

To Study the Number of Population Suffering from Congenital Heart Disease

Muhammad Arsalan Wani,
Department of Zoology,
The Oxford College of Science H.S.R Layout Bangalore
Email: maw.uzair@gmail.com

Abstract:

Congenital heart disease refers to a range of birth defects that affect the normal way the heart works. The term “congenital” means the condition is present from birth. Congenital heart defects is one of the most common types of birth defect, affecting up to 8 in every 1000 babies born in the U K. Congenital heart defects (CHDs) affect a large number of newborns and account for a high proportion of infant mortality worldwide. There are regional differences in the prevalence and distribution pattern of Congenital Heart Defects. The aim of this study is to estimate the distribution pattern and prevalence of Congenital Heart Defects among the population of India and to get an overview of prevalence of CHDs in India.

Keywords — Congenital heart disease, infant mortality.

I. INTRODUCTION

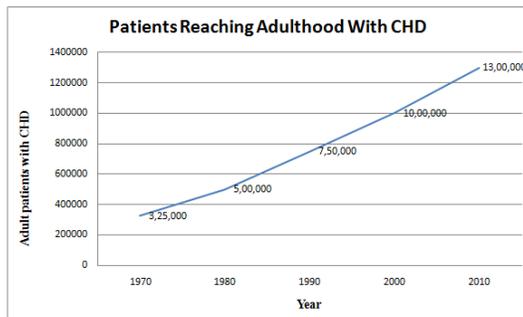
Congenital heart disease (CHD) is a general term used for structural or functional heart diseases, which are present at birth. Some of these may be discovered later. These are primarily seen in neonates, infants and children, although in our country it is not uncommon to see adults suffering from CHD. 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. It is believed that this incidence has remained constant worldwide. Nearly one third to half of these Congenital heart defects are critical, requiring intervention in the first year of life itself. Rapid advances have taken place in the diagnosis and treatment of CHD over the last 5 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 74% 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 Congenital Heart Disease do not get the necessary care, leading to high morbidity and mortality.

DATA AND STATISTICS ON CONGENITAL HEART DISEASE

Congenital heart defects (CHDs) are the most common types of birth defects, and babies born with these conditions are living longer and healthier lives. Find more statistics about Congenital Heart Defects below;

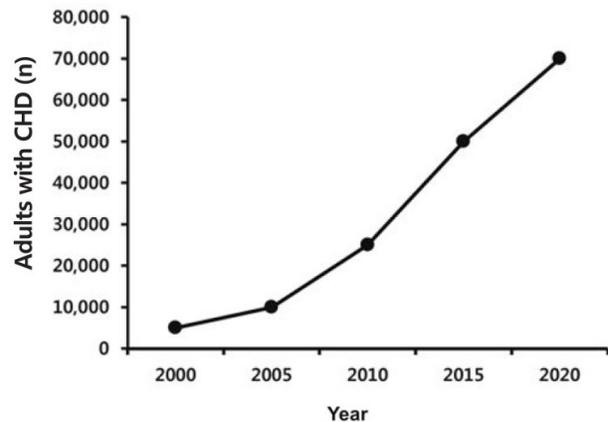
- Congenital Heart Diseases affect nearly 1% of or about 40,000—births per year in the United States.
- The prevalence (number of babies born with heart defect compared to the total number of births) of some CHDs, especially mild types, is increasing, while the prevalence of other types has remained stable. The most common type of heart defect is Ventricular Septal Defect (VSD).
- About 26% of babies with a CHD have a critical Congenital Heart Defect. Infants with critical Congenital Heart Defects generally need surgery or other procedures in first year of their life.
- The prevalence of all types of CHDs, including critical Congenital Heart Defects, varies by state and by type of defect.
- Congenital heart defect (CHD) is the most frequently occurring congenital disorder, responsible for 29% of all congenital birth defects. The birth prevalence of CHD is reported to be 8-12/1000 live births. Considering a rate of 9/1000, about 1.36 million babies are born with CHD each year globally.



PREVALENCE OF CHD IN INDIA

We have no community-based data for incidence of Congenital Heart Defect 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. There are a few studies of prevalence of

Congenital Heart Disease in school children; these are mainly offshoots of prevalence studies for rheumatic fever and rheumatic heart disease. Since a large number of Congenital Heart Defects are critical, leading to death in early life itself, these studies on school children have limited value and underestimate the true burden of Congenital Heart Disease. Going by the crude birth rate of 27.3/1000 (2001 Census data), 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 12% of present infant mortality in India may be accounted for by Congenital Heart Disorders alone. In this way every year a large number of children are added to the total pool of cases with CHD. We also have a large number of adult patients with Congenital Heart Defects, primarily because of inadequate health care facilities and lack of health awareness.



