RESEARCH ARTICLE

Factors affecting the level of parental knowledge about their children's congenital heart diseases and their care

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Abstract

Objective: To assess parental knowledge about their children's congenital heart disease using a newly-designed scale.

Method: The cross-sectional study was conducted from June 2020 to May 2021, at Alkhansaa maternity and child hospital, Mosul Iraq; after approval from the ethics review committee of Ninevah Medical College, Ninevah University, Iraq, and comprised parents with children having congenital heart disease. Data, including age, gender, type of congenital heart disease as well as parents' educational and socioeconomic levels, residence, internet use and knowledge of the disease with respect to type, burden, bacterial endocarditis, outcome, etc. was noted. Parental knowledge levels were measured using a self-designed scoring scale, having a total score of 18 and 4 categories; <6 = some knowledge, 7-12 = good knowledge, 13-17 = very good knowledge, and 18 = full knowledge. Data was analysed using SPSS 26.

Results: There were 364 children with mean age 83.72±47.4 months and a male-female ratio of 0.98. The mean age at diagnosis was 12.1±8.32 months. The overall mean parental knowledge level was 8.41± 3.88, with 126(34.6%) parents having some knowledge, 178(48.9%) having good, 58(16%) having very good, and 2(0.5%) having full knowledge about their children's health condition (p<0.001) There was a significant association of parental knowledge with educational level, socioeconomic status and the type of doctor caring for the child (p<0.05). The duration of the illness showed a significant correlation with knowledge level (p=0.021).

Conclusion: The level of parental knowledge about congenital heart disease in children was not satisfactory.

Key Words: Heart Defects, Congenital, Endocarditis, Bacterial, Social Class

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Introduction

Cardiac anomalies are found in approximately 8 of every 1,000 newborns, and their families confront a variety of decisions and challenges post-diagnosis. Approximately 90% of babies with congenital heart disease (CHD) can survive into childhood, and many of them remain with chronic complaints and require regular follow-up. Parental understanding of the disease's nature, course, complications and the final outcome can significantly influence the patient's treatment plan and follow-up[1-4].

Studies regarding parental knowledge (PK) about CHD in children are limited, and the available studies have shown a significant lack of PK regarding disease complications, risk of endocarditis, indications for bacterial endocarditis (BE) prophylaxis, and details about the drugs used for their child's treatment[5-8]. The level of PK was found to be positively correlated with educational level and the child's age. The establishment of an effective parental educational programme for children with CHD is crucial for improving their knowledge and psychiatric status in relation to these types of diseases[9-13].

A significant number of parents lack knowledge regarding their children's CHD and lifelong care, including treatment requirements, BE risk, and prophylaxis, as well as the final outcome of the disease. This is an issue that warrants the requirement of instructive programmes because knowledge inadequacy is reflected as underestimation of disease impact and insufficient care of the patient[7,8,13].

The current study was planned to evaluate total and segmented PK of their children's CHD using a newly-designed scale, and to determine the factors affecting the level of PK.

Subjects and Methods

The cross-sectional study was conducted from June 2020 to May 2021, at Alkhansaa maternity and child hospital, Mosul Iraq; after approval from the ethics review committee of Ninevah Medical College, Ninevah University, Iraq. The sample size (364) was calculated using the formula:

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N= Z2P(1-P)/d2, with z score 1.44 at 85%confidence level, P being the highest prevalence of CHD reported in Iraq, and margin of error 0.0105[14,15]. This sample was raised using nonprobability sampling technique for a single dependant sample from among those visiting the outpatient department (OPD). Every other child visiting the cardiac unit every day was enrolled in an alternating way to ensure sample randomisation. After taking written informed consent, data was collected through face-to-face interviews with the parents.

The children were evaluated non-invasively by authorised paediatric cardiologist using an echocardiography machine (Affinity 30, Philips Ultrasound, Inc. United States.) and age-compatible probes. Chest radiography (CXR) and electrocardiography (ECG) were also performed to establish a definite diagnosis whenever necessary.

Data about the different aspects of PK regarding children's CHD was gathered using a self-designed questionnaire that had 3 sections. The first section related to patient's demographic and clinical data, including gender, current age, age at diagnosis, type of CHD, number of siblings, presence of other siblings affected by CHD, and type of attending physician, like paediatric cardiologist, cardiac surgeon, paediatrician, or general practitioner (GP).

The second section related to parent's residence, use of the internet to understand their child's disease, their socioeconomic status (SES) and educational level, considering the one with the higher level as the reference point.

