

## Original Article

# Important knowledge for parents of children with heart disease: parent, nurse, and physician views

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**Abstract** *Objectives:* Parental understanding of their children's heart disease is inadequate, which may contribute to poor health outcomes. The purpose of this study was to determine what parental knowledge is important in the care of children with heart disease from the perspective of parents, nurses, and physicians. *Methods:* Focus groups were formed with parents of children with single ventricle congenital heart disease (CHD), biventricular CHD, and heart transplantation, and with nurses and physicians who provide care for these children. A nominal group technique was used to identify and prioritise important parental knowledge items and themes. The voting data for each theme were reported by participant type – parent, nurse, and physician – and patient diagnosis – single ventricle CHD, biventricular CHD, and heart transplantation. *Results:* The following three themes were identified as important by all groups: *recognition of and response to clinical deterioration, medications, and prognosis and plan.* Additional themes that were unique to specific groups included the following: *medical team members and interactions* (parents), *tests and labs* (parents), *neurodevelopmental outcomes and interventions* (physicians), *lifelong disease requiring lifelong follow-up* (physicians and nurses), and *diagnosis, physiology, and interventions* (single ventricle and biventricular CHD). *Conclusions:* Parents, nurses, and physicians have both common and unique views regarding what parents should know to effectively care for their children with single ventricle CHD, biventricular CHD, or heart transplantation. Specific targeted parental education that incorporates these findings should be provided to each group. Further development of questionnaires regarding parental knowledge with appropriate content validity is warranted.

Keywords: Parental knowledge; children; parents; CHD; focus groups

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## Introduction

Understanding the nature of one's disease, its treatments, and potential complications promotes good health behaviour and is associated with better disease management and treatment compliance.<sup>1–3</sup> For children with heart disease, a better understanding by parents has been shown to promote compliance and reduce parental anxiety.<sup>4,5</sup> Studies have indicated that there are important knowledge gaps among parents of children with heart disease, which suggest that the current educational offerings are inadequate;<sup>6–14</sup>

however, the questionnaires used in these studies may not adequately assess the most important areas of knowledge, as their content was identified primarily by physicians with little input from nurses and no input from parents.<sup>8,11,12</sup> Furthermore, these questionnaires did not include questions to assess knowledge that might be uniquely important for parents of children with specific heart conditions including single ventricle congenital heart disease (CHD), biventricular CHD, and orthotopic heart transplantation. Although these groups clearly have some shared educational needs, each of them also likely have additional unique educational needs. Developing a knowledge questionnaire with specific subsections for parents of children with single ventricle CHD, biventricular CHD, and heart transplantation will provide important information

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to identify current gaps in knowledge and direct the development of educational interventions.

The purpose of this study was to determine what areas of parental knowledge are most important in caring for children with single ventricle CHD, biventricular CHD, and heart transplantation – patient diagnosis groups – from the perspective of parents, nurses, and physicians – participant types. The areas of parental knowledge identified from these focus groups will be used to develop parental knowledge questionnaires for these sets of patients and improve the education we offer their parents.

## Materials and methods

### *Study design*

This qualitative study used focus group methodology to elicit participants' views. A total of 11 focus groups were formed; five focus groups were comprised of parents/guardians including the following: two groups of parents with a single ventricle CHD child, two groups of parents with a biventricular CHD child, and one group of parents with a heart transplantation child. The remaining six groups were comprised of three physician groups and three nurse groups, each having one for each of the three patient conditions. The study was approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board.

### *Participants, selection, and recruitment*

Potential participants were English-speaking parents/guardians of children with single ventricle CHD, biventricular CHD, and heart transplantation between 0 and 18 years of age, who had at least one cardiac-related admission to Cincinnati Children's Hospital Medical Center between 1 January, 2010, and 1 January, 2013. The list for each condition was stratified by age (i.e. 0–4, 5–12, and 13–18 years) and re-ordered using a random number generator. The primary investigator (J.D.) proceeded down each list contacting households by telephone until a sufficient number of parent/guardians agreed to participate. The caregiver who provided “the most care for the child” was invited to participate. Although an equal number of parents from each age group (0–4, 5–12, and 13–18 years) was recruited, no additional steps were taken to guarantee equal representation from each group. Physicians and nurses from the Heart Institute at Cincinnati Children's Hospital Medical Center with at least 3 years of experience caring for children with heart disease were invited to participate. These included attending paediatric cardiologists, advanced practice nurses, and nurses from the cardiac intensive care unit, non-cardiac intensive care unit inpatient, and outpatient areas. Physicians and nurses with expertise and experience in

a specific patient diagnosis group were encouraged to participate in that particular focus group – for example, heart transplant physician specialists participated in the heart transplant physician focus group. Advanced practice nurses and bedside nurses were combined within the nurse focus groups. Each focus group session had a targeted recruitment of 6–10 participants.

