

## Review Article

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# Communication and decision-making regarding children with critical cardiac disease: a systematic review of family preferences

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## Abstract

Critical heart disease in the pediatric population is associated with high morbidity and mortality. Research around the most effective communication and decision-making strategies is lacking. This systematic review aims to summarise what is known about parent preference for communication and decision-making in children with critical heart disease. Database searches included key words such as family, pediatric heart disease, communication, and decision-making. A total of 10 studies fit our inclusion criteria: nine were qualitative studies with parent interviews and one study was quantitative with a parent survey. We found three main themes regarding physician–parent communication and decision-making in the context of paediatric heart disease: (1) amount, timing, and content of information provided to parents; (2) helpful physician characteristics and communication styles; and (3) reinforcing the support circle for families.

Heart disease remains a leading cause of death in infants and children in the United States despite medical and surgical advances.<sup>1</sup> Most of these deaths occur in ICUs after prolonged hospitalisations, with over half occurring after withdrawal of life-sustaining treatments including mechanical ventilation and circulatory support.<sup>2</sup>

Data from other pediatric populations suggest that the quality of physician–family communication influences the decisions that are made, including decisions about end-of-life care. Data from paediatric oncology suggest that parental understanding that their child is dying despite medical interventions lags behind physicians'; importantly, those parents who had an earlier understanding of the inevitability of their child's death were more satisfied with their child's end-of-life care.<sup>3</sup> Much remains to be explored regarding gaps in communication between physician and parents of seriously ill children. It has been shown, for instance, that physicians and parents often walk away from end-of-life discussions with different perceptions of what was discussed: physicians may believe they offered the possibility of limiting interventions, but parents say they did not hear this option.<sup>4</sup> Studies show that physicians may not explore parents' understanding often enough, which can perpetuate diverging perceptions of a child's prognosis and treatment options.<sup>5,6</sup>

Despite the prevalence of, and mortality associated with, paediatric heart disease, we lack an evidence base to guide communication and decision-making with these families. There has been research into the importance of teamwork and shared decision-making within paediatric cardiology and cardiac surgery to optimise the care of these children,<sup>7</sup> and it is important to include families as members of the team. Notably, a recent systematic review confirmed that as many as 80% of parents of children with critical heart disease have symptoms of trauma, whereas another 25–50% have symptoms of anxiety, depression, and/or post-traumatic stress disorder.<sup>8</sup> Given data from a variety of patient groups suggesting that good communication with physicians can moderate parents' long-term outcome,<sup>9,10</sup> there is a need for evidence-based, effective, family-centred communication techniques relevant to paediatric heart disease.

This systematic review summarises what is known regarding parent preferences for communication and decision-making for children with critical heart disease.

## Methods

Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines,<sup>11</sup> literature review was completed in February, 2018. Relevant electronic databases, including Pubmed (biomedical and life sciences literature), EMBASE (Excerpta Medica

dataBASE), PsycINFO (psychology/psychiatry literature), and CINAHL (The Cumulative Index to Nursing and Allied Health Literature), were searched for English-language studies and dissertations with data about parents' experience with communication and decision-making for children with high-risk/life-limiting congenital and acquired cardiac disease. Because research in this area is limited, there were no eligibility restrictions on study design, country of origin, single versus multi-institutional recruitment, or inpatient versus outpatient setting. We included studies of prenatal and postnatal communication because critical decisions about heart disease treatment are made during each of these times. Search terms were key words related to communication and decision-making in critical heart disease listed in Table 1. We also hand-searched the reference lists of all included articles to identify additional studies.

The initial search yielded 10,247 papers. In a pre-selection process, one author (K.N.) screened titles and abstracts for content relevant to physician–family communication and decision-making for children with critical cardiac disease. In all, fifty-four articles and dissertations remained, and two authors – K.N. and E.P.W. – then performed full-text article review. A third author, P.K.D., adjudicated disputes regarding inclusion of individual articles. Figure 1 summarises study selection and articles excluded from full-text screening.

Data extraction from included articles was performed by two authors – K.N. and E.P.W.. Information about study design, sample size, outcomes, and specific findings regarding physician–family communication and decision-making was recorded.

## Results

A total of 10 studies – nine articles and one dissertation – met the inclusion criteria. Among them, six were conducted in the United States, three in Scandinavia, and one in Taiwan; all were published between 1996 and 2017. Table 2 summarises study characteristics. In all, four studies recruited families of hospitalised children, two recruited from outpatient cardiology clinics, two from fetal cardiology clinics, and two recruited both from inpatient and outpatient settings. Data collection for nine studies

was through qualitative parent interviews; one study utilised parent surveys. The number of parents interviewed or surveyed ranged from 11 to 88 for a total of 255 parents. The majority of parents were mothers.

