



# Assessment of Parents' Awareness About Their Child's Congenital Heart Disease

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## Abstract

**Objectives:** Parents with children suffering from congenital heart disease (CHD) faced with a severe emotional crisis. This study was conducted based on the idea that the more knowledgeable the parents are about such diseases, the more they can cooperate with the physician in the child's treatment process.

**Materials and Methods:** Given the aim of the study, parents' information of 104 children who were referred to the outpatient clinic was collected by a questionnaire. The instrument contained five questions regarding the awareness of the name of the child's heart disease, the ability to indicate the location of the disease on a schematic image of the heart, the knowledge of the symptoms of the heart disease, the awareness of the causes of CHD, and the importance of children's oral hygiene.

**Results:** Children's mean age was  $4.8 \pm 4.3$  years. Based on the results, there was a significant association between parents' education and the above-mentioned parameters except for the importance of children's oral hygiene ( $P < 0.05$ ).

**Conclusions:** In this study, parents' information about their children's heart disease was largely incomplete which was generally attributed to the parents' level of education. Currently, it seems that the probable explanations provided by physicians about children's illnesses play no effective role in creating the awareness of parents, especially those with lower levels of education.

**Keywords:** Awareness, Knowledge, Congenital Heart Disease

## Introduction

Congenital heart diseases (CHD) are considered chronic in terms of many aspects. Although some residual deficiencies may frequently remain in spite of attempts for correcting the disease, no complete corrective operation is possible. Consequently, such children come along with partial correction of the lesion (referred to as palliative operation) which is performed to improve the quality of their lives. In addition, complications such as growth retardation, heart rhythm disorder (arrhythmia), heart failure, infectious endocarditis, and pulmonary artery disease are permanently lurking in these children (1, 2).

The moment a mother and father first encounter the diagnosis of their child's CHD, they go through great anxiety in their family life which leads to a new, stressful crisis. Meanwhile, they need to seek more information and accurate knowledge in order to better understand their child's disease so that to choose the best treatment in this regard. Since most parents have no basic medical information background, they often feel frustrated and helpless and become restless and irritable due to their lack of awareness of the diagnosis and treatment processes without paying enough attention to doctors' explanations.

On the other hand, many doctors get tired of repeated explanations and feel that it is a waste of time. Furthermore, it is proven that the more information parents receive about their child's disease, the less stress they encounter as they are better suited to diagnosis and treatment, making them highly cooperative in the treatment process of the patient (3-6).

Considering the above-mentioned explanations, the present study aimed to obtain an overview of parents' information on children with CHD who were referred to the pediatric heart clinic (outpatient) during three months (Fall, 2016).

## Materials and Methods

The parents' information of 104 children, who referred to the outpatient clinic of Rajaie Cardiovascular Medical and Research Center in Tehran, was collected by a questionnaire during September-November 2016. The questionnaires were completed in the presence of the parents by expert echocardiography nurses (echo technicians) who had complete knowledge about pediatric cardiac diseases and therapeutic procedures. In fact, although the original questions were predefined, it was more like a structured

Received xx xx 2018, Accepted xx xx 2018, Available online xx xx 2019

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face-to-face interview.

The inclusion criteria included children with at least three referrals to the pediatric heart clinic due to their initial diagnosis of heart disease during the three past months.

In addition, the exclusion criteria were children who were protected by an orphanage (orphans) with complicated diseases such as single ventricle defects, transposition of the great arteries, and heterotaxy syndromes, along with the caregivers' lack of interest to participate in the interview.

Some questions from "Leuven Knowledge Questionnaire for congenital Heart Disease" (7) were chosen and translated to Persian. Then, the nurses personally asked mothers, fathers, or both parents, and if needed, a more detailed explanation was provided about the questions. Five basic questions were posed as follows.