CURRENT STATUS OF CARE IN INDIA

Gross disparity exists between high-income countries and LMIC as far as care of children with Congenital Heart Disease 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. Similarly, the number of cardiac surgeons is also much more in North America and Europe (one cardiac surgeon per 3.5

million population) as compared to Asia (one cardiac surgeon per 25 million population). Of the 240,000 children born with Congenital Heart Disease 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 Congenital Heart Disease.

babies born with Congenital Heart Defects is likely to be much more in regions with high birth rates.

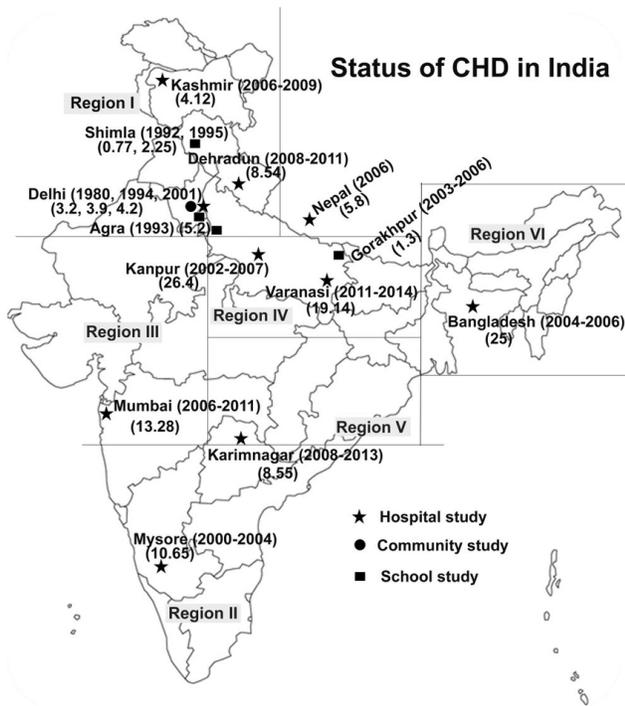


Figure 1. Prevalence rates per 1000 population of congenital heart disease across different regions of India. Region I, northern India; region II, southern India; region III, western India; region IV, north-central India; region V, south-central India; region VI, eastern India.

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 Eastern and Northern parts of India (Delhi, Jammu and Kashmir, Haryana, Punjab, Himachal Pradesh, Rajasthan, Uttar Pradesh, Bihar, Uttarakhand, Jharkhand, Orissa and West Bengal) as compared to rest of four regions (Southern, Central, Western and North-East). Consequently, the total number of

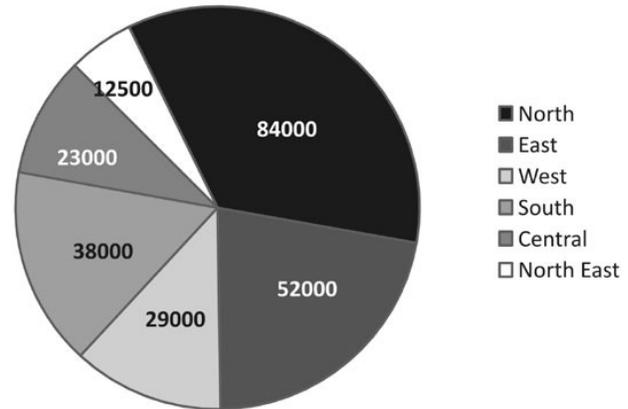


Fig. 2 Regional distribution of infants born with CHD in India every year.

When considering the critical Congenital Heart Defect (requiring intervention in first year of life), the Western and Southern states of India have fared much better than other regions (**Fig. 2**). On the contrary, states such as Bihar, Uttar Pradesh, Jharkhand and Madhya Pradesh, which presumably have much higher CHD burden as compared to other states, have fared much worse. The data suggest that children born with serious Congenital Heart Defect in Southern India have a 71% 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 Central and Eastern 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 like All India Institute of Medical Sciences (AIIMS). These institutes are already operational in various states, including those in central, eastern and northern parts of India. Currently, the number of congenital heart surgeries is less in these institutes, especially for neonates and infants.

