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RESEARCH ARTICLE

Barriers to paediatric cardiac rehabilitation among congenital heart diseases in twin cities of Pakistan - A cross-sectional survey

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ABSTRACT

Background: Congenital Heart Disease (CHD) presents significant physical and psychological challenges for affected individuals and their families.

Objective: The purpose of this study was to identify the barriers to paediatric cardiac rehabilitation.

Methods: Descriptive cross-sectional study was conducted on 200 parents of patients with congenital disease in 1 year from 2022 to 2023. The study included biological parents of patients aged from birth to 12 years who had a medical history of congenital heart diseases such as cardiac myopathies, septal defects, and valvular defects. Patients with other congenital disorders were not part of the study. After taking ethical approval with ethical approval number: Riphah/RCRS/REC/01447, data was collected through cardiac rehabilitation barrier scale and analyzed by SPSS 21.

Results: The age distribution revealed that 94 (47%) participants from birth to 4 years, 68 (34%) were with 5-8 years, and 38 (19%) were with 9-12 years. 124 (62%) were male, while 76 (38%) were female, 112 (56%) had history of surgery while 88 (44%) had not. 52(26%) were strongly agree with the barriers of Ability to travel 81(40.5%). Work responsibilities 75(37.5%), Poor transportation 85(42.5%), long Distance 85(42.5%), Cost of the rehabilitation programs 68(34%).

Conclusion: The study concluded that the major barriers to paediatric cardiac rehabilitation were work responsibilities in addition to overall cost of treatment and travel.

Keywords: Barriers, Cardiac Rehabilitation, Congenital Heart Diseases, Paediatrics.

DOI: https://doi.org/10.33897/fujrs.v4i2.379

Introduction:

Cardiac rehabilitation is a vital component of comprehensive care for individuals with cardiac conditions, aiming to improve their physical fitness, reduce cardiovascular risk factors, enhance overall well-being, and promote a successful transition to a healthy lifestyle.(1) While cardiac rehabilitation programs have shown significant benefits in adults, the importance of paediatric cardiac rehabilitation is increasingly recognized. Paediatric patients with cardiac conditions face unique challenges that impact their physical and psychological well-being, highlighting the need for specialized rehabilitation services tailored to their specific needs.(2)

Paediatric cardiac rehabilitation encompasses a range of interventions, including exercise training, education, counselling, and psychosocial support, designed to optimize the recovery and long-term outcomes of children with congenital or acquired heart diseases.(3) By addressing the physical limitations, psychosocial concerns, and barriers to physical activity faced by these children, cardiac rehabilitation programs aim to enhance their quality of life, functional capacity, and overall cardiac health.(4)

Michael G et al. in 2020 conducted a study on Cardiac Rehabilitation in patients born with Progressive Heart Disease that showed that periphery variables had a bigger impact on children who had centralized cardiovascular problems during rehab frequently. There are peripheral musculoskeletal and central cardiovascular restrictions on aerobic activity in those with CHD. Most critically, there are almost never suitable control groups and almost always varied subject populations.(5)

In this study, biological parents of the pediatric patients were involved in order to find out what are

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Received: November 24th, 2023; **Revision:** June 11th, 2024.
Acceptance: July 5th, 2024

How to Cite: Razzaq M, Rafaqat K, Umar S, Bibi H, Javaid R, Khaliq E. Barriers to paediatric cardiac rehabilitation among congenital heart diseases in twin cities of Pakistan - A cross-sectional survey. Foundation University Journal of Rehabilitation Sciences. 2024 July;4(2):100-104.

the barriers they are facing in order to attend the cardiac rehabilitation programs. In this study, the barriers will be enlisted, and measuresare mentioned that can be taken by hospitals in order to overcome those barriers and increase awareness of the pediatric cardiac rehabilitation programs. The objective of this analysis was to determine barriers to pediatric cardiac rehabilitation.(6)

Many studies have been conducted on how important cardiac rehabilitation is for the pediatric population but there are not enough to rule out the hurdles that come in the way. In this study, biological parents of the pediatric patients were involved in order to find out what barriers they are facing in order to attend the cardiac rehabilitation programs. In this study the barriers will be enlisted, later on measures can be taken by the hospitals in order to overcome those barriers and increase awareness of the pediatric cardiac rehabilitation programs.