1. What is the name of your child's heart disease? The name of the disease might have been mentioned in English or Persian. For example, a hole between the ventricles. There was no rigor in accepting the response, but parents' response was regarded as unacceptable and negative if they stated "*I do not know*" or "*I only know that my child has heart disease*".
2. Can you show your child's heart lesion in the picture? (The nurses showed a very simple and schematic image of the heart to parents. A comprehensive, yet simple and understandable explanation was provided to the parents about the four main chambers, the vessels, and the walls of the heart so that they could guess the location of the lesion according to previous knowledge about their child's disease even if they had not already observed such picture.)
3. What do you know about heart disease symptoms in children?
4. What information do you have about the causes of CHDs (Maternal diabetes, viral infection and drug consumption during pregnancy, and the like)?
5. Do you know how important it is to observe the oral health of your children? Do you also know that you need to take more accurate care of your children's teeth?

### Statistical Methods

Continuous quantitative variables were presented as mean  $\pm$  standard deviation (SD) and qualitative variables were expressed as numbers (percentages). Further, the Chi-square method was used to compare the categorical variables. Furthermore, the one-sample Kolmogorov-Smirnov test was utilized to evaluate the distribution of data. To compare the mean variables between the two groups, an independent *t* test or Mann-Whitney U test was applied while the Mann-Whitney U test was employed to evaluate the relationship between nominal and ordinal variables. Finally, statistical analysis was performed by SPSS 15 for Windows (SPSS Inc., Chicago, Illinois).

### Results

The age group of children was 6 months to 16 years with an average of  $4.3 \pm 4.8$  years. Furthermore, mothers were within the age range of 18 to 49 years with an average age of  $32.09 \pm 6.31$  and fathers' age ranged from 22 to 71 years with an average age of  $36.74 \pm 7.69$ . In 25% of mothers and 22% of fathers had primary education or lower and only 1% of the parents were divorced. Moreover, the minimum and maximum number of visits to the clinic was 3 and 21 times, respectively, with a median of 7 times. In this study, 14 (13.5%), 24 (23.1%), and 75 (72.1%) patients had systemic diseases other than the heart problem, a history of CHD in the family, and underwent catheterization or surgery, respectively.

It was also revealed that 65 (62.5%) parents knew the name of the disease in English or its equivalent in Persian and 18 (17.5%) of them could show the location of the heart lesion on the schematic image. Additionally, 15 (14.4%), 19 (18.3%), and 4 (3.8%) parents were aware of the heart disease and its significance, completely aware of the importance of oral health and had some information in this regard, respectively.

Table 1 shows the relationship between the studied variables and the indication of the name of the heart disease in English or its equivalent in Persian. There was a significant relationship between mothers ( $P=0.02$ ) and fathers' ( $P=0.01$ ) education, the history of angiography or surgery ( $P=0.006$ ), and the parents' awareness of the name of the heart disease in English or its equivalent in Persian. In other words, parents with a diploma or higher education were found to be more aware of the name of their child's disease compared to those who had elementary and post-secondary education. Similarly, the parents of children who had already undergone angiography and surgery in Rajaie Center or other medical centers were more aware of the name of their child's disease. However, no significant relationship was observed between other variables such as the number of referrals to the clinic, working mothers or parents' age, and the awareness of the name of the heart disease in English or its equivalent in Persian ( $P>0.05$ ).

The obtained data regarding the relationship between the studied variables and the ability to show the location of the child's lesion on the schematic image of the heart are summarized in Table 2. Based on the results, a significant relationship was found between mothers ( $P=0.06$ ) and fathers' ( $P=0.03$ ) education and the ability to show the location of the child's lesion on the schematic image of the heart. It was reported that parents who had a diploma or higher education could better show the location of their child's lesion on a schematic image compared to those who had primary education or lower than a diploma. Other variables revealed no significant relationship with the parents' awareness of the location of the lesion on a schematic image of the heart ( $P>0.05$ ).

