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CONGENITAL HEART DISEASE;

KNOWLEDGE AND MYTHS IN PARENTS ATTENDING CARDIOLOGY DEPARTMENT OF CHILDREN HOSPITAL AND INSTITUTE OF CHILD HEALTH, LAHORE.

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ABSTRACT... Objective: To assess the parental knowledge and myths related to etiology of congenital heart disease. **Design:** A cross sectional descriptive study. **Place and Duration of Study:** Out patient department, indoor and echocardiography rooms of Children Hospital and Institute of Child Health (CH & ICH) Lahore, in two weeks of October, 2007. **Patients and Methods:** Convenient sampling technique was used to recruit 299 children between 1 month and 14 years of age, suffering from congenital heart disease. Cases of rheumatic fever and associated congestive cardiac failure were excluded from the study group. A structured questionnaire was used to interview parents of the study group. Descriptive statistics was determined in terms of percentages. **Results:** Out of total 299 patients included in this study, 132 were in the age group of 1-5 years (44%), with the mean age 1.86 years ± 0.886 SD. 200 were males (67 %) and 99 were females (33%). The respondents included 71% mothers and 27% fathers. Ventricular septal defect (VSD) was the most common disease encountered in 128 children (43%). Regarding the causes of congenital cardiac defects, parents blamed cousin marriage (41%), inheritance (26%), increased maternal age(16 %), maternal smoking(16%) and paternal smoking (39%). Other responses included evil spirits, moon and sun eclipses and bad wishes/evil eye. 57% of the respondents said that there is no relationship between gender and congenital cardiac malformation and 85% respondents believed that there is no relation with the food taken in pregnancy and subsequent cardiac defects. High Salt intake was considered as an associated factor by 47 (15%) of the respondents. Naming the cause of cardiac malformations, 41% of the parents said drugs taken in pregnancy, 13% of the respondents blamed alcohol, cocaine and opium intake. Among parents, 73% were aware of the fact that maternal health is important for disease causation in neonates but could not name any particular disease. **Conclusion:** The parents of those children, who have congenital malformation, have different myths and fallacies associated with disease causation. Adequate health education strategies should be adopted towards mass dissemination of information in the community about this important issue.

Key words: Congenital Heart Diseases, Myths, Knowledge.

INTRODUCTION

Congenital heart disease (CHD) is defined as an abnormality in the heart structure or function present at birth[1]. Worldwide, congenital heart disease remains a leading cause of neonatal and infant mortality[2].

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Its reported incidence is 8-10/1000 live births[3], which has remained constant[4]. In India, prevalence of CHD varies between 2-5 cases per 1000 live births, where nearly 180,000 children are born with this disease each year, contributing approximately 10% to the present infant mortality[5]. In Pakistan, no community-based data is available on CHD for the whole country, however, its reported incidence in NWFP is 8/1000 of live birth[6]. The number of patients with congenital heart disease is on increase because of steady addition of cases and increased longevity[7].

Globally, ventricular septal defect (VSD) remains the commonest CHD in neonates, closely followed by patent ductus arteriosus. Transposition of great arteries is seen in one fifth of neonates and pulmonary atresia is seen in about 13% of cases having CHD[8]. In Pakistan, a hospital based study revealed that CHD were found, in around 17% of total subjects studied. The most common CHDs were VSD (45%), ASD (14%) and pulmonary stenosis (14%), Tetrology of Fallot and patent ductus arteriosus (10% each)[5].

Multifactorial etiology of congenital heart disease involves the chromosomal abnormality of the fetus, maternal diabetes, systemic lupus erythematosis, alcohol intake, smoking, fetal and maternal exposure to radiations, teratogenic drugs and maternal rubella infection during early pregnancy[9]. In general, many myths, fallacies and superstitions are attached with the understanding of congenital disease causation[10,11].

Every society has its own beliefs about the vulnerability of the mother and the fetus during pregnancy, with culture-related ideas to explain a retarded, deformed or sick child[12]. An association is being made between spilling liquids on the mothers' body and birthmarks on the baby, the mother carrying keys and cleft lip in the baby, the mother wearing sunglasses and blindness in the baby, unfulfilled wishes of the mother to eat something and various abnormalities in the baby[13]. Most of the time woman is held responsible in the event of a negative outcome[12]. A study conducted in Brazil showed that majority of mothers' indicate guilt-punishment as the rational for explaining some congenital abnormalities, e.g. having sinned, looking or laughing at abnormal people, rejecting the pregnancy, cursing, getting married while pregnant and pornography-related activities[12]. In some instances the birth of a child with congenital heart disease, is considered a form of God's punishment[14].

