

Cardiac Diseases among Children and its Impact on Family: a Cross Sectional Survey

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ABSTRACT

Objective: To determine the impact of cardiac disease on family among children.

Subjects and methods:

A cross-sectional study was conducted with a sample of 405, raised through non-probability convenient sampling technique. The recruitment of subjects was undertaken within September 2019 to February 2020. Parents of children both male and female having age within 5-12 years with diagnosed cardiac diseases were included in our study. Tool for data collection used in our study was PedsQL™ Family impact Module version 2.0 (PARENT REPORT). Data analyzed through SPSS 21.

Results:

Most of the children diagnosed with congenital heart disease were 72.6% and others with acquired heart diseases were 27.4%). Physical functioning and emotional functioning domain showed moderate impact on family both in congenital and acquired diseases. All other domains demonstrated mild impact on family.

Conclusion: According to results of current study it was concluded that children who are suffering from heart diseases also have impact of family with mild to moderate intensity.

Keywords: Congenital Heart Defect, Cardiac Diseases, Quality of life

INTRODUCTION

The cardiovascular system plays an important part in delivery of oxygenated blood to the tissue and organs.¹ This system transport carbon dioxide to the lungs .Cardiovascular system also provides nutrients and chemical signals, such as hormones, to the tissues and organs of organisms.² Diseases of the heart, vascular diseases of the brain and diseases of blood vessels are called cardiovascular diseases. Mainly deaths occur worldwide due to cardiovascular diseases (CVDs). 17.3 million Deaths occur each year due to CVDs and are the main reason for death worldwide³.

Congenital heart diseases are most common defect present at birth. ⁴Most common congenital heart disease is tetralogy of fallout. 1-3 cases of TOF present in per 1,000 births globally. Dextro-transposition globally is approximately 1 in 4,000 newborns. Levo-transposition occurs in approximately 1 in 13,000 infants globally. Persistent Truncus Arteriosis present in 1 in 11,000 infants globally.⁵ The exact frequency of congenital heart diseases in our country is not known but usually it occurs to be 8/1000 live births except the congenital bicuspid aortic valve. Exact incidence of cardiac diseases in children is not known yet because there is no national data registry in Pakistan.⁶

Few studies in Pakistan are conducted mainly in hospital admitted population shows prevalence percentage of congenital heart disease from 16.76–60%. Ventricular septal defects are the commonest Congenital heart disease noted in <10%.⁷ A life in which the individual is well-being and normally satisfied with his life is quality of life. Health-related quality of life specially focuses on aspects of quality related to their health.⁸

Congenital heart diseases can be divided into cyanotic or non-cyanotic heart diseases.⁹ Non-cyanotic congenital heart diseases include atrial septal defect, ventricular septal defect, patent ductus arteriosus,¹⁰ aortic stenosis, pulmonary stenosis and cyanotic heart disease includes tetralogy of fallout. The symptoms of cyanotic heart diseases are present at the time of birth.³

Children with surgical correction for cyanotic heart problems negatively impact their academics functioning compared with children with spontaneously closure of ventricular septal defect. Their concentration and learning abilities also affected.¹¹ There is worsening in performance and they achieved lower scores who were suffering from cyanotic problems than those with acyanotic problems postoperatively. Dependency and inactivity are two main problems faced by parents of children with cyanotic lesions. Intelligence also worsens with congenital heart defects. Cognitive functioning also seen impaired in older children with congenital heart disease, mostly those with cyanotic lesions.¹²

Neurodevelopmental problems also affect the development of motor and language, cognition and higher-order cognitive functioning of the children. Motor development is also affected in children during their early life.¹³ They mostly achieve motor milestones slowly. They also presented with clinical signs of muscular hypotonic. Afterwards, children also suffer from slower development of cognition and language. School going children with cardiac disease mostly presented with different types of problems in learning, memory function, language expression and behavioral functions.¹⁴ When children become older and enter adolescence stage they presented with dysfunctions of cognitive and motor that leads to poorer achievement of academics.¹⁵

Current study aimed to enlighten the type of congenital and acquired cardiac diseases among children and impact of children health on their families.