Table 3 presents data related to the relationship between the intended variables and information on the symptoms

**Table 1.** Relationship Between the Studied Variables and the Awareness of the Name of the Heart Disease in English or its Equivalent in Persian

Variable	Not Having Knowledge About Their Child's Heart Disease	Having Knowledge About Their Child's Heart Disease	P Value
Mothers' age	32.38 ± 7.12	31.92 ± 5.81	0.712
Fathers' age	37.30 ± 8.98	36.40 ± 6.84	0.703
Mothers' education, No. (%)			
Elementary or lower	13 (33.3)	13 (20.0)	
Post-secondary	20 (51.3)	28 (43.1)	0.021
Diploma or higher diploma	4 (10.3)	23 (35.4)	
Bachelor's degree or higher	2 (5.1)	1 (1.5)	
Fathers' education, No. (%)			
Elementary or lower	13 (33.3)	10 (15.6)	
Post-secondary	21 (53.8)	34 (53.1)	.010
Diploma or higher diploma	2 (5.1)	19 (29.7)	
Bachelor's degree or higher	3 (7.7)	1 (1.6)	
Working Mothers, No. (%)	5 (12.8)	7 (10.8)	.612
History of angiography or surgery, No. (%)	22 (56.4)	53 (81.5)	.006
Child's gender (boy/girl), N	20/19	28/37	.402
Number of referrals to the clinic Median (IQR)	6 (2-11)	10 (4-11)	.061

Note. Statistical tests: the Mann-Whitney U test or *t* test and the chi-square test; IQR: Interquartile range.

**Table 2.** Relationship Between the Studied Variables and the Awareness of the Location of the Lesion on Heart Schematic Image

Variable	Not Knowing About the Location of the Lesion on a Schematic Image of Heart	Knowing About the Location of the Lesion on a Schematic Image of Heart	P Value
Mothers' age	32.22 ± 6.48	31.61 ± 5.69	0.705
Fathers' age	37.08 ± 7.74	35.29 ± 7.68	0.111
Mothers' education, No. (%)			
Elementary or lower	26 (30.6)	0 (0.0)	
Post-secondary	38 (44.7)	9 (50.0)	0.042
Diploma or higher diploma	18 (21.2)	9 (50.0)	
Bachelor's degree or higher	3 (3.5)	0 (0.0)	
Fathers' education, No. (%)			
Elementary or lower	22 (25.9)	0 (0.0)	
Post-secondary	44 (51.8)	11 (64.7)	0.030
Diploma or higher diploma	16 (18.8)	5 (29.4)	
Bachelor's degree or higher	3 (3.5)	1 (5.9)	
Working Mothers, No. (%)	8 (9.4)	4 (22.2)	0.112
History of angiography or surgery, No. (%)	64 (75.3)	11 (61.1)	0.278
Child's gender (boy/girl), N	40/45	8/10	0.850
Number of referrals to the clinic Median (IQR)	8 (4-11)	5 (4-11)	0.281

Note. Statistical tests: the Mann-Whitney U test or *t* test and the chi-square test; IQR: Interquartile range.

of heart disease. The results represented a significant relationship between mothers ( $P > 0.001$ ) and fathers' ( $P > 0.001$ ) education, mothers' employment ( $P = 0.04$ ), and parents' knowledge about the symptoms of the heart disease. More precisely, more educated parents (those with higher than a diploma degree) had more complete information about their child's disease compared to the other parents. Likewise, working mothers were more knowledgeable about the symptoms of their child's illness

when compared to housewives.

