

Care of Children with Congenital Heart Disease in India: An Unmet Need



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Let us picture the following scenario

A recently married middle class couple have a child. The mother and child get discharged in a few days. All seems well, but some days later, the young mom starts to notice blueness over the baby's eyebrows and his refusal to feed beyond the initial attempts, along with fast breathing. They take him to a children's doctor who detects cyanosis (blueness of lips, tongue and nailbed) along with a musical sound from heart called murmur, heard using stethoscope. Doctor advises a test in which pictures of the heart are obtained using sound waves (echocardiogram, echo). There is bad news. Echo shows that baby has a major structural defect in heart where both the arteries from the heart arising in an inverted pattern. He is being kept alive by a small hole in the heart that is allowing mixing of red and blue blood. The condition is called Transposition of the Great Arteries (TGA). This is a type of congenital heart disease (CHD). The baby needs urgent open-heart surgery for survival. Untreated, he faces certain death. However, there is hope. With an operation called the Arterial Switch operation, he has the promise of a completely normal life, indistinguishable from a child born with a normal heart. The pediatrician refers them to a reputed tertiary care government medical center. There is no bed vacant at the government hospital and they need to wait for an unspecified period of time.

But the baby cannot wait. The desperate father goes to the private hospitals in the city. They are ready to admit, but cost of surgery will come to at least 3.5 Lakh Rs, if the baby gets discharged within 10 days after surgery. If not, it will go up by Rs 50,000/day. The father has a blue-collar job, and cannot afford such money. He finds to his dismay there is no insurance in India that covers birth defects. He runs from

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relatives to friends trying to collect the money. In the span of a few days, the young couple's life has turned topsy-turvy.

This is the harsh reality today in India. Fortunately, most child bearing couples escape this harsh reality since the incidence of congenital heart disease is only 1 per 100 live births. And among these only 20 % will require urgent treatment. Yet, how many of us could come up with such money at short notice at that age, or, for that matter, at any age? No private hospital will start treatment unless the entire amount is deposited upfront.

Options are rather limited. Couples may end up mortgaging their houses, borrowing money at large interest, or selling their family possessions to gather the required amount. And still, there is no guarantee the child will survive (although results for most conditions are now excellent, with > 95% survival from most operations in the experienced centers).

The reality today in India: if your child is born with a birth defect as described above, you need to be rich enough to buy your child's life. Many poor people, in sheer desperation, take the choice of not opting for expensive surgery, putting their bet on the next child, who, hopefully, would be born normal.

We all have come across various crowd funding platforms on the internet. Some have wailing mothers desperately pleading and begging for money to help their child live. These posts, are enough to shake anybody's soul and though they may succeed in collecting the money, thanks to generous contributors, are so pitiable and mind shattering, that one does not have the guts to see them through. Shouldn't there be a mechanism to help such needy families, without them having to resort to such inhuman and degrading practices? The truth today is that a child who is not born perfect is an unwanted guest in society. Since 97% of society is not affected by these problems, the problem remains unnoticed.

Most CHD are eminently treatable. However, timely intervention is crucial for successful outcomes of the surgery for infants and children with congenital heart conditions. Delay can jeopardize the course of treatment as well as cause post-surgery complications. The child may then grow up with a suboptimal heart function – compromised physical activity through childhood and throughout the adult life. A normal life is possible with just a simple step of undergoing surgery at the right time in early childhood. Time is of essence.

On its part the government has taken many steps to help children born with congenital heart disease. It has initiated various schemes that offer either financial support or

even free treatment. But most of these schemes are only applicable in government-run hospitals. In reality, that there are only a handful of government hospitals in the entire country that offer treatment of good standard and centers of excellence such as the All India Institute of Medical Sciences, New Delhi (AIIMS) have unacceptably long waiting lists. Yojanas like Ayushman or Rashtriya Bal Sewa Karyakram (RBSK) are open to private hospitals, but the private hospital charges are at least double of what the payout covers and except for a few simple conditions. As a result, private hospitals are reluctant to accept these schemes. It's mostly about money.

