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## Parents of Children with Congenital Heart Disease Prefer More Information Than Cardiologists Provide

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### Abstract

**OBJECTIVES**—To determine whether pediatric cardiologists and parents of older children with congenital heart disease (CHD) share similar expectations regarding the education and counseling that should be provided to parents of children with CHD in both the prenatal and neonatal period.

**DESIGN**—Consenting parents of older children with CHD (age > 3 years) and cardiologists ranked the importance of education topics on a scale of 1 (unimportant) to 10 (very important). The rankings of parents and cardiologists were compared using Student's *t*-test.

**RESULTS**—We had 38 cardiologists and 41 parents complete the questionnaire. There was a statistically significant difference in rankings between cardiologist and parents of children with CHD ( $p < 0.03$ ). Parents consistently ranked topics as more important than cardiologists with a mean difference in rank score of  $0.85 \pm 0.3$ . In the prenatal period, the most significant differences between parents and cardiologists were noted for information related to the child's quality of life. For neonatal counseling, the most significant differences were noted for information regarding follow-up care and the parent's ability to describe the child's CHD to medical personnel.

**CONCLUSION**—Parents of older children with CHD would prefer to receive more counseling and education in the prenatal and newborn period than cardiologists perceive is wanted.

### Keywords

congenital heart disease; prenatal diagnosis; parent counseling; parent education; parent-physician relationship

### INTRODUCTION

The incidence of congenital heart disease (CHD) ranges from 4 to 75 per 1000 live births, about 1/3 of which consist of moderate to severe disease that will require neonatal surgery (1). Newborns and young children with CHD require specialized care, both from a medical and a social standpoint. Parents must be equipped with the information necessary to provide

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#### AUTHOR CONTRIBUTIONS

Bhawna Arya, MD: Data collection, data analysis/interpretation, drafting article, critical revision of the article.

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such care. Prenatal diagnosis has been shown to improve parent understanding of the child's medical condition and special needs (5). Even with prenatal diagnosis, however, gaps in parent understanding persist.

Cardiologists play a critical role in providing information and materials to a family that will help them care for their child. However, how much information is necessary to deliver to the parent in the neonatal and prenatal period is not clear. For instance, is it important for parents to understand the implications of their infant's cardiac condition on future reproductive potential – or is this information better delivered in a conversation when the child is older? Lalor et al. found that mothers whose fetuses held a prenatal diagnosis of fetal abnormality were divided in their desire for information. Some mothers preferred to have increased information up front in order to “wrap their head around the disease”, while other mothers felt that too much information up front increased anxiety and would rather “cross that bridge when they came to it” (4). Furthermore, mothers often could not recall all of the information that had initially been given to them. We found that within our group of cardiologists, there was no consensus regarding how much information was sufficient and whether any amount could in fact be too much. Whether cardiologists and parents agree on the amount of information necessary for parents of children with CHD has not previously been reported.

Prenatal diagnosis of CHD and adequate counseling of the parents also plays an important role in pregnancy continuation decision-making. Khoshnood et al. demonstrated that as prenatal diagnosis of CHD in Paris increased over a 15 year period, the percentage of pregnancy termination increased as well (10-15%), with termination being largely related to complex CHD. Neonatal mortality during that time decreased by 15%. The authors theorized that this was at least partly related to pregnancy decision-making (3). Furthermore, a population based study across 12 European countries reported that of terminations that occurred at gestational age of 24 weeks or more, 11% of the 678 fetuses held a diagnosis of an isolated cardiac anomaly (2). Although there are no studies in the current literature regarding the trends in fetal diagnoses of CHD and pregnancy decision-making, there is some evidence from other parts of the world that as prenatal diagnoses of CHD increases, the incidence of pregnancy termination has also been increasing. Thus, it is important for cardiologists to counsel and educate families so that parents can make informed decisions.

This study aimed to determine whether cardiologists and parents of older children with CHD have the same expectations of education and counseling needed in both the prenatal and neonatal period.

## **PATIENTS AND METHODS**

### **Settings and Procedure**

An IRB-approved cross-sectional survey of cardiologists and parents of older children (greater than 3 years of age) was conducted at the Morgan Stanley Children's Hospital of New York from January 2008 to January 2009.

