DOI: 10.53555/ks.v12i4.3137

Patterns of Emotional Behavioral Issues in Different Types of Congenital Heart Disease among Children and Adolescents

Dr. Asma Riaz Hamdani^{1*}, Dr. Rabia Khawar², Ghazala Fazaldad³, Asma Majeed⁴, Dr. Amna Hassan⁵, Asima Munawar⁶

^{1*}Assistant Professor (OPS), Department of Applied Psychology, GCUF, Faisalabad

²Professor. Department of Applied Psychology, GCUF, Faisalabad

³Assistant headmistress, Islamabad College for girls F-6/2 Islamabad

⁴Lecturer, Applied Psychology. Kinnaird College for Women, Lahore

⁵Lecturer Department of Psychology, IIUI, Islamabad

⁶Lecturer Department of Psychology, Capital University of Science and Technology, Islamabad

Abstract

Objective To determine the pattern of Emotional Behavioral issues in Children and Adolescents with Congenital Heart Disease (CHD) in Pakistan

Study Design: Comparative group design was used to study variables

Place and Duration: Faisalabad Institute of Cardiology, April 2021 to November 2021

Methodology: A sample of 300 children and adolescents diagnosed with cyanotic and cyanotic CHD was studied to assess the prevalent emotional behavioral problems in different patterns of CHD. The strength and difficulty questionnaire was used to measure the emotional behavioral issues. Parent-reported form for children below 7 years of age and self-report for above 7 years was used. Detailed history and demographics were taken.

Results: The results explained that 65% of the CHD population is in the clinical range of emotional behavioral issues. The comparison of gender mean difference shows that male CHD population as compared to females(p<.05). Whereas no difference was found in internalizing problems in both genders while males have more externalizing issues and females are better in prosocial behavior as compared to male counterparts. Children and adolescents with cyanotic CHD have more clinical range of emotional and behavioral issues(p<.01).

Conclusion: Children and adolescents now have a long life as compared to previous decades but with this growing age and having a congenital condition they are having problems in their psychological health which is in need of assessment and repair.

Keywords: Emotional Behavioral Issues, Externalizing, Internalizing, Gender

INTRODUCTION

Congenital illness usually has an impact on the psychological health and well-being of any individual. An illness of early onset with a need for frequent hospital visits, admissions, or different diagnostic and therapeutic procedures creates an adverse effect on the social and emotional health of children and adolescents¹

Congenital heart disease (CHD) has several birth defects, which disturb the normal functioning of the heart These defects can start from abnormal development of the heart's or major blood vessels' structures. CHD can present at the time of birth but in many cases, it can be detected in the prenatal environment. Many studies with children and adolescents have revealed increased life expectancy and normal growth ². The global mortality rate significantly reduced between 1990 to 2010. These contributing factors now resulted in a shift within future research. Now the researchers focused to sort out the ways to improve the paired emotional behavioral issues and quality of life in these children and growing adolescents³.

With this increased focus the assessment was around the psychosocial functioning of CHD children and adolescents. The prime objective of all clinical care was not only to achieve life expectancy but research shifted to explore more possible psychological care and improved quality of life. There is no consensus among different researchers on assessing psychology but they are sorting out many ways to move forward. Many studies started to explore emotional behavior problems that can reduce their psychological and cognitive functioning as compared to healthy children of their age ⁴.

Children and adolescents with CHD experience challenges in their all-over development. The congenital conditions can be affected by several factors that contribute to severe emotional and behavioral issues, that make a hindrance in their normal development, socialization, or future life. Such behaviors include aggressive or destructive behavior, temper tantrums, and social issues ⁵. Follow-up studies investigated psychosocial outcomes and reported contradictory results in different cultures Moreover, very few studies have evaluated the impact of CHD on the psychological health of the Pakistani population. Therefore, the following study assesses the relevant psychosocial problems in the CHD population.

The major objective of the current study is to explore the level and nature of emotional behavioral issues in local tertiary care hospital. As per our knowledge, it is the first study of its kind where the rate of CHD is quite higher than its neighboring countries. The advancement in pediatric cardiac care units has made it possible for the long-term life of the CHD population. But with their increased life-years along with a congenital condition created many hurdles in their normal psychosocial

functioning and daily routine. The assessment of these issues can help clinicians tackle them in a better way. Furthermore, this assessment helps to pave the way for their psychosocial care and improved quality of life.

