

# Congenital Heart Disease in India: A Status Report

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**Abstract.** Pediatric cardiac care in India is still in its infancy. We have no data on congenital heart disease (CHD) prevalence at birth or on proportional mortality from CHD. The resources are not only limited but also are at times improperly utilized. There are very few specialized pediatric cardiology training programs, those that are, are concentrated in certain regions of India and are often imparted through combined adult and pediatric programs. The existing number of trained personnel for pediatric cardiology and pediatric cardiac surgery is inadequate. Above all there is no national policy for pediatric heart care. Increasing awareness of the problem amongst the pediatricians through CMEs, seminars, symposia is likely to be most helpful in early diagnosis and timely referral of cases. Training programs exclusively dedicated to pediatric cardiology and pediatric cardiac surgery need to be established in centres with good standards of pediatric cardiac care.

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Congenital heart diseases (CHD) refer to structural or functional heart diseases, which are present at birth. Some of these may be discovered later. These are primarily seen in neonates, infants and children, although in our country it is not uncommon to see adults with uncorrected CHD. The burden of congenital heart disease in India is likely to be enormous, due to a very high birth rate. This heavy burden emphasizes the importance of this group of heart diseases. The reported incidence of CHD is 8-10/1000 live births according to various series from different parts of the world.<sup>1</sup> It is believed that this incidence has remained constant worldwide.<sup>2</sup> Nearly one third to half of these CHD are critical, requiring intervention in the first year of life itself.<sup>3</sup> Rapid advances have taken place in the diagnosis and treatment of CHD over the last 6 decades. There are diagnostic tools available today by which an accurate diagnosis of CHD can be made even before birth. With currently available treatment modalities, over 75% of infants born with critical heart disease can survive beyond the first year of life and many can lead near normal lives thereafter. However, this privilege of early diagnosis and timely management is restricted to children in developed countries only. Unfortunately majority of children born in developing countries and afflicted with CHD do not get the necessary care, leading to high morbidity and mortality.

## Prevalence of CHD in India

We have no community-based data for incidence of CHD at birth in India. Since a large number of births in our

country take place at home, mostly unsupervised by a qualified doctor, hospital statistics are unlikely to be truly representative. Various series available for prevalence of CHD in India are summarized in table 1.<sup>4-9</sup> As one can see, the prevalence varies from as low as 2.25 to 5.2/1000 live births. There are a few studies of prevalence of CHD in school children; these are mainly offshoots of prevalence studies for rheumatic fever and rheumatic heart disease. Since a large number of CHD are critical, leading to death in early life itself, these studies on school children have limited value and underestimate the true burden of CHD. Going by the crude birth rate of 27.2/1000 (2001 Census data),<sup>10</sup> the total live births are estimated at nearly 28 million per year. With a believed incidence rate of 8/1000 live births, nearly 180,000 children are born with CHD each year in India. Of these, nearly 60,000 to 90,000 suffer from critical CHD requiring early intervention. Approximately 10% of present infant mortality in India may be accounted for by CHD alone. In this way every year a large no of children are added to the total pool of cases with CHD. We also have a large no of adult patients with CHD, primarily because of lack of health awareness and inadequate health care facilities.

## Profile of CHD in India

The profile of CHD varies depending upon the age group studied (Table 2). Simple and potentially correctable heart defects, like ventricular septal defect, patent ductus arteriosus and atrial septal defect, are common at all ages. However autopsy studies are likely to show a higher incidence of serious and complex CHD. The autopsy series of 270 cases by Kinare *et al*, published in 1981 gives a high prevalence of different variants of hypoplastic left heart syndrome like mitral atresia, aortic atresia and

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TABLE 1. Prevalence of Congenital Heart Disease in India

Author/year	Age group	Hospital/ Community based	Total number	No. of Congenital Heart Disease/1000
Shrestha <i>et al</i> 1980	5-16 years	Community	34,198	3.2
Gupta <i>et al</i> 1992	6-16 years	Community	10,264	0.8
Vashishtha <i>et al</i> 1993	5-15 years	Community	8,449	5.2
Khalil <i>et al</i> 1994	Live births	Hospital	10,964	3.9
Thakur <i>et al</i> 1995	5-16 years	Community	40,950	2.25
Chadha <i>et al</i> 2001	< 15 years	Community	11,833	4.2

TABLE 2. Profile of Congenital Heart Disease in India

Author/year	Age group	No with CHD	Profile (% of all CHD)							
			ASD	VSD	PDA	TOF	TGA	HLH	CoA	PAtr
Shrestha 1980	5-16 years	111	23	30	11	4				
Kinare 1981	< 1 year	270		4	9	12	12	10	8	
Vashishtha 1993	5-15 years	44	11	41	4	14				
Thakur 1995	5-16 years	30	38	32						
AIIMS 1996 (Sharma <i>et al</i> )	≤ 12 years	5000	13	53	13	32	22		8	6
AIIMS 1995	<1month	574	25	35	28	7			7	13

