) lifelong intervention, *b*) limitations in physical activity, and *c*) limitations in learning, development and behaviour.”

acknowledging that the diagnosis was recent (< 1 month). Almost all (96%) of the fathers surveyed thought they understood their child’s prognosis “extremely well” or “well,” with more than half (15/26, 58%) of fathers wanting to know more about prognosis. Over one-fifth (6/27, or 22%) thought their child’s care team knew something about their child’s prognosis that they did not know (Figure 2).

Only sixteen fathers (16/27, 59%) thought that they were “very prepared” for the medical problems that their child was experiencing in the previous week.

When asked about elements of prognosis (Figure 3), 11/27 (41%) of fathers thought it “not likely” that their child would require lifelong interventions or treatment, 7/27 (26%) of fathers thought it was “not likely” that their child would have limitations in

physical activity, and 8/26 (31%) of fathers thought it would be “not likely” that their child would have limitations in learning, development, and behaviour.

When asked, “*What is your current understanding of how long your child will live?*”, one-third of fathers expected their child to have normal life expectancy (8/25, or 32%) or expected their child would live into adulthood (11/25, or 44%).

### Communication

Of the 13 fathers that reported having a discussion of what would happen if their child got sicker, all reported that they found this conversation helpful.

All fathers were also asked the subsequent question, “*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?*” More than three-quarters of fathers (21/27, 78%) reported they had a discussion with their child’s medical provider. Of those fathers, nine (43%) thought the conversation was “somewhat” or “a little” confusing. Nearly all fathers (96%, or 20 of the 21 who had a discussion) perceived this conversation as having been open and honest, and almost all of them reported that it allowed them to express their worries (95%) “a great deal” or “a lot” and have their worries adequately addressed (100%) by “a great deal” or “a lot.” The vast majority of these fathers (91%) thought they were able to express their hopes in this conversation “a great deal” or “a lot,” and almost all fathers (95%) thought their hopes were adequately addressed in this conversation “a great deal” or “a lot.”

When asked to rate how adequate their communication with the healthcare team had been overall, 93% (25/27) of fathers responded “a great deal” or “a lot.” Yet, over one quarter (8/27, or 29%) of fathers said they received conflicting information from the healthcare team. About one-third of fathers (9/26, or 35%) reported they had to tell health professionals medical details of their child’s condition because the health professionals did not seem to know or had incorrect information.

### Parental differences

There were no significant differences ( $p < 0.05$ ) in predictor variables of the understanding of prognosis or reports of healthcare communication by caregiver type (mother vs. father).

Analysis of life expectancy and caregiver type (mother or father) showed a  $p$ -value of 0.059 trending toward significance. More than two-thirds of mothers (84/121, or 69%) expected their child hospitalised with advanced heart disease to live “into adulthood,” compared to less than half of fathers (12/26, or 46%).

### Discussion

This study explores pilot data of the experience of fathers of children hospitalised with cardiac disease. Notably, fathers report that they possess a strong understanding of their child’s prognosis but also report they want to know more information about prognosis. Second, fathers may overestimate the life expectancy of and underestimate the lifelong limitations and treatments/interventions that will be required for their child hospitalised with advanced heart disease. Third, communication was felt to be very good and helpful to fathers, with their hopes and worries supported, despite elements of conflicting information and medical team knowledge gaps.

Fathers found conversations about their children’s prognosis helpful, despite often feeling confused by the conversations. They consistently felt their hopes, wishes, and dilemmas were addressed during these conversations with clinicians. The conversations overwhelmingly were felt to be honest and open. This is important insight into fathers’ capabilities and desires. In the United States of America over time, traditional roles of caregiving and income generation have changed,<sup>12</sup> and the multiple ways that fathers contribute and function as caregivers in the hospital warrants an inclusive approach. The lack of literature on the role of fathers in caring for seriously ill children may reflect under-appreciation for these roles, suggesting these conversations and overall engagement are worthwhile.

