SPECIAL ARTICLE

Congenital Heart Disease in India: A Status Report

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Considering a birth prevalence of congenital heart disease as 9/1000, the estimated number of children born with congenital heart disease in India is more than 200,000 per year. Of these, about one-fifth are likely to have serious defect, requiring an intervention in the first year of life. Currently advanced cardiac care is available to only a minority of such children. A number of cardiac centers have been developed over the last 10 years. However, most are in the private sector, and are not geographically well-distributed. Challenges to pediatric cardiac care include financial constraints, health-seeking behavior of community, and lack of awareness. Government of India is taking a number of steps for improving health of children through its various program and schemes that are likely to benefit children with congenital heart disease, especially those who are vulnerable and marginalized.

Keywords: *Epidemiology, Birth defects, Congenital heart defects, Echocardiography.*

Congenital heart disease (CHD) is the most frequently occurring congenital disorder, responsible for 28% of all congenital birth defects [1]. The birth prevalence of CHD is reported to be 8-12/1000 live births [2,3]. Considering a rate of 9/1000, about 1.35 million babies are born with CHD each year globally [4].

With rapid advances in diagnosis and treatment of CHD, vast majority of children born with CHD in high-income countries reach adulthood. However, this is not the case for children born in low- and middle-income countries (LMIC) as such advanced care is not available for all children. Considering a birth prevalence as 9/1000, the estimated number of children born with CHD every year in India approximates 240,000, posing a tremendous challenge for the families, society and health care system. This article discusses the current state of cardiac care available to children with CHD and how it has changed over last decade [5].

EPIDEMIOLOGY

The birth prevalence of severe CHD has been consistently reported as 1.5 - 1.7/1000 live births [3,6,7]. Use of echocardiography is associated with higher birth prevalence as many milder cases are also detected [6-8]. Similarly, hospital-based data is unlikely to be representative of community prevalence in LMIC where a substantial proportion of births occur at home. Critical CHD, especially those dependent on patency of ductus arteriosus, may go undiagnosed in these settings.

Most studies reported from India are on prevalence at a given point of time, and not on prevalence at birth. Many reported studies are based on data from pediatric patients reporting to hospitals leading to a possible sampling bias [9-14]. The profile of patients with CHD that present to healthcare facilities in LMIC is largely determined by the natural history of individual conditions. A high attrition of patients with serious CHD results in low frequency of these lesions encountered in hospital settings, and may contribute to the prevailing perceptions on their rarity.

The true incidence or birth prevalence has been reported only in few studies from India, which also include only babies born in the hospital (***Table*** I) [15-18]. In two of these studies, echocardiography was performed for all newborns. The birth prevalence of CHD in these studies was higher in comparison to data available from other countries. Several other studies have reported the prevalence of CHD during childhood, and, it varies from 1.3 to 9.2/1000 population (***Table* II**) [19-27]. The wide variation is partly explained by population studied and the diagnostic method used for evaluation.

CURRENT STATUS OF CARE IN INDIA

The issue of pediatric cardiac care in India has been discussed earlier [28,29]. Gross disparity exists between high-income countries and LMIC as far as care of children with CHD is concerned. Whereas one cardiac center caters to a population of 120,000 in North America, 16 million population is served by one center in Asia [30]. Similarly, the number of cardiac surgeons is also much more in North America and Europe (one

TABLE I BIRTH PREVALENCE OF CONGENITAL HEART DISEASE IN INDIA

Author [Ref.]	*No. screened*	*Screening method*	*No. with CHD*	*Prevalence/ 1000 live births*
Khalil, *et al*. [15]	10964	Clinical examination only	43	3.9
Vaidyanathan, *et al*. [16]	5487	Clinical, Pulse oximetry, Echocardiography in all cases	Minor*: 408 at birth 119 at 6 weeksMajor**:17	Minor CHD*:74.4 at birth 21.7 at 6 weeks Major CHD**:3.1
Sawant, *et al*. [17]	2636	Clinical; echocardiography in suspected cases only	35	13.3
Saxena, *et al*. [18]	20307	Clinical, Pulse oximetry, Echocardiography in all cases	Significant[#]: 164 Major[##]: 71 Major[##]: 4.5/1000	Significant[#]: 8.1 (95% CI 6.94; 9.40)