The relationship between the variables under investigation and the causes of the incidence of heart disease is shown in Table 4. Based on the findings, there was a significant relationship between mothers ( $P > 0.001$ ), fathers' ( $P = 0.001$ ) education, mothers' occupation ( $P > 0.001$ ), and the parents' knowledge of the causes of the heart disease. In other words, those parents with higher education, as well as working mothers had more complete

**Table 3.** Relationship Between the Studied Variables and the Knowledge of the Symptoms of Heart Disease

	Not Knowing About Heart Disease Symptoms	Knowing About Heart Disease Symptoms to Some Extent	Knowing About Heart Disease Symptoms Completely	P Value
Mothers' age	32.34 ± 6.92	32.18 ± 6.34	31.35 ± 5.13	.8130
Fathers' age	37.40 ± 6.67	36.94 ± 8.86	34.75 ± 4.73	0.494
Mothers' education, No. (%)				
Elementary or lower	15 (46.9)	11 (20.0)	0 (0.0)	<0.001
Post-secondary	11 (34.3)	34 (61.8)	3 (17.6)	
Diploma or higher diploma	5 (15.6)	10 (18.2)	12 (70.6)	
Bachelor's degree or higher	1 (3.1)	0 (0.0)	2 (11.8)	
Fathers' education, No. (%)				
Elementary or lower	12 (37.5)	10 (18.2)	1 (6.3)	
Post-secondary	3 (18.8)	37 (67.3)	15 (46.9)	<0.001
Diploma or higher diploma	4 (12.5)	6 (10.9)	11 (68.8)	
Bachelor's degree or higher	1 (3.1)	2 (3.6)	1 (6.3)	
Working mothers, No. (%)	3 (9.4)	3 (5.5)	6 (35.3)	0.040
History of angiography or surgery, No. (%)	19 (59.4)	44 (80)	12 (70.6)	0.111
Child's gender (boy/girl), N	16/16	25/30	7/10	0.859
Number of referrals to the clinic median (IQR)	4.5 (2-11)	10 (4-11)	6 (5-11)	0.060

Note. Statistical tests: the Mann-Whitney U test or *t* test and the chi-square test; IQR: Interquartile range.

**Table 4.** Relationship Between the Studied Variables and Knowledge of the Causes of Heart Disease

	Not Knowing About the Causes of Heart Disease	Knowing About the Causes of Heart Disease to Some Extent	Knowing About the Causes of Heart Disease Completely	P Value
Mothers' age	32.05 ± 7.25	31.69 ± 4.88	34.71 ± 4.60	0.525
Fathers' age	37.53 ± 9.09	35.34 ± 5.35	37.85 ± 4.94	0.445
Mothers' education, No. (%)				
Elementary or lower	22 (37.9)	4 (10.3)	0 (0.0)	
Post-secondary	28 (48.3)	20 (51.3)	0 (0.0)	0.001>
Diploma or higher diploma	7 (12.1)	14 (35.9)	6 (85.7)	
Bachelor's degree or higher	1 (1.7)	1 (2.6)	1 (14.3)	
Fathers' education, No. (%)				
Elementary or lower	72 (29.3)	6 (15.8)	1 (6.3)	
Post-secondary	32 (55.2)	22 (57.9)	1 (14.3)	<0.001
Diploma or higher diploma	6 (10.3)	10 (26.3)	5 (71.4)	
Bachelor's degree or higher	3 (5.2)	0 (0.0)	1 (14.3)	
Working mothers, No. (%)	4 (6.9)	4 (10.3)	4 (57.1)	<0.001
History of angiography or surgery, No. (%)	40 (69.0)	30 (76.9)	5 (71.4)	0.605
Child's gender (boy/girl), N	30/28	16/23	2/5	0.317
Number of referrals to the clinic median (IQR)	8.5 (3-11)	7 (4-11)	6 (3-11)	0.862

Note. Statistical tests: the Mann-Whitney U test or *t* test and the chi-square test; IQR: Interquartile range.

information about the causes of their child's heart disease as compared to the other parents.

As shown in Table 5, none of the studied factors had a significant relationship with the importance of oral hygiene ( $P>0.05$ ).

