

How to select a destination for your child's heart treatment?



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Parents of children with congenital heart defects are often confronted with several challenges as soon as the diagnosis is made and the news is broken to them. One of the most significant of these challenges is to find a reliable institution that can provide comprehensive care that could include surgery, catheter interventions and intensive care. Finding a suitable destination for a child with congenital heart disease perhaps the most important decision that parents have to make. This is largely because there is still considerable variation in the quality of care between individual hospitals.

There is also a substantial difference in costs among these hospitals. Unlike in some countries such as the United Kingdom, it is not mandated in India that individual hospitals share their results openly in the public domain. It therefore becomes difficult for an individual parent to find out how good the results are for specific heart operations. Often, parents also have logistic challenges in that they may find it difficult to travel to far off places for their child's surgery. However, local convenience may not always translate into reliable outcomes.

This brief article outlines important considerations that can serve as a guide to parents of children with congenital heart disease in identifying a suitable destination for treatment. A very basic requirement for any hospital is accreditation by the National Accreditation Board for Hospitals (NABH). But this accreditation quite general and is not specific for pediatric cardiac care.

Before listing out the key considerations for selection of institutions, it is important also to be aware of certain common pitfalls that commonly misguide parents.

1. Do not base judgements on isolated media reports that come out of individual institutions describing successful operations or procedures. Often these are shared with the press for the sake of publicity. These reports do not present the entire picture for the given institution. A common example is reporting a successful heart transplant operation. A single successful heart transplant operation conveys very little about the capability of the institution to do other specific cardiac surgeries.
2. Internet searches on given hospitals or doctors, also do not provide an accurate assessment of the institution's capabilities. Information in the internet is essentially unfiltered and tends to often provide a distorted picture.
3. Do not base your judgement on other services provided by the hospital. For example, having a good adult cardiology and cardiac surgery facility with capabilities of doing advanced heart operations in adult does not necessarily translate into paediatric cardiac expertise.
4. Do not base your judgement on the presence of one or two highly famous superstar cardiologists, or surgeons in a given institution. It is the team that matters much more than individuals.

A Checklist for Parents:

Below is a 10-item checklist that could serve as a useful guide to parents in identifying a suitable destination for their child's cardiac care. I acknowledge that it is not necessarily easy for the parents to obtain specific insights into each of these items.

1. **High level of skill among caregivers:** Taking care of children requires high-level of skills in distinct disciplines that include Pediatric cardiac surgery, Pediatric cardiology and Pediatric cardiac Anesthesiology/ intensive care. There is also requirement for other skilled personnel that include nurses, perfusion, technologists and respiratory therapists. The role of a Paediatric Cardiologist is in making an accurate diagnosis and planning the surgery.

Some conditions can be managed by the cardiologist through catheter interventions. However, even for those conditions that can be managed in the catheter lab, it is always useful to have surgical back up in the rare event that there is a complication. While visiting program for the first time, it is quite reasonable for you to enquire about the members of the team.

2. Cohesive teamwork: It is not enough just to have individuals with skills. These individuals have to work together cohesively. One way of knowing that the hospital has well-coordinated and cohesive team is to determine whether the team has been working together over reasonable period of time. Cohesive teamwork is perhaps the most critical component of a successful paediatric heart program.

3. Quality Infrastructure & equipment: While many hospitals advertise and display that they may have the most recent equipment and facilities such as robotic surgery, the truth is that the most advanced technology does not necessarily translate into safe outcomes. While the hospitals should have updated and well-functioning equipment, it is not the most critical aspect of a paediatric heart program. To a substantial extent, individuals matter much more than machines and equipment

4. Constant focus on quality improvement- Pediatric heart programs that have a conscious focus on quality improvement are likely to deliver the best results. Often such programmes voluntarily share their results in multi-institutional collaborative networks. One example of such a program is the quality improvement collaboration for congenital heart disease (IQIC). Pediatric heart teams have a strong focus on quality improvement, also, invest a great deal in Infection control and quality of their nursing.

5. A system for charitable care: Pediatric heart operations and catheter procedures are expensive. Many families are significantly challenged when they have to generate the entire costs out of their own pocket. Many insurance companies still do not provide cover for congenital heart care. If you are likely to be financially challenged, you must look for hospitals that work with funding agencies and philanthropic organisations to find ways to help parents overcome this financial challenge.

6. Evidence of a Strong Ethical framework: It is generally challenging to determine whether or not a hospital has a strong ethical framework. However, many corporate hospitals tend to compensate physicians or surgeons based on the number of procedures they perform. This can lower the threshold to do procedures. This is particularly true for catheter-based procedures. For example, a small ventricular septal defect (VSD) in many instances does not need closure, but catheter closure may be offered just because it's possible. This is extremely controversial area, but in circumstances where your child is completely well and the defect is small, it is always good to get a second opinion if a procedure is being recommended.

7. Support from other pediatrics specialties: Pediatric heart disease often does not manifest in isolation. Other organ systems may also be affected or your child may have a genetic or developmental issue that merits attention from other Pediatric specialists. In general, the quality of care is better and more comprehensive in Pediatric heart programmes that are located in large multispecialty hospitals that are supported by other pediatric specialities.

8. Other support systems such as social workers: Support staff, such as social workers, play a very significant role in enabling care and serving as a liaison with funding agencies. Departments with a strong presence of medical social workers can help ease the parental anxiety and help secure funding assistance from philanthropic organisations.

9. Communications: Like in other areas, the promptness of responses and quality of communication from a department are a good indicator of their professionalism.

10. Word of Mouth - Experiences of previous patients: Once you have identified or shortlisted a potential destination for your child, it's always useful to speak to other parents about their experiences with heart surgery, or other procedures in the place that you are considering. You can run the individual aspects of this checklist with them.