Questionnaires were derived during brainstorming sessions during which the investigators discussed what information is generally provided to families in the prenatal and postnatal period. The questions have not been previously validated.

Surveys were distributed to parents of older children with CHD. Participants had to be able to read and write in the English language. Parents were approached by research assistants in the waiting room of the outpatient area or in the patient's room on the inpatient floors. The questionnaires were collected at the end of the outpatient visit or during the course of the

hospital stay. The parent questionnaire (Appendix B) asked how important it was for new parents of children with CHD to be educated about specific aspects of their child's CHD on a scale of 1 (unimportant) to 10 (very important) in both the prenatal period and in preparation for discharge from a neonatal intensive care unit (NICU) after cardiac surgery. The neonatal questions referred to all babies with CHD irrespective of whether diagnosis had occurred in the prenatal or postnatal period.

All attending level cardiologists practicing at the hospital were eligible for participation. Cardiologists received the questionnaire via intra-office mail. The cardiologist questionnaire (Appendix A) asked how important it was for parents of children with CHD to be educated about specific aspects of their child's CHD on a scale of 1 (unimportant) to 10 (very important) in both the prenatal period and in preparation for discharge from a NICU after cardiac surgery.

The mean rank scores of 52 common questions were compared between parents and cardiologists; 32 questions pertained to the prenatal period and 20 questions pertained to the newborn period.

In addition to questions about medical information, the questionnaires asked subjects about their perspectives regarding pregnancy decision making in order to investigate if this differed between cardiologists and parents. The questionnaires asked both groups to choose the 3 most important factors in deciding whether or not to continue a pregnancy of a fetus with CHD, as well as their general opinion regarding pregnancy termination.

### Statistical Analysis

Independent samples Student's *t*-tests compared the mean ranking scores between parents and cardiologists. The alpha value was set at 0.05. This was a hypothesis generating pilot study; therefore no control for multiple comparisons was done. Statistics were calculated using SPSS for Windows, Version 16.

## RESULTS

During the 1 year period, 39 out of 47 cardiologists and 41 out of 49 parents completed the respective questionnaires.

### Demographics

**Parent group**—Demographic information for the study cohort is listed in Table 1. The average age of the child at the time of the survey was  $9.4 \pm 4.8$  years. The average age of the child at time of first surgery was  $0.62 \pm 0.68$  years. Table 2 lists the specific cardiac lesion of the children of parents who answered the questionnaire.

**Cardiologist group**—Demographic information for the study cohort is listed in Table 3. The average number of years practicing pediatric cardiology was  $16.4 \pm 10.7$  years. The average number of days per week spent in an office setting was  $3.4 \pm 1.4$  days.

**Within group comparison**—There was no statistically significant difference in ranking scores within the parent group due to race, sex of child, child age at initial surgery, or child age at time of completion of questionnaire. Similarly, there was no statistically significant difference in ranking scores within the cardiologist group due to number of practice years, number of days spent in an office setting, type of practice (subspecialty versus general cardiology), and whether or not the cardiologist provided prenatal counseling to his/her patients.

**Between group comparison**—Table 4 and Table 5 present the means and standard deviations of the ranking scores for the parents as compared with those for cardiologists. Only the questions that showed a statistically significant difference between the 2 groups are presented. Of the questions, 20 (63%) of 32 prenatal topics and 11 (55%) of the 20 newborn topics resulted in a statistically significant difference in ranking between the parent and cardiologist groups. The parent group consistently ranked the topics as more important than cardiologists with a mean difference of  $0.85\pm 0.3$  in rank.

For questions relating to the prenatal period, the most significant differences between the two groups were noted for: number of lifetime surgeries needed (mean difference  $1.48\pm 0.2$ ), potential need for transplant (mean difference  $1.76\pm 0.4$ ), exercise limitations (mean difference  $1.95\pm 0.2$ ), and potential for child to have his/her own baby with CHD (mean difference  $2.06\pm 0.4$ ). Parents consistently ranked these to be of higher importance than the cardiologists.