Many anthropologists believe that these rituals and taboos associated with pregnancy act as a predictor of the health related behaviour of the parents towards their child's illness. Many parents show great anxiety when ever the presumptive diagnosis of congenital heart disease is given[15]. Parents experience a mixture of shock, disbelief, fear, anger, and often a profound sense of sadness[16]. On the contrary, accurate understanding of illness is associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatment, and a better emotional status, all key factors for good health-related quality of life[17].
The present study was conducted to assess the parental knowledge and myths related to etiology of congenital heart disease in a Children hospital. The insight provided by the study would be used to enhance the quality of management of CHD patients and assurance, counseling and health education of their parents.

PATIENTS AND METHODS

This cross sectional descriptive study was conducted at Children Hospital and Institute of Child Health (CH & ICH) Lahore, in first two weeks of October, 2007. A convenient sampling technique was used to recruit 299 children including both males and females between ages of 1 month and 14 years, suffering from congenital heart disease. Cases of rheumatic fever and associated congestive cardiac failure were excluded from the study group. These cases were selected from the out patient department, indoor, echocardiography room and cardiac intensive care unit. A structured questionnaire was used to interview parents of the study group, to assess their knowledge and myths related to etiology of congenital heart disease. The questionnaire was piloted before final study. Data was collected and then analyzed on SPSS version 12. Descriptive statistics is presented in terms of percentages.

RESULTS

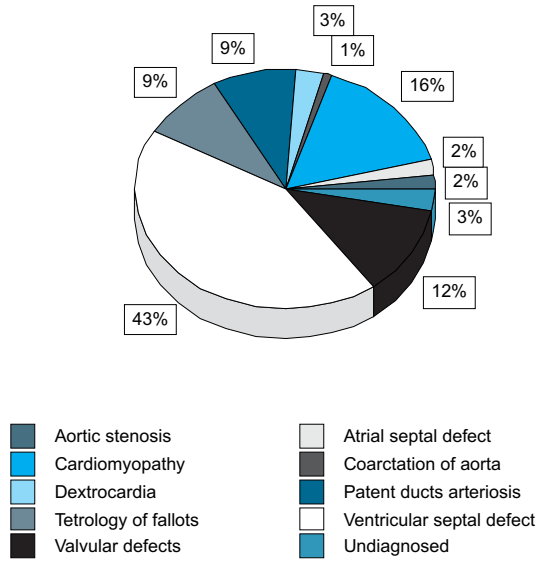
Out of total 299 patients included in this study, 116 were below one year of age (39%), 132 were in the age group of 1-5 years (44%), 30 were in age group of 5-10 years (10%) and 21 belonged to age group 10 years and above (7%) (mean age 1.86 years ± 0.886 SD). Among the patients, 200 were males (67 %) and 99 were females (33%). The respondents included 216 mothers (71%) and 83 fathers (27 %). Table I depicts that, 75 fathers (25%) and 104 mothers (35 %) were illiterate. 48 (16%) fathers and 49 (16.4%) mothers were primary pass. Only 20 fathers (6.7%) and 14 mothers (4.7%) were graduate and above.

Table-I. Educational status of the parents of children suffering from congenital heart disease

Education Status	Father		Mother	
	n	%	n	%
Illiterate	75	25	104	34.8
Primary	48	16	49	16.4
Middle	41	14	45	15.1
Matric	72	24	62	20.7
Inter	43	14	25	8.4
Graduate or above	20	6.7	14	4.7
Total	299	100.0	299	100.0

Figure 1 shows the pattern of congenital heart diseases observed in the study sample. Ventricular septal defect (VSD) was the most common disease encountered in 128 children (43%) while atrial septal defect was present in only 5 of the patients (2%). Other defects commonly found in the study group included Cardiomyopathy in 50 children (16%), Tetrology of Fallot (TOF) in 26 patients (9%) and patent ductus arteriosus (PDA)in 26 children (9%). Dextrocardia was seen in 8 patients (3%). Coarctation of Aorta and transposition of great arteries were seen in 2 children (1%), respectively. Valvular defects were present in 36 patients (12%), and the most common valvular defect being mitral stenosis observed in 13 patients. Remaining 8 patients (3%), were undiagnosed at the time of the present study.