### *Focus group structure and content*

The sessions were co-facilitated by the primary investigator (J.D.) and a co-investigator (K.D.) who have significant professional experience running healthcare-related focus groups. Each session began with a brief explanation regarding the purpose of the focus group and how the data would be used. A nominal group technique, a structured method for brainstorming designed to elicit contributions from all participants,<sup>15–18</sup> was then used to gather responses to the scripted question “What information is most important for [you/parents] to know in order to care for [your child/their children] with heart disease?”

Participants began the session by recording their individual responses. Each participant was then asked in turn to share an idea, which was captured electronically in summary format as a single item and projected for all to see. This process continued in rotation until every unique idea had been captured. Each item was then reviewed and discussed to ensure clarity and to combine those with significant overlap. Each participant was then given a printed copy with instructions to use 10 total votes to indicate the items they felt were most important. Using a multi-voting process, participants could place more than one vote on an item but had to place at least one vote on five separate knowledge items. After recording their votes privately, participants were free to leave. Sessions typically lasted between 1.5 and 2 hours, and were audio recorded for review purposes.

### *Data analysis*

Knowledge items and the votes received were combined into a single file, with each identified by its source – that is, focus group. Combining items across groups into unifying themes was straightforward in most cases because many items were the same or very similar. In the few cases, where items varied somewhat across groups, the primary investigator (J.D.) identified a theme, which was independently reviewed for agreement by two of the co-investigators (B.M., M.F.). For each case, the co-investigators were able to reach a consensus regarding the selection of an appropriate theme. In some instances, a single focus group identified and voted on multiple separate items

that other groups had identified as one item. Consequently, some themes included multiple items and corresponding votes from a single focus group. Recorded audio dialogue was coded and linked to the appropriate theme by a co-investigator (M.F.) using NVivo,<sup>19</sup> and was reviewed as part of the thematic grouping process to ensure that all concepts and nuances were accurately captured.

The relative importance of each theme was analysed by calculating an endorsement percentage and standardised importance score across all groups, for each participant type and for each patient diagnosis group. The endorsement percentage refers to the percentage of participants within a given group who gave at least one vote to an item under a given theme. The importance score accounts for the fact that individuals could give more than one vote to a particular item and was calculated for each item by taking its vote total, dividing it by six – that is, the maximum number of votes any individual can give an item – multiplying it by the number of people in the group, and multiplying it by 1000. The resulting importance score can range from 0 to 1000. The importance score for a theme is the total importance score for all items under that theme for a given group. A prioritised list of themes based on endorsement percentage was generated based on all groups combined and for each participant type and patient diagnosis group. Statistical analyses to compare endorsement percentages or scores across groups were not conducted because the data were based on qualitative methodology.<sup>20</sup>

## Results

### Study groups

Of the 352 eligible parent/guardians contacted to participate, 144 were successfully reached by phone, 73 (51%) of whom agreed to participate, and 34 (27%) of whom attended a focus group. Over 80% of the physicians and nurses who were contacted participated – 26 nurses and 21 physicians. The demographics for all participants are noted in Tables 1a and 1b. Primary cardiac diagnoses of children whose parents participated in the study are shown in Table 2.

### Knowledge content items and themes

A total of 289 knowledge content items were identified across all groups. These items and associated votes were combined into 45 themes; 41 of those themes received at least one vote with a median (range) endorsement of 12% (1–73%) and a median (range) importance score of 23 (2–229). The 20 most important themes by endorsement percentage and their corresponding knowledge content items are shown in Table 3. Table 4 shows these same themes

Table 1a. Parent demographics.

	n (%)
Number of participants	34
Age of participant (mean $\pm$ SD, years)	42.2 $\pm$ 9.0
Gender of participants	
% male	6 (18%)
% female	28 (82%)
Race of participants	
White	31 (91%)
Not reported	3 (9%)
Family status	
Both parents	28 (82%)
Primarily one parent	4 (12%)
Shared care	1 (3%)
Neither parent	1 (3%)
Relationship to patient	
Mother	27 (79%)
Father	6 (18%)
Grandparent	1 (3%)
Usual employment pattern	
Full time	15 (44%)
Part time	4 (12%)
Contract work/variable hours	2 (6%)
Not at all	13 (38%)
Highest level of education completed	
High school graduate	1 (3%)
Partial college or trade school	9 (27%)
College graduate	16 (47%)
Post-graduate degree	5 (15%)
Not answered	3 (9%)
Combined household yearly income	
<\$25k	3 (9%)
\$26–50k	6 (18%)
\$51–75k	5 (15%)
\$76–100k	5 (15%)
\$101–150k	8 (24%)
>\$150k	7 (21%)
Age of child (mean $\pm$ SD, years)	8.9 $\pm$ 5.9
Gender of child	
% male	19 (56%)
% female	15 (44%)
Race of child	
White	31 (91%)
Black	2 (6%)
American Indian	1 (3%)