ASD: Atrial septal defect, CHD: Congenital heart disease, CoA: Coarctation of aorta, HLH: Hypoplastic left heart, PAtr: Pulmonary atresia, PDA: Patent ductus arteriosus, TGA: Transposition of great arteries, TOF: Tetralogy of Fallot, VSD: ventricular septal defect.

coarctation of aorta.<sup>11</sup> Similarly hospital series in neonates and infants show higher incidence (50%) of serious CHD like transposition of great arteries, pulmonary atresia *etc.* Ventricular septal defect, patent ductus arteriosus and atrial septal defects are relatively more frequent in older children. CHD in neonates is increasingly recognized in India, perhaps due to increasing awareness in pediatricians who are the primary health care provider. This trend may also be related to widely available echocardiography machines and trained personnel, since echo forms the mainstay of diagnosis of CHD in neonates. In the outpatient department of All India Institute of Medical Sciences, New Delhi, the neonates with CHD form about 10% of all CHD cases seen in 2004, an increase from less than 4% in 1991. The commonest CHD in neonates remains ventricular septal defect. This is closely followed by patent ductus arteriosus. Transposition of great arteries is seen in one fifth of neonates having CHD. Pulmonary atresia and its variants are seen in about 13% of cases<sup>12</sup>.

### Resources and Infrastructure

Managing CHD in India as indeed in any developing country is an important issue, often overlooked, despite the enormity of the problem. The resources and infrastructure are abysmally limited. There are only 14 centres in the country, which have facilities for pediatric cardiac care including infant and neonatal cardiac surgery. Majority of these institutions have busy adult cardiac surgery programs and much of the infrastructure is shared by the adults and pediatric cardiac services. As

per guidelines of American College of Cardiology, it is recommended that for every 5 million people, there should be at least one pediatric cardiac program. Accordingly, the estimated number of cardiac centers required for the entire population of India will be about 200. Of the 14 existing centers for cardiac care of infants and children, only one center is in a government hospital, rest are all in private or semiprivate sector where the cost of treatment may be several times that in a government setup. Another problem is the geographical location of these centres. Most of cardiac care centres are either in southern part of India or in National Capital of Delhi. Unfortunately some of the most populous states like UP, Bihar, MP, Assam, Orissa have least or no resources for treatment of neonates, infants and children with CHD. An encouraging trend is perceptible in the last 7 or 8 years, six of the total 14 pediatric cardiac centers have come up during this period.

The total number of dedicated pediatric cardiologists and cardiac surgeons is also very low (about 25 pediatric cardiologist and 10-12 pediatric cardiac surgeons), actually a small fraction of what is required for optimal care. The total number of cardiac surgeries for CHD at all age groups in all centres combined in India approximates 6500 per year, of these only about one-fourth are in neonates and infants. The analysis of this data highlights that less than 2% of total number of infants and newborns requiring heart surgery actually receive optimal treatment. Since the referral of cases is often late, several of even these fortunate 2% infants have co-morbid conditions like chest infection, severe pulmonary arterial

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hypertension, pulmonary vascular obstructive disease etc., thereby increasing the perioperative mortality and morbidity. The remaining 98% of infants born with CHD probably do not survive. This will include a large number of infants with potentially correctable lesions like ventricular septal defect, patent ductus arteriosus etc.

### Reasons for Poor Cardiac Care

1. Lack of awareness. Only a very small fraction of CHD cases are detected at birth and during infancy. This is probably the most important reason for the dismal state of affairs concerning children with CHD in our country. Firstly, most births occur without supervision of a pediatrician. Secondly, the ability of most pediatricians to detect heart disease is very limited, because of inadequate exposure to pediatric cardiology during their postgraduate training program. This is especially true for newborns where the abnormality on clinical examination may be very subtle. Additionally, there are no compulsory update programs for practicing pediatricians to keep them abreast of the upcoming developments. Several pediatricians still believe that a newborn baby with CHD has a near 100% mortality, even if operated.
2. Due to the limited knowledge of natural history of CHD, there is considerable time lag between diagnosis and referral to a pediatric cardiac center for intervention. In addition, delay may also result from inaccurate diagnosis. Often there is total lack of awareness about what facilities are available with in the country and about recent developments in the specialty. Some of the pediatricians specially in rural and semi urban areas, still believe that a child with ventricular septal defect can only be operated after he or she attains a weight of 10 kg. This delay may result in complications like hypoxic brain damage, Eisenmenger's syndrome etc. These complications not only compromise on the results of intervention, but also result in sub optimal utilization of limited resources available for the pediatric cardiac care in India.
3. There are no pediatric cardiac care programs in several states in India as highlighted earlier. Families have to travel hundreds of kilometers to reach a centre, which is equipped with necessary facilities. Besides expenses involved in traveling and staying in an alien city, there is considerable income loss due to lost work for number of days. This double disincentive often results in further delay to the point of sometimes making it too late for treatment.
4. Pediatric cardiac care is too expensive for the average Indian family despite subsidies from hospital, government and voluntary organizations. An open-heart surgery costs approximately Rs. 50,000-60,000 in a government set up; the cost may be 2-5 times in private and semiprivate hospitals, making it unaffordable for the vast majority of families.