## Discussion

During the past decades, the survival of patients born with CHDs has dramatically increased all over the world

including Iran. According to Bethesda Conference held in 2001, the number of adults living with CHD was estimated to be more compared to the children and these patients, as adults, were expected to take responsibility for their own health care. However, various studies showed that most of these patient adults have no knowledge of their disease even regarding their initial diagnosis (8). This problem is believed to result from their parents' ignorance. In other words, knowledge can be transferred to the child if the

**Table 5.** Relationship Between the Studied Variables and Knowledge of the Importance of Oral Health

	Not Knowing About the Importance of Oral Hygiene	Knowing About the Importance of Oral Hygiene to Some Extent	Knowing About the Importance of Oral Hygiene Completely	P Value
Mothers' age	31.65 ± 6.48	30.75 ± 6.70	34.26 ± 5.19	.2210
Fathers' age	36.33 ± 7.60	34.25 ± 3.77	39.16 ± 8.32	0.258
Mothers' education, No. (%)				
Elementary or lower	23 (28.4)	0 (0.0)	3 (15.8)	2760.
Post-secondary	35 (43.2)	4 (100)	9 (47.4)	
Diploma or higher diploma	20 (24.7)	0 (0)	7 (36.8)	
Bachelor's degree or higher	0 (0.0)	0 (0.0)	3 (3.7)	
Fathers' education, No. (%)				
Elementary or lower	20 (24.7)	0 (0.0)	3 (16.7)	0.834
Post-secondary	43 (53.1)	3 (75.0)	9 (50.0)	
Diploma or higher diploma	15 (18.5)	1 (25.0)	5 (27.8)	
Bachelor's degree or higher	3 (3.7)	0 (0.0)	1 (5.6)	
Working mothers, No. (%)	9 (11.1)	0 (0.0)	3 (15.8)	.6800
History of angiography or surgery, No. (%)	55 (67.9)	3 (75.0)	17 (89.5)	0.152
Child's gender (boy/girl), N	39/42	2/2	7/12	.6460
Number of referrals to the clinic median (IQR)	7 (3-11)	8.5 (3.75-11)	11 (5-11)	0.088

Note. Statistical tests: the Mann-Whitney U test or *t* test and the chi-square test; IQR: Interquartile range.

parents are aware of their child problem. To the best of our knowledge, no study has so far evaluated the parents' awareness of their children's heart defect in Iran except for a limited number of studies by dentists regarding the oral hygiene in children CHD thus treatment initiation may only be based on parents' information. Therefore, considering time as a major factor, the incompleteness of parents' information in these circumstances may have irreparable consequences.

The disappointing findings may reflect the inadequacies of parental knowledge about the nature of heart disease and its treatment, as well as its impact on exercise capacity, infective endocarditis, and its prevention. Moreover, the majority of adult patients have a poor understanding of the impact of cardiac risk factors such as gestational diabetes mellitus on heart disease and the hereditary nature of their cardiac conditions (5,9-11).

In this study, parents with a high school diploma (12 years of study) and above were more aware of the name of their child's disease and could better show the location of their child's lesion on a schematic image as compared to parents with lower secondary education. Similarly, parents of children who had previously undergone angiography or surgery were more aware of the name of their child's disease. The underlying knowledge of parents was certainly effective in understanding and remembering their child's heart problems. Furthermore, some parents became more curious and had more information about this issue through seeking hospitalization and performing diagnostic and therapeutic interventions. In a study by Kaden, the parents' perceptions of CHD were related to their job (2) while in this present study, there was no relationship between parents' occupation, their age, the

frequency with which they were referred to the clinic, and their knowledge of their child's illness.

In addition, parents with higher education than a high school diploma had more complete information about their child's disease when compared to the other parents. Further, working mothers were more likely to be aware of the symptoms of their child's illness than the housewives. Animasahun et al. concluded that the awareness of parents in Nigeria had no relation with their social class (3). Although the social class problem was not considered in this study, the majority of the population referring to Rajaie Cardiovascular Medical and Research Center were of middle and lower social-economic classes since it is a government hospital. Remarkably, in addition to the role of mothers' education in the knowledge of the symptoms of the heart disease, their employment played a role in their awareness by attending the community and exchanging ideas with other people.