Outcomes from the 10 studies regarding physician–parent communication and decision-making in the context of paediatric heart disease can be combined into three themes: (1) amount, timing, and content of information provided to parents;<sup>12–15</sup> (2) helpful physician characteristics and communication styles;<sup>14–19</sup> and (3) reinforcing the support circle for families.<sup>13,17,20</sup>

### Amount, timing, and content of information that parents want

The most common theme that emerged from the 10 studies was that parents often wanted more information than they felt they received from physicians about their child's disease and about the larger picture of what the prognosis meant for their child and family, including potential quality of life and physical and developmental limitations.<sup>12–14,21</sup> More information, both verbal and written, almost always helped parents make decisions.<sup>12–14,21</sup> Parents valued information that was timely and honest, including physician candidness about severity of disease and possibility of a shortened life or significant morbidities.<sup>12–14</sup> This was especially important for parents facing decisions regarding pregnancy continuation or during their child's acute complications.<sup>13,14</sup> Information about what to expect before cardiac surgery, when surgery is planned, and helping the family visit the ICU to meet staff and ask questions helped parents prepare for future communication with new physicians.<sup>12,15</sup> Updates during a surgical procedure helped reduce family anxiety and stress.<sup>15</sup>

For some parents, disclosure of all potential outcomes, including death, was overwhelming and made it difficult to hear additional information, if not permitted time to process.<sup>15</sup> Given this, parents also appreciated repeated information over time.

### Physician characteristics and communication styles

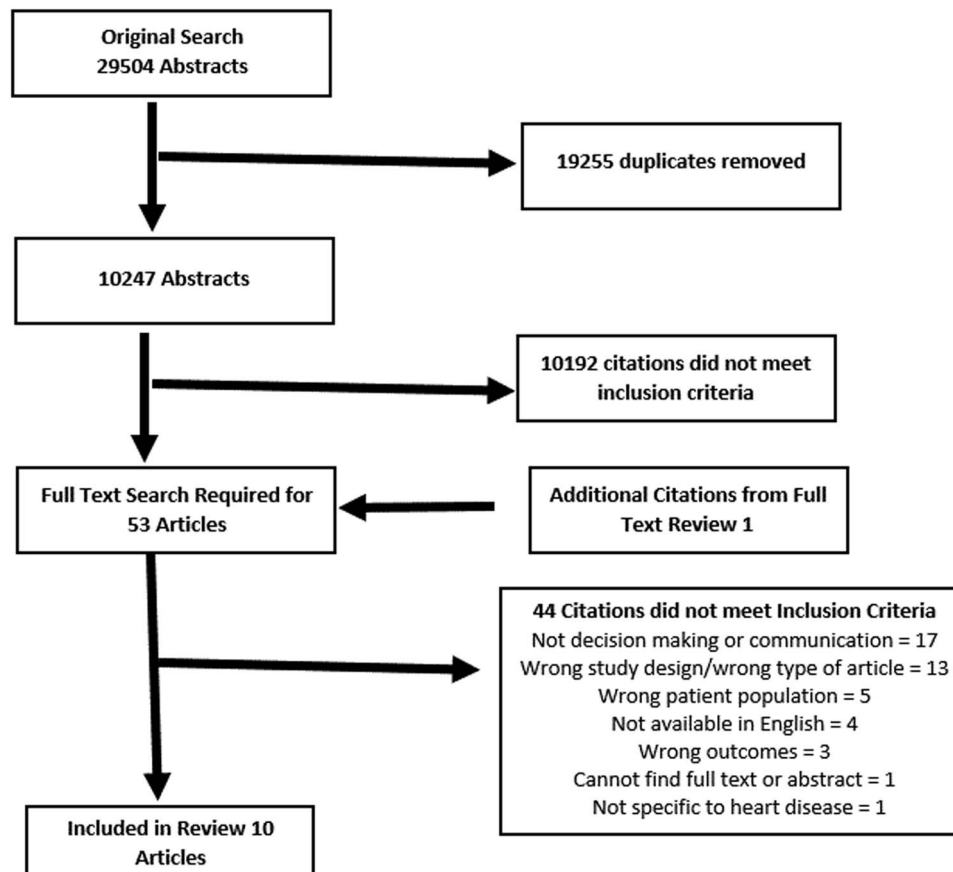
Parents described physician characteristics and communication styles that helped them through difficult times and decisions. The most common theme was that parents valued support and encouragement from physicians throughout the process of making serious decisions. Types of support that were meaningful included the opportunity to get to know treating physicians and to be able to contact physicians for follow-up questions;<sup>13,17</sup> both helped build a trusting relationship.<sup>15–17</sup> Parents also trusted physicians who were present and mindful with families during difficult times and were relatable on a human level.<sup>19,21</sup> Parents appreciated when physicians cared not just for their child but for the whole family;<sup>16,19</sup> in one study, home visitation by physicians promoted a trusting relationship, demonstrating to parents individualised care.<sup>15</sup> Parents valued physicians who spent time exploring the parents' experience and who tried to anticipate and validate parents' emotions during difficult times.<sup>19</sup> Families appreciated encouragement and guidance from physicians that their family could get through difficult situations.<sup>16,19</sup>