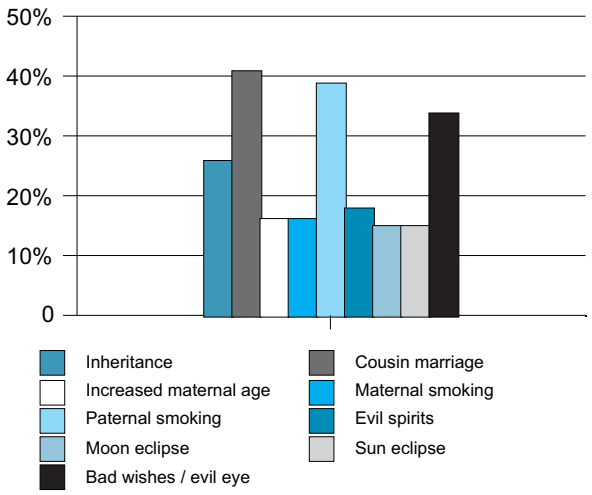
Fig-1. Pattern of congenital heart diseases in 299 patients



During study when the parents were asked to name the disease of their children, it was observed that not even a single parent was familiar with the name in medical terminology but 165 (55 %) of the parents knew the nature of lesion in local language, 134 (45 %) were only able to tell that the child is suffering from some heart problem.

When the parents were asked to name different causes of congenital cardiac defects, following responses were obtained. One hundred and twenty two parents (41%) said that cousin marriage is the cause of cardiac defects at birth. Seventy six parents (26%) mentioned inheritance. 48 (16 %) parents mentioned increased maternal age other 48 (16%) blamed maternal smoking and 39% (116) named paternal smoking as a cause. Fifty two parents (18%) blamed evil spirits, moon and sun eclipses was mentioned by 45 parents (15%) and 102 parents (34%) suggested bad wishes/evil eye as the cause of congenital heart defects in children.

Fig-2. Parents' knowledge about causes of congenital heart diseases (Multiple Responses)



When probed about the relationship of gender in causing congenital heart diseases, 172 respondents (57%) said that there is no relationship between gender and congenital cardiac malformation. Eighty seven parents (29%) said that males are more prone and 40 (14%) believed that females were more vulnerable for congenital cardiac defects. While ascertaining the role of diet, 254 respondents (85%) believed that there is no relation with the food taken in pregnancy and subsequent cardiac defects. High Salt intake was considered as an associated factor by 47 (15 %) of the respondents. Twenty one parents made an association with beef (7%), 12 of them (4%) blamed fats and 15 parents (5%) named pickles, spices and water as the culprit. One hundred and twenty one (41%) of the parents thought that drugs taken in pregnancy can cause cardiac defects in newborns. Out of them 38 parents (13%) blamed alcohol, cocaine and opium intake was mentioned by 18 (6%) and 24 (8%) parents respectively. Twenty seven parents (9%) believed that use of IV drugs in pregnancy produce this effect. Fifty four parents (18%) of the population could not name any drug causing cardiac abnormalities in children. Association of maternal diabetes with cardiac defect in newborn was pointed out by 38 (13 %) and hypertension during pregnancy by 12 parents (4 %). Approximately 73% of the parents were aware of the fact that maternal health is important for disease causation in neonates but could not name any particular disease. Fifty seven parents (19%) reported family history of congenital cardiac defect in their families and 36 of them (12 %) reported congenital heart disease associated mortality in their family.

DISCUSSION

Congenital heart diseases (CHD) are taking high position on the list of neonatal and infant mortality with increasing incidence worldwide. Pakistani population has incidence of congenital heart disease in 8/1000 of live births[5]. There is no community based data available to calculate the prevalence, only some hospital based studies have the relevant information. A recent study conducted in Jinnah Post graduate Medical Center children Unit shows that out of 7,480 patients 190 patients (2.5%) had congenital heart disease[18].

Dr. Shafqat and colleagues[19] conducted a study on 200 patients with congenital heart disease. In this study Ventricular Septal Defect (VSD) was the commonest lesion seen in 42 (21%) patients, Atrial Septal Defect (ASD) was seen in 32 (16%) of patients. Patent ductus arterious (PDA) were seen in 24 (12%) patients Other defects they noted included transposition of the great vessels, tricuspid artesia, ASD with pulmonary stenosis, persistent truncus arterious and Eisenmenger's syndrome etc.

The pattern of congenital heart diseases observed in our study showed that Ventricular septal defect (VSD) was the most common disease encountered in 128 children (43%) while atrial septal defect was present in only 5 of the patients (2%). Other defects commonly found in the study group included Cardiomyopathy in 50 children (16%), Tetrology of Fallot (TOF) in 26 patients (9%) and patent ductus arteriosus (PDA)in 26 children (9%) . Dextrocardia was seen in 8 patients (3%), coarctation of Aorta and transposition of great arteries wais seen in 2 children (1%), respectively. Valvular defects were present in 36 patients (12%), and the most common valvular defect being mitral stenosis observed in 13 patients.

Remaining 8 patients (3%) were undiagnosed at the time of the present study. The international literature reports the frequency of VSD 25%, ASD 6%, PDA 6% and Tetrology of Fallot 5%[10].

