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Editorial

Building a pediatric cardiac care unit: the need and the hurdles

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The incidence of congenital heart diseases remains same over the years without significant geographical variation of 8/1000 in various studies, responsible for 28% of all congenital birth defects [1,2]. Every year about 90% of approximately 1 million of children born with a congenital heart defect around the world do not have access to appropriate care [1,2,3,4].

A congenital cardiac care unit (CCCU) has different goals during its evolution. At the inception of an idea of such a group, it requires a specialist with the various skill needed to come together and bring or develop paramedical support skills necessary for the basic functionality of the clinical work. The skill sets required are good congenital cardiac surgeon, pediatric cardiologist, pediatric cardiac anesthetist, intensivists, pediatric perfusionists, and pediatric cardiac nursing staff both for the operative room as well as intensive care unit. The core group needs to come forward and take training efforts for paramedical staff to develop an understanding of disease and management and postprocedure care. In a survey conducted between 2007 and 2009 by the World Society of Pediatric and Congenital Heart Surgery, it was seen that there is one congenital heart surgeon for every 35 lakhs individuals in Europe and North America, one every 65 lakhs in South America, and one for every 250 and 380 lakhs in Asia and Africa, respectively. Although the data are not collected for other specialists involved, the deficit expected to be similar [1].

Where to set up a CCCU is a crucial decision to make. An exclusive cardiac specialty hospital gives the advantage of quick recognition among the colleagues at the hospital and easy to make management to understand the needs and difficulties of running CCCU. Whereas, being at a multispecialty hospital has the advantage of the availability of all pediatric super-specialties along with excellent obstetric and neonatology services. The disadvantage here is getting enough space for the unit, take a longer time to get your work to be recognized among your colleagues, and most importantly, to have coordination with management. It is challenging to make management understand that these babies require a longer time to recover and thus need more space for less patient ratio. Also, difficult to negotiate quality versus revenue generation.

There should be short-term and long-term goal of such a unit. First should be to get the unit running. To start with simple and less complex surgeries and gain the confidence of the hospital and get the morale of the group up and keep increasing the complexities of the operations as the team is ready to handle the preprocedure and postprocedure care. Eventually, the goal here should include almost all possible surgeries and intervention to the repertoire of the unit. This requires getting all equipment, including extracorporeal membrane oxygenation and inhaled nitric oxide equipment, and personnel to run them.

Long-term goal is much more complex, and it is like a vision of the unit “timely detection of a defect, timely management of a defect, and making the treatment accessible to all.”

To begin with, the timely detection of congenital cardiac defects requires the sensitization of individuals regarding the importance of early recognition of critical congenital heart disease (CHD). This requires continuous medical education to a broader area beyond the hospital and the city. Sometimes, this also requires basic echocardiography (functional ECHO) skills for the pediatrician, intensivists, and neonatologists. Second, it requires education regarding early management of a suspected or proven critical CHD. Most of the time, awareness of possible available treatment is present, but treatment could not be initiated because of unavailability of medicine, fear of side-effects, and understanding of reversible nature of the patient condition, or the possibility of deterioration of the patient condition if the medication is not administered. Finally, the transportation of the baby to the unit from the periphery is a challenging task. High-end transport requires higher cost and involvement of trained personnel.

Timely management of CHD is essential for both a critical CHD and other CHDs. Again, this requires a significant amount of continuous medical education for recognition and well correct timing of management. With advancement, the timing and modality and outcome of the CHD keep changing and needs to be updated to the primary caregiver. The availability of good echocardiography services could be a significant limitation, and incomplete diagnosis, incorrect diagnosis, and missed diagnosis could be a substantial hindrance to the continuity of care. The expert personnel should spare time to visit outreach places where the ECHO equipment is available to help the local caregiver to manage their patients. This also helps in following up with the postrepair patients in these cities.