For questions relating to the neonatal period, the most significant differences were noted for: why the child has CHD (mean difference  $2.38\pm 0.4$ ), why he/she needs surgery (mean difference  $1.12\pm 0.7$ ), ability to explain the CHD to a doctor (mean difference  $1.26\pm 1.0$ ), and follow-up needed (mean difference  $1.26\pm 0.3$ ). Again, the parents consistently ranked these to be of higher importance than cardiologists.

**Prenatal diagnosis and counseling**—The cardiologists gave a higher importance ranking as compared with the parent group for only one of the questions, “option to not continue the pregnancy” (mean difference=1.28). This refers to the cardiologist's role in providing the family information regarding the option to terminate the pregnancy after fully understanding their child's diagnosis. 54% of the parent group and 2% of the cardiologist group opposed pregnancy termination for either religious or moral reasons. The most important factors in deciding whether or not to continue the pregnancy of a known fetus with CHD for the cardiologist group were: quality of life for the child, potential for neurodevelopmental delay, survival into adulthood, and severity of the CHD. For the parent group the most important factors that influenced decision making for or against a termination were: quality of life for the child, moral/religious beliefs, and survival into birth and adulthood (Table 6).

## DISCUSSION

The results of this study suggest that parents of older children with CHD place greater importance on educational information in the prenatal and neonatal periods than do cardiologists. Parents would like to receive more counseling than cardiologists believe is desired or warranted. There are multiple potential explanations for these differences. Clearly cardiologists and parents have different life experiences that shape their perceptions of what information is needed to care for these children. Cardiologists go through years of specialized training to gain the scientific knowledge necessary to medically diagnose and treat children with CHD. In addition, cardiologists' perspectives may be influenced by elements of paternalism. Cardiologists may not want to provide too much information all at once due to concern that families might be overwhelmed or shocked. The results of our study imply that parents are eager for more information than cardiologists feel is necessary to deliver early on in the care of a fetal and newborn patient with CHD.

We noted several interesting trends in our analysis of the data. In the prenatal period, the most significant differences between cardiologists and parents regarded information related to the child's quality of life (number of lifetime surgeries, potential need for transplant, exercise limitations, potential for child to have his/her own baby with CHD). Parents

receiving information in the prenatal period might be more focused on the quality of life of their future child as this may allow them to psychologically prepare for the arrival of their child. This information may also be important to parents as it might affect the family's decision to continue the pregnancy. Long term outcomes including potential for neurodevelopment delay and survival, as well as the quality of life for the child may be influential in the consideration of termination decision-making.

For neonatal counseling, the most significant differences were noted for information regarding follow-up care and the parent's ability to understand the child's CHD (why the child has CHD, why he/she needs surgery, ability to explain the CHD to a doctor, and the type of follow-up needed). Parents receiving information prior to discharge from the NICU may be more concerned about the immediate medical care of their child as well as the ability to provide accurate information to other care providers such as the outside primary pediatrician.

Several similarities were also noted between the physician and parent groups. Both groups felt that during prenatal counseling, parents should understand the name of the heart condition, what to expect in the first few hours of life, probability of survival to birth, childhood and adulthood, comorbidities, option not to intervene medically after birth, and how to seek additional emotional/psychological support. During the neonatal period, both groups agreed that parents should know the name of the heart lesion, the name of their cardiologist and pediatrician, discharge medications (including dosage and use), comorbidities, when to seek medical attention, and CPR training

Although the primary purpose of this study was to compare information provided by physicians and the information parents wish to receive, a secondary difference was noted. Parents retrospectively ranked issues related to long term outcomes and quality of life as very important during prenatal counseling. Comparatively, they felt topics related to immediate care of their child upon discharge would have been most important in the neonatal period. The variation in the type of information parents retrospectively felt was important to receive in the prenatal versus immediate postnatal period suggests that parents might value different types of information in different time periods. Accordingly, cardiologists may want to customize the counseling they provide specifically to the prenatal and postnatal periods.

