

From the Editor's Desk: Congenital heart surgery in India – At the crossroads?



This issue of *Annals of Pediatric Cardiology* witnesses a change of guard at the Editor's Desk. Dr. Krishna Kumar has decided to pass on the baton after skillfully steering the Journal to new heights. The Pediatric Cardiac Society of India owes him a debt of gratitude for his tremendous and selfless contribution. As I take over the reins of the Journal, I need to acknowledge his gracious support in the transition period and his continued involvement. As the first surgeon editor of the Journal, I thought that it would be most appropriate of me to pen a few words about the state of congenital heart surgery in our country in this first editorial.

The past two decades have witnessed a phenomenal growth in the field of congenital heart surgery in our country. In the early 90s, there were only two or three institutions in the country offering some infant cardiac surgery. Neonatal cardiac surgery was performed sporadically and largely limited to palliative procedures. Today, neonatal and infant surgery is available in most metro cities and many tier two cities as well. There has been a steady growth in the number of dedicated pediatric cardiac surgeons and a trend toward surgeons returning to the homeland after training overseas, rather than settling there. Many factors have contributed to this much-needed growth of the specialty some of which I have enumerated as follows:

1. The advent of coronary bypass surgery in the early 90s in the private sector spurred the creation of heart hospitals and institutions. Some of these encouraged the development of congenital heart surgery as a goodwill service or even as a unique selling product.
2. The start of the Fellowship Course in Pediatric Cardiology by the National Board of Examinations. With the increased availability of trained pediatric cardiologists, surgeons were more confident of developing pediatric programs. Referral patterns improved. More babies were diagnosed on time and perioperative care improved. At the same time, the numbers of home-grown pediatric cardiac surgeons (trained within the country) have steadily increased.
3. An upswing in the economy meant that more families could afford surgery. The internet explosion and ready access to information on platforms such as Google enabled faster spread of awareness, allowing

- parents of affected children to explore treatment options.
4. The formation of the Pediatric Cardiac Society of India – a move that gave the specialty a much-needed face and identity. The annual meetings became an inspiration for tentative new entrants to the specialty.
5. Some governmental initiatives in recent times providing financial support to children requiring heart surgery, for example, the Rashtriya Bal Vikas Yojana and the Arogyashree program in Andhra Pradesh.
6. With reductions in infant mortality from readily preventable causes such as respiratory infections and diarrheal diseases, congenital heart disease (CHD) has gained importance in many parts of the country that have shown improved human developmental indices. Indeed, the distribution of new pediatric heart programs closely mirrors this demographic transition in pediatric disease.

The numbers of surgeries performed annually remain speculative in the absence of a national registry or database, but a rough estimate would peg it around 30,000–50,000 congenital heart surgeries annually. Although the number seems sizeable, it remains far short of the required need. In the absence of an organized national program for the treatment of CHD, delivery of care is through individual programs that have developed on their own, and most are based in the nongovernmental sector. The rapid growth of corporate health-care delivery in the country has meant that a sizeable proportion of CHD surgery is now performed in corporate multispecialty hospitals that are relatively expensive and generally beyond the reach of the common man. However, many do provide help to financially constrained patients by sourcing funds from corporate social responsibility programs or donations from philanthropic organizations. Nevertheless, the vast majority of neonatal and complex congenital heart surgery today is performed in the private sector. Outcomes in many of these units are comparable with the leading hospitals in developed countries.

The situation in public hospitals has improved but remains far from satisfactory. Limitations of funds, staffing, and hierarchical functioning have hampered the development of successful pediatric cardiac programs

that could address the needs of the vast majority of patients who cannot afford to go to private hospitals. Trained pediatric cardiac surgeons generally cannot find a position in a government hospital because the recruitment process does not allow lateral entry. In hospitals that have nevertheless managed to beat the odds and have developed active programs, long waiting lists are the norm. An encouraging trend has been the setting up of the Sri Sathya Sai Sanjeevani chain of hospitals where pediatric cardiac care is being provided free of cost. Although they still serve only a small percentage of the patients, it is hoped that other philanthropic organizations will take their lead and set up more such facilities.

For the practicing pediatric surgeon in this country, the challenges are many. The patient population is diverse and ranges from newborns with critical heart disease to adolescents and adults presenting with late or neglected CHD. Comorbidities such as malnutrition, viral infections, and respiratory disorders are commonplace and contribute to postoperative morbidity. Setting up a pediatric cardiac program and sustaining it is usually the surgeon's initiative and responsibility and running a successful program with limited staff and a constant resource crunch is always a "tightrope walk."

Much needs to be done to improve the situation. It is imperative that a national registry for congenital heart surgery is established so that reliable statistics are available. Functioning units need to be networked and referral pathways established so that patients can be treated without having to travel enormous distances. The state and central governments should be encouraged to develop public-private partnerships so that the expertise available in the private sector can be harnessed to improve the situation in the government hospitals. Simultaneously,

there needs to be rationalization of federal or state reimbursements for congenital heart surgery so that optimal care can be provided and hospitals are not forced to incur losses or cut down on quality.

Ours is a land with the largest numbers of patients with CHD in the entire world. Providing life-saving surgery to this huge population is a daunting task, but we need to work toward that goal. The Pediatric Cardiac Society of India has to be the key driver of initiatives that will help achieve this goal.

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