The third section related to PK, including the description of the heart defect, drugs being used in terms of type, dose, benefits and adverse effects, indications, benefits and risks of defect correction by the trans-catheter method or surgery, burden of the disease on the child's health, the importance of oral hygiene, risk of BE, and indications for BE prophylaxis (BEP).

The level of PK for each variable was classified as absent knowledge (AK), partial knowledge (PK), sufficient knowledge (SK), or optimal knowledge (OK), with a score of 0, 1, 2, or 3, respectively, depending on how sufficient the parental response for each question was. For example, in relation to the description of heart defect in case of ventricular septal defect (VSD), if the parent did not know the type of CHD, they were scored AK, if they just knew the name VSD, they were scored PK, if they could describe the nature of the disease, such as a hole between the ventricles causing mixing of blood, they were scored SK, and if they could share more details about the size of the defect and its effect on the heart, they were scored OK. The total number of parameters used to determine PK level was 6, and the maximum total score was 18. It was categorised as <6 = some knowledge, 7-12 = good knowledge, 13-17 = very good knowledge, and 18 = full knowledge.

CHDs were divided into three groups: cyanotic defects left-to-right shunts, such as VSD, atrial septal defect (ASD), patent ductus arteriosus (PDA), and atrioventricular septal defect (AVSD); cyanotic defects right-to-left shunts, such as Tetralogy of Fallot (TOF), transposed great arteries (TGA) and tricuspid atresia (TA), and obstructive defects, such as aortic stenosis (AS), pulmonary stenosis (PS) and coarctation of the aorta (CoA).

The effects of various patient- and parent-related factors on the total score of PK were analysed to identify those with significant effects. The correlations between the PK level and the number of siblings and disease duration were noted. The SES was calculated using the equation:

SES score = Education + Occupation + House ownership * 0.5 + Car ownership * 0.1 + (age-20)/100)16. Score <4.68 was taken as low SES, 4.68-9.36 as middle SEDS, and >9.36 as high SES.

Data was analysed using Microsoft Excel 2020 and SPSS 26. Linear regression was used to calculate relationships among study variables, and Pearson's correlation coefficient was used to study the correlations. P<0.05 was taken as statistically significant.

Results

There were 364 children with mean age 83.72±47.4 months and a male-female ratio of 0.98. The mean age at diagnosis was 12.1±8.32 months. Of all the patients, 256(70.3%) had acyanotic CHD, 42(11.5%) had cyanotic CHD, and 66(11.1%) had obstructive CHD.

Table-1: Level of parental knowledge as assessed using a scale with maximum score 18

Level of knowledge	No	%
Some knowledge (score≤6)	126	34.6
Good knowledge (score=7-12)	178	48.9
Very good knowledge (score=13-17)	58	16
Full knowledge (score=18)	2	0.5
Total	364	100

The overall mean PK score was 8.41± 3.88, with 126(34.6%) parents having some knowledge, 178(48.9%) having good, 58(16%) having very good, and 2(0.5%) having full knowledge about their children's health

Table-2: Factors that may affect the parental knowledge level.

Factors		Level of parental knowledge					
		Some No (%)	Good No (%)	Very good No (%)	Full No (%)	Total No (%)	*P value*
Type of CHD	Cyanotic	86(23.6)	120(33)	48(13.2)	2(0.5)	256(70.3)	**0.7**
	Acyanotic	20(5.5)	18(4.9)	4(1.1)	0(0)	42(11.5)	
	Obstructive	20(5.5)	38(10.4)	8(2.2)	0(0)	66(18.1)	
Previously affected child	Yes	20(20.1)	20(5.5)	18(11.5)	0(0)	58(15.9)	**0.11**
	No	106(5.5)	156(42.9)	42(4.9)	2(0.5)	306(84.1)	
Type of caring doctor	GP	10(2.7)	10(2.7)	2(0.5)	0(0)	22(6)	**0.04**
	Paediatrician	72(19.8)	78(21.4)	16(4.4)	2(0.5)	168(46.2)	
	Ped. cardiologist	26(7.1)	54(4.8)	36(9.9)	0(0)	116(31.9)	
	Cardiac surgeon	18(4.9)	34(9.3)	6(1.6)	0(0)	58(15.9)	
Type of residence	City	64(17.6)	122(33.5)	46(12.6)	2(0.5)	234(64.3)	**0.12**
	Town	40(11)	40(11)	12(3.3)	0(0)	92(25.3)	
	Village	22(6)	14(3.8)	2(0.5)	0(0)	38(10.4)	
Parental educational level	Illiteracy	24(6.6)	14(3.8)	4(1)	0(0)	42(11.5)	**0.003**
	Primary school	64(17.6)	80(22)	20(5.5)	0(0)	164(45.1)	
	Secondary school	28(7.7)	52(14.3)	10(2.7)	2(0.5)	92(25.3)	
	University or higher	10(2.7)	30(8.2)	26(7.1)	0(0)	66(18.1)	
Socioeconomic level	Low	58(15.9)	70(19.2)	22(6)	2(0.5)	152(41.8)	**0.03**
	Middle	68(18.7)	98(26.9)	28(7.7)	0(0.5)	194(53.3)	
	Good	0(0)	8(2.2)	10(2.7)	0(0)	18(4.9)	
Parental use of internet	Yes	18(4.9)	36(9.9)	10(2.7)	0(0)	64(17.6)	**0.7**
	No	108(29.2)	140(385)	50(13.7)	2(0.5)	300(82.4)	

