



UTILIZATION AND AVAILABILITY OF CARDIAC SURGERY FOR CHILDREN SUFFERING FROM CONGENITAL HEART DISEASES AT A TERTIARY CARE HOSPITAL IN NORTH INDIA.

Paediatrics

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ABSTRACT

Congenital heart disease is the most common congenital anomaly seen in children. Many cases require early surgical intervention. We studied children suffering from congenital heart disease who were advised surgery in pediatric OPD to see how many of them actually underwent surgery during follow up and reasons behind not being able to undergo one. Only 10.6% of our study population actually underwent surgery after being advised. The major reasons behind not undergoing surgery in the remaining children were unaffordability (37.3%), pediatric cardiac surgery not being available locally (37.3%) and long waiting lists at the pediatric cardiac surgery centres (20.3%). Hence, the utilization and availability of pediatric cardiac surgery for children with CHD is very poor in this region of the country.

KEYWORDS

Cardiac surgery, congenital heart disease, children.

INTRODUCTION

Worldwide various studies have reported that the incidence of congenital heart disease (CHD) in children is 8-10/1000 live births, and 35-50% of these are critical CHD who require intervention in infancy (1, 2). The estimated annual incidence of CHD in children in India is 180000 to 200000 and many of them require surgical intervention for optimal management (3, 4). But when we come to the availability and utilization of cardiac surgery by children with CHD, the picture in our country is not so bright. There are a very limited number of specialized pediatric cardiac centres and dedicated pediatric cardiologists/pediatric cardiac surgeons in the country, who are overloaded with sheer numbers of patients leading to long waiting lists (5). Moreover, most of the patients are unable to afford the high cost of pediatric cardiac surgical procedures without any external help (5, 6, 7). All this leads to a grossly unsatisfactory management of CHD in children. Hence, we conducted this study to find out the proportion of children suffering from CHD who actually underwent surgery after being advised, and the underlying reasons for not being able to do so.

MATERIALS AND METHODS

This is a prospective observational study conducted at the pediatrics OPD of Era's Lucknow Medical College, Lucknow. It was approved by the institute ethics committee. All the children presenting to pediatric OPD between 01 September 2017 and 31 August 2018 suffering with CHD who were advised surgical intervention, were included in the study after obtaining informed consent from the parent/primary caregiver. The epidemiologic profile and clinical findings were entered in a standard proforma. These children were kept under regular follow up. The parents/primary caregiver of the children who did not undergo surgery despite being advised were asked the reason during follow up visits. Analysis of data was performed using SPSS version 23.

RESULTS

During the study period, total 153 children suffering from congenital heart disease presented to pediatric OPD, whose clinico-epidemiologic profile has been described in one of our earlier study (8). Out of them, 66 (43.1%) were advised to undergo surgery. Their characteristics have been described in table 1. Their median age was 12 months (range 2 to 156 months). A huge majority of these children [59 (89.4%)] were males whereas 7 (10.6%) were females. Thirty six (54.5%) of the children who were advised surgery suffered from cyanotic CHD, out of which, the most common diagnosis was tetralogy of Fallot [18 (27.3%), followed by transposition of great arteries [9 (13.6%)] and double outlet right ventricle [3 (4.6%)]. Out of the remaining 30 (45.5%) children who had acyanotic CHD, the most common was patent ductus arteriosus [14 (21.2%)] followed by ventricular septal defect [9 (13.6%)] and atrial septal defect [4 (6.1%)]. These children were followed up for a median duration of 13 months (range 9-20 months).

Table 1- Characteristics of children with congenital heart disease who were advised surgery (n=66)

Variable	N (%)
Age (in months)	12 (2-156)*
Sex	
Male	59 (89.4)
Female	7 (10.6)
Diagnosis	
ACHD	30 (45.5)
VSD	9 (13.6)
ASD	4 (6.1)
PDA	14 (21.2)
Others	3 (4.6)
CCHD	36 (54.5)
TOF	18 (27.3)
TGA	9 (13.6)
DORV	3 (4.6)
Others	6 (9.1)
Duration of follow-up (months)	13 (9-20)*
Surgery done	7 (10.6)**

* median (range)

** PDA- 5, ASD- 1, Pulmonary stenosis- 1

ACHD- acyanotic congenital heart disease, ASD, atrial septal defect, CCHD, cyanotic congenital heart disease, DORV- double outlet right ventricle, PDA- patent ductus arteriosus, TGA- transposition of great arteries, TOF- tetralogy of Fallot, VSD- ventricular septal defect.

