

## Physician and Parent Perceptions of Prognosis and End-of-Life Experience in Children with Advanced Heart Disease

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### Abstract

**Background:** Little is known about how physician and parent perspectives compare regarding the prognosis and end-of-life (EOL) experience of children with advanced heart disease (AHD).

**Objective:** The study's objective was to describe and compare parent and physician perceptions regarding prognosis and EOL experience in children with AHD.

**Methods:** This was a cross-sectional survey study of cardiologists and bereaved parents. Study subjects were parents and cardiologists of children with primary cardiac diagnoses who died in a tertiary care pediatric hospital between January 2007 and December 2009. Inclusion required both physician and parent to have completed surveys respective to the same patient. A total of 31 parent/physician pairs formed the analytic sample. Perceptions were measured of cardiologists and bereaved parents regarding the EOL experience of children with AHD.

**Results:** Nearly half of parents and physicians felt that patients suffered 'a great deal,' 'a lot,' or 'somewhat' at EOL, but there was no agreement between them. At diagnosis, parents more often expected complete repair and normal lifespan while the majority of physicians expected shortened lifespan without normal quality of life. Parents who expected complete repair with normal life were more likely to report 'a lot' of suffering at EOL ( $p=0.002$ ). In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared.

**Conclusion:** Both parents and physicians perceive suffering at EOL in patients who die of AHD. Moreover, parent expectations at diagnosis may influence perceptions of suffering at EOL. Physicians overestimate the degree of parent preparedness for their child's death.

### Introduction

**D**ESPITE SIGNIFICANT IMPROVEMENTS in short- and long-term outcomes for infants and children with heart disease in the United States, cardiac disease remains one of the leading causes of nonaccidental death in childhood.<sup>1</sup> Most children who die from advanced heart disease (AHD) die before a year of age with multiorgan system failure in an intensive care unit setting.<sup>2</sup> To date, most research related to pediatric AHD has focused on improvement of medical technologies aimed at prolonging survival; less is known

about how parents and physicians perceive the end-of-life (EOL) care experience of children with AHD.

While investigators have begun to define unmet physical and psychological needs of children with life-threatening illness and their families,<sup>3</sup> including those with AHD,<sup>2,4</sup> the great majority of pediatric palliative care research has been conducted in pediatric oncology. These data have revealed a significant gap between physician and parent understanding of prognosis and highlight areas for improvement in communication between physicians and families.<sup>5-7</sup> Additionally, studies have shown that parental understanding of

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prognostic information is associated with greater peace of mind<sup>8</sup> and a greater sense of hope.<sup>9</sup> We have previously shown that parents of children who died of AHD perceive suffering at EOL, and come to realize late that their child has no realistic chance of survival, often once death is imminent.<sup>4</sup> To understand this further, in this study we aimed to describe and compare the perspectives of primary cardiologists and parents who cared for children who died of AHD.

## Methods

### Study design

This is a cross-sectional comparative survey study of parents and primary cardiologists of patients less than 21 years of age who died in the inpatient setting from AHD between January 2007 and December 2009 at a large pediatric cardiology center. This is a substudy related to an original cohort study of parents alone, which contained 50 parent surveys from two institutions.<sup>4</sup> The physician-matched cohort was only undertaken at a single site. The full study and survey design is outlined in a prior manuscript by Blume, et al.<sup>4</sup> Patient characteristics were collected by retrospective chart review. Parent and physician characteristics were obtained through survey questions.

### Survey development

The Survey about Caring for Children with Heart Disease (SCCHD) at EOL contains 110 mostly retrospective questions in 10 different domains. Its development and pilot phase are previously described.<sup>4</sup> The SCCHD-physician survey instrument was developed directly from the SCCHD for this substudy, containing 11 questions, 7 of which directly mirrored questions from the parent survey. Shared domains between the two surveys include treatment goals at diagnosis, quality of life (QOL), EOL decision making, quality of communication, and caregiver-family relationship.