CHD: Congenital heart disease

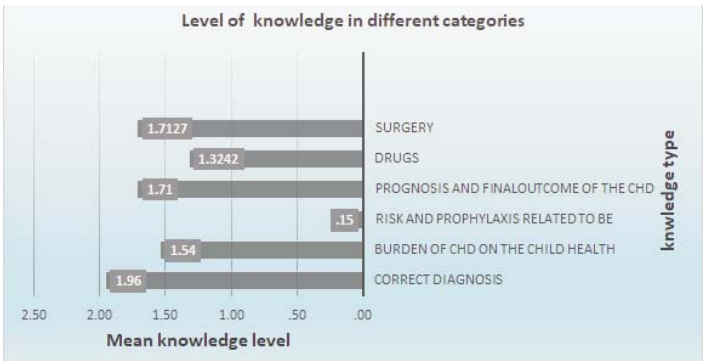

Figure: Mean score of different aspects of parental knowledge (PK) about their children's congenital heart disease (CHD).

condition (p<0.001) (Table 1). The best PK was related to describing their children's CHD356(97.8%), while the lowest level was for the risk and prophylaxis of BE 30(8.2%) (Figure).

Significant associations of PK were observed with the type of doctor attending the child, parental educational level, and the family SES (Table 2).

In the correlation analysis, the number of siblings, i.e., family size, did not significantly correlate with PK (p=0.27). The duration of the illness calculated from the diagnosis date until the time of interview showed a significant correlation (p=0.021) with PK level, and

linear regression showed a weak direct relationship to PK level (R2 =0.025).

Discussion

In the current study, despite the overall good level of PK (mean 8.41±3.88) on the newly-designed scale, a substantial group that constituted more than one-third of the families (34.6%) had only some knowledge (score ≤6), which was practically insufficient. Some comparable studies[4,5,7] conducted in the United States, Germany and Taiwan inferred close results and stated that approximately 50% of the parents had insufficient knowledge about their children's CHD. Daily et al.[12] emphasised the importance of quality educational programmes to upgrade families' knowledge levels. The strength of the current study is in the design of the total knowledge measurement scale, which was based on individual knowledge parameters related to the different disease aspects.

The weakest point was in PK regarding BE risk, prophylaxis and dental hygiene. On the contrary, more than two-thirds of the parents described their child's defect completely or in a good manner, and only 2.2% parents had no idea about it. Hagg et al.8 reported similar findings in a study done in Brazil. The problem is actually universal.[6,17,21-22] The ability to describe the heart defect correctly was satisfactory to a certain extent, although similar results were observed in other studies wherein 59-82% of parents could describe their children's CHD satisfactorily.[4-6,10,16,21]

In the current study, the strongest factor associated with PK was parental educational, and, hence, the SES, which is generally based on one's the educational level in its calculation. Simultaneously, the defect type showed no significant association with PK. It was thought that complexity of the CHD can decrease the understanding and knowledge level of parents, as has been reported by other comparable studies.[4,7,10,16] Other factors, including the type of family residence, history of presence of a previous child with CHD, and, interestingly, a parental internet search for the disease, did not show a significant association with PK. The type of caring doctor was significantly associated with PK, especially if the care was provided by a paediatrician or paediatric cardiologist, with least association for cardiac surgeon or GP.

It is logical for the parents to have increased knowledge with time. More clinic visits, and more extensive discussions contribute to this significant correlation between the duration of the disease and parental knowledge total score.

Conclusion

The level of PK about CHD in their children was not satisfactory, especially in relation to BE risk and prophylaxis. Parental knowledge about their children's CHD was mainly affected by parental educational level, SES, and the type of doctor caring for the child, and PK could increase with time.

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