METHODOLOGY

This was descriptive cross-sectional survey. The data was collected from the following Hospitals of the twin cities (Rawalpindi and Islamabad): Pakistan Institute of Medical Sciences (PIMS), Rawal Institute of Cardiology (RIC), Rawal General Hospital and Community. The collection of data was undertaken within September 2019 to February 2020. Ethical approval for study was taken from Institutional Review board & Research ethical committee of Riphah international University Islamabad (Riphah/RCRS/REC/00621). Written informed consent was taken from the patients; the researcher described the detail procedure and purpose of study to the patients along with risks and benefits.

The targeted sample size calculated through RAO software was 377 while total number of subjects who participated in the study was 405. Purposive non-probability convenient sampling technique was used to select sample from the population. Parents of children both male and female having age within 5-12 years with diagnosed cardiac diseases were included in our study. Parents of children with other than cardiac diseases were excluded. Tool for data collection used in our study was PedsQL™ Family impact Module version 2.0 (PARENT REPORT).

PedsQL family impact module questionnaire was taken from parents of children with congenital heart diseases in pediatric cardiology hospitals. Parent scores on the PedsQL generic core scales were discussed. This family impact module composed of 36 items and comprising of 8 dimensions which includes physical functioning (tired during the day, feel physically weak), emotional functioning (sad, angry, feel helpless or hopeless), social functioning (difficulties in performing social activities, feel isolated from others), cognitive functioning (difficulties in paying attention on things, difficulties in remembering things), communication functioning (difficulty to discuss their child’s health with someone), worries problems (worried about my child’s medical treatments, worried about my child’s future), daily activities problems (taking more time and effort in performing daily activities) and family relationships problems(stress and tension between family members). Sum of the items over the number of items answered, mean score was calculated. Data was analyzed through SPSS (statistical package for social science) version 21.0 software.

RESULTS

The total 405 children’s data was analyzed out of which the frequency of the males were 58.5 % (237) and females were 41.5% (168). The mean age of all the participants’ children was 6.36±3.68. Mean BMI came out to be 16.49±3.54. Percentage of school going children was 59.5%. Most of the children were diagnosed with congenital heart disease with 72.6% and others with acquired heart diseases 27.4%. Types of congenital and acquired diseases are presented in Figure 1 and 2.

Table 1: Mean and SD of parent report

Parent Report	(MEAN±SD)	
	Congenital heart disease	Acquired heart disease
Physical Functioning	2.65±0.95	2.8±0.96
Emotional Functioning	2.01±1.08	2.08±1.1
Social Functioning	0.97±0.91	0.92±0.89
Cognitive Functioning	1.16±0.98	1.23±1.08
Communication	0.87±1.07	1.04±1.09
Worry Problems	0.49±0.68	0.48±0.66
Daily Activities	1.57±1.35	1.73±1.42
Family Relationships	0.83±0.51	0.97±0.65

SD: Standard deviation

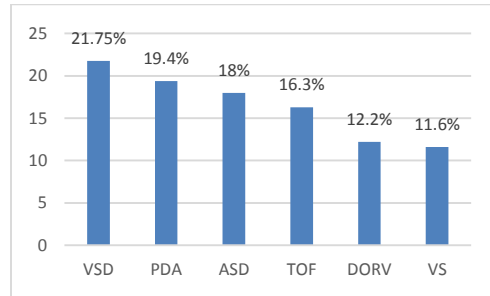


Figure 1: Frequency of Congenital Heart Diseases

VSD: Ventricular Septal Defect; PDA: Patent Ductus Arteriosus; ASD: Atrial Septal Defect; TOF: Tetralogy of Fallot; DORV: Double outlet right ventricle ;VS: Valvular stenosis