### Participants

Eligible participants were primary cardiologists and parents who cared for a patient under the age of 21, who died in the hospital from cardiac disease between January 2007 and December 2009. Parents and primary cardiologists were identified through medical record review. Parents were excluded if they could not complete a survey in English or if they had previously denied permission to provide contact information for research purposes. Permission to contact the family was sought from the patient's primary cardiologist as part of the physician survey instrument. Inclusion into the final analysis group required both the physician and parent to have completed surveys regarding the same patient.

Medical record review for patient characteristics was performed. Data collection included demographics, age at diagnosis, etiology of heart disease, surgeries and catheterizations, interventions at EOL, and cause of death. Mode of death was coded by structured chart review and then adjudicated by a single pediatric cardiologist (EDB). Mode of death was defined based on the following criteria: (1) withdrawal of disease-directed care: the patient was declared brain dead or was receiving life-sustaining interventions that were discontinued; (2) death during resuscitative efforts: the patient was undergoing cardiopulmonary resuscitation when

a decision was made to cease; and (3) comfort care after birth: the patient never received any cardiac-directed therapy except prostaglandin E<sub>1</sub>.

The institution's review board approved the study protocol and survey instruments.

### Data management and statistics

Parent and physician survey responses were recorded in Research Electronic Data Capture (REDCap), a secure password-protected electronic database.<sup>10</sup> Auto-queries and auto-validations were incorporated into REDCap during the design phase to minimize data entry error. Data accuracy and completeness were verified by research investigators. Each participant was assigned a unique study number. Analyses were performed using Stata statistical software version 12.1 (StataCorp., College Station, TX).

Descriptive statistics, including percentages, medians, and ranges, were primarily employed. Bivariate relationships were assessed using either Fisher's exact test or correlation coefficients, such as Pearson's test and Spearman's.

## Results

Thirty-three of seventy-eight parents approached completed surveys, forming a response rate of 42%. Of the 33 parents who completed surveys, 31 of the cardiologists who cared for those bereaved parents' children completed the physician survey (response rate 94%). Therefore, the final sample size for the proposed analyses was 31 parent/physician pairs. Seventeen individual cardiologists participated. Total number of surveys completed per cardiologist ranged from one to six with a median of one.

TABLE 1. PATIENT CHARACTERISTICS<sup>a</sup>

Characteristic	Number (%) or median (range)
Age at death	6 mos (4 d–20.4 yrs)
Duration of last hospital stay	22 d (1 d–193 d)
<b>Cardiac diagnosis</b>	
CHD—single ventricle	12 (39)
CHD—two ventricles	14 (45)
Acquired	5 (16)
Prenatal diagnosis	21 (68)
Total number of surgeries	3 (0–8)
Death in CICU	29 (94)
<b>Mode of death</b>	
Withdrawal of life-sustaining interventions	23 (74)
During resuscitative efforts	5 (16)
Comfort care	3 (10)
<b>Interventions at end of life</b>	
Intubated	28 (90)
ECMO or VAD	17 (55)
Intravenous inotropy	29 (94)
CPR within 24 hours of death	7 (23)

<sup>a</sup>n = 31.

CHD, congenital heart disease; CICU, cardiac intensive care unit; CPR, cardiopulmonary resuscitation; ECMO, extracorporeal membrane oxygenation; VAD, ventricular assist device.

### Patient characteristics

Patient characteristics are summarized in Table 1. The median age at death of the 31 patients in the study group was 6 months (range, 4 days to 20.4 years). Median length of last hospital stay was 22 days (range, 1–193 days). Most of the patients (26/31, 84%) had a diagnosis of congenital heart disease, with 12/31 having single ventricle physiology. Sixty-eight percent of patients (21/31) were diagnosed prenatally and 26% (8) more within the first month of life. The median number of surgeries prior to death in this cohort was three (range, 0–8). Some of the patients required peritoneal drains (6, 19%), gastrostomy tubes (8, 26%), or tracheostomy tubes (2, 6%) at some point in their lives.