with endorsement percentage, importance score, and ranking for all groups combined and within each participant type and patient diagnosis group. The three themes that received the highest endorsement percentage across all participants were *recognition of and response to clinical deterioration* (73%), *medications* (68%), and *prognosis and plan* (62%).

### Analysis of important themes by participant type

There were six common top 10 themes across the parent, nurse, and physician groups as follows: *recognition of and response to clinical deterioration*; *medications*; *prognosis and plan*; *disease impact on family and resources*; *diagnosis*,

Table 1b. Nurse and physician demographics.

	n (%)	n (%)
	Nurses	Physicians
Number of participants	26	21
Age of participants (mean $\pm$ SD, years)	37.0 $\pm$ 9.2	43.0 $\pm$ 9.0
Gender of participants		
Male	0 (0%)	18 (86%)
Female	26 (100%)	3 (14%)
Race/ethnicity of participants		
White	24 (92%)	19 (91%)
Black	1 (4%)	1 (5%)
American Indian	0 (0%)	0 (0%)
Not reported	1 (4%)	1 (5%)
Experience		
3–5 years	7 (27%)	6 (29%)
6–10 years	10 (39%)	8 (38%)
11–15 years	6 (23%)	2 (10%)
16–20 years	3 (12%)	0 (0%)
>20 years	0 (0%)	5 (24%)
Expertise*		
CICU	15 (58%)	8 (38%)
Non-CICU inpatient	12 (46%)	17 (81%)
Outpatient	9 (35%)	20 (95%)
Catheterisation lab	1 (4%)	5 (24%)
Imaging	1 (4%)	7 (33%)

CICU = cardiac intensive care unit; lab = laboratory

\*Participants may have multiple areas of expertise

Table 2. Primary diagnoses.

	Total
Biventricular CHD	14
Coarctation of the aorta	2
Conotruncal anomaly	10
Tetralogy of Fallot	3
Tetralogy of Fallot with pulmonary atresia	3
TGA s/p arterial switch operation	3
TGA s/p Rastelli	1
Semilunar valve diseases	1
Pulmonary stenosis	1
Septal defects	1
Atrioventricular septal defect	1
Single ventricle CHD	11
Stage 1 palliation	1
Pulmonary atresia with intact ventricular septum	1
Glenn palliation	2
Tricuspid atresia	1
Univentricular heart, other*	1
Fontan palliation	8
Hypoplastic left heart syndrome	1
Double outlet right ventricle	2
Tricuspid atresia	2
Univentricular heart, other*	3
s/p heart transplant	9
Total	34

s/p = status post; TGA = transposition of the great arteries;

Diagnosis includes one primary diagnosis per unique child

\*Includes dextrocardia with ventricular inversion and pulmonary atresia, double inlet single left ventricle, and criss-cross heart

physiology, and interventions; and potential complications of heart disease and its treatments. Other top 10 themes varied across the participant type groups. Parents ranked the themes *medical team members and interactions* (parents: 44%, nurses: 8%, physicians: 19%) and *tests and labs* (parents: 38%, nurses: 12%, physicians: 5%) higher than nurses and physicians. *Infection avoidance* was ranked 10th among parents – mostly from the heart transplantation group – and was not endorsed as a top 10 theme by either nurses or physicians. For nurses, unique top 10 ranked themes included *preventative care, feeding, and compliance*. Physicians strongly endorsed *neurodevelopmental outcomes and interventions* (76%) compared with parents (44%) and nurses (19%). Both physicians and nurses ranked the theme *lifelong disease requiring lifelong follow-up* among their top 10 (parents 18%, nurses, 31%, physicians 33%). *Activity and exercise recommendations* were ranked in the top 10 by physicians but not by either parents or nurses.