What is the Situation in the World?

Diagnosis and treatment require specialized facilities and trained medical personnel. Children born in high income countries get detected early and undergo timely treatment. In contrast, the lower and middle-income countries, which are more densely populated and have higher birth rates, also have higher incidence of CHD and are therefore faced with a major problem due to lack of facilities and affordability among the population. Out of an estimated 1.35 million babies born annually with CHD throughout the world, 90% are born in non-affluent countries and hence the bulk do not get access to adequate treatment.

CHD Burden in India

Given our population and the birth rate, every year approximately 240,000 newborns are born in our country with a heart defect. In India, common to other lower income countries, there is a gross disparity between facilities and doctors' availability and the population to be served. While one cardiac center in the United States caters to a population of 120,000 and one surgeon to 3.5 million, in India the cardiac center to population ratio is 1:16 million, while the cardiac surgeon to population ratio is 1: 25 million.

Health is a state subject. Overall child health levels and healthcare standards vary vastly between states. Certain states (Kerala is the prime example) have achieved significant reductions in disease indices like infant mortality rate. The governments understandably have been focused on more basic issues such as taking care of the more fundamental causes of infant and child mortality like hunger, malnutrition, and communicable diseases. CHD as a cause of mortality becomes important only once these problems have been taken care of. However, it is also true that CHD surgery, in up to 70% of congenital heart conditions, is a one-time surgical intervention and do not require vast programs with repetitive wasted effort on a large scale where societal behavior patterns need change. The other 30% of cases, CHD may require repeat surgery

or tackling of issues that arise as time elapses. The other fact about CHD is that all CHD patients will not die if left unoperated. Instead, many such unfortunate children will survive and become handicapped and incapacitated. This places a significant burden on the family and society, both financially and psychologically.

Given the subset of population (240,000 per year plus untreated arrears) in need of intervention, government hospitals are obviously not equipped for this daunting task. Private health care has, since 1990, played a significant role in supporting successful cardiac treatment of the affected children in India.

The Role Served by Private Health Care in India

Cost of a procedure to the patient in a private hospital is at least two to three times higher than in the government counterparts since the overheads like staff salaries, and all hospital operational expenditure have to be met through patient bills. Standards of care are high, since experienced surgeons, cardiologists, anesthesiologists, and intensive care specialists from government setups are recruited at senior positions to run departments. The remunerations here are better and since they are not drowned in work, and obviously carrying their learning and experience, quality delivery is equivalent, if not superior to the best available government setup. Waiting lists are usually nonexistent or small. The government schemes that have private hospitals on their lists, provide partial payment, yet these are not enough to take care of the entire expense for more complex conditions. Despite financial difficulty, the poor and the underprivileged who do not have means to afford such expensive treatment aspire to get their near and dear ones operated in private hospitals, as the facilities are more esthetic, doctors are competent and there is no wastage of time in instituting treatment. In the current situation, of all children coming to private hospitals, about 80% of families must meet expenditure through their own means. In this situation, if a child operated at a private hospital were to need to stay longer than the package allows, for treatment of a complication or an unexpected situation, the expenses can really hit the roof. Many families are known to get pushed below the poverty line getting treatment in private hospitals, in this situation.

India is promoting itself as hub of medical tourism, there is a race amongst private hospitals to cater to international clientele with paying ability. Given the expertise of our doctors and nurses, the cost of treatment is much lower as compared to what the West as well as far Eastern (Thailand, Singapore) charges for the same procedures. Ironically the same hospitals remain unaffordable and out of reach for many of our Indian patients.

Medical Insurance (or The Lack of It!)

In this entire scenario, Medical Insurance is the elephant in the room. Medical Insurance in India, without exception, excludes all congenital defects from its ambit. The wealthy and affluent can afford anything; the poor have below poverty line (BPL) schemes; but the tax paying middle class are the orphans, left to fend for themselves. Doesn't the tax paying salaried middle class at least deserve to have their children covered? If not by free health care, by insurance, that they themselves would pay for, if it existed? Unfortunately, children with birth defects are BARRED from any insurance!