Almost all patients (29, 94%) died in the cardiac intensive care unit. Twenty-three (74%) died after discontinuation of disease-directed interventions, 5 (16%) died during resuscitative efforts, and 3 (10%) died while receiving comfort care after birth. Within 24 hours prior to death, 28 (90%) patients were intubated and over half (17, 55%) required mechanical circulatory support. Ninety-four percent of patients (29) were receiving inotropic support and 23% (7) had documentation of cardiopulmonary resuscitation within the 24 hours prior to death.

### Parent and physician characteristics

Parents nearly all identified as married (28, 90%), non-Hispanic white (29, 94%) mothers (30, 97%) with a median age of 37.4 years (range, 22.8–48.6 years). Seventy-seven percent (24) were local to New England, 19% (6) other United States locations, and 3% (1) international. Surveys of both the parents and cardiologists were completed a median of 3 years after the patient's death (range, 1.2–4.2 years). Cardiologists surveyed had a median of 14 years of experience following fellowship (range, 3–37 years).

### Expectations at diagnosis for child's heart

Cardiologists expected long-term survival at diagnosis in 32% of patients (2 'very likely,' 8 'somewhat likely.'). At diagnosis, most physicians' primary expectations for the patients' hearts were 'for complete repair, shortened lifespan,

limited QOL (11/23, 48%) or 'to improve heart but without complete repair and with shortened lifespan and limited activity and QOL (9/23, 39%) (see Fig. 1). In contrast, most parents reported that their 'primary hope and expectation' for their child's heart around time of diagnosis was for 'complete repair with normal lifespan' (12/31, 39%) or for 'complete repair, normal lifespan, but limited activity/QOL (14/31, 45%). Therefore, most physicians' expectations at diagnosis included shortened lifespan (20/23, 87%), while most parents expected a normal lifespan (26/31, 84%).

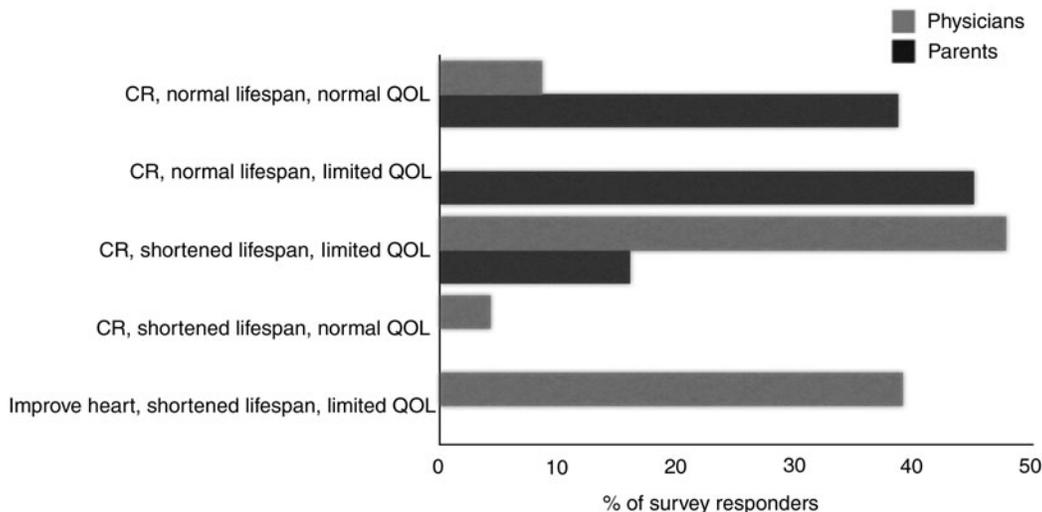
### Suffering

Nearly half of parents (13/28, 46%) and physicians (13/26, 50%) reported that they perceived the patient had suffered either 'a great deal,' 'a lot,' or 'somewhat' at EOL (see Fig. 2). There was no agreement in perceptions between physicians and parents (Spearman's coefficient 0.22,  $p=0.64$ ) suggesting that while roughly half of both parents and physicians perceived some suffering at EOL, they were not regarding the same set of patients. Moreover, no physicians thought a patient had suffered a 'great deal,' while about 15% of parents did. Additionally, parents more often reported no suffering at all than did physicians.