This study has a few limitations. Only a small number of subjects were enrolled in both groups, and power to detect multiple associations is limited. Another potential limitation is ascertainment bias. Neither all cardiologists nor all parents approached for participation completed the questionnaire. While we assume that time constraints were the most likely reason to decline enrollment, we cannot be sure. Furthermore, the questionnaire utilized in this study was created by the investigators and has not been previously validated. The study was limited by potential recall bias by the parents. We purposefully restricted study participation to parents of older children as we felt these parents would be better equipped to understand the importance of each of the survey questions than parents of newborns with CHD. However, our parent study cohort may not accurately remember how overwhelming the time of initial diagnosis of the fetus/child may have been. Parents of older children may place greater importance on receiving information with hindsight, without recognizing that too much information in the prenatal or neonatal period may have resulted in increased anxiety or inability to truly comprehend all of the issues.

Finally, as a tertiary care referral center, many patients who received prenatal care in our institution had already decided to continue the pregnancy. As a result, parents who

considered termination may be under-represented in this study, and due to study design, parents who chose termination may not be represented.

Compared with cardiologist, parents were more likely to select religious/moral beliefs as an important factor in determining pregnancy outcome decisions. Nevertheless, parents and cardiologists generally agreed on the important factors that would affect pregnancy decision making, with quality of life of the child being the most important. Thus, it is important for cardiologists to counsel and educate parents with objective sensitivity to allow parents to make their own personal informed decisions.

## CONCLUSIONS

To our knowledge, this is the first published study investigating the discordance in the importance of parental education topics between parents of children with CHD and cardiologists. We conclude that cardiologists should seek to increase the amount of education delivered to parents in accordance with their requests, beginning as early as the prenatal period and continuing throughout the patient's life.

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## Abbreviations

<b>CHD</b>	Congenital Heart Disease
<b>NICU</b>	Neonatal Intensive Care Unit

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**Table 1**

## Patient Characteristics

Characteristic	Number of Patients N = 41 (%)
<b>Gender</b>	
Male	27 (66)
<b>Race</b>	
Caucasian	26 (63)
African American	5 (12)
Hispanic	5 (12)
Asian	5 (12)
<b>Current Age</b>	
0-5 years old	13 (32)
6-10 years old	12 (29)
11-15 years old	12 (29)
16-20 years old	3 (7)
21-25 years old	1 (2)
<b>Years Since First Intervention</b>	
No intervention	1 (2)
< Less than 1 year	5 (12)
1-5 years	12 (29)
6-10 years	9 (23)
11-15 years	12 (29)
16-20 years	1 (2)
21-25 years	1 (2)

**Table 2**

Distribution of Children's Cardiac Lesions in the Parent Group

Cardiac Lesion	Number of Children n = 41 (%)
Hypoplastic Left Heart Syndrome	5 (12)
Transposition of the Great Arteries	6 (15)
Ventriculoseptal Defect	2 (5)
Atrioseptal Defect	1 (2)
Pulmonic Atresia/Stenosis	2 (5)
Atrioventricular canal (including partial/transitional)	5 (12)
Double Outlet Right Ventricle	3 (7)
Aortic Stenosis	6 (15)
Tricuspid Atresia	3 (7)
Tetralogy of Fallot (and variants)	6 (15)
Dilated Cardiomyopathy	1 (2)
Double Inlet Left Ventricle	1 (2)



**Table 3**

## Cardiologist Characteristics

Characteristic	Number of Cardiologists n = 38 (%)
<b>Gender</b>	
Male	21 (55)
<b>Practice Years</b>	
15 years	18 (47)
> 15 years	20 (53)
<b>Practice Type</b>	
Hospital-based practice	26 (68)
Private practice	12 (32)
<b>Subspecialty</b>	
General pediatric cardiology	20 (53)
Subspecialty pediatric cardiology	18 (47)
<b>Clinic Days</b>	
3 days/week spent in an office setting	19 (50)
> 3 days/ week spent in an office setting	19 (50)
<b>Counseling Provided</b>	
Provide prenatal counseling	26 (68)

**Table 4**

Prenatal importance rankings with significant difference between parents and cardiologists