Patients and Methods

This study, based on a cohort was completed in 10 months. This study was conducted in a tertiary care hospital, FIC (Faisalabad institute of Cardiology). The initial approval was forwarded to the Ethical committee review board from FIC and after this approval, the university IRB approval was taken. 300 children and adolescents were involved in the study. The standardized tool, strength and difficulty questionnaire⁶ was used in the study. The Strengths and Difficulty Questionnaire(SDQ) is a valid and reliable measure for assessing the mental health status of people in the age range 2 to 18. 4500 clinical and academic studies used SDQ and over 5 million assessments of young people have been carried out on a single website since 1998. It takes 3 to 5 minutes to complete this scale. SDQ comprises 25 items based on 5 subscales for which each subscale score ranges from 0 to 10. Children with different types of CHD were recruited from the prospective cohort. A separate Demographic sheet was attached to record all the demographic details of children and adolescents with CHD. The data of the study were collected from April 2021 to December 2021. The informed consent from parents, as well as a self from the participants above 16, was taken and all the rights were given to the population as they can withdraw from the study at any time.

RESULTS

variables	N	%	Mean	SD
Gender				
Male	169	51.8	4.26	
Female	157	46.2	4.20	
Age				
>_9	146	44.7	10.11	4.1
9-13	82	20.6		
< 13	98	30		
Diagnosis				
PS	23	7.1		
ASD	76	23.3		
AVSD	41	12.6		
PDA	31	9.5		
VSD	73	22.3		
TGA	6	1.8		
TOF	76	23.4		
Medication Adherence			.89	.31
yes	289	88.7		
no	37	11.3		
Surgery	33	10.1	.10	.3
Non Surgery	293	89.9		

Table 2: Mean differences between Externalizing and Internalizing problems in different types of CHD

Diagnosis	Externalizing M(SD)	Internalizing M (SD)
PS	9.56 (2.10)	7.95 (3.06)
ASD	9.11 (3.45)	7.82 (3.23)
AVSD	9.68 (2.90)	9.78 (3.92)
PDA	8.25 (2.88)	7.12 (2.60)
TGA	7.00 (1.78)	7.66 (3.72)
TOF	9.07 (2.52)	8.96 (2.99)
VSD	9.32 (2.76)	8.30 (2.98)

Note= PS (pulmonary valve stenosis), ASD (atrial septal defects), AVSD (atrioventricular septal defects), PDA(patent ductus atrocious). TGA (dextotransposition of great artery), TOF(teratology of fallout), VSD (ventricular septal defect)

Table 3 : Prevalence of Emotional behavioral issues as per gender and diagnosis of CHD population

		diagnosis of disease						Total	
		PS	ASD	AVSD	PDA	TGA	TOF	VSD	
Gender(F,M)		(12,11)	(42,34)	(17,24)	(18,13)	(4.2)	(39,37)	(25,48)	(157,169)
EB	Non-clin	5	20	4	12	2	9	13	65
	Borderline	6	26	12	8	2	24	23	101
	Clinical	12	30	25	11	2	43	37	160
Total		23	76	41	31	6	76	73	326

Note = EB(emotional behavioral issues), Non-clin(non-clinical range of EB), Borderline(borderline range of EB), Clinical(clinical range of EB)



Figure 1: Gender differences in emotional behavioral issues in CHD Children and Adolescents

Figure 2: Prevalence of emotional behavioral issues in different diagnostic categories of CHD



Out of 326 children and adolescents 51.8() were males and 46.2() were females. The male-to-female ratio was 1.2:1. Most of the children were below the age of 9. Both cyanotic and cyanotic patients were present in the sample. Most prevalent types of CHD were ASD (Atrial septal defect), VSD(ventricular septal defect), and TOF(teratology of fallout) which were 23.3%,22.3, and 23.4 respectively.88.7 % of patients were taking their treatment and still on medicine while the other 11.3% were not on medication as they have come to their follow-up for symptomatic issues arise whenever. Out of 326,160 (49.1%), children and adolescents were above the clinical cutoff of emotional behavioral issues. While 101(31.1%) children and adolescents were at the borderline level in emotional behavioral difficulties.

Figure 1 explains that male children and adolescents have more emotional behavioral issues than the female population. Whereas Figure 2 explains that the TOF group has more emotional behavioral issues as compared to other diagnoses.

DISCUSSION

This study serves as the first of its kind for exploring the relative psychological functioning in terms of their emotional behavioral issues in children and adolescents with CHD a with valid and reliable assessment tool. Moreover, exclusion of other acute and chronic illnesses, genetic anomalies, mental retardation, and psychiatric disorders that might have negatively impacted on psychological health was important to clearly evaluate specific emotional behavioral issues in children and adolescents with CHD. Striking results were obtained through this methodology.