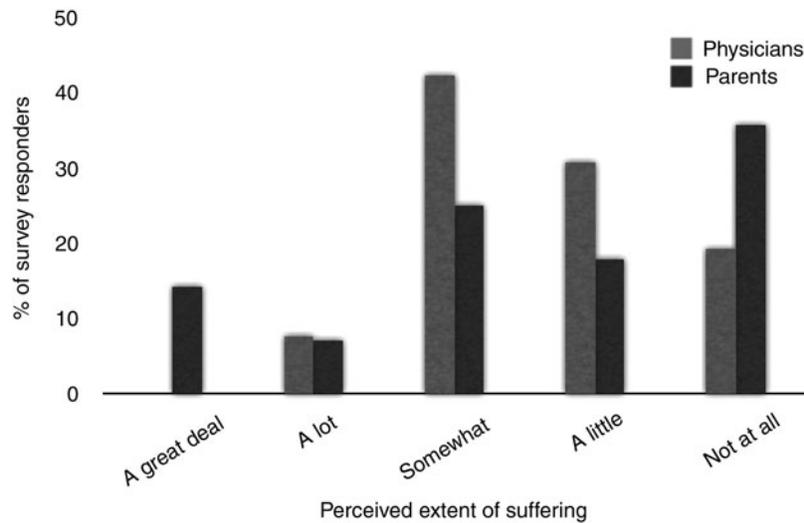
There was a significant association between parent expectations at diagnosis and parent perceptions of patient suffering at EOL. Those who reported they had expected 'complete repair with normal lifespan and normal QOL' reported more suffering at EOL ( $p=0.002$ ). Specifically, 50% of parents who expected 'complete repair with normal lifespan and normal QOL' perceived 'a lot' of suffering at EOL; whereas none of the parents with other, less optimistic expectations reported 'a lot' of suffering at EOL.

### Goals for child during end-of-life care

The 'end-of-life care period' was consistently defined for both physicians and parents as 'the time after which you realized your child had no realistic chance of survival.' The majority of both physicians (18/23, 78%) and parents (16/31, 52%) reported that their primary goal for the medical care provided to the patient once they realized there was no



**FIG. 1.** Parent and physician expectations for child's heart at diagnosis. CR, complete repair; QOL, quality of life.



**FIG. 2.** Physician and parent perceptions of child suffering during the end-of-life care period.

realistic chance of child survival was ‘to lessen the patient’s suffering as much as possible.’ More than a third of parents at EOL, however, reported their goal was to ‘make sure [they] had done everything’ (7/31, 23%) or to still ‘fix [the] child’s heart’ (4/31, 13%) (see Fig. 3).

**Communication**

While 42% (13/31) of parents in this cohort felt they “sometimes” received conflicting information from members of the care team during their child’s EOL care period, only 25% (7/28) of physicians reported that they thought the parents had perceived care team conflict. Moreover, 39% of physicians answered ‘strongly disagree’ when faced with the statement, ‘This family felt conflict among the members of the child’s care team.’