*CHD: congenital heart disease; *Those which are likely to normalize by 6 weeks and include; atrial septal defect >5mm, patent ductus Arteriosus >2 mm with left ventricular volume overload, ventricular septal defect with gradient of >30 mmHg, aortic stenosis/pulmonic stenosis with gradients of <25 mmHg and pulmonary artery branch stenosis with gradients of <20 mmHg; **CHD that is likely to require early intervention; [#]atrial septal defect >5 mm, patent ductus arteriosus >2 mm with left ventricle volume overload, restrictive VSD, and valvular aortic/pulmonary stenosis with gradients <25 mmHg (in addition to Major CHD); [##]any CHD that is likely to require intervention within the first year, including newborns with critical CHD that require intervention within the first 4 weeks of life.*

TABLE II PREVALENCE OF CONGENITAL HEART DISEASE IN CHILDREN BEYOND NEONATAL AGE

Author [Ref]	*Age group (y)*	*Setting*	*Place of study*	*Total No.*	*Screening method*	*No. with CHD*	*Prevalence per 1000*
Gupta, *et al*. 1992 [19]	6-16	Community	Jammu	10263	Clinical	8	0.8
Vashishtha, *et al*. 1993 [20]	5-15	School	Agra	8449	Clinical	44	5.2
Thakur, *et al*. 1995 [21]	5-16	School	Shimla	15080	Clinical	30	2.25
Chadha, *et al*. 2001 [22]	<15	Community	Delhi	11833	Clinical	50	4.2
Misra, *et al*. 2009 [23]	4-18	School	Eastern Uttar Pradesh	118212	Clinical Echo for suspected cases only	42	1.3
Kumari, *et al*. 2013 [24]	5-16	School	Dist. Prakasam, Andhra Pradesh	4213	Clinical and Echo in all	39	9.2
Saxena, *et al*. 2013 [25]	5-15	School	Ballabgarh, Haryana	14716	Clinical Clinical and echo	3577	2.37 5.23
Bhardwaj, *et al*. 2016 [26]	All age groups 19.5 y	Community	Himachal Pradesh	1882 (<18 y: 660)	Clinical Echo for suspected cases only	12	6.312.95 (in <18 y)
Nisale, *et al*. 2016 [27]	1st to 10th class	School	Latur, Maharashtra	3,53,761	Clinical Echo for suspected cases only	143	0.4

cardiac surgeon per 3.5 million population) as compared to Asia (one cardiac surgeon per 25 million population) [3]. Of the 240,000 children born with CHD each year in India, about one fifth would need early intervention to survive the first year of life. A large pool of older infants and children who may have survived despite no intervention add to the burden of CHD.

Status of Care for Serious CHD

A number of cardiac care centers have come up in India over the last decade. The total number approximates to 63; ten of these can be considered high volume centers (more than 500 cardiac surgeries per year). As per data provided by all large and medium volume centers and a majority of small volume centers, a total of approximately 27,000 patients with CHD underwent cardiac surgery over a one-year period (2016-2017). Of this, about 9,700 patients were infants (<1 year), and about 1700 were neonates (<1 month). Considering the birth prevalence of serious CHD (requiring intervention in first year of life) as 1.6/1000 live births, about 43,000 babies are born in India every year with serious CHD, of which only about one-fourth seem to be receiving optimal cardiac care. This proportion, though still very low, is much better when compared with similar projections from India a decade ago [5,31]. These data suggest that pediatric cardiac care is gradually improving in India; although, we still have a long way to go.

Regional Variations

There is marked regional variations in the population and crude birth rates in various parts of India. The total number of births are much higher in Northern and Eastern parts of India (Delhi, Jammu and Kashmir, Punjab, Haryana, Himachal Pradesh, Rajasthan, Uttar Pradesh, Uttarakhand, Bihar, Jharkhand, Orissa and West Bengal) as compared to rest of four regions (Southern, Western, Central and North-East). Consequently, the total number of babies born with CHD are likely to be much more in regions with high birth rates (***Fig.* 1**).

Based on the information provided by 47 centers in India, there is a clear paradox as many centers are located in regions with lower burden of CHD. When considering the critical CHD (requiring intervention in first year of life), the Southern and Western states of India have fared much better than other regions (***Fig.* 2**). On the contrary, states such as Uttar Pradesh, Bihar, Jharkhand and Madhya Pradesh, which presumably have much higher CHD burden as compared to the rest of states, have fared much worse. The data suggest that children born with serious CHD in Southern India have a 70% chance of receiving good cardiac care even if we consider that some of the children operated in these centers are from other parts of India. In contrast, babies born in Eastern and Central parts of India have a much lower chance of receiving an intervention. This status may soon change as the pediatric cardiac care centers start within the campuses of newly opened government institutes (All India Institute of Medical Sciences). These institutes are already operational in various states, including those in eastern, central and northern parts of India. Currently, the number of congenital heart surgeries is less in these institutes, especially for neonates and infants.

