### Fetal cardiology in India - At the crossroads

Congenital heart disease (CHD) contributes to a large share of infant mortality in the developing world. An important reason for this excess mortality in low- and middle-income countries like India is delayed recognition of critical CHDs,[1] which often need urgent life-saving interventions in the early neonatal or infantile period. Fetal echocardiography enables timely recognition of critical CHDs and thus, helps prevent the catastrophic consequences arising due to delayed diagnosis. Fetal echocardiography has become the standard of care in many developed countries. Studies have consistently demonstrated improved survival and surgical outcomes in babies with antenatally diagnosed CHD.[2] One in six children born globally is born in India, and it is estimated that 67,385 babies are born every day in India.[3] Apart from high birth rates, there are multiple challenges in the appropriate utilization of fetal echocardiography in India. In this editorial, we have focused on some of the challenges encountered in fetal cardiology in India, including delivery of fetal echocardiography services, research, and training.

## PRACTICE OF FETAL ECHOCARDIOGRAPHY IN INDIA

#### Who should perform fetal echocardiography?

The first aspect needing focus is who should do fetal echocardiography. Ideally, a pediatric cardiologist, who has a better understanding of the hemodynamics and natural history of various CHDs and has the experience managing these conditions after birth, should be performing fetal echocardiography. However, if this modality needs to be applied to a vast majority of our population, the number of trained pediatric cardiologists in the country is woefully inadequate.[1] Hence, the next best options include radiologists and fetal medicine specialists who have received adequate training in fetal echocardiography. Radiologists and fetal medicine experts need to be trained in a structured fashion to acquire and interpret fetal cardiac views, including situs assessment, four chambers, outflow tract, bicaval, ductal arch, and aortic arch views. Recently, the Indian Radiological and Imaging Association has proposed a practical guide for performing and reporting fetal echocardiography for radiologists in rural and semi-urban India.[4] In this issue, Karippaliyil et al. have compiled an excellent collection of fetal cardiac sectional schemas.<sup>[5]</sup> These publications would be of use to radiologists and fellows who are interested in learning the nuances of fetal echocardiography. In an ideal scenario, all abnormal scans should be interpreted

and confirmed by a trained pediatric cardiologist, who also should be providing antenatal counseling for these parents. With the increasing use of telemedicine and artificial intelligence, it is possible to deliver such services even to the remote corners of India. Provisions of the Pre-Conception and Pre-Natal Diagnostic Techniques Act (PC PNDT) pose certain challenges in the widespread application of fetal echocardiography. For instance, trained pediatric cardiologists in some states could not register themselves for performing fetal ultrasounds. We need to evolve a uniform policy at the same time abiding by all the provisions of the PC-PNDT act.

#### Timing of fetal echocardiography

The timing of fetal echocardiography is important for the sake of decision-making by the family. It should begin with the first trimester screening including nuchal translucency and a basic survey for major anomalies. The second trimester anomaly scan (18 - 22 weeks) is expected to pick up the rest of the major anomalies. Quality reporting of second-trimester anomaly scans is especially important for suspecting CHDs. Various international bodies have laid down guidelines for the indications and performance of fetal echocardiography. [6,7] However, only a small proportion of indicated mothers get fetal echocardiography in India. Although accurate estimates in India are lacking, only 1%-2% of pregnant mothers were estimated to avail of fetal echocardiography, according to a report published in 2013.[8] However, these estimates are based on a survey by obstetricians in Mumbai and a true estimate across the country is likely to be much lower. The proportion of fetal echocardiography done at the ideal gestation is abysmally low. In most of the reported series, the mean gestation for fetal echocardiography is beyond 20 weeks.[9,10]

The recent (2021) amendment to the Medical Termination of Pregnancy (MTP) Act extends the upper limit for MTP from 20 to 24 weeks for certain categories of women, including fetuses with serious congenital malformations that are incompatible with life or at risk of being seriously physically challenged. Whereas there is some consensus regarding extending the limits of MTP for maternal indications, there is lack of uniformity among medical boards in extending the limits for fetuses with serious cardiac malformations.