#### Important themes by patient condition

There were three common top 10 themes across patient diagnosis groups, including *medications, recognition of and response to clinical deterioration, and prognosis and plan*. The heart transplantation group endorsed *potential complications of heart disease and its treatments* at a higher percentage (65%) than the single ventricle CHD (10%) or biventricular CHD (35%) groups. *Infection avoidance* (54%), *compliance* (46%), and *rejection* (35%) were also endorsed at higher percentages within the heart transplantation groups. Single ventricle CHD groups uniquely ranked *preventative care, medical team members and interactions, and feeding* among their top 10 themes. Compared with participants within the biventricular CHD group, those within both the heart transplantation and single ventricle CHD groups endorsed the themes *lifelong disease requiring lifelong follow-up, disease impact on family and resources, and neurodevelopmental outcomes and interventions* at a higher percentage. The single ventricle CHD and biventricular CHD groups both ranked *diagnosis, physiology, and interventions* in their top 10 (single ventricle CHD: 48%, biventricular CHD: 73%). Biventricular CHD groups uniquely ranked *test and labs, medical passport, activity and exercise recommendations, and postoperative care* among their top 10.

#### Discussion

To our knowledge, this is the first study to use focus group methodology to identify parental knowledge necessary to care for children with heart disease from the perspective of parents, nurses, and physicians.

Table 3. Most important themes with associated knowledge content item(s).

Theme	Specific knowledge item(s) with descriptions	Group endorsing*
1. Recognition of and response to deteriorating clinical status	Knowing what signs and symptoms to look for, how to look for them, and what they indicate	All
	Knowing when to seek medical care and how to seek medical care (call the on-call physician, go to emergency department, call 911, etc.)	All
	Knowing whom to call based on day/time, how to call them, and expected response time	All Pa
2. Medications	Name, dosage, reason for taking, potential interactions, how they work, side effects, and expected duration of medication course	All
	Where to obtain, how to store, how to administer, and how to handle if dose is missed, vomited, or given inappropriately	All Pa and RN
3. Prognosis and plan	Life expectancy	All
	Long-term plan for future surgeries and interventions (Glenn, Fontan, heart transplant, etc.)	All
	Understanding treatment options (surgery, medications, no action, etc.), likely outcomes (percentages), reasoning/risks for each option, and timing of each option	All
4. Disease impact on family and resources	Likelihood of receiving and rules for future heart transplantation	Dr OHT
	Psychological impact on individual family members and family dynamics (impacts marriage, sibling dynamics, etc.)	All
	Financial impact (may need to move, someone may need to quit job)	All
	Availability and how to access financial support (social workers, financial advocates, social security, Medicaid, etc.)	All
	Availability and how to access other types of support including psychological (support groups, other families, heart camp)	All
5. Neurodevelopmental outcomes and interventions	Resources available while in the hospital (child life, meditation room, holistic health) and for families travelling to the hospital for care	All Pa
	Neurodevelopmental impact of heart disease and its treatments and expected quality of life (can he live normally, will he have problems at school)	All Dr and Pa
	Need for and availability of interventions related to neurodevelopment (physical therapy, occupational therapy, early intervention, etc.)	All Dr and Pa
6. Diagnosis, physiology, and interventions	Name and physiology of cardiac diagnosis and how it compares with normal heart anatomy	All
	Name, date, and understanding of previous surgeries/interventions	All
7. Potential complications of heart disease and its treatments	Potential/expected complications in the entire body (e.g. arrhythmia, kidney dysfunction, liver dysfunction, cancer, diabetes, graft coronary artery disease)	All
	Potential and expected behavioural effects of treatments (e.g. behavioural effects of steroids)	OHT Pa
8. Preventative care	Importance of healthcare maintenance (immunisations, dental care, normal newborn care)	All
	Importance of healthy living (diet, exercise, safe sex, avoiding alcohol, drugs, and cigarettes)	All
9. Lifelong disease requiring lifelong follow-up	Understanding that this is a life-long disease with no cure and will need life-long follow-up	All
	Need for eventual transition to adult congenital specialist and what is involved with that transition	All SV and BV
10. Medical team members and interactions	Members of medical team, their roles, limitations of each, and how to co-ordinate care among them (e.g. paediatrician, cardiologist, surgeon, and other specialists)	SV RN, SV and OHT Pa
	Importance of mutually understood and consistent physician/parent communication	All Dr and Pa
	Importance of the parents' role on the medical team and what that role is	SV and OHT Pa
11. Feeding	Understanding your child's specific diet and the importance of nutrition	All
	Infant feeding specifics (breast feeding, how to cope with inability to breastfeed, how to give tube feeds, how to concentrate feeds)	All RN and Pa
12. Tests and labs	Understanding of commonly used labs (what they are for, what abnormalities mean)	All
	How to handle blood draws, testing, procedures, etc. (knowing what works for your child)	All Pa
13. Immediate follow-up plans	Immediate follow-up plan (when to follow-up, what tests to get, what meds to change, etc.)	All
14. Infection avoidance	Importance of avoiding infectious diseases (hand washing, how to handle/limit exposure, etc.)	SV and OHT Pa and RN
15. Activity and exercise recommendations	Physical limitations/restrictions (including specific sports)	All
	Exercise recommendations	All
16. Demystifying hospital and surgery	How the hospital works, where everything is in the hospital, and how to navigate it	All Pa
	Understanding of specifics during surgery (what is involved, how long, what will happen directly after, what will they look like after, etc.)	All RN and Pa