OBSTACLES TO PEDIATRIC CARDIAC CARE IN INDIA

Lack of awareness and delay in diagnosis: A substantial proportion of births in India occur at home, and the infant is likely to die before the critical, ductus-dependent CHD is diagnosed. Fortunately, the rate of hospital deliveries have significantly increased due to several incentivized schemes by the Government of India. Ductus-dependent CHD may still escape detection as babies are often discharged earlier. Pre-discharge screening of newborns by pulse oximetry, which may pick up these CHDs, is often not practiced, especially in rural and semi-urban centers. Frontline health workers and primary caregivers are not sensitized to the problem of CHD and a number of them believe that a child with CHD is doomed and will never be able to lead a fruitful life, even if intervened. Delay in referral results in poor outcomes as complications and co-morbidities (such as under-nutrition) may have already set in.

Maldistribution of resources: The resources for treatment of CHD are not only inadequate but also seriously mal-distributed. As mentioned earlier, the geographical distribution of these centers is very uneven. Poverty,

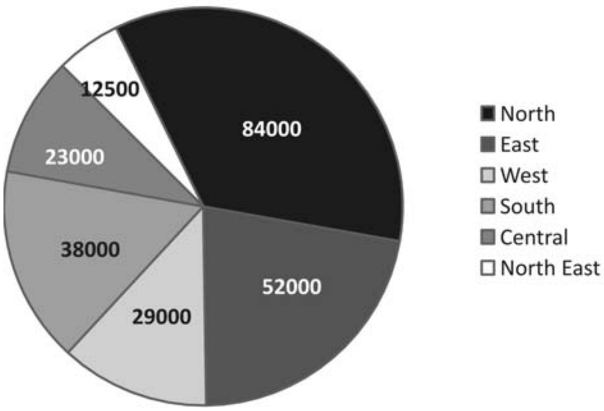

FIG. 1 *Regional distribution of infants born with CHD in India every year. (See color figure at website)*

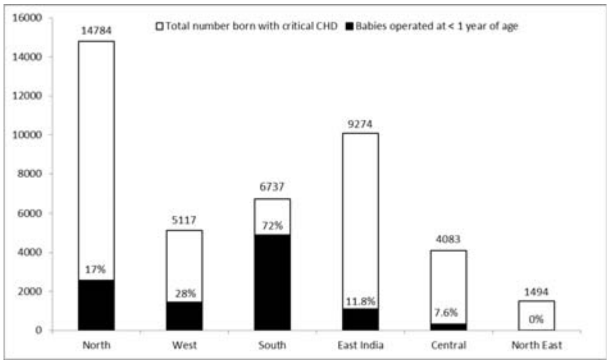

FIG. 2 *Regional distribution of infants with critical heart disease accessing surgery as compared to total number born with critical heart disease.*

which is the greatest barrier to successful treatment of CHD is more common in states with little or no cardiac care facilities. Transport of newborns and infants with CHD is another neglected issue in India. There is practically no organized system for safe transport of newborns and infants with CHD. The risks of developing hypothermia and hypoglycemia during long, unsupervised transport further adds to the already serious condition of the infants with CHD [32]. Limited resources and inefficient governance further compromise a fair distribution.

Financial constraints: Medical insurance is practically nonexistent in India, especially for birth defects. In most instances, families are expected to pay for the treatment out of their pocket, which they can barely afford. In a study from Kerala [33], surgery for CHD resulted in significant financial burden for majority of families. Approximately half of the families borrowed money during the follow-up period after surgery [33]. Many families lose their wages as they are away from work during care of these children. Though several state government level programs, microfinance schemes, charitable and philanthropic organizations exist for the benefit of economically weaker sections of the society, awareness amongst community about such programs is very low. The number of public hospitals which provide care at a low cost are very few. Most cardiac centers, especially those set-up more recently, are in the private sector and may not be affordable for the majority. Public hospitals are faced with a very large number of patients and have waiting lists ranging from months to years. Children undergoing surgery are often in advanced stages of disease with associated malnutrition [34]. The results of intervention in such settings are expected to be less than ideal.