1204 Patterns of Emotional Behavioral Issues in Different Types of Congenital Heart Disease among Children and Adolescents

Congenital illness creates significant impairment everyday functioning of children and adolescents with CHD which requires complete medical care and suitable interventions for day-to-day activities. In a study where a researcher explored the difference between healthy children and other chronically ill children, the pediatric cardiac patients displayed more poor physical and psychosocial health⁷.

The present study depicts that all types of CHD results create different emotional and behavioral issues which display the clinical cut off as well. The long-term illness and physical weakness experienced by this population create hindrance to their normal mental health and well-being. Their condition limits them from normal daily, school, and social functioning. The resultant anxiety and stress create many emotional and behavioral issues in this population⁸.

When investigating the relationship between the presence of emotional behavioral difficulties it reveals that the male CHD population showed greater problems as compared to female CHD children and adolescents. Although the parallel prevalence rate of CHD in both gender the difference depict that male have more relative stress due to hurdles and hindrances in the normal functioning of life. Previous studies also demonstrate this trend. In post-surgical treatment group Boys unlike girls demonstrated more psychosocial issues (23.8% vs 12.6%) as compared to their female counterparts^{2,9-11}. More than half of the population was showing clinical trends of malfunctioning in their psychological health. In which the diagnosis which has more complexities and prolonged treatment (TOF, VSD, ASD) has more emotional and behavioral issues. A study compared four CHD diagnostic groups of different CHD severities, they found that children and adolescents with VSD revealed more social (mean 4.4) and externalizing problems (mean 9.0) than children and adolescents with a trial septal defect (mean 2.2 and 5.2, respectively) and pulmonary stenosis (mean 2.4 and 5.0, respectively). Clinically VSD comprises more severe symptoms than ASD and PS.

In another study of infants of 36 months with different variations in CHD diagnosis, infants did not differ in showing any risks of developing emotional problems, however, In growing time they demonstrated more behavioral issues with different modalities in their severity. They are 60% higher risk of emotional problems Hence, these results suggest that children and adolescents with high disease severities develop more problems in their later life than lower disease severities ¹³⁻¹⁵.

Reportedly the ratio of emotional and behavioral issues in different cultures varied, some studies of children and adolescents with different severities of CHD found no differences in behavioral and emotional problems were found across all severities of CHD like research in Norway assesses the same level of emotional behavioral issues across all modalities of CHD. In contrast, in Turkey, it was found that the more severe the cardiac condition, the higher the withdrawal behavior (p ¹/₄ .002) and externalizing issues in the population with CHD ¹⁶⁻¹⁷⁻¹⁸.

This study result was also explaining that the more severe or complex the diagnosis the more internalizing and externalizing issues the population was suffering. It is also showing that the male population has more issues. The mean differences were showing that all types of CHD showed greater externalizing problems as compared to internalizing issues except TGA and AVSD.

Long hospitalization, complex invasive treatments, long treatment hours, more hospitalization, and relative stigma can be reasons for these resultant issues. Another explanation is the development of these emotional behavioral issues is due to a genetic link between a child's heart and emotions.

Age gender and parent-child interaction, as well as socio-demographic factors like socioeconomic condition parental education, family system, and size of family, also contribute to these issues.

Implications for practice

It is anticipated that the findings of current research provide help to Healthcare Professionals in gaining new knowledge and paying particular attention to the psychosocial functioning of the growing CHD population. It also them to refer and seek appropriate support for better psychological health. Future research will potentially inform the development of future preventive interventions, such as support groups of behavioral and emotional care for CHD children and adolescents

Conclusion: All previous studies in Pakistan mainly relied on the reporting of prevalence and level of GHD but this study assesses behavior and emotions relevant to their health-related quality of life. Furthermore, the investigation around the relationship between gender and behavioral and emotional issues also assessed CHD which was needed earlier. It was identified that there is a need for future qualitative studies that explore in-depth these issues in CHD and how their behavior and emotions, effecting the younger population.