Parents also appreciated when physicians respected parents' role, acknowledging that parents have their child's best interest in mind and know them the best.<sup>19</sup> Including parents in daily decisions and allowing them to participate in daily care in the hospital allows parents a feeling of control and recognises them as experts in their child's care.<sup>15</sup> They also valued when physicians

**Table 1.** Search terms.

Patients/subjects (A)	Disease state (B)	Characteristics (C)
Pediatrics	Cardiovascular Disease	Communication
Infant	Heart defects	Decision Making
Parents	Congenital Heart disease	Quality of Life
		Psychology
		Social Support
		Decision Support
		Systems
		Religion
		Socioeconomic Factors
		Palliative Care
		Hospice
		Nursing
		Bereavement
		Grief
		Decision Aid
		Decision Tool
		Psychosocial
		End of Life

Three word phrases were used, one from each column in all possible arrangements; "A" AND "B" AND "C"



**Figure 1.** Summary of search strategy results.

**Table 2.** Study characteristics.

Studies	Type	Analysis	Theoretical framework	Population	Recruitment location
Arya	Quantitative survey	Descriptive	None	Parents of children >3 years old with CHD	Inpatient and outpatient
Bratt	Qualitative interviews	Content analysis	None	Parents with prenatal CHD diagnosis	Outpatient fetal centre
Brown	Qualitative interviews	Grounded theory	None	Parents of children with CHD with past ICU stay	Inpatient tertiary paediatric hospital (CICU)
Carlsson	Qualitative interviews	Content analysis	None	Parents with prenatal CHD diagnosis	Outpatient fetal centre
Higgins	Qualitative interviews	Ethnography	Psychological decision-making theory	Parents of heart transplant candidates	Outpatient and inpatient transplant centre
Kupst	Qualitative interviews	Content analysis	None	Parents of children awaiting cardiac surgery	Outpatient cardiology office
Lan	Qualitative interviews	Content analysis	Phenomenology; family systems theory	Mothers of children who had cardiac surgery at <3 years old	Outpatient Cardiology office
Vandvik	Qualitative interviews	Content analysis	None	Mothers of children with HLHS	Inpatient tertiary paediatric hospital
Wei	Qualitative interviews	Content analysis	Swanson caring theory	Parents of children with CHD undergoing heart surgery	Inpatient tertiary paediatric hospital
Lopez	Qualitative interviews	Content analysis	None	Parents of children with CHD undergoing heart surgery	University-affiliated tertiary paediatric hospital

CICU = cardiac ICU; HLHS = hypoplastic left heart syndrome

recognised parents' need to balance caring for the whole family when making decisions for their child.

Parent desire for physician recommendations was common in situations where treatment options included withholding/withdrawing of life-sustaining therapies.<sup>16,18</sup> Parents reported feeling shocked, exhausted, and overwhelmed by these complicated decisions; they were anxious for physician guidance in the face of such important choices.<sup>16,18</sup> Some parents felt they could not make decisions about limiting life-sustaining therapies without physician support, believing that such decisions should not be made by parents alone.<sup>16,18</sup>

### Reinforcing family support

The final theme was the need for physicians to reinforce parents' support outside of the medical setting.<sup>13,17,20</sup> Parents often prized help from other family members when making serious decisions for a child; this support was strengthened when physicians facilitated inclusion of those family members in important discussions.<sup>13,20</sup> In multiple studies, parents appreciated when physicians arranged for parents to meet other families who have experienced similar situations, especially families of children with comparable diagnoses.<sup>13,17</sup>

Key take-home points for physicians regarding communication and decision-making with families of children with heart disease are shown in Table 3.