Methods:

The study followed a descriptive cross-sectional design. The overall number of samples was 200. Non-probability convenient sampling was used. This method involves selecting participants based on their easy availability and accessibility rather than through random selection. The study was conducted at the Armed Forces Institute of Cardiology. The inclusion criteria included all patients from infancy to 12 years of age, of both genders, and with biological parents. Patients with other congenital diseases such as Cerebral Palsy and cancer were excluded from the study.

The researchers used a standardized questionnaire called the Cardiac Rehabilitation Barrier Scale (CRBS) to collect data. The participation in cardiac rehabilitation was used to evaluate the criterion validity of the CRBS scale, with a statistically significant result (p=.001). The test-retest reliability of the CRBS was satisfactory, with an interclass correlation coefficient of 0.64. This indicates a moderate level of consistency in responses over time.

Permission was taken from Riphah Research Ethical Committee. The ethical approval number is Riphah/RCRS/REC/01447. Secondly, approval was obtained from the Armed Forces Institute of Cardiology for data collection process. Before enrolling, participants were informed about study's goal and nature, and their informed consent was acquired. The biological parents of cardiac pediatric patients undergoing rehabilitation (from birth to 12 years) provided data for this study. Participants in this study were guaranteed confidentiality. The consent form would outline the study procedures, detailing the process of completing the questionnaire regarding barriers to pediatric cardiac rehabilitation. It highlights that participation is voluntary, with the option to withdraw at any time without repercussions. Parents are assured of the strict confidentiality and anonymity of their personal information and responses throughout the study.

Data analysis was performed using SPSS version 21. The data were tabulated using percentage distribution and described descriptively using frequency, percentage, and mode. Overall, the study aimed to describe the barriers to cardiac rehabilitation in pediatric patients using a specific scale, while also assessing the validity and reliability of the scale itself. The findings were analyzed using statistical software to draw conclusions about the barriers faced by this population.

Results:

The mean + SD of age was 0.72 + 0.765. Frequency and percentage of age was shown n=94 participants (47%) were 0-4 years old n=68 (34%) was 5-8 years n=38 (19%) was 9-12 year.

Frequency and percentage of gender was shown, n=124(62%) were male, n=76 (38%) were females. The sample was highly masculine. Frequency and percentage of participants based on surgery was shown n=112(56%) participants had surgery, while n=88 (44%) had not. The data did not specify surgery kind or cause.

Frequency and percentage of participants as shown in Table 1 based on disease showed ventricular septal defect n=74(37%) cases was the most prevalent disease reported followed by tetralogy of fallot at n=36 (18%) cases, patent ductus arteriosus n=18 (9%), dilated cardiomyopathy n=15(7.5%), pulmonary atresia n=15(7.5%), atrial septal defect n=17 (8.5%), atrioventricular septal defect n=15 (7.5%), and pulmonary stenosis n=10 (5%) account for other percentages. The mode value of 0 means (strongly agree), mode value of 1 means (agree), mode value of 2 means (Neutral), mode value of 3 means (disagree), mode value of 4 means (strongly disagree).

Discussion:

In this study, the issue of the ability to travel to rehabilitation center was considered the potential barrier to pediatric cardiac rehabilitation in the twin cities of Pakistan. The study by Guimaraes et al. in 2019 highlighted that due to the few transportation alternatives and lengthy travel times between residences and the rehabilitation facility, many families have difficulty getting access to pediatric cardiac rehabilitation. This obstacle can further be explained by the limited accessibility of public transit in some

Table 1: presents the frequency, percentage, and modes of the most familiar barriers to paediatric cardiac rehabilitation.

