Nigerian Medical Journal
NIGERIA MEDICAL ASSOCIATION
Print ISSN 0300-1652, E-ISSN 2229-774X

Original Research

Factors Leading to Delay in Surgical Treatment of Paediatric Congenital Heart Diseases in Rural Western India – A Hospital-Based Study.

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Abstract

Background: Congenital heart diseases (CHD) account for 28% of birth defects in India. Treatment options and long-term outcomes have significantly improved over the past six decades. However, there is a notable delay in diagnosing CHD and initiating treatment for diagnosed patients. This study seeks to identify factors influencing the treatment timing of CHDs in paediatric patients residing in rural areas of India.

Methodology: Cross-sectional survey. The study uses descriptive statistics and chi-square tests for comparing categorical data between groups to identify factors contributing to delays.

Results: A total of 115 patients were enrolled. Ventricular septal defect was the most prevalent diagnosis (40 patients), followed by Tetralogy of Fallot (23 patients). 47 % of patients experienced delayed diagnosis, while 69% experienced delayed treatment. Notably, the severity of delayed treatment was more pronounced in acyanotic heart diseases compared to cyanotic heart diseases. Financial constraints were cited as the primary reason for delayed treatment in 27.8% of cases, while social factors were the most common reason for delayed treatment despite diagnosis in the remaining 72.2%.

Conclusion: Despite substantial government financial support for treatment and diagnosis, further delays in treatment remain significant. Social factors, other than economic factors, appear to be the primary contributors to these delays. Sample size and in-hospital study limitations are acknowledged.

Keywords: Delay; Surgical Treatment; Paediatric; Congenital Heart Disease; India.

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How to cite: Shah A, Bhalodiya P, Patel P, Trivedi B, Tandon K, Bhende V.Factors Leading to Delay in Surgical Treatment of Paediatric Congenital Heart Diseases in Rural Western India – A Hospital-Based Study. Niger Med J 2025; 66 (4):1623-1630.https://doi.org/10.71480/nmj.v66i4.1014.

Quick Response Code:

Introduction:

Congenital heart disease (CHD) accounts for 28% of birth defects in India, with an estimated prevalence of 8–12 per 1000 live births at birth [1,2]. Despite advancements in pediatric cardiology, survival rates and quality of life, delayed treatment significantly impacts morbidity and mortality among affected individuals [3]. Therefore, understanding the factors contributing to delayed treatment of CHD is paramount [4]. Delay in diagnosis was defined based on the guidelines that emerged following expert deliberations at the National Consensus Meeting on Management of Congenital Heart Diseases in India. These guidelines have been individualised to each congenital heart disease and have been modified taking into consideration factors affecting Indian pediatric population such as malnutrition and anemia. There is a substantial delay between diagnosis and treatment for CHD in India. Studies from India and other low and middle-income countries have demonstrated the severity of this delay, with a significant portion of patients presenting with cyanotic or acyanotic CHD [5]. A study conducted in Indonesia revealed that the delay in diagnosis of CHD was observed in 6 out of 10 children with CHD [6]. Timely intervention is crucial for CHD patients, as untreated CHD drastically reduces life expectancy [7].

Objective: This study aims to address this gap by investigating the factors that influence the delay in treatment of CHD in Indian children.

Methodology:

Study Design: Cross-sectional study. The study was conducted at the Department of Paediatrics at Shree Krishna Hospital and B and M Patel Cardiac Centre, affiliated with Bhaikaka University in Karamsad, India. The study period spanned from December 2022 to February 2024. A consecutive sampling method was employed. All patients fulfilling the inclusion criteria and presenting at the hospital during the study period were approached for participation. Eligibility Criteria: All patients younger than 17 years of age at the time of consultation were included. The study included both first-time diagnoses of congenital heart disease (CHD) at the centre and known cases of uncorrected CHD. Previously operated cases of congenital heart diseases, children who underwent staged surgery for single ventricle palliation and parents of children who declined consent to participate in the study were excluded. Ethical Approval: Ethical approval was obtained from the Institute Ethics Committee. Data Collection: Data were collected through interviews with parents or relatives of children who were admitted or visiting the outpatient department using a structured questionnaire. Personal identifiers were removed, and the analysis was conducted using SPSS version 23.

Results:

Data were analysed using descriptive statistics (mean, standard deviation, median, and proportions) to summarize baseline characteristics. Group comparisons for categorical variables were performed using the Chi-square test. A p-value <0.05 was considered statistically significant. A total of 115 participants were enrolled in the study. The mean age of the study participants was 50 months (standard deviation +/- 49.6). The study population predominantly comprised of patients under five years of age (71.3%). Further demographic details are provided in Table 1.