**Preparedness for child’s death**

Fifty-five percent (17) of parents reported feeling unprepared for the way their child died while only 29% of

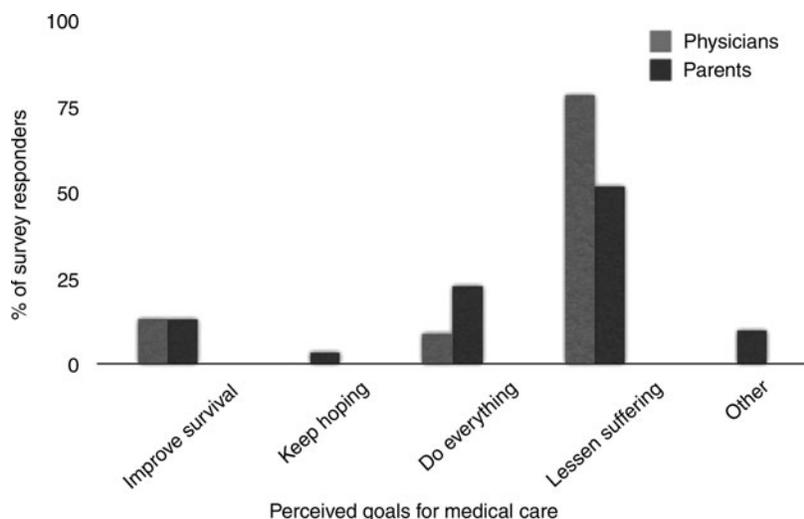
physicians perceived that parents felt unprepared. More specifically, in nearly half of matched pairs (12/28, 43%), physicians reported having perceived that the parents were prepared for the way the patient died, while the parents reported feeling unprepared.

**Quality of care**

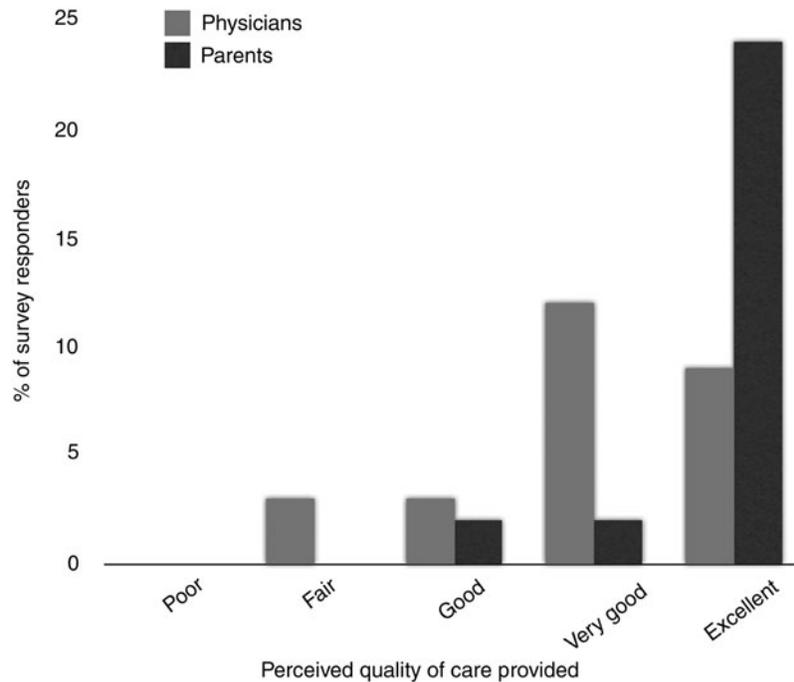
The majority of parents (29, 93%) felt that quality of care during the last month of the patient’s life was ‘excellent’ or ‘very good’ compared to only 78% (24) of physicians. No parents or physicians reported quality of care to be ‘poor’ (see Fig. 4).

**Discussion**

Children who die of AHD in the hospital do so in an intensive care setting, most often following the withdrawal of highly invasive interventions.<sup>2</sup> According to their parents, many children with AHD experience suffering in the EOL care period.<sup>4</sup> Additionally, for most, realization that their



**FIG. 3.** Physician and parent goals for medical care once realization was made of no realistic chance of survival.



**FIG. 4.** Physician and parent perceptions of quality of care provided during the child's last month of life.

child has no realistic chance of survival does not occur until death is imminent.<sup>4</sup> This study describes how physician and parent perspectives compare regarding expectations at diagnosis and EOL experience in children with AHD.

