

Pediatric Cardiac Care

“Heart Disease in Children”, the title itself invokes strong emotional feeling as it’s the combination of two words. First heart defects which can distressing to anybody and second children, the most vulnerable group in the society. Breaking a news of a heart defect in a child to the family is the most stressing feeling for any treating physician. The major surgery which the child has to undergo plus the financial implications of the same can be very stressful to the family.

The spectrum of heart disease in children is very different from that in adults as congenital heart defects constitute the majority of cardiac disease in children. According to March of Dimes (MOD) global report on birth defects, worldwide 7.9 million births occur annually with serious birth defects. India has the largest no. of births with estimated 17 lakhs babies are born with birth defects which accounts for 9.6% of all newborn deaths. Among all birth defects congenital heart defects (CHDs) are the most common defects about 28% of all defects. The burden of CHD in India is likely to be the largest among all nations in the world simply because of the fact that there are more children born in India than anywhere else. The majority of children with congenital heart defects (CHD) in our region escape detection, for the small percentage of cases where the condition is diagnosed early enough for treatment, families are often intimidated by financial implications and the prospect of seeking care at a far-off centre. Considering birth prevalence as 9 out of 1,000, the estimated number of children born with CHD every year in India is approximately 2.4 lacs and about 3 out of 1000 births are of critical CHDs which need immediate attention. With the advancement of technology and increased awareness, more children are now being diagnosed with heart defects. However there is still a big gap in the number of children with CHDs and hospitals capable of handling such children.

Establishment of quality institutions providing comprehensive paediatric heart care that includes prenatal screening, early diagnosis and management is the need of the hour. But establishing a dedicated pediatric cardiac programme is really a challenge.

Disease Burden

The actual number of children born with heart defects in our country is not known as there are very few population-based systematic surveys on disease prevalence performed for CHD at birth.

Developing a team

The most important component of Pediatric cardiac programme is creation of a cohesive team of individuals. This team is constituted by paediatric cardiologists, paediatric cardiac surgeons, anaesthesiologists, intensive care experts, nurses, technologists (catheterisation, perfusion, ultrasound) and other support personnels. This is an arduous task as only a small handful of individuals seriously pursued paediatric cardiology and the number of dedicated paediatric cardiac surgeons in the country even more scarce, similar is the situation for other members of the team.

Quality of care

The outcomes after paediatric cardiac surgery in infants and newborns are critically dependent on the skills and cohesiveness of the individual team members and this is one of most difficult hurdle to cross for a newly established institution especially in a government sector.

Specialised staff: *training and retaining*- This is a major problem as there is major paucity of trained staff and even more difficult to retain them.

Cost of Infrastructure and equipments is exorbitant as compared to any other speciality. Perhaps because of these reasons all existing paediatric heart programmes in India are in hospitals with busy adult cardiology and cardiac surgery programmes and not as a separate speciality.

Transport of Children with CHD- Transport of the children with CHD is always an arduous task especially if the child is sick and is from remotest of areas.

Delayed Presentation

It is not rare that child presents with one and another complications besides high prevalence of malnutrition and associated infections in our region even more complicate the picture and significantly affects the outcome.

Sustainability

If the task of establishing a pediatric cardiac unit is difficult then even more difficult aspect is to carry it forward especially the financial viability of paediatric heart programmes. There was never a consensus in the matter of it being a system of socialized healthcare, a private healthcare, pay out of pocket system or an insurance based co payment system. In the absence of health insurance the costs of paediatric heart operations and catheter interventions are out of reach of majority of Indian families.

Public Health Priority

Luckily government has come up with various schemes like Aarogyasri, Rashtriya Bal Swasthya Karyakaram (RBSK) and more recently Ayushman Bharat in which treatment is provided completely free of cost to the patient. RBSK is a beautiful and noble initiative by Govt. of India aimed at screening and treating 0 to 18 year children for 4 Ds - Defects at birth, Diseases, Deficiencies and Development Delays including Disabilities. Children diagnosed with illnesses will receive treatment including surgeries at tertiary level, free of cost under National Health Mission (NHM). In this programme the children are screened at delivery points, home and schools for any evidence of heart defect and if there is any suspicion the child is shifted to a tertiary care hospital for the definitive surgery by mobile health team under RBSK. Besides specific heart defects, management of the child is done holistically under a single roof at District Early Intervention Centre (DEIC), the nodal point of this programme.

RBSK is a unique initiative in which there is comprehensive evaluation of the child especially children with congenital heart defects. It is because of this programme lot of children with heart defects even from remotest area have received timely intervention and are thriving well.

A dedicated Pediatric Cardiac Unit has been established at JN Medical, AMU Aligarh under Rashtriya Bal Swasthya Karyakram (RBSK) National Health Mission and is serving children from whole of the state. DEIC, which is the primary contact of the child was established first and subsequently the cardiac unit became functional in the hospital.

Another big challenge for Pediatric cardiology programme is maintaining the standards over extended period of time which can be dealt by robust systems for training of successive generations of caregivers. The people who gets trained will serve at their respective places and will further strengthen the care.

Comprehensive Pediatric Cardiac care for each and every kid with heart defect is the ultimate goal, though the road to it is difficult but a concerted and dedicated effort can bring about the change.