### Discussion

As medical and surgical interventions continue to improve outcomes for paediatric heart disease, there will always remain a group of patients whose conditions will lead to chronic disability and/or early death. The tension between the risks and benefits of escalating interventions for those children means that there may be no consensus about "best" treatment options. Our professional obligation in these situations is to help families understand what they most want to achieve, and avoid, in the course of their child's care. To do this well, physicians need more than ad hoc counselling skills – we need a robust evidence base regarding family's needs to inform our approach to communication and decision-making. We performed this review to summarise what is known about family preferences regarding communication and decision-making in the context of critical paediatric cardiac disease. Our

most important finding was that the data regarding parent experience are sparse, a concerning deficit in light of disease prevalence and severity. The existing data do offer several indications of what approaches physicians can take when counselling families and joining with them in serious decisions.

First, many parents want more, and timelier, information in order to understand and plan for the future. Because none of the existing studies included recorded family–physician conversations, we cannot assess what families were told; we only know what they feel they heard. Multiple studies show that intense emotions reduce a person's capacity to hear and process cognitive information;<sup>22,23</sup> physicians should expect and plan for this likelihood when counselling families of very sick children. Parents in the studies we reviewed made it clear that sharing information about their child's illness, potential treatments, and prognosis should be repeated, in different formats, to reinforce and clarify the essential information. Studies in other populations demonstrate the value of a coordinated, interdisciplinary approach to sharing information – families may hear information more clearly from nurses who spend more time with the family and seem less intimidating than physicians. Importantly, parents' desire for more information extends well beyond short-term details of expected cardiac interventions: parents want doctors to talk about what to expect from the future, to help them prepare for the "big picture" of their child's prognosis for quality and length of life. This reflects data from parents of children with other critical illnesses, who report that this "big picture" information is very valuable to families but is often missing from physician counselling.<sup>24</sup>

Second, parents were clear that they need more than just information from physicians. Parents whose fetus or child has a life-threatening diagnosis are profoundly stressed and distressed. Physicians can add to this distress if they limit their interactions with families to simply relaying medical information without acknowledging and processing how this information is life-changing for the whole family. Other studies of parents of very ill children suggest that physicians can be supportive in different ways – by physically or verbally sharing their own emotions, by specifically articulating how hard this is for the family, by pausing to allow space for intense emotion – all approaches that take little physician time and build family trust.<sup>4</sup> Third, parents in several of the studies we reviewed wanted treatment recommendations, especially during high-stakes decisions about life-sustaining therapies. Although collaborative decision-making is the ethical gold standard in

**Table 3.** Communication and decision-making take-home points.

Key themes families value around communication and decision-making	Specifics points on these themes
Information	<ul style="list-style-type: none"> <li>• Candid information about potential positive and negative outcomes</li> <li>• Address the "big picture" of anticipated quality of life</li> <li>• Verbal and written information repeated over time</li> </ul>
Physician communication style	<ul style="list-style-type: none"> <li>• Support during serious decisions, including treatment recommendations</li> <li>• Spending time exploring parents' experience</li> <li>• Recognising impact on whole family</li> <li>• Validating emotions</li> <li>• Encouragement without being overly optimistic</li> </ul>
Reinforce family/outside supports	<ul style="list-style-type: none"> <li>• Facilitate inclusion of family supports in meetings</li> <li>• Facilitate meeting other families of children with similar conditions</li> </ul>



paediatrics, physicians may instead relegate all decision-making authority to parents, for instance by simply providing information and asking parents to make the decision. Data from other paediatric populations suggest that a minority of families want to be in complete charge of high-stakes medical decisions for their child; most want physicians to share or even direct the decisions.<sup>25,26</sup> Therefore, while there is often a physician reluctance to make treatment recommendations,<sup>27</sup> the fact that many parents find them helpful suggests that physicians should consider including these more commonly in their counselling of families.

Finally, parents in the reviewed papers appreciated physician guidance in accessing sources of support. Families were often discussing their child's illness and care with extended family and friends, and relied on those people to help them shape their values related to their child's care. This process was strengthened when physicians included important support people in medical discussions when possible. Parents also found it extremely helpful when physicians facilitated meetings with other parents who had been through similar situations with their child. Most departments have ongoing relationships with parents who have made variable treatment choices; a process for connecting willing families with other families could be an important support.

The findings of this systematic review also highlight that the research on communication and decision-making in the paediatric cardiology population is very limited, and the field is in need of rigorous studies to answer the question of how best to facilitate communication and decision-making between the medical team and families of children with critical heart disease. We are currently conducting a multi-centre study to evaluate how parents of children with cardiac conditions experience their child's illness and medical treatment and how clinicians can help meet their needs, from diagnosis to end-of-life care. We hope this research will help define how clinicians and families can work as a team to improve the care of children with critical heart disease.

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