<b>Educational Information Prenatally</b>	<b>Parent Mean Ranking</b>	<b>Cardiologist Mean Ranking</b>	<b>p-value</b>
Ability to describe the heart lesion	9.52±1.1	8.84±1.5	0.02
Explain the heart condition to another doctor	8.70±1.8	7.76±2.0	0.03
Location of lesion on a diagram of the heart	8.68±1.9	7.16±1.9	0.001
Reason why baby will need surgery at birth	9.85±0.4	9.55±0.7	0.03
When cardiac surgery would take place	9.69±0.7	9.16±0.9	0.006
Risks associated with neonatal surgery	9.72±0.7	8.87±1.3	0.001
Length of NICU stay	9.47±1.0	7.00±1.7	<0.001
Whether baby will require future surgeries	9.63±1.1	8.66±1.3	0.001
Number of lifetime surgeries	9.37±1.6	7.89±1.8	<0.001
Potential need for heart transplant later in life	9.10±1.9	7.34±2.3	<0.001
NICU discharge medication name, dose, function, side effects	8.97±1.7	7.18±1.9	<0.001
Why the baby has a heart condition	8.72±6.5	6.45±2.2	<0.001
Probability of having another baby with CHD	8.72±2.1	7.82±1.5	0.04
Probability of baby having children of his/her own with CHD	8.38±2.5	6.32±2.1	<0.001
Type of follow-up medical care needed	9.36±1.4	8.74±1.2	0.04
Whether child will have exercise limitations	8.79±1.8	6.84±1.6	<0.001
Whether child can attend regular school	8.60±2.1	7.55±1.7	0.02
Potential difficulty in securing health and life insurance for adult with CHD	7.51±3.0	5.58±2.4	0.003
Option to not continue the pregnancy	7.95±3.1	9.23±1.4	0.02
Websites for more information about CHD	8.72±1.9	7.47±1.9	0.006
Books/pamphlets for information about CHD	8.87±1.7	7.74±1.8	0.007
How to find/talk to other families of children with CHD	8.90±1.7	7.63±1.7	<0.002

(10 = very important; 1 = unimportant)

**Table 5**

Postnatal importance rankings with significant difference between parents and cardiologists

Educational Information Postnatally	Parent Mean Ranking	Cardiologist Mean Ranking	p-value
Name of baby's cardiac surgeon	9.66±0.7	7.79±1.9	<0.001
Explain the heart condition to another doctor	9.68±0.7	8.42±1.7	<0.001
Explain the heart condition to a friend	7.61±2.3	5.92±1.9	0.001
Location of lesion on a diagram of the heart	8.15±2.0	6.32±2.2	<0.001
Reason why the baby needs surgery	9.73±0.7	8.61±1.4	<0.001
Number of lifetime surgeries	9.20±1.7	7.87±2.0	0.003
Why the child has a heart condition	8.83±1.9	6.45±2.3	<0.001
Probability of baby having children of his/her own with CHD	8.25±2.5	6.39±2.4	0.001
Type of follow-up medical care needed	9.58±1.3	8.32±1.6	<0.001
Whether child will have exercise limitations	9.20±1.6	6.82±2.0	<0.001
Whether child can attend regular school	8.66±2.0	7.16±2.1	0.002

(10 = very important; 1 = unimportant)

**Table 6**

## Cardiologist and parent factors in deciding to continue pregnancy

Factor in Deciding to Continue Pregnancy (lay terminology)	Number of Cardiologists n = 38 (%)	Number of Parents n = 41 (%)
Moral/religious beliefs	7 (18)	13 (32)
Quality of life of the child	34 (89)	21 (51)
Potential neurodevelopmental delay (learning disabilities and delay)	23 (61)	3 (7)
Probability of child surviving until birth	2 (5)	11 (27)
Probability of child surviving into early childhood	1 (3)	9 (22)
Probability of child surviving into adulthood	8 (21)	10 (24)
Impact on quality of life for the family/siblings	10 (26)	3 (7)
Potential need for repeated surgeries and hospitalizations	5 (13)	3 (7)
Need for Fontan palliation vs. two-ventricle repair (severity of heart disease)	10 (26)	9 (22)
Potential need for a heart transplant	3 (8)	2 (5)

(Participants were asked to rank the 3 most important factors; all 3 factors are included for each subject. Therefore percentage summation is greater than 100.)