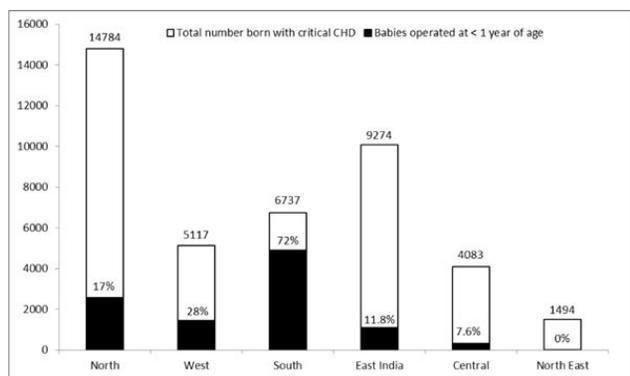


Fig. 3 Regional distribution of infants with critical heart disease accessing surgery as compared to total number born with critical heart disease.

OBSTACLES TO PEDIATRIC CARDIAC CARE IN INDIA

A. 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 Congenital Heart Disease 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 Congenital Heart Diseases, is often not practiced, especially in semi-urban and rural centers. Frontline health workers and primary caregivers are not sensitized to the problem of Congenital Heart Defect and a number of them believe that a child with Congenital Heart Defect is doomed and will never be able to lead a fruitful life, even if intervened. Delay in referral results in poor outcomes as co-morbidities and complications (such as under-nutrition) may have already set in.

B. MALDISTRIBUTION OF RESOURCES:

The resources for treatment of Congenital Heart Defect are not only inadequate but also seriously

mal-distributed. The geographical distribution of these centers is very uneven. Poverty, which is the greatest barrier to successful treatment of Congenital Heart Disease, 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 Congenital Heart Disease. The risks of developing hypoglycemia and hypothermia during long, unsupervised transport further adds to the already serious condition of the infants with CHD. Inefficient governance and limited resources further compromise a fair distribution.

C. FINANCIAL CONSTRAINTS:

Medical insurance is practically non-existent in India, especially for birth defects. In most cases, families are expected to pay for the treatment out of their pocket, which they can barely afford. In a study from Kerala and Tamil Nadu, surgery for Congenital Heart Defect resulted in significant financial burden for majority of families. Approximately half of the families borrowed money during the follow-up period after surgery. Many families are away from work during care of these children and lose their wages. 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 numbers of public hospitals which provide care at a low cost are very few. Most cardiac centers, especially that 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. The results of intervention in such settings are expected to be less than ideal.

D. HEALTH SEEKING BEHAVIOUR 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.

E. 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.

F. 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 Congenital Heart Disease

Table 1. Deaths due to CHD (India).

AGE	2010	2015	INCREASE FROM 2010 TO 2015(%)
All	2.3	2.9	26

<50 years of age	1.14	1.5	32
<40 years of age	0.70	0.92	31
<30 years of age	0.33	0.42	27

RESULTS:

Out of 34 617 individuals examined, 669 were diagnosed with Congenital Heart Defects, giving a prevalence of 19.18 per 1000 individuals. The most common defect was Ventricular Septal Defect (34%), followed by Atrial Septal Defect (19%) and tetralogy of Fallot (15%). The majority of Congenital Heart Disease cases (59%) diagnosed were between 0 and 5 years of age. The prevalence of CHDs in adults was 2.5 per 1000 individuals in this cohort, with Atrial Septal defect (44.6%) being the most frequent defect.

CONCLUSION:

The care available for children with Congenital Heart Defects is vastly different in MIC, including India, from that in high-income countries. A large proportion of children with Congenital Heart Defects go undiagnosed and untreated in India due to the large numbers and limited resources. A significant progress has been made in India for the management of children with CHD over the last four 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 Congenital Heart Defects. Advocacy with health policy makers is very important so that more resources are allocated to care of children with Congenital Heart Disease – at primary, secondary and tertiary levels. Potential solutions to improve access to cardiac care must consider the local economic, social and political systems for each region. A locally relevant research must be a part of this endeavor. The prevalence of Congenital Heart Defects in our cohort was high,

possibly because of the power of the diagnostic methods we used and the inclusion of all age groups. Adults with Congenital Heart Defects may significantly contribute to the prevalence of Congenital Heart Defects in the next generation, and this needs to be considered when estimating prevalence rates. Although several small regional studies have been carried out in India, there is an urgent need to establish a nationwide database/registry for congenital heart disorders.

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