According to data collected from 47 centers in India, about 35% of cardiac surgeries are funded by families themselves. Government schemes, mostly at state level, cover about 40% of all surgeries for CHD patients. Many hospitals partner with charitable non-government organizations and multinational companies to assist economically weaker families. About 20% of cardiac surgeries are funded by such organizations. Other less common (<5%) funding sources include parents' employer and donations. Some of the charitable cardiac centers are providing completely free treatments; however, such centers generally have long waiting lists.

Health seeking behavior of the community: Often the parents seek medical care only when child develops significant symptoms. This may not be only due to financial constraints. Local religious and socio-cultural practices in India affect the level of care received by children with CHD. Illiteracy may be partly contributing to such behavior. Gender bias, as prevalent in some societies, may put girls at a disadvantage compared to boys. In a study from a referral tertiary care center, girls were less likely to undergo cardiac surgery for CHD than boys [35].

Lack of follow-up care: Most children with CHD, including those who have undergone an intervention, require long-term care for a good outcome. Unfortunately, a large number of children in India, especially those from middle or lower socioeconomic strata, are lost to follow-up. The onus of follow-up is totally on the family of the affected child as our health system is not proactive despite having a network of primary health care units.

Other factors: Investment on healthcare is one of the lowest in India when compared with several other countries, including many LMIC. There is no national policy for CHD. Rapid population growth, competing priorities, inefficient and inadequately equipped infrastructure, and a deficit of trained staff at all levels of healthcare are some of the other major roadblocks to cardiac care of children with CHD.

STRATEGIES FOR IMPROVEMENT OF CARDIAC CARE

To make meaningful reductions in mortality and morbidity from CHD, it is imperative to focus on comprehensive newborn and infant cardiac care. However, improvements in maternal and child health services must occur simultaneously. Health is a state subject and the various states of India differ vastly in their economy, literacy levels, population, languages, cultural beliefs and human development indices. This regional diversity makes the task more difficult as 'one size fits all' approach is not tenable [36].

Increasing awareness: Community needs to be sensitized to the problem of congenital defects, through electronic and print media. Targeting pediatricians and educating them not just about diagnosing CHD in a newborn, but also about the advancements that have occurred in the care of children with CHD should also be helpful.

Preventive measures and screening: So far, little emphasis has been placed on preventive measures for CHD. This needs to be stressed as the investment required is much smaller. Mass immunization against Rubella should be the starting point at the national level. Although one can have a specific preventive program for children with CHD, a more comprehensive program which caters to the well-being of children in general, and incorporates a number of other common disorders is more likely to be sustainable. A flagship scheme of

Government of India (Rashtriya Bal Swasthya Karyakram, RBSK) has been launched in February 2013 with a mandate to screen all children, aged 0-18 years for early detection and management of birth defects and other diseases. Under this initiative, comprehensive health care is expected to be provided for all diagnosed cases of birth defects. Periodic education programs to sensitize the practicing physicians and pediatricians are necessary. The frontline health workers as well community in general should be made aware of the availability of advanced care in India for children with CHD. Screening newborns with pulse oximetry to diagnose critical CHD should become a part of newborn care [37].

Geographic distribution of centers of excellence: Establishing more centers for cardiac care would be ideal, but this is a very challenging task. One not only needs sophisticated technology and infrastructure, but also a motivated team of health professionals. Pediatric cardiac care is a team effort involving cardiologists, surgeons, anaesthesiologists and intensive care specialists. There should be at least one center in each state unit, may be more in populous states, so that families do not have to travel long distances to new cities with different local environments and languages. Ideally, these centers should be supported by the government, either directly or through welfare schemes, so that families belonging to middle and lower strata on socioeconomic scale can also reap the benefits. This would also maintain a high volume of cases, leading to professional satisfaction and motivation of the employed staff.

Optimal utilization of resources: The model of piggybacking pediatric cardiac program on a successful ongoing adult cardiac program is useful for optimizing resource utilization, and has been successfully used in several hospitals. The cardiac catheterization laboratory, operating rooms, staff and other services are shared for both pediatric and adult patients. In such ‘adult-program first’ models, the pediatric cardiac program is gradually expanded. However, this model is not without problems as adult care may get preference over pediatric care as adult program are much less resource-intense. Collection of outcome data to assess the quality of program is very important for self-sustainability.