#### **Expectations at diagnosis**

When asked to report their primary expectations for the patient's heart at diagnosis, just over a third of physicians said they expected a shortened lifespan with limited QOL and another third said shortened lifespan with limited quality of life and limited activity. Parents, in contrast, more often said their expectation was for complete repair and normal lifespan, some with limited activity and QOL. This suggests that there is a gap between parent and physician understanding of expectations around the time of diagnosis in children who eventually die of AHD. It is unclear whether this gap is the result of ineffective communication by the physician, lack of understanding by the parents, or solely reflects the 'hope' that parents have for their child's future. Perhaps physicians in retrospect, knowing that the patient did eventually die, are more likely to report that their understanding of prognosis at diagnosis was less optimistic than it actually was. Additionally, the degree of emotional stress the parents felt at time of diagnosis may have clouded their ability to understand what the physician was attempting to communicate. This becomes even more critical to understand, since those parents who expected complete repair with normal lifespan were significantly more likely to report a lot of suffering at EOL. Further attention to improving communication around uncertain prognosis is warranted.

#### **Perceived end-of-life experience**

Communication gaps in other pediatric palliative care populations are a common theme in the medical literature. In

one study, investigators linked the presence of a primary oncologist who actively coordinates the team with improved pain management and promotion of the child's experience of peacefulness.<sup>6</sup> Perceived receipt of conflicting information from the child's care team was associated with parental reports of child suffering from pain. Another study found that higher parent ratings of care were associated with physicians giving clear information about what to expect during the child's EOL care period.<sup>7</sup> In contrast, physician care ratings were not associated with communication factors but instead were higher when associated with less parent-reported pain and fewer days in the hospital at EOL.

In this study parents more often reported 'excellent' or 'good' quality of care during their child's last month of life as compared to the physicians, but overall, quality of care was thought to be very high by both groups. Approximately half of both parents and physicians perceived the child to have suffered at least 'somewhat' at EOL. However, the physicians and parents who felt this way did not correspond with each other, again suggesting a disconnect between parent and physician perceptions of the patient's EOL experience.

Moreover, almost twice as many parents reported having received conflicting information from members of the patient's care team as was perceived to be the case by the physicians. This suggests that parents may perceive conflict while physicians are unaware. Similarly, over half of parents reported feeling unprepared for the way their child died, while less than a third of physicians thought parents felt unprepared.

#### **Limitations**

This comparative survey study has several limitations. Primarily, the retrospective nature of the surveys may bias parent and physician recollection of the circumstances surrounding and leading up to the patient's death. Similarly,

respondent perspectives may have changed over time. Additionally, the single-institution sample size was small, with a homogenous parent population consisting of English-speakers and two-parent families, which may limit the generalizability. Additionally, the patients included all died in the hospital, almost all in the intensive care unit, and most receiving highly invasive interventions. Thus, the results may not be generalizable to patients with AHD who die at home or who are receiving comfort care measures only. Lastly, the physician perspectives came only from primary cardiologists and thus did not include the perspectives of intensivists or nurses, who may have been more directly involved in clinical care at EOL.

### Conclusion

This study explores and compares physician and parent expectations and perceptions of prognosis and EOL experience of children with AHD. Our results suggest that cardiologist and parent recollection of expectations for a patient's heart at time of diagnosis differ; that parents who expect complete heart repair, normal lifespan, and QOL at diagnosis are more likely to report more suffering at EOL; and that physicians underestimate how often parents feel unprepared or perceive conflicting information from the patient's care team. Overall, the results of this study highlight areas for improvement in parent and care team communication regarding expectations for children with cardiac disease at time of diagnosis as well as care at EOL. Further investigation is required to prospectively analyze the perspectives of parents and physicians caring for children with AHD.

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### Author Disclosure Statement

The authors have no financial relationships relevant to this article to disclose. The authors have no conflicts of interest to disclose. Drs. Elizabeth D. Blume and Emily Morell Balkin had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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