Discrepancies in estimates and/or understanding of prognosis reported by fathers were highlighted in multiple contrasting reports. First, nearly all fathers reported they understand their child’s prognosis well or extremely well, yet many also reported wanting to know more about prognosis and/or felt their medical team knew information they did not know about their child’s prognosis. Second, half of fathers reported they felt very prepared for the medical problems their child would experience despite grossly overestimating their life expectancy and underestimating the lifelong limitations and required treatments/interventions.

Gender norms, roles, and expectations could explain some of the discrepancy between reported confidence in prognostic awareness and overestimates of their child’s future lifespan and functioning. Rather than this discrepancy representing misunderstanding about a child’s future prognosis, fathers may be portraying themselves (i.e. their answers) one way for appearances despite feeling the opposite.<sup>13</sup> This is the Front Stage vs. Back Stage self-presentation phenomenon.<sup>14</sup> To project a “Front Stage self,” fathers may want to maintain an appearance that they are aware, prepared, and confident their child will have a better prognosis, when in reality their “Back Stage self” depicts a more realistic, vulnerable presentation of them as parents who may be less knowledgeable, involved, and/or have significant negative emotions about prognosis.<sup>15</sup> This phenomenon is not exclusive to fathers. Mothers can and do exhibit Front Stage versus Back Stage behaviours, too, but it is a more well-described common approach taken by North American men in previous decades.

Most fathers reported they expect their child to have normal life expectancy or at least live into adulthood. These expectations contrast with the existing literature: life expectancy for this population can vary by specific advanced heart disease diagnosis but has been reported to be shorter than the normal life expectancy of healthy children and adults without advanced heart disease. Almost one-third of fathers thought it unlikely that their child would have limitations in learning, development, and behaviour. This contrasts with the existing literature, which provides evidence that some children with advanced heart disease, such as single ventricle physiology, had decreased health-related quality of life in both the physical domain and in the psychosocial domain (including emotional, social, and school domains).<sup>16,17,18</sup>

The results of communication with medical providers and healthcare teams showed some reassuring points of discussion and some room for improvement given the discrepancies fathers reported about prognosis. Paediatricians have a unique role in shaping the father’s caregiving experience, as paediatricians serve as the earliest healthcare team member to include and engage fathers in the care of their child and in their parental role. When this connection is not successful, poorer father involvement can manifest later in the child’s life,<sup>19</sup> and this is critical to improve



given the lifelong needs of most children with advanced heart disease. There is encouraging literature on interventions to improve father and team communication and the overall healthcare environment through parent education programmes and exploration of more evidence-based interventions for fathers of young children with complex needs.<sup>20</sup> This warrants more concerted implementation and efficacy studies.

That there were no significant differences found between the perceptions and experiences of fathers and mothers should challenge clinicians to provide the same support and communication improvements to all parents. It also warrants more intentional studies designed to compare the experiences of all parents, not only the parents that self-select and may be available to participate in in-person surveys.

### Limitations

There are several limitations to this study. This study is limited by selection bias since it did not primarily intend to enroll all fathers. It was therefore not powered to compare mother versus father response. Second, time at the bedside and presence at family meetings were not recorded and may be a factor in communication outcomes. Third, this is a specific cohort of hospitalised children with advanced heart disease from a single quaternary care institution with mostly White, English-speaking parents and may not be generalisable to all families.

### Conclusion

Although fathers report excellent understanding of their child's illness and positive experience around expressing hopes and fears, there remain many opportunities to improve communication, prognostic awareness, and participation of fathers of children who are hospitalised with advanced heart disease. These findings offer insight into the caregiver experience of fathers and highlight a need for their intentional inclusion in future research and interventions.

**Acknowledgements.** We thank the parents and providers who participated in this study for sharing their experiences and perspectives.

**Financial support.** This research was supported by the Joseph Middlemiss Foundation and the Fazzalari Fund for Cardiac Research and the Advanced Cardiac Therapies Fund at Boston Children's Hospital.

**Competing interests.** None.

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

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