Table 3. Continued

Theme	Specific knowledge item(s) with descriptions	Group endorsing*
17. Compliance	Importance of compliance (medications, follow-up, and other restricted behaviours) and impact of non-compliance (rejection, will not receive future heart, death)	OHT Dr and RN
18. Post-operative care	Incision care, sutures, signs and symptoms of infection, pain control, activity restriction, bathing/swimming, how to hold the baby	All
19. Medical passport	Need for a medical passport and what should be on it (diagnosis, surgeries, medications, allergies, etc.)	All
20. Rationale for decisions	Why we do what we do (give medications, recommend surgery, etc.) Understanding of why we are doing things in everyday language	RN and Pa OHT BV Pa

Pa = Parent; Dr = physician; RN = nurse; SV = single ventricle CHD; BV = biventricular; OHT = heart transplant

\*Indicates which group(s) endorsed the item

This study reveals that parents, nurses, and physicians identify both common and unique areas of important parental knowledge for children with single ventricle CHD, biventricular CHD, and heart transplantation.

Some themes cut across all participant types and patient diagnosis groups, including *recognition of and response to clinical deterioration, medications, and prognosis and plan*. These three themes have been at least in part included in existing educational programmes<sup>21</sup> and previous parental knowledge questionnaires.<sup>8,10</sup> *Recognition of and response to clinical deterioration* is critical to all patients with severe heart disease. Children with hypoplastic left heart syndrome following the Norwood procedure are at risk for clinical deterioration while at home,<sup>22</sup> and educating their parents regarding signs and symptoms of deterioration reduces their mortality.<sup>23,24</sup> Data from this investigation indicate that parents of children with other types of severe heart disease also need, and would likely benefit from, this education. The consistent endorsement of *medications* as a theme is due to the important role of medications in the management of paediatric heart disease, and the fact that medication administration is usually the responsibility of the parent. Many of these patients take multiple *medications* and the associated burden has been shown to negatively impact patient quality of life.<sup>25</sup> One parent explained that *prognosis and plan* is important because “parents are the ultimate decision makers”, which is consistent with statements by the American Academy of Pediatrics and the Institute of Medicine, which recommend that healthcare providers actively engage parents in shared decision-making.<sup>26,27</sup> An understanding of their child’s prognosis and plan enables parents to make these decisions and provides both meaning and sense to an understanding of their child’s heart disease, which increases the chances that the information will be stored in long-term memory.<sup>28</sup>

The perceived importance of a number of other themes differed by varying degrees among participant types and patient diagnosis groups. The theme *disease*

*impact on family and resources* was recognised as very important by all participant types and patient diagnosis groups, with the exception of the biventricular CHD group. Parents of children with heart disease have increased stress and financial strain and have the need for medical and spiritual support.<sup>29–32</sup> In addition, social support has been demonstrated to be a resilience factor between family stress and coping, and the lack of social support is a predictor of poor quality of life.<sup>33,34</sup>

A number of themes were uniquely identified as important by parents. Parents’ emphasis on *medical team members and interactions* has been demonstrated for children with special healthcare needs and is consistent with previous findings that parents of children with heart disease prefer to have a single “contact person” to assist with patient care.<sup>35–37</sup> Parents of children with heart disease often co-ordinate care between multiple healthcare providers who have different roles and perspectives and often do not communicate with one another, which can be confusing and frustrating to parents. *Tests and labs* was another theme identified more frequently by parents. Parents noted that they often do not understand the rationale, interpretation, or implications of these tests, and often feel frustration and anxiety as a result.

Physicians’ and parents’ strong endorsement of *neurodevelopmental outcomes and interventions* is consistent with previous findings.<sup>25,38</sup> The exceptionally high endorsement rate by physicians (77%) may be reflective of the growing number of survivors with neurodevelopmental morbidities and the increasing efforts taken towards research in this area.<sup>38</sup> The low rate of endorsement by nurses (19%) may be related to the high proportion of the nurses in this study who practice primarily in inpatient settings where neurodevelopmental issues are less relevant and not frequently considered. Physician and nurse endorsement of *lifelong disease requiring lifelong follow-up* may be driven by gaps in care for adult patients with CHD and the resulting clinical decompensations that often follow.<sup>39</sup> Parents’ relative under emphasis of this as

Table 4. Important themes by focus group type.