Likewise, the results of the study by Ndile and Kohi showed that 78% of parents did not know the most important and life-threatening symptoms in congenital conditions, which was related to their level of education (6).

Although 62% of parents could name the cardiac lesion, either in part or completely, they had limited knowledge of the etiology and causes of their children's CHD. Further, Cheuk et al. reported that only half of the parents were aware of the cause and hereditary nature of their children's CHD (12).

Based on the reports by Moons et al, parental understanding of the etiology of CHD correlated with parental occupation and educational level, which is in line with our findings (7).

Given the issue of endocarditis prevention, the parents of children with CHD were expected to at least know the importance of oral hygiene. Contrarily, it was found that the level of awareness about the importance of oral hygiene was low. Interestingly, this lack of parents' awareness, unlike other cases, was not related to parents' education. Several studies focused on this issue. For instance, Suvarna et al demonstrated the lack of knowledge and awareness in parents of children with CHD about the importance of dental care (4). Furthermore, in another study conducted by Haag et al, it was found that 43.3% of parents of the study knew about the importance of oral hygiene in children with CHD although 56.7% of them had no information in this regard (5).

Several studies in Iran also indicated the lack of parents' knowledge about the importance of the oral health of children with CHD (13-15).

Despite the diversity of studies and the differences in the conclusions that could be due to cultural and social differences, as well as differences in parents' education, all researchers agreed that parents' information was definitely less than their expectation. Obviously, in both advanced and developing countries, parents' information was reported to be insufficient. Most probably, development in diagnostic and therapeutic methods is considered as one of the major causes of this rapid and unpredictable growth of the CHD population while there is still no clear plan for educating and improving the awareness of these children's parents.

The findings of this study revealed that the number of referrals to the clinic had no effect on increasing the awareness of parents in this respect. It seemed that other factors are involved in this problem, such as the low awareness of parents (with lower education), overcrowding and inadequate opportunities for doctors in government centers, the lack of parents' knowledge about the anatomy and natural physiology of the heart, an excessive use of medical terminology by pediatric cardiologists, which causes confusion for the parents.

Our study was planned to be simple as much as possible and evaluate the very basic information of parents, therefore, it did not investigate parents' knowledge about different diagnostic modalities in CHD, like transthoracic echocardiography, transesophageal echocardiography, fetal echocardiography, angiography and catheterization, CT scan, and magnetic resonance imaging (16-21).

### Limitations

We tried to narrow the domain of our questions in order to be more precise and focus on some basic knowledge. Nonetheless, this policy can be considered as a limitation of this study because parents are expected to have at least some knowledge about diagnostic tools like echocardiography, CT scanning, and MRI which routinely are used in medical clinics. The other limitation is the small size of the studied population thus we cannot

generalize the results.

### Conclusions

According to the results of this study, there is an urgent need to promote the awareness of parents, and consequently, children concerning CHD. The authors of this paper believe that the most practical way to address this problem is to establish a scientific and advocacy association for congenital heart patients. This can be achieved by providing brochures, holding private or public consultation meetings in various fields such as dental health, nutrition, the psychological problems of puberty and marriage, lifestyle modification, and the like. Accordingly, these actions would help reduce the patient's feelings of anxiety and concerns by improving their level of awareness and knowledge and thus increasing their cooperation with the doctor in the process of treatment.

### Conflict of Interests

Authors have no conflict of interests.

### Ethical Issues

The study protocol was approved by the Ethics Committee of Rajaie Cardiovascular Medical and Research Center; University of Medical Sciences, Tehran, Iran (Ethics Code RHC.AC.IR.REC1396.12). All patients were informed and given written consent forms.

### Financial Support

There was no financial disclosure in this study.

### Acknowledgments

The authors would also like to announce their appreciation and gratitude to Mr. Ali Gordjahanbeiglou who was responsible for the classification of information and English editing of the text.

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