5. Unlike for adult cardiology, there is very little support from the pharmaceutical industry for development of pediatric cardiac care programs in the country.
6. Several private hospitals excelling in adult cardiac care indirectly discourage pediatric surgical programs, as pediatric programs are more demanding and more expensive and are associated with higher morbidity and mortality.
7. The social importance of pediatric cardiology and pediatric cardiac surgery is much less as compared to adult cardiology and coronary artery surgery which gives more limelight to the cardiologist and the surgeon. Given a choice, very few specialists choose pediatric cardiology and pediatric cardiac surgery over adult cardiology and adult cardiac surgery respectively, which are far more lucrative.
8. Heart disease in children is not identified as a health priority by the government in our country. There are no government policies for cardiac care in children. This is perhaps related to the prevailing notion that CHD is uncommon, often fatal and is therefore not worth expanding national resources.
9. Many families in rural and semi urban parts of India seek advice from unqualified, self-proclaimed "doctors" and quacks because of common beliefs and myths. This further adds to the delay in diagnosis and proper management of the child with CHD.

### Suggested Remedial Measures

1. Increasing awareness about CHD in general population through electronic and print media. For this venture, pediatricians, pediatric cardiologists, voluntary organizations, industry and media need to collaborate. Scientific societies like Indian Academy of Pediatrics, Pediatric Cardiac Society of India can take lead role to make it a reality.
2. Increasing awareness amongst pediatricians through seminars, symposia, CMEs etc. Pediatricians should be trained to recognize CHD in newborn period. Since clinical examination is often not informative at this age, routine use of pulse oximetry to detect serious CHD should be used.<sup>13</sup> This is an important agenda for the Pediatric Cardiac Society of India, which is conducting regular CMEs, conferences etc in various parts of India inviting local pediatricians. A more concerted effort is needed.
3. Formalized programs for pediatric cardiology training are the need of the day as individuals specially trained in pediatric cardiology can only provide the desired level of care. Training programs in pediatric cardiology have been an integral part of the care systems in all developed and some developing nations for a long time.
4. Financial assistance for providing care to the affected child. This can be given by: (a) Government agencies through various policies/welfare funds (b) Medical

- insurance of expecting mothers to insure the child (c) Nongovernmental and voluntary organizations
5. Involvement of voluntary organizations and industry to support and develop pediatric cardiac care programs in various existing centers, which have good adult cardiac care facilities. These centers have infrastructure available, which can be utilized. Training in pediatric cardiac care can be initiated by bringing in staff from well-developed centres; either in India or abroad, the local staff can be trained in a gradual manner.
  6. Optimal utilization of technology. Unlike in the West, for India, it may be more economical to share infrastructure with adult cardiology and cardiac surgery, which is much better established in different parts of India. The feasibility and logistics can be sorted out if there is willingness to share. Similarly the ancillary staff and junior fellows can be shared with adult cardiology and surgical units which can help to run both the programs with increased buffer available in case there is shortage of personnel. This scheme sometimes has the disadvantage of preferential adult care over pediatric care.
  7. Creation of a national database for epidemiology, cardiac surgery, cardiac intervention etc. This database will help us to recognize and understand the problems specific to India, differences from western data and help devise solutions. The response from government is likely to be better, if a plan is formulated based on the experience from our own country. It is difficult to make national policies for the future if accurate statistics and demographic data are not available.
  8. Prioritization of care: Since we have limited resources, some people have argued for prioritization of care according to complexity of CHD. For example, parents of a newborn with single ventricle of right ventricular morphology with situs ambiguous may be discouraged to enter the surgical program, which may go on in three stages with impaired quality of life even at the end of complete palliation. This baby, if operated may remain in intensive care unit for several weeks. On the other hand a child with a simple ventricular septal defect, where quality of life is likely to be normal after correction should be given priority. Several others oppose this scheme, as ideally every child should be given equal opportunity to get best treatment available. A consensus needs to evolve on this issue.
  9. A more active role is required from the state and federal governments in formulation of policies for betterment of care for children with CHD. For achieving this the pediatric cardiac care centers should provide data to show that the current mortality and morbidity of cardiac surgery for large

majority of children is very low. This may change the prevailing beliefs and bring in active participation of the policy makers in the government. Establishment of more government sponsored centers, which can provide excellent care at affordable cost should be encouraged.

To conclude, the current status of practice of pediatric cardiology in India leaves lot to be desired. The magnitude of the problem is enormous and resources are very limited. As the preventable causes of mortality in children decline, the importance of CHD is likely to increase. It is time to take stock of the situation and formulate guidelines for improving cardiac care for infants and children. It appears that there is a trend for betterment in the level of cardiac care over the last 6 years or so. More centres catering to needs of neonates and infants with CHD are being established. A few training programs for cardiologists and cardiac surgeons have also started. The awareness amongst pediatricians is increasing. Overall, there is hope!

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