List of Barriers	Mode	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Ability to travel to rehabilitation center	4	81 (40.5%)	69 (34.5%)	22 (11%)	19 (9.5%)	9 (4.5%)
Work responsibilities of adult caregivers	4	75 (37.5%)	71 (35.5%)	2 (11%)	19 (9.5%)	13 (6.5%)
Problem with transportation	4	85 (42.5%)	54 (27%)	22 (11%)	33 (16.5%)	6 (3%)
Distance to rehabilitation center	4	85 (42.5%)	50 (25%)	51 (25.5%)	8 (4%)	6 (3%)
Cost of the rehabilitation program	4	68 (34%)	46 (23%)	23 (11.5%)	38 (9%)	25 (12.5%)
Patient's cardiologist cleared them for more activity	4	55 (27.5%)	25 (12.5%)	36 (18%)	33 (16.5%)	51 (25.5%)
Family responsibilities	3	62 (31%)	74 (37%)	25 (12.5%)	25 (12.5%)	14 (7%)
Weather	3	24 (12%)	59 (29.5%)	51 (25.5%)	31 (15.5%)	35 (17.5%)
Rehabilitation was too much of a time commitment	3	41 (20.5%)	62 (31%)	25 (12.5%)	22 (11%)	50 (25%)
Time constraints of the family	3	44 (22%)	85 (42.5%)	35 (17.5%)	22 (11%)	14 (7%)
Insurance coverage was not sufficient	3	36 (18%)	80 (40%)	18 (9%)	34 (17%)	32 (6%)
Time from referral to start of rehabilitation	2	30 (15%)	35 (17.5%)	55 (27.5%)	35 (17.5%)	45 (22.5%)
Rehabilitation was not an enjoyable experience	2	46 (23%)	19 (9.5%)	72 (36%)	41 (20.5%)	22 (11%)
Recommended duration and timing of rehabilitation was unclear	2	21 (10.5%)	24 (12%)	64 (32%)	39 (19.5%)	52 (26%)
Patient was too sick to attend rehabilitation	0	15 (7.5%)	27 (13.5%)	22 (11%)	45 (22.5%)	91 (45.5%)
Rehabilitation was not felt to be necessary	0	1 (0.5%)	6 (3%)	35 (17.5%)	54 (27%)	104 (52%)
Rehabilitation was not felt to be effective	0	25 (12.5%)	58 (29%)	43 (21.5%)	12 (6%)	62 (31%)
Exercises were not enjoyable	0	20 (10%)	36 (18%)	27 (13.5%)	53 (26.5%)	64 (32%)
Family would prefer to take care of healthcare problems at home	0	3 (1.5%)	27 (13.5%)	30 (15%)	35 (17.5%)	110 (55%)
Patient felt better and no longer needed rehabilitation	0	13 (7%)	2 (1%)	1 (0.5%)	46 (32%)	13 (66.5%)
Belief that patient does not need cardiac rehabilitation	0	10 (5%)	27 (13.5%)	2 (1%)	49 (24.5%)	112 (56%)
Belief that others do not do cardiac Rehabilitation and are fine	0	18 (9%)	7 (3.5%)	12 (6%)	73 (36.5%)	108 (54%)
Belief that patient is too young for cardiac rehabilitation	0	47 (23.5%)	19 (9.5%)	8 (4%)	49 (24.5%)	77 (38.5%)

places, especially rural ones, and the ensuing costs of private travel.(7)

The second potential barrier to pediatric cardiac rehabilitation in the twin cities of Pakistan was the excessive work responsibilities of adult caregivers. The study by Nasuni et al. (2019) demonstrated that adult care takers may find it difficult to accompany their children to therapy sessions due to their obligations, including strict employment. This busy schedule of employment can result in poor health conditions for suffering children.(8)

The barrier of family time constraints was also experienced by the participant of our study as a potential resistance in pediatric cardiac rehabilitation in the twin cities of Pakistan. The study by Hardy et al. in 2018 highlights that due to a variety of obligations, like job, school, or other appointments, families frequently struggle with time limitations. It may be difficult to allot enough time for pediatric cardiac rehabilitation programs.(9)