	All Groups (n = 81)			Parents (n = 34)			Nurses (n = 26)			Physicians (n = 21)			SV-CHD (n = 29)			BV-CHD (n = 26)			OHT (n = 26)		
	%	IS	Rank	%	IS	Rank	%	IS	Rank	%	IS	Rank	%	IS	Rank	%	IS	Rank	%	IS	Rank
1. Recognition of and response to clinical deterioration	73	229	1st	65	167	2nd	81	242	2nd	76	279	1st	79	204	1st	73	336	2nd	65	148	2nd
2. Medications	68	156	2nd	53	124	3rd	85	178	1st	71	165	3rd	59	100	5th	62	161	4th	85	206	1st
3. Prognosis and plan	62	162	3rd	68	134	1st	50	98	4th	67	254	4th	72	278	2nd	77	136	1st	35	72	9th
4. Disease impact on family and resources	51	123	4th	50	169	4th	58	112	3rd	43	89	6th	72	179	3rd	15	27		62	165	4th
5. Neurodevelopmental outcomes and interventions	44	102	5th	44	98	6th	19	30	5th	76	178	2nd	66	163	4th	23	44		42	100	7th
6. Diagnosis, physiology, and interventions	41	111	6th	32	57	9th	46	100	5th	48	177	5th	48	108	6th	73	226	3rd	0	0	
7. Potential complications of heart disease	36	70	7th	35	71	8th	35	64	9th	38	76	7th	10	20		35	53	7th	65	138	3rd
8. Preventative care	28	44	8th	26	42		42	60	6th	14	29		45	69	7th	23	29		15	33	
9. Lifelong disease requiring lifelong follow-up	26	58	9th	18	36		31	65	10th	33	72	8th	31	63	10th	12	12		35	98	8th
10. Medical team members and interactions	26	58	10th	44	126	5th	8	10		19	39	10th	41	102	8th	12	16		23	56	
11. Feeding	21	35		18	33		38	64	7th	5	8		38	63	9th	19	36		4	6	
12. Tests and labs	21	31		38	64	7th	12	19		5	9		0	0		38	49	5th	27	43	
13. Immediate follow up plan	19	36		15	36		31	53		10	19		28	53		27	54	10th	0	0	
14. Infection avoidance	19	30		29	61	10th	19	31		0	0		3	5		0	0		54	86	5th
15. Activity and exercise recommendations	17	33		26	47		0	0		24	52	9th	10	29		31	52	9th	12	19	
16. Demystifying hospital and surgery	16	23		15	22		31	48		0	0		21	30		15	21		12	19	
17. Compliance	15	49		0	0		35	99	8th	14	49		0	0		0	0		46	147	6th
18. Postoperative care	15	26		12	20		27	49		5	9		10	15		31	57	8th	4	6	
19. Medical passport	14	31		9	20		23	56		10	19		3	10		35	78	6th	4	6	
20. Rationale for decisions	14	26		6	12		19	31		19	35		0	0		8	12		35	66	*

\*10th for OHT was the theme Rejection, % = endorsement percentage, IS = importance score, OHT = orthotopic heart transplantation, SV-CHD = single ventricle CHD, BV-CHD = biventricular CHD

an important theme is consistent with a previous study that demonstrated that only 44% of parents of children with moderate or complex CHD recognised that their child's cardiology care should be guided by an adult congenital specialist in adulthood.<sup>40</sup>

Both single ventricle CHD and biventricular CHD groups strongly endorsed *diagnosis, physiology, and interventions*, which often form the basis of educational programmes and are the topics most heavily tested with parental knowledge questionnaires.<sup>8,10,21</sup> In CHD, as opposed to heart transplantation, these vary significantly from one child to another, which may explain the emphasis in the single ventricle CHD and biventricular CHD groups compared with heart transplantation groups. The two themes that were emphasised by single ventricle CHD and heart transplantation groups but not by biventricular CHD – that is, disease impact on family and resources, and *neurodevelopmental outcomes and interventions* – likely relate to the relatively greater levels of disease severity in these two groups, which has been shown to impact both of these themes.<sup>34</sup> The heart transplantation groups identified some unique themes as important, including the *potential complications of heart disease and its treatments, infection avoidance, rejection, and compliance*. All of these themes relate to the transplantation of a foreign organ that is at high risk of rejection and requires treatment with immunosuppressive medications, compliance with these medications, and close surveillance of the resulting negative impacts of immunosuppression.