The justification given (and obviously this has the tacit approval of everybody, including society, the government, and the judiciary, so far) is that a congenital defect is a pre-existing condition. The result is that in a country where 41% of the population is below 18 years of age, 50% below 25 years of age and 65% less than 35 years of age, where 70,000 children are born every day, if all your organs are not born picture perfect and your parents are not rich enough to afford treatment in a private hospital, all you have access to is the long waiting list in a government hospital.

In an era when Social Media rules, and there is sensitivity or perhaps hypersensitivity of any perceived injustice or discrimination, it is time voices are raised on the issue of insurance cover to children with birth defects. The great civilization which we espouse, where a guest is God, has forgotten to pay heed to the most precious gift to a newly married couple: a new addition to their family. A young couple, at the threshold of professional life, is unable to afford a complex surgical treatment - funding takes time to collect. Unfortunately, the natural history of some congenital heart conditions does not allow the luxury of time and the poor innocent child pays the price.

It is a fact that today, advocacy covers everything from HIV to Cancer to LGBTQ rights but one for the poor defenseless newborn who enters this world with CHD, is hard to come by. Isn't it time to shift this sad paradigm?

Apart from an occasional public interest litigation (PIL) on the subject, there is precious little that appears if one were to search the net, and that too was met by the judgement that it is the private business of the insurance company!

A society is judged by the way it handles its weakest and most defenseless. We have categorized and attended to many other deserving category, but the child born with a defect has always fallen on our collective blind spot.

Would We Like to Change This Status Quo?

The time has come for the government and the judiciary of the country to ensure that justice to the child is delivered and the shameful, immoral practice of not supporting children born with abnormality comes to an end. In a country where only 2% of the

children with CHD get treated, there is hardly room to create exclusion categories. Categorizing preexistent condition as a disqualification for any group is inhuman, more so for the poor defenseless child. Coverage of birth defects is the inalienable right of everyone born with a defect in the entire civilized world.

Today, fetal echo picks up heart defects at 18 weeks gestation. Should society prevent the parents with an unborn child detected to have an eminently curable defect on fetal echo, but whose treatment requires money they cannot afford, from seeking a termination of the pregnancy? This scenario is not inconceivable. The one child policy in many districts of China reduced the incidence of CHD dramatically as fetal echo was a much sought-after investigation by anxious expecting parents. What would that tell of our society?

The success of the farmers' insurance (Yashaswini) in the state of Karnataka has shown that, with the government giving a helping hand, the poorest of the poor can benefit. Here, each farmer family pays Rs 5 every month and the government contribute the same amount. Similarly, if uniform payment of premiums is ensured on every pregnancy, there is no way insurance companies can be a loser considering low incidence of congenital heart disease and the needy will get precious support. The time to act is far overdue.

Health insurance increases premiums for preexisting conditions which are not congenital in origin. It does not disqualify them. In the case of congenital defects, it disqualifies them. Why?

It also raises the question: Why are congenital defects regarded as preexisting conditions? In our opinion, the definition of preexisting condition by Health Insurance is faulty. When at age 40 yrs., I get insured, some insurance companies I approach for health coverage may conduct certain tests, others may not. They may elevate premiums if I am diabetic. But they still do not do an angiogram. So, they enroll me in the insurance as without preexistent CAD without fully investigating me. To rule out preexisting CAD, they should study all my risk factors and do an angiogram. Which they do not. If I do end up having a coronary bypass surgery a year after enrolling, which obviously could not have developed within the year, will they disqualify me from reimbursement? So why this attitude towards congenital defects?

We hope that fairness will prevail in our society and in our country and the child born imperfect will be given a chance at a normal life, that is his or her birth right. An open debate on this topic is urgently needed.
