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EDITORIAL

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Burden of Congenital Heart Disease in Pakistan

Congenital heart diseases (CHD) are the most common birth defects. The birth prevalence of CHD is reported to be between 8 and 12 per 1000 live births.^{1,2} Reported figures vary worldwide, and majority of studies from Asia and Africa are either hospital based or community based. The low prevalence is likely to be due to a paucity of data, lack of access to health care, lack of trained health personnel, and very early mortality due to CHD. In fact, the birth prevalence of CHD in some of these low and middle-income countries may be higher due to increased rates of consanguinity, maternal infections such as rubella, and higher rates of diabetes mellitus and nutritional deficiencies in mothers. No birth prevalence study is available from Pakistan and most studies from the region including India have shown almost uniform prevalence rates for CHD across the globe.³

Considering a rate of nine per 1000 births, about 1.35 million babies are born with CHD each year globally.⁴ The true burden of the congenital heart disease (CHD) is not known as no birth prevalence study has ever been conducted in Pakistan. There is no national, provincial or regional program of newborn screening for critical CHD. Similarly there are no proper checks at school entry anywhere in the country. One-third births are still home deliveries, not attended by a skilled health personnel, hence hospital data will only give data of those children who actually make it to a hospital. The diagnosis of CHD in countries like Pakistan is also typically a chance event. A doctor or pediatrician makes the diagnosis when a doctor sees the baby for an illness or vaccination as routine postnatal check. The published hospital data clearly shows that the average age when the diagnosis of CHD is made is usually 6-12 months, which essentially means that majority of infants with critical CHD, do not make it to a hospital.^{5,6} There is a high rate of consanguinity and data from Pakistanis living in UK shows a higher incidence of CHD especially complex congenital

heart disease in the immigrant population as compared to the local caucasians.⁷ The incidence of post-viral as well as genetic and metabolic myocardial disease is also high due to a higher ratio of an inbreed community.

Pakistan with an estimated population of over 220 million is the fifth most populous country on the globe. It has one of the highest growth rates in the world (2%) and children under 18 years of age constitute 48.7% of the total population.⁸ The estimated number of children born with CHD in Pakistan with an assumed birth prevalence of 8-12/1000 and annual birth rate of 2%, is 40000 to 50000 children born with CHD every year. There is double burden of un-operated CHD in adolescents and adults, which is essentially unknown.

The authors from Jinnah Hospital Lahore (Iqbal et al) is publishing an original article in this issue of the journal, which focuses on frequencies of different congenital heart diseases in children coming for echocardiography in a tertiary care hospital.⁹ The department of cardiology in this hospital primarily focuses on adult cardiology and children from pediatric unit are referred for echocardiography. The authors conclude that in children, the most frequent congenital heart diseases were VSD, ASD, TOF and PDA in descending order of frequency. The most common acyanotic and cyanotic heart diseases were VSD and TOF respectively. This data is very similar to data reported from other institutions in the country.¹⁰⁻¹²

There are many limitations to delivery of care to these patients and the major limitations include overwhelming patient burden, too few centers, limited trained staff at all levels and not enough resources as treatment is very expensive and highly technology dependent. The highly trained staff is paid minimally in the government hospitals and has to work extra hours in private hospitals to earn their living. This not only affects the patient care at both government and private set-ups but also affects the quality of life and many professionals get frustrated and leave for Middle

East or return to the west (brain drain). There are patient related specific factors too like late presentation leading to pulmonary vascular disease, malnutrition, respiratory tract infections, anemia and other contributory factors like tuberculosis and worm infestation. Infection control and emergence of multi-drug resistant organisms is a major challenge in cardiac intensive care units and theatres.

Another important factor in future context is going to be adults with CHD. There are no specialized centers for adults with CHD. The exact prevalence is not known but there is a sizable population of un-operated adults with CHD and the number of adults with operated CHD is growing with the availability of treatment at major cities.

Most children with CHD living in developing countries do not have access to quality care. It is well established that the treatment of CHD is cost-effective, and this justifies the concept of pediatric cardiac care. However, a number of challenges/barriers need to be overcome before an average child living in a developing country has access to comprehensive cardiac care. Setting up programs that can deliver good outcomes at par to international programs is a huge challenge. The governmental support is key to the success of any program although support from NGOs can contribute too. The quality assurance is a major challenge in countries like Pakistan too. Currently infant and neonatal surgery is being offered in only couple of centers in the country and results although encouraging are not at par with advanced programs in the developed world. Setting up programs of CHD is a challenge but sustaining the program is an even bigger challenge and requires not only sustained financial resources and commitment of the government but an ongoing effort on part of the committed professionals.

We need to continue making efforts to improve the care of children with CHD, which must be complemented with research that is locally relevant.

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