Our findings demonstrate that important themes are absent in previous parental knowledge questionnaires.<sup>8,10–12</sup> The involvement of parents and nurses in questionnaire development results in different content generation compared with development by physicians alone, and our study includes these knowledge themes.<sup>25</sup> In previous questionnaires, the themes *disease impact on family and resources, neurodevelopmental outcomes and interventions, and potential complications of heart disease* have had very limited assessment, and the themes *medical team members and interactions* and *tests and labs* have not been previously included at all.<sup>8,10–12</sup>

These apparent discrepant perspectives regarding necessary parental knowledge have important educational and clinical implications. To maximise the efficacy of cardiovascular care, physicians and nurses need to ensure that parents possess the knowledge needed to effectively care for their child at home. Parents in this investigation identified important areas of knowledge that are possibly being ignored in current efforts to assess parental knowledge and provide education. The variation among heart conditions in terms of what knowledge is important raises questions as to whether or not current assessment and

educational efforts are effectively targeting the knowledge areas for specific patient diagnosis groups.

The primary limitation of this study is the generalisability of the results to other medical centres, regions, and populations. The research was conducted in a single medical centre with disproportionate representation from White, higher income, and very highly educated families, which raises the potential for institutional, cultural, and socio-economic bias. Second, the fact that groups were comprised only of those who agreed to participate in a focus group might have resulted in a self-selection bias. The limited number of slots may have resulted in a sample that is not representative of the population. Third, the grouping of patients by the three patient diagnosis groups may have resulted in parents of children with different educational needs being placed in the same group. Fourth, it is possible that participants might have based their final votes on what they sensed was important to other group members rather than their own views. Fifth, as the themes upon which people voted included various numbers of individual items, it is possible that there was a bias towards selecting themes based on the number of items rather than the individual importance of a particular item within a theme.

This study reveals that parents, nurses, and physicians have both common and unique views regarding what parents should know to effectively care for their children with single ventricle CHD, biventricular CHD, or heart transplantation. Healthcare providers should focus parental educational on the most important areas identified in this investigation. This information will be used to develop parental knowledge questionnaires that will be used to detect knowledge gaps, identify determinants of parental knowledge, and improve educational interventions with the ultimate goal of reducing morbidity and mortality in the high-risk paediatric heart disease population.

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### Conflicts of Interest

The authors have no conflict of interest to disclose.



## 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 has been approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board.