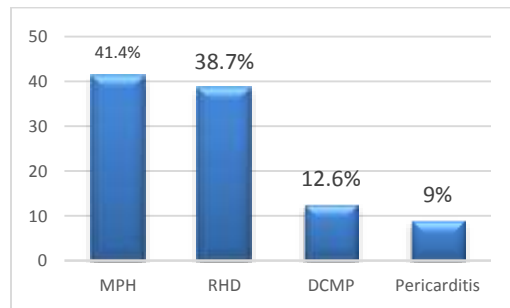


Figure 2: Frequency of Acquired Heart Diseases

MPH: Mild pulmonary Hypertension; DCMP: Dilated Cardiomyopathy; RHD: Rheumatic Heart Disease

Our study also observed the family impact through PedsQOL questionnaire. According to our Family Impact Module questionnaire mean scoring is 0-5. 0-1 means mild impact, 2-3 means moderate impact and 4-5 means severe impact on family of children with cardiac disease. According to our results mean scores were around 1 and 2 showing as mild to moderate impact on family. No difference observed in mean of congenital heart disease and acquired heart disease showing similar impact on all domains of family impact module. (Table 1)

DISCUSSION

The care of children with cardiac diseases produces emotional and financial adversities for their parents and families. In current study we determined the frequency of cardiac diseases and its family impact as main objective.

For this purpose, the PedsQL tool (family impact module) was used.

The results of present study demonstrated that majority of the children with cardiac diseases were male. Mohammad N et al¹⁵ also conducted a study on similar topic and noticed that majority of the children with cardiac diseases was male. Similar trends were observed in a study conducted by other national researchers who observed male dominance.^{7, 16} while another study from neighboring country India showed 66% of male participants with CHD.¹⁷

Current study reported that mean age of the children with cardiac diseases was 6.3 ± 3.68 but in the relevant literature mostly authors reported age below one year.¹⁸ There are number of factors involved around the globe which results into greater variation in age group of children with heart diseases. Many of the children with cardiac diseases are commonly undiagnosed especially minor defects which are often asymptomatic till the specific age group.¹⁹

According to our result, congenital heart diseases were most frequent among the participants. Ventricular septal defect (VSD) was the most common heart lesion among congenital heart defects. Similar results demonstrated in previous studies conducted in Pakistan.^{6, 20}

Another study conducted by Sharifi, A. M, discuss about Pattern and frequency of pediatric congenital heart disease at Afghanistan, founded similar results. The ASD and VSD were the most common lesions in their study. In our study PDA was the second most common disease but in their study VSD was found to be 2nd most common disease.²¹

In current study we use family report of PedsQL generic core scale 2.0 version consist of multiple domains of physical, emotional, communication, cognitive functioning, worry problems and daily activities. We assessed the Mean and SD of different domains of family impact module. Mild to moderate family impact was observed. Another study was conducted by James W. Varni they also use PedsQL family impact module in medically unfit children with chronic conditions who stay in hospital for longer period of duration. They presented similar trends of all domains.²²

Similar study conducted on parent's report quality of life among young children suffered from congenital heart defects and their families and reported similar results. Parents of children (infants and toddlers) with CHD demonstrated higher levels of parenting stress, sleep problems, and maladjustment in another study.²³

CONCLUSION

Our study revealed that the most frequently occurring congenital heart diseases were Ventricular septal defect (VSD), Patent ductus arteriosus (PDA) and Atrial septal defect (ASD) defects among population of twin cities. The most frequently occurring acquired heart disease was mild pulmonary hypertension. Mild to moderate family impact was witnessed in parents of children with cardiac diseases.

Limitations of study: The current study had few limitations. Health related quality of life of children was not assessed as we could not get permission for tool for health

and wellbeing of children. We took data from open population not from age specific which was mentioned in our study.

Conflict of interest: Authors declared no conflict of interest.