In-country training of staff: Currently India has approximately 130 pediatric cardiologists and 110 pediatric cardiac surgeons. These numbers are grossly inadequate, but are much better than what it was a decade ago. Given a choice, very few specialists choose pediatric cardiology and cardiac surgery as these specialities are much more demanding, less glamorous and provide lower monetary return. Hand-holding of new recruits by senior staff/expatriates on short-term deputation from established cardiac centers, is likely to improve skills and morale of junior surgeons. With ever increasing numbers of centers, in-country structured training programs for pediatric cardiac care specialists are necessary as has been successfully done in some countries [38]. In the last five years or so, some good quality training programs have started in India, including a three year courses in pediatric cardiology. Incorporating research into a training program is also very important, and helps in its sustainability.

Indigenization and innovation: For cardiac surgery and interventions to be affordable, cost-containment is necessary. Currently, majority of equipment and disposable items required for cardiac surgery are being imported. Encouraging home grown technology will reduce the cost of equipment considerably. Few LMIC, such as Brazil and Mexico, are manufacturing products locally, reducing the costs significantly. However, high standards have to be prescribed for local manufacturers and a strict quality control is necessary.

Prioritization of care: A contentious issue is prioritizing CHD care for those cases which are ‘one time fixes’ with good long-term outcome over those with complex CHD requiring multistage, often palliative surgeries with suboptimal long-term survival. This issue gains importance because of the enormous burden of CHD in India and availability of limited facilities for their management. The denial of cardiac surgery to children with complex CHD and single ventricle physiology (*e.g.*, heterotaxy syndromes) and to those associated with significant extra-cardiac malformations is for efficient resource utilization in a resource-constrained setting. Such decisions can be challenged and are best taken in consultation with parents.

Providing financial support for treatment: A number of financial models are supporting healthcare in India. Many of them cater to children and cover for CHDs. Some of the private hospitals support patients utilizing funding from corporate social responsibility programs. Payment is sometimes linked to the patient’s capacity to pay, helping to subsidize services for poorer patients. Charitable hospitals often depend on donations. Insurance is another way to provide high quality care. One of the successful schemes adopted by Karnataka, called Yeshashwini, is a microfinance scheme where each member of a cooperative group pays a nominal amount to create a corpus which is used to fund surgeries [39]. Several other states have similar schemes under different names. A number of initiatives by the central government

KEY MESSAGES

- Over 200,000 children are estimated to be born with congenital heart disease in India every year.
- About one-fifth of these suffer from critical heart disease requiring early intervention.
- The currently available care for these children is grossly inadequate.
- There are over 60 centers that cater to children with congenital heart disease; majority are in southern states of India.
- Most of babies born with congenital heart disease in most populous states of India, such as Uttar Pradesh and Bihar, do not receive the care they deserve.
- Improving care of children with congenital heart disease is an uphill task, but needs to be addressed.

are directed at health of children. Provision is also provided for free treatment of children from families which are below poverty line. In addition, poor patients can get financial help from Prime Minister's Relief Fund and Chief Minister's Relief Fund. The policy makers and others in the government are taking note of pediatric health, and in future, we may see more schemes for the benefit of children with CHD. However, we must have the infrastructure to take care of this increasing demand.

Recently government of India has launched a National Health Protection Scheme, which is a flagship program under Ayushman Bharat [40]. This scheme is expected to cover over 10 crore poor and vulnerable families (approximately 50 crore people). Under this scheme, a coverage up to Rs. 500,000 per family per year will be provided, for secondary and tertiary care hospitalization. Whether this scheme would significantly impact the cardiac care of children with CHD is to be seen, considering the mismatch between the high load of cases and number of cardiac care centers in India.

CONCLUSION

The care available for children with CHD is vastly different in MIC, including India, from that in high-income countries. A large proportion of children with CHD go undiagnosed and untreated in India due to the large numbers and limited resources. A significant amount of progress has been made in India for the management of children with CHD over the last three decades, but it still remains grossly inadequate. Interactions with pediatricians and other front line health staff are necessary to improve the overall outlook for children with CHD. Advocacy with health policy makers is very important so that more resources are allocated to care of children with CHD – at primary, secondary and tertiary levels. Potential solutions to improve access to cardiac care must consider the local social, economic and political systems for each region. A locally relevant research must be a part of this endeavor.

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