In this study, Naomi Gauthier's research from 2020 indicated that patients with congenital heart disease who are eight years and older have better prognoses. Cardiovascular effects from children's programs for cardiac rehab have proven to be reliable, efficient, and secure. However, only a very small percentage (19%) of kids with congenital cardiac disease is prescribed exercise.(10) Children with congenital heart disease typically engage in less daily exercise and are more likely to be obese than their healthy colleagues. Compared to other children, children who suffer from chronic illnesses are more prone to be inactive, and their risk of morbidity from extra health issues triggered by their inactivity is higher.(11)

In this study, children who underwent surgical procedures were 112 in contrast to a study by Jingpo Qu MD in 2020, 311 kids between the ages of 6 and 18 were enrolled in the study. There were 122 kids (102 boys and 80 girls) with congenital cardiac abnormalities who had previously undergone surgical treatments to correct them.(12)

In this study, 36 children were treated for tetralogy of Fallot, and Shivani M. Bhatt discovered 148 cases in total (mean age, 12.3 +/- 3.1 years) in 2020. TOF repair and TOF with pulmonary stenosis were performed on the vast majority of patients (80%).In this study, there were 74 patients with VSD disease, compared to a study conducted by Yen-Yu Chen in January 2023, where there were 182 individuals total, 18 of whom had VSD.(13)

The majority of those who took part in the above research were men, in contrast to a study by Mahdieh Ghanbari Firozabad from 2023 that revealed that female patients had more difficulty participating in cardiac rehab than male patients. Women are substantially less likely to be referred and registered, despite likely having greater needs for a number of clinical and behavioral factors.(14) The largest barriers for female patients were practical concerns (cost, difficulties getting there, and transportation) and comorbidities/ functional status (such as finding exercise to be hard or painful, having little energy, having health conditions, and being older). In countries with the lowest levels of gender equality, the likelihood that a woman will be referred to and take part in CR is lower.(15)

This study faced significant challenges in terms of data collection and achieving the intended sample size. These obstacles may have included limited participant availability, non-responses and logistical issues. This limitation highlights the need for improved strategies in future research to ensure more effective data collection and complete sampling.

In order to overcome barriers to paediatric cardiac rehabilitation, future recommendations include some recommendations. Paediatric cardiac rehabilitation should be necessary to improve the health of children with congenital and acquired cardiac issues. It is recommended to address the barriers involved in paediatric cardiac rehabilitation. It is recommended that paediatric cardiac rehabilitation must start in different areas of Pakistan in order to avail paediatric cardiac rehabilitation. It is suggested that healthcare provider should educate and encourage the children and their families to follow exercise and physical activities that are involved in paediatric cardiac disease.

Conclusion:

The study found that the main barriers preventing 67% of parents identified the distance to cardiac rehabilitation centers as a barrier, while 73% cited work responsibilities and 68% mentioned family obligations. Additionally, 57% reported financial costs as a significant obstacle, exacerbated by 58% indicating insufficient insurance coverage. Despite recognizing the benefits of these programs, these obstacles made it challenging for parents to consistently bring their children to rehabilitation sessions.

Acknowledgement: I would like to acknowledge my indebtedness and render my warmest thanks to Dr. Brig Khurram Akhtar, Armed Forces of Cardiology (AFIC).

Disclaimer: This article was part of thesis of Doctor of Physical Therapy degree submitted in Riphah International University. The article has been presented

as a poster in 4th International Conference on Rehabilitation Sciences (ICRS) and the 1st International Conference on Allied Health Sciences (ICAHS) conducted by Riphah International University held in Lahore from 6th-8th October, 2023. This article is the only online version available for the readers.

Conflict of interest: None to declare

Source of funding: None to declare

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Authors Contribution

Razzaq M: Conception of idea, article writing and critical evaluation.
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