REFERENCES

- Romero SA, Minson CT, Halliwill JR. The cardiovascular system after exercise. *Journal of Applied Physiology*. 2017;122(4)
- Knight J, Nigam Y. Anatomy and physiology of ageing 1: the cardiovascular system. *Nursing Times*. 2017;113(2)
- Mendis S, Puska P, Norrving B, Organization WH. Global atlas on cardiovascular disease prevention and control: World Health Organization; 2011.
- Lopes SAVda, Guimarães ICB, Costa SFdO, Acosta AX, Sandes KA, Mendes CMC. Mortality for critical congenital heart diseases and associated risk factors in newborns. A cohort study. *Arquivos brasileiros de cardiologia*. 2018;111(5)
- Suluba E, Shuwei L, Xia Q, Mwangi A. Congenital heart diseases: genetics, non-inherited risk factors, and signaling pathways. *Egyptian Journal of Medical Human Genetics*. 2020;21(1)
- Komarlu R, Morell VO, Kreutzer J, Munoz RA. Dextro-transposition of the great arteries (D-TGA). *Critical Care of Children with Heart Disease*: Springer; 2020. p. 351-67.
- Sehar T, Sheikh AM, Kanwal A. To identify pattern of congenital heart diseases in a newly developed tertiary care unit. *Pakistan Armed Forces Medical Journal*. 2019;69(4)
- Wray J, Sensky T. Congenital heart disease and cardiac surgery in childhood: effects on cognitive function and academic ability. *Heart*. 2001;85(6)
- Galvis MMO, Bhakta RT, Tarmahomed A, Mendez MD. Cyanotic heart disease. *StatPearls [Internet]*. 2020
- Jia X, Ma X-H, Liang J-W. Application of voxel-based morphometric method to detect brain changes in children with non-cyanotic congenital heart disease. *World journal of radiology*. 2020;12(9)
- Eichler A, Köhler-Jonas N, Stonawski V, Purbojo A, Moll GH, Heinrich H, et al. Child neurodevelopment and mental health after surgical ventricular septal defect repair: risk and protective factors. *Developmental Medicine & Child Neurology*. 2019;61(2)
- Latal B. Neurodevelopmental outcomes of the child with congenital heart disease. *Clinics in perinatology*. 2016;43(1)
- Naef N, Liamlahi R, Beck I, Bernet V, Dave H, Knirsch W, et al. Neurodevelopmental profiles of children with congenital heart disease at school age. *The Journal of pediatrics*. 2017;188
- Nattel SN, Adrianzen L, Kessler EC, Andelfinger G, Dehaes M, Côté-Corriveau G, et al. Congenital heart disease and neurodevelopment: clinical manifestations, genetics, mechanisms, and implications. *Canadian Journal of Cardiology*. 2017;33(12)
- Mohammad N, Shaikh S, Memon S, Das H. Spectrum of heart disease in children under 5 years of age at Liaquat University Hospital, Hyderabad, Pakistan. *Indian heart journal*. 2014;66(1)
- Arshad MS, Anwar-ul-Haq HM, Adnan M, Zulqarnain A. Frequency and pattern of Paediatric Heart Diseases: Five years experience at The Children's Hospital, Multan. *Pakistan Journal of Medical Sciences*. 2020;36(6)
- Maya S, Gunawijaya E, Yantie NVK, Windiani IT. Growth, Development, and Quality of Life in Children with Congenital Heart Disease Children. *Open Access Macedonian Journal of Medical Sciences*. 2020;8(B)
- Rizvi SF-u-H, Mustafa G, Kundi A, Khan MA. Prevalence of congenital heart disease in rural communities of Pakistan. *Journal of Ayub Medical College Abbottabad*. 2015;27(1)
- Serinelli S, Arunkumar P, White S. Undiagnosed congenital heart defects as a cause of sudden, unexpected death in children. *Journal of forensic sciences*. 2018;63(6)
- Mostefa-Kara M, Houyel L, Bonnet D. Anatomy of the ventricular septal defect in congenital heart defects: a random association? *Orphanet journal of rare diseases*. 2018;13(1)
- Sharifi AM. Pattern and frequency of pediatric congenital heart disease at the Cardiac Research Institute of Kabul Medical University, Afghanistan. *Paediatrica Indonesiana*. 2018;58(3)
- Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. Health and quality of life outcomes. 2004;2(1)
- Bishop MN, Gise JE, Donati MR, Shneider CE, Aylward BS, Cohen LL. Parenting stress, sleep, and psychological adjustment in parents of infants and toddlers with congenital heart disease. *Journal of pediatric psychology*. 2019;44(8)