Table 2- Reasons for surgery not being done despite being advised (n=59) in children with congenital heart disease.

Reason for Not Undergoing Surgery	N (%)
Not affordable	22 (37.3)
Not available	22 (37.3)
Prolonged waiting	12 (20.3)
Others	3 (5.1)

Only 7 (10.6%) children who were advised surgery actually underwent one during the follow up period (table-1). Table 2 depicts the reasons why the remaining 59 (89.4%) children did not undergo surgery. The most common reasons were inability to afford the procedure due to financial constraints [22 (37.3%)] and unavailability of the facility for surgical correction locally and inability to travel to another centre [22 (37.3%)]. Twelve (20.3%) children could not undergo surgery during the follow up period because of a prolonged waiting period. The remaining 3 children could not undergo surgery due to other reasons, 1 was non-compliant with the treatment and 2 did not have sufficient domestic support despite the willingness of the mother.

DISCUSSION-

Our study demonstrated that only 10.6% of the children suffering from CHD, who were advised surgery, actually underwent surgery during

the study duration. This is a very unsatisfactory figure. In an earlier study from Delhi, 61.2% children with CHD underwent surgery within 12 months after being advised, which is quite larger number as compared to our study, probably because the centre at which this study was performed has a pediatric cardiology facility (9).

The 2 most common reasons for not undergoing surgery in our study were non-affordability, and unavailability of pediatric cardiac surgery at local level, responsible in 37.3% cases each. Most of the population that our hospital caters belongs to lower socioeconomic status and they are unable to meet the high cost of cardiac surgical procedures. Moreover, there was no state health insurance program until recently to help these patients (10). The infrastructure and expertise required to manage children with CHD is also grossly inadequate (7). According to the American College of Cardiology, there should be a pediatric cardiac centre for every 50 lac population, as per this estimate, India should have at least 200 pediatric cardiac centres. But according to a 2005 estimate, there were only 14 pediatric cardiac centres in India with approximately 25 dedicated pediatric cardiologists and 10-12 pediatric cardiac surgeons all over the country (3). There is no pediatric cardiology centre in our state, i.e. Uttar Pradesh, which is the most populous state of the country. The nearest pediatric cardiology centre from this hospital is approximately 600 kilometres away. The cost of travel, stay, food etc. also adds to the cost of surgery. Moreover, there is a long waiting list at these centres because of a large backlog. We also found that 20.3% of children in our study could not get operated due to a prolonged waiting period.

Most of the public health programs in developing nations are directed at combating nutritional and infectious diseases because they are responsible for majority of morbidity and mortality in our population. Moreover, management of congenital heart diseases demands a lot of expertise, financial resources and time, which may not be feasible to make it a priority for the government (11). These factors are also responsible for poor availability of treatment of CHD in our country.

Various strategies have been suggested for improvement of care of CHDs in children in developing countries which include increasing awareness, financial help by government/NGOs, increasing pediatric cardiology training programs and sharing infrastructure with adult cardiology centres (3).

CONCLUSION

CHD is the most common congenital anomaly found in children, but its management in our country is far from satisfactory. Only a few children with CHD are able to undergo surgery, mostly because of financial constraints and poor availability of facility for pediatric cardiac surgery centres.

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Conflicts of Interest: None

Abbreviations:

CHD – congenital heart disease

ACHD – Acyanotic congenital heart disease

CCHD – Cyanotic congenital heart disease

DORV-Double outlet right ventricle

VSD-Ventricular septal defect

PDA-Patent ductus arteriosus

TOF-Tetralogy of Falot

TGA-Transposition of great arteries

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