## References

- Whittemore R. Strategies to facilitate lifestyle change associated with diabetes mellitus. *Journal Nurs Scholarsh* 2000; 32: 225–232.
- Henley LD, ID Hill. Errors, gaps, and misconceptions in the disease-related knowledge of cystic fibrosis patients and their families. *Pediatrics* 1990; 85: 1008–1014.
- Gochman DS. *Handbook of Health Behavior Research*. Plenum Press, New York, 1997.
- Offord DR, Cross LA, Andrews EJ, Aponte JF. Perceived and actual severity of congenital heart disease and effect on family life. *Psychosomatics* 1972; 13: 390–396.
- Chan CS, Molassiotis A. The effects of an educational programme on the anxiety and satisfaction level of parents having parent present induction and visitation in a postanaesthesia care unit. *Paediatr Anaesth* 2002; 12: 131–139.
- Beeri M, Haramati Z, Rein JJ, Nir A. Parental knowledge and views of pediatric congenital heart disease. *Isr Med Assoc J* 2001; 3: 194–197.
- Veldtman GR, Matley SL, Kendall L, et al. Illness understanding in children and adolescents with heart disease. *Heart* 2000; 84: 395–397.
- Cheuk DK, Wong SM, Choi YP, Chau AK, Cheung YF. Parents' understanding of their child's congenital heart disease. *Heart* 2004; 90: 435–439.
- Bulat DC, Kantoch MJ. How much do parents know about their children's heart condition and prophylaxis against endocarditis? *Can J Cardiol* 2003; 19: 501–506.
- Chessa M, De Rosa G, Pardeo M, et al. What do parents know about the malformations afflicting the hearts of their children? *Cardiol Young* 2005; 15: 125–129.
- Moons P, De Volder E, Budts W, et al. What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart* 2001; 86: 74–80.
- Yang HL, Chen YC, Wang JK, Gau BS, Chen CW, Moons P. Measuring knowledge of patients with congenital heart disease and their parents: validity of the 'leuven knowledge questionnaire for congenital heart disease'. *Eur J Cardiovasc Nurs* 2012; 11: 77–84.
- Van Deyk K, Pelgrims E, Troost E, et al. Adolescents' understanding of their congenital heart disease on transfer to adult-focused care. *Am J Cardiol* 2010; 106: 1803–1807.
- Williams IA, Shaw R, Kleinman CS, et al. Parental understanding of neonatal congenital heart disease. *Pediatr Cardiol* 2008; 29: 1059–1065.
- Tuffrey-Wijne I, Bernal J, Butler G, Hollins S, Curfs L. Using nominal group technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *J Adv Nurs* 2007; 58: 80–89.
- Berenholtz SM, Pronovost PJ, Ngo K, et al. Developing quality measures for sepsis care in the ICU. *Jt Comm J Qual Patient Saf* 2007; 33: 559–568.
- Carney O, McIntosh J, Worth A. The use of the nominal group technique in research with community nurses. *J Adv Nurs* 1996; 23: 1024–1029.
- Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. *Am J Public Health* 1984; 74: 979–983.
- NVivo Qualitative Data Analysis Software. Version 10 ed.: QSR International Pty Ltd., Doncaster, Australia, 2012. [https://www.qsrinternational.com/support\\_faqs\\_detail.aspx?view=11](https://www.qsrinternational.com/support_faqs_detail.aspx?view=11).
- Haugh KH, Salyer J. Needs of patients and families during the wait for a donor heart. *Heart Lung* 2007; 36: 319–329.
- Pye S, Green A. Parent education after newborn congenital heart surgery. *Adv Neonat Care* 2003; 3: 147–156.
- Ohye RG, Schonbeck JV, Eghtesady P, et al. Cause, timing, and location of death in the single ventricle reconstruction trial. *J Thorac Cardiovasc Surg* 2012; 144: 907–914.
- Ghanayem NS, Hoffman GM, Mussatto KA, et al. Home surveillance program prevents interstage mortality after the Norwood procedure. *J Thorac Cardiovasc Surg* 2003; 126: 1367–1377.
- Hansen JH, Furck AK, Petko C, et al. Use of surveillance criteria reduces interstage mortality after the Norwood operation for hypoplastic left heart syndrome. *Eur J Cardiothorac Surg* 2012; 41: 1013–1018.
- Marino BS, Tomlinson RS, Drotar D, et al. Quality-of-life concerns differ among patients, parents, and medical providers in children and adolescents with congenital and acquired heart disease. *Pediatrics* 2009; 123: e708–e715.
- The Pediatrician's role in family support programs. Committee on Early Childhood and Adoption, and Dependent Care. *Pediatrics* 2001; 107: 195–197.
- Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press, Washington DC, 2001.
- Sousa DA. *How The Brain Learns*. Sage; Thousand Oaks, California, 2011.
- Rodrigue JR, MacNaughton K, Hoffmann RG 3rd, et al. Transplantation in children: a longitudinal assessment of mothers' stress, coping, and perceptions of family functioning. *Psychosomatics* 1997; 38: 478–486.
- Lee SL, Chen YC. Stressors and coping behaviors of mothers with child receiving open heart surgery. *Hu Li Yan Jiu* 2001; 9: 172–182.
- Pelchat D, Ricard N, Bouchard JM, et al. Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child Care Health Dev* 1999; 25: 377–397.
- Ludlow LH, Levy S. Personal space as a function of infant illness: an application of multidimensional scaling. *J Pediatr Psychol* 1984; 9: 331–347.
- Tak YR, McCubbin M. Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *J Adv Nurs* 2002; 39: 190–198.
- Lawoko S, Soares JJ. Quality of life among parents of children with congenital heart disease, parents of children with other diseases and parents of healthy children. *Qual Life Res* 2003; 12: 655–666.
- Wood DL, McCaskill QE, Winterbauer N, et al. A multi-method assessment of satisfaction with services in the medical home by parents of children and youth with special health care needs (CYSHCN). *Matern Child Health J* 2009; 13: 5–17.
- Kendall L, Sloper P, Lewin RJ, Parsons JM. The views of parents concerning the planning of services for rehabilitation of families of children with congenital cardiac disease. *Cardiol Young* 2003; 13: 20–27.
- Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics* 2008; 122: e922–e937.
- Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management a scientific statement from the American Heart Association. *Circulation* 2012; 126: 1143–1172.
- Mackie AS, Ionescu-Ittu R, Therrien J, Pilote L, Abrahamowicz M, Marelli AJ. Children and adults with congenital heart disease lost to follow-up: who and when? *Circulation* 2009; 120: 302–309.
- Fernandes SM, Verstappen A, Ackerman K, et al. Parental knowledge regarding lifelong congenital cardiac care. *Pediatrics* 2011; 128: e1489–e1495.