Table 1 - Demographic profile of study population

Group	Numbers	Birth Weight (kg) (Mean, SD)	Current Weight (kg) (Mean, SD)	Height(cm) (Mean, SD)
Total	115	2.6, 0.4	11.21, 7.8	87.4, 13.6
Age - < 1 year	37	1.5, 0.49	2.9, 1.15	55, 8.9
1 < Age < 3	16	2.56, 0.259	7.763, 2.74	72, 10.4
3 < Age < 5	29	2.69, 0.459	10.438, 1.69	94.6, 7.28

5 < Age	33	2.69, 0.418	20.63, 8.37	123, 16.69

Based on these demographic profiles, the mean age of suspicion of congenital heart disease, confirmed diagnosis and treatment done was further identified. It is represented in table 2 below.

Table 2: Mean age (in months) of suspicion, diagnosis and treatment of congenital heart disease

Age of Suspicion of congenital heart disease	Mean - 19.7 (SD 31.5), Median – 6
Age of Confirmed diagnosis	Mean - 24.8 (SD 28.3), Median – 7
Age of treatment (surgery / catheterization)	Mean - 58.4 (SD 52.5), Median – 43

Out of the 115 children enrolled, 98 were suspected of having heart disease by their physician during their visit for an illness and were subsequently referred for further evaluation at the cardiac centre. Table 3 represents the individuals who suspected the paediatric patients in this study of having CHD in the study population.

Table 3: Person Suspecting Study Population having congenital heart disease in study.

Serial	**Person suspecting**	**Number**
1.	Doctors	98
2.	Community Health Care Worker	13
3.	Parents	4

The most common symptoms which lead to the suspicion of congenital heart diseases, as reported by the doctors were recurrent cough and cold, failure to gain weight, diaphoresis during feeding and breathlessness at the time of playing.

Of the study population, 40 patients (35%) had ventricular septal defect, representing the largest group. Tetralogy of Fallot accounted for 20% of the population. Table 4 represents a detailed list of diagnoses and their respective frequencies.

Table 4: Common diagnosis of the study population.

Sr.No	**Disease**	**N (%)**		**Sr.No**	**Disease**	**N (%)**
1.	Ventricular Septal Defect	40 (35)		5.	Pulmonary Stenosis	6 (5)
2.	Tetralogy of Fallot	23 (20)		6.	Atrio-ventricular canal defect	5 (4)
3.	Patent Ductus Arteriosus	19 (17)		7.	Aortic Stenosis	4 (3)
4.	Atrial Septal Defect	16 (14)		8.	Others	2 (2)

The mean age at suspicion of a patient having heart disease was 19.7 months with a standard deviation of +/- 31.5 months. The mean age of a confirmed diagnosis was 24.8 months with a standard deviation of +/- 28.3 months. The mean age of treatment was 58.4 months with a standard deviation of +/- 52.5 months.

37 patients received a diagnosis prior to their first birthday and were advised either surgical or catheter-based treatment before the completion of one year of age. Out of these 37 patients, 17 underwent treatment before the age of one. Table 5 shows further details regarding the distribution of patients who received treatment.

Table 5: Distribution of patients who were treated.

	AGE AT THE TIME OF TREATMENT		
AGE OF DIAGNOSIS	< 1 Years	1 – 5 Years	> 5 Years
< 1 Year	17	10	10
1 – 5 Years	0	11	2
> 5 Years	0	0	12

The guidelines presented by Saxena et al were utilized to assess the delay in diagnosis and treatment among the patients. [i]

The findings revealed that 54 (47%) patients experienced a delay in diagnosis. Out of 115 patients who were advised for surgical or cath-lab-based intervention in the past, 46 % (53) patients did not undergo the treatment. Among those who got treated, 52% of the patients with acyanotic I were treated without delay while 88% with cyanotic I were treated without delay. Overall, 38% of the patients who got treated had delayed treatment. Table 6 presents the disparity in the time to diagnosis and treatment among individuals with acyanotic and cyanotic heart disease.

Table 6: Comparison of numbers of participants between acyanotic and Cyanotic congenital heart disease in delay in diagnosis, delay in treatment and not getting treated

GROUPS	**Delayed Diagnosis**	**Timely Diagnosis**		**Not Treated**		**Timely Treatment**	**Delayed Treatment**
ACYANOTIC	23	55		34 (43%)		23	21
CYANOTIC	31	6		19 (51%)		16	2
	Chi Square – 29.7 (P <0.01)					Chi Square – 7.34 P <0.01)	

The most prevalent reason for the delay in diagnosis was financial constraints. The second significant reason was social apprehension regarding the necessity of undergoing heart surgery. Table 7 presents the diverse reasons cited by participants as contributing to the delay in treatment.