Making the treatment accessible to all or management of funds for the procedure is a significant challenge. To begin with, the surgeries and interventions for CHD involve a higher cost. If a unit wants to keep the level high in terms of quality equipment and supplies used and the number of people involve for managing these children, the cost is even higher, and quality treatment should always be the goal. The CHD is usually not a priority for the

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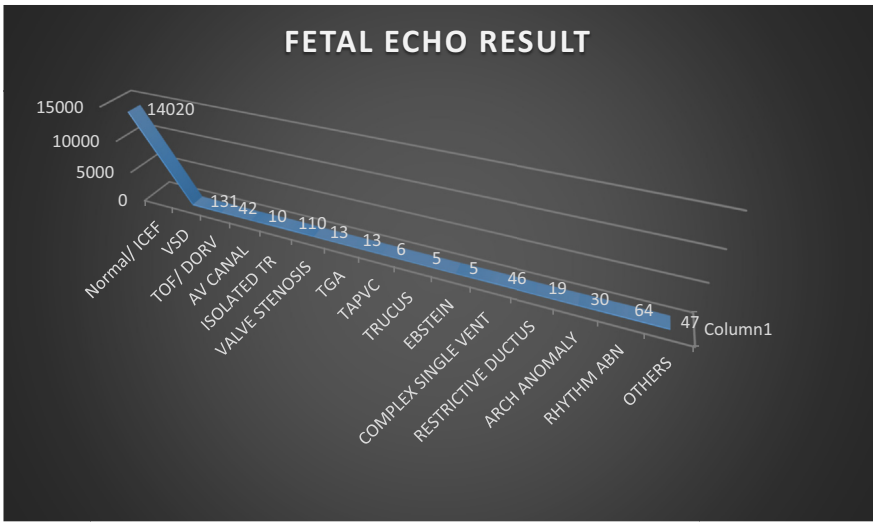

Fig. 1. Fetal ECHO result. ICEF, intracardiac echogenic foci; TOF, tetralogy of fallot; DORV, double outlet right ventricle; AV CANAL, atrio-ventricular canal; TR, tricuspid regurgitation; TGA, transposition of great arteries; TAPVC, total anomalous pulmonary venous connection; TRUNCUS, truncus arteriosus; EBSTEIN, Ebstein anomaly; RHYTHM ABN, rhythm abnormalities.

government, sometimes even in developed countries and if the government recognize it as well, even then there is the unwillingness to allow an appropriate amount of funds required for treatment of that defect. And thus, there is a significant amount of reluctance to incorporate these programs willingly as part of the unit. The CCCU requires a considerable amount of supports from non-governmental organizations (NGOs). A study has shown that most of the NGOs have shown decline or lack of growth in their activity, and other NGO supports minimal numbers of the procedure as compared with the requirement [5]. NGOs also have a significant amount of dissatisfaction when it comes to higher sum required for complex procedures that may sometimes have adverse outcomes. Continuous interaction with NGOs and medically educating the nature of illness and the outcome in the lack of treatment is required. An appreciation and meeting of families to NGOs always help to boost their morale and help them recognize the difference they are making.

The long-term goal of a CCCU should include research work and teaching. Research work is essential to improve understanding and finding a better outcome with a change in approach. Research work and publication also increase the acceptability of the CCCU to other center and various places. The presence of a recognized teaching process for a new person in the unit allows an increase in the number of trained personnel for the specialty, as well it gives the satisfaction of giving back to the medical society.

Finally, the antenatal detection of CHD is also essential to the progress of a CCCU. Timely fetal echocardiography helps to diagnose CHD in utero and allow the parents to plan the delivery at a center where early management can be provided if required for the defect. At our center, the incidence of CHD among all pregnancy (14561) referred for fetal echo over 8 years (2011–2018 is 3.7% (541), with ventricular septal defect (VSD) attributing 24.2% (131) of all positive cases. The outcome of babies operated for complex CHD at birth or within 10 days (n = 29) has shown good result as there were no surgical or postoperative mortality in this group (Fig. 1).

Conflict of interest

None.

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