References

- 1. Dekker MC, Koot HM, Ende JV, Verhulst FC. Emotional and behavioral problems in children and adolescents with and without intellectual disability. Journal of Child Psychology and Psychiatry. 2002 Nov;43(8):1087-98.
- Dahlawi N, Milnes LJ, Swallow V. Behaviour and emotions of children and young people with congenital heart disease: A literature review. Journal of Child Health Care. 2020 Jun;24(2):317-32.
- Lozano R, Naghavi M, Foreman K, Lim S, Shibuya K, Aboyans V, Abraham J, Adair T, Aggarwal R, Ahn SY, AlMazroa MA. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. The lancet. 2012 Dec 15;380(9859):2095-128.
- 4. Miatton M, De Wolf D, François K, Thiery E, Vingerhoets G. Behavior and self-perception in children with a surgically corrected congenital heart disease. Journal of Developmental & Behavioral Pediatrics. 2007 Aug 1;28(4):294-301.

- 5. Wilmot I, Cephus CE, Cassedy A, Kudel I, Marino BS, Jefferies JL. Health-related quality of life in children with heart failure as perceived by children and parents. Cardiology in the Young. 2016 Jun;26(5):885-93.
- 6. Goodman A, Goodman R. Strengths and difficulties questionnaire as a dimensional measure of child mental health. Journal of the American Academy of Child & Adolescent Psychiatry. 2009 Apr 1;48(4):400-3.
- McWhorter LG, Christofferson J, Neely T, Hildenbrand AK, Alderfer MA, Randall A, Kazak AE, Sood E. Parental post-traumatic stress, overprotective parenting, and emotional and behavioural problems for children with critical congenital heart disease. Cardiology in the Young. 2022 May;32(5):738-45.
- 8. Werninger I, Ehrler M, Wehrle FM, Landolt MA, Polentarutti S, Valsangiacomo Buechel ER, Latal B. Social and behavioral difficulties in 10-year-old children with congenital heart disease: prevalence and risk factors. Frontiers in pediatrics. 2020 Dec 11;8:604918.
- 9. Dahlawi N, Milnes LJ, Swallow V. Behaviour and emotions of children and young people with congenital heart disease: A literature review. Journal of Child Health Care. 2020 Jun;24(2):317-32.
- 10. 10. Sertçelik T, Alkan F, Sapmaz ŞY, Coşkun Ş, Eser E. Life quality of children with congenital heart diseases. Turkish Archives of Pediatrics/Türk Pediatri Arşivi. 2018 Jun;53(2):78.
- 11. 11. Abasse KS, Gartner JB, Labbé L, Landa P, Paquet C, Bergeron F, Lemaire C, Côté A. Benefits and Limitations of Business Process Model Notation in Modeling Patient Healthcare Trajectory: A Scoping Review Protocol.
- 12. 12.Denniss DL, Sholler GF, Costa DS, Winlaw DS, Kasparian NA. Need for routine screening of health-related quality of life in families of young children with complex congenital heart disease. The Journal of pediatrics. 2019 Feb 1;205:21-8.
- 13. Clancy T, Jordan B, de Weerth C, Muscara F. Early emotional, behavioural and social development of infants and young children with congenital heart disease: a systematic review. Journal of Clinical
- 14. Psychology in Medical Settings. 2020 Dec;27(4):686-703.
- 15. Kovacs AH, Brouillette J, Ibeziako P, Jackson JL, Kasparian NA, Kim YY, Livecchi T, Sillman C, Kochilas LK, American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young; and Stroke Council. Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association. Circulation: Cardiovascular Quality and Outcomes. 2022 Jul 14:10-161.
- 16. Khaled EM. Iron Deficiency and Behavioral Disorders in Children with Congenital Heart Disease. Saudi J Med. 2021;6(7):198-205.
- 17. Finkel GG, Sun LS, Jackson WM. Children with Congenital Heart Disease Show Increased Behavioral Problems Compared to Healthy Peers: A Systematic Review and Meta-Analysis. Pediatric Cardiology. 2022 Jun 4:1-8.
- 18. Mohsen AA, Kassem MG, Antonios MA. Psychosocial assessment and quality of life assessment in children with congenital heart in a developing country. Egyptian Pediatric Association Gazette. 2021 Dec;69(1):1-7.
- 19. Larsen SH, McCrindle BW, Jacobsen EB, Johnsen SP, Emmertsen K, Hjortdal VE. Functional health status in children following surgery for congenital heart disease: a population-based cohort study. Cardiology in the Young. 2010 Dec;20(6):631-40.
- McCusker CG, Doherty NN, Molloy B, Casey F, Rooney N, Mulholland C, Sands A, Craig B, Stewart M. Determinants
 of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. Archives of
 disease in childhood. 2007 Feb 1;92(2):137-41.