Table 7: Factors responsible for delay in treatment

FACTORS RESPONSIBLE	%	FACTORS RESPONSIBLE	%
Lack of financial means for treatment	27.8 %	Parents were not aware of the defect	8.7 %
Lack of awareness about the degree of disease	16.5 %	Parents felt that the child was too small in age /weight	5.2 %
Social or community hesitancy	18.3 %	Fear of adverse outcome of treatment	5.2 %
Alternative therapy: Ayurvedic/Homeopathy	10.4 %	Other	7.8 %

Discussion:

Our study population had a 32.2 % prevalence of congenital heart disease among patients under one year of age. Approximately 39.1 % of the patients were within the age range of one to five years. A demographic study conducted in a central state of India revealed a similar pattern, with 56.28% of the study population affected by congenital heart disease being less than one year of age.[2]

Another epidemiological study conducted on a broader population for I demonstrated that 33% of the study population was under one year of age.[3] As evidenced in Table 1, the mean current weight of patients under one year of age is only 2.9 +/- 1.15 kg whereas, for patients between one and three years of age, it is 7.763 +/- 2.74 kg. These figures are significantly lower than those of the typical paediatric population. Balu et al. also reported a prevalence of 59% in their study population, which predominantly consisted of infants.[4] Malnutrition makes patients vulnerable to respiratory infections and can even affect their post-treatment outcomes.[5]

The average age of suspicion for congenital heart disease (CHD) in patients is 19.7+/- 31.5 months. months, while the average age of confirmed diagnosis is 24.8+/- 28.3 months. There is a substantial delay in the initial suspicion and confirmation of the diagnosis when compared to the established guidelines. [8] The delay in receiving treatment for congenital heart diseases in lower- and middle-income countries is well documented. For instance, Young et al. reported that less than 1.5% of patients receive appropriate treatment within the ideal time frame. [6]

The most prevalent congenital heart disease observed in the study population was ventricular septal defect, accounting for 35% of the cases. Tetralogy of Fallot was the second most common condition, affecting 20% of the study population. Similar findings were reported in a study conducted by Bharti et al. [7]

The delay in diagnosis was observed in 23 out of 78 patients in the acyanotic heart disease group, while it was seen in 31 patients out of 39 in the cyanotic heart disease group. These findings are consistent with the study conducted by Rashid et al and Jain et al [8,9]. It is surprising to note that despite having visible bluish discoloration of nails, cyanotic CHDs in our study were diagnosed late. One of the possible explanations can be provided by the presence of malnutrition and associated anaemia. In the presence of moderate to severe anaemia, cyanosis is not visible. The blood indices of the study participants were not collected; thus, the extent of anaemia is not known.

The analysis revealed substantial delays in the commencement of corrective treatment for congenital heart disease, encompassing both non-surgical and surgical interventions. Just like the findings which were reported in a study conducted in Indonesia, which demonstrated that the delay in treating cyanotic

heart diseases was less pronounced compared to that of acyanotic heart diseases, our study also showed a significant delay in treatment for acyanotic CHDs [9].

A substantial body of literature exists elucidating the factors contributing to the delayed diagnosis of congenital heart diseases. [2-4] However, the available data about the reasons for delayed treatment after getting diagnosed in India is limited. The analysis of the current study revealed that while financial constraints were the most frequently cited factor by parents as a cause of delayed treatment (mentioned by 27.8%), they were not the sole factor. The remaining factors were primarily associated with stigma, apprehension regarding surgical intervention, and misconceptions about the long-term prognosis of patients with congenital heart disease. Similar findings were obtained in a study conducted in Guyana in 2021, which demonstrated that despite financial support for treatment, parents were reluctant to undergo surgical intervention. The cited reasons for their hesitation included fear of adverse outcomes and distrust in the healthcare system's ability to provide effective treatment. [2] The Government of India initiated the Rashtriya Bal Swasthya Karyakram (National Child Health Scheme) in 2012 with the objective of early screening to identify paediatric populations at risk of diseases and refer them to appropriate treatment centres. Notably, since 2018, each state in India has been mandated to implement a government-supported health insurance scheme that provides coverage for the treatment of patients with congenital heart disease. However, despite these initiatives, there are a limited number of dedicated paediatric cardiac care centres in India, and their distribution is uneven. Access to quality care remains a significant challenge.

Conclusion:

The study uncovered that social factors, excluding financial constraints, are the primary obstacles to timely treatment even after a diagnosis. It is crucial to highlight the favourable outcomes of surgical treatment for congenital heart disease (I) and the long-term survival prospects to dispel community apprehension. A crucial intervention to address this delay is to raise awareness about the condition. Educating primary care providers on how to bridge these knowledge gaps can help prevent the increasing mortality rate associated with congenital heart diseases. However, the study's limited sample size poses a limitation. The nutritional status of the study participants was not analysed, which could give additional information. Furthermore, the study's confined setting may not adequately represent the broader population that encounters barriers to accessing healthcare facilities due to various reasons.

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