There is clear cut sex demarcation in occurence of congenital cardiac defects. In a study conducted in Karachi, ratio of males to females in a paediatric cardiac unit was re ported as 9:5[19]. Same results are seen in our study. Out of these 299 patients, (67 %) were males and only (33%) were female patients. Out of 299 respondents, 171 (57 %) responded that there is no relation of sex with the congenital cardiac malformation. Eighty seven (29 %) said that males are more prone to get these cardiac defects while 40 (14 %) believed that more females get congenital cardiac defects.

In the present study there were only 83 (27 %) fathers who responded to interview but 216 (71 %) mothers participated in the study. When the status of father's education was asked by the respondent of interview , it was seen that 75 (25%) were illiterate, 48 (16%) were primary pass,41 (14%) were middle pass,72 (24%) were matric pass, 43 (14%) were inter pass and only 20 (7%) were graduate and above. (table I) Regarding mother's education, the results of study revealed that 104 (35 %) of the mothers were illiterate, 49 (16.4%) were primary, 45 (15%) were middle, 62 (21%) were matric, 25 (8.4 %) were inter pass. Only 14 (4.7%) were graduate and above.(table II).

It has been observed that regardless of the parental educational level, the very early dissemination of information about their child having congenital cardiac defect produces feelings of anger and grief in them[15].

Parental knowledge of their child's heart disease, while often overlooked, contributes to compliance and reduces anxiety. During this study when the parents were asked to name the disease of their children, it was observed that not even a single parent was familiar with the name in technical language but 165 (55 %) of the parents knew the nature of lesion in local language, 134 (45 %) were only able to tell that the child is suffering from some heart problem. This evidence is supported by another study conducted in Israel to assess the parental knowledge about cardiac defect of their children. It was observed that 36% of parental diagnostic descriptions are incorrect [20].Ignorance of their child's problem did not correlate with its severity or complexity but rather with parental background: the less educated the parent, the more likely was the problem perceived incorrectly. Another study conducted in USA was to ascertain the impact of literacy level on parents' understanding of medical information and ability to follow therapy prescribed for their children, and it was observed that Parental literacy level did not correlate with use of preventive services or parental understanding of or ability to follow medical instructions for their children[21]. In our study same finding are being supported. When the parents were asked to name different causes of congenital cardiac defects, following responses were obtained. Only 76 parents (26 %) out of 299, said that inheritance plays a role in formation of congenital cardiac defects in children. Rest of the 74 % denied this fact. One hundred and twenty two parents (41 %) said that cousin marriage is the cause of cardiac defects at birth. Same results were obtained in an other study which showed that a positive correlation has been reported between advanced maternal age, cousin marriage and incidence of congenital heart disease[18].

In our results about 83% of the respondents denied the role of increased maternal age in causation of CHD and only 48 (16 %) considered it a fact.

Out of 299 respondents only 16 % (48) thought maternal smoking and 39% (116) thought paternal smoking as a cause of cardiac defect. This is different from another study where smoking was considered as a causative factor for congenital heart abnormalities 88.4% of the mothers[12].

In our present study, 17.4 % (52) considered the role of evil spirit as an etiological factor. Approximately 15 % of the population blamed moon and sun eclipse as a cause and 34% (102) people believed that Bud nazar or bud dua is the major cause in producing cardiac defects in children. Another similar study supported role of evil

spirits and God's punishments in congenital heart disease causation[22]. The lack of knowledge about particular aspects of the disease causation as well as myths and fallacies attached to it may have major consequences in management of the problem[23].

When relation of food with cardiac defects was asked, majority of the respondents (85%) believed that there is no relation with the food taken in pregnancy and cardiac defect in child born. High Salt intake was considered as an associated factor by 47 (15 %) of the respondents. Some of the parents also mentioned an association with beef (6.5 %), fats (3.7 %), pickles (2 %), spices (1.8 %), and water (1%). These responses are supported by another study conducted in California[24].

One hundred and twenty one (40.5%) of the participants thought that drugs taken in pregnancy could have caused cardiac defects in newborns. Out of these 38 (12.7 %) blamed alcohol intake for these structural abnormalities. Alcohol is also strongly associated with congenital cardiac defects in a study of Finland[25].

Association of maternal diabetes with cardiac defect in newborn was pointed out by 38 (13 %) and hypertension during pregnancy by (4 %) of the parents. Approximately 73 % of the parents were aware of the fact that maternal health is important for disease causation in neonates but could not name any disease. Investigators in a tertiary care outpatient pediatric cardiac center in Hong Kong revealed that majority of parents lack knowledge about congenital cardiac defects in their children[26].

CONCLUSION

The parents of those children, who have congenital malformation, have different myths and fallacies associated with disease causation. Their knowledge of disease etiology determines the behavior and attitude towards treatment and preventive strategies. Adequate health education strategies should be adopted towards mass dissemination of information in the community about this important issue.

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