### What happens with a fetal diagnosis of serious congenital heart disease?

The role of fetal echocardiography is infallible and has immense impact; provided it is done and interpreted in time and proper counseling is done. The place, timing, and mode of delivery are decided according to the severity of CHD and the requirement for immediate postnatal intervention. In certain cases, identification of a CHD in the fetus may lead toward testing for underlying syndromic association and genetic counseling. Social support groups may be created with the parents who have already been through these stages and/or received treatment for their children with CHD so that guidance could be provided from a parental or family perspective. However, such organized teams helping families with an informed decision is lacking in India. The role of counseling cannot be overemphasized. It is expected that the pediatric cardiologist, who is familiar with the natural history and hemodynamics of CHD and is aware of the timing of interventions, provides basic counseling to families with an antenatal diagnosis of CHD. The availability of such expertise is restricted to the limits of major metropolitan cities, and this is especially true in some of the most populous states of our country.[1] It may be overwhelming for the pediatric cardiologists in India, once the number of fetal diagnoses go up.

Obstetricians are the primary caregivers for a pregnant women and decisions regarding pregnancy are typically taken by patient in consultation with their obstetrician. Awareness building amongst obstetricians is perhaps the most critical initiative, which can make a substantial change in informed collective decision making. We need to change from a "Stand alone" approach of functioning to a system driven "all-inclusive approach." We need to develop an efficient in-utero referral network that suits the need and availability of expertise in each region. Such an approach is possible even in low resource settings as evident from the Kerala model.<sup>[9]</sup>

### Is fetal echocardiography a double-edged sword in India?

The socio-cultural beliefs in India are very varied and hence the diagnosis may culminate in termination for simple lesions or continuation of pregnancy even if complex lesions are diagnosed well in time. A balanced approach would be ideal. However, the decision to terminate pregnancy is complex and the determinants include anticipated outcome of CHD, associated noncardiac anomalies and expectations/attitudes of parents and their educational status. In contrast to western data, limited data from Indian centers suggest that fetal echocardiography does not result in the increase in utilization of neonatal cardiac services. A few reports suggest that the increase in resource utilization after fetal diagnosis is only 20%, and nearly 50% fetuses do not survive even with treatable CHD.[8,9,11,12] Prenatal diagnosis is often associated with higher rates of chromosomal anomalies and complex CHD. Still, more than 50% fetuses getting terminated may indicate that we are possibly not using fetal echocardiography optimally

in India. Widespread availability of MTP, lack of neonatal cardiology services, and lack of financial support are some of the factors that result in lesser survival among fetuses with CHD. Without a pediatric cardiology team capable of delivering excellent outcomes in neonates, prenatal diagnosis cannot achieve the objectives it intends to achieve. Funding for such care remains a major challenge in India. Initiatives like Hridyam scheme in Kerala and inclusion of pediatric cardiology services under the ambit of public/private health insurance will be essential to make the services affordable.

It is difficult to come up with guidelines about when to terminate pregnancy considering the various cultural, social, economic, and religious factors playing a significant role in addition to the cardiac diagnosis and its outcome. Pediatric Cardiac Society of India (PCSI) has constituted a writing committee to formulate position statement for the management of pregnancy and MTP following antenatal diagnosis of various CHDs.

#### Fetal cardiology beyond echocardiography

Apart from diagnostic aspects, there has been expanding interest in the area of fetal therapeutics such as transplacental therapy for arrhythmias or rhabdomyomas. A few case series from India report successful management of various fetal arrhythmias<sup>[13]</sup> and rhabdomyoma.<sup>[14]</sup> A handful of fetal structural interventions have also been performed in few centers in India. However, they are yet to be established as a standard of care, which may be due to the lack of dedicated fetal cardiac units/specialists, and preoccupation with other priorities.

# RESEARCH IN FETAL CARDIOLOGY IN INDIA

Most of the published papers on fetal echocardiography from India focused on the feasibility and description of fetal cardiac diagnosis from single large centers. [10,15-18] A few papers reported fetal diagnosis and outcome of specific lesions including univentricular hearts, [9] conotruncal anomalies, [19] aortopulmonary window, [20] double outlet right ventricle, [21] and vascular rings. [22] An interesting study reported fetal diagnostic yield in Indian diabetic mothers. [23]

A few Indian studies have highlighted the impact of fetal echocardiography on the postnatal outcomes of children born with CHD.<sup>[9,11,12,19,22,24,25]</sup> Studies suggested that fetal echocardiography improved postnatal outcomes,<sup>[12,13,19]</sup> reduced cost of care by 16.2%,<sup>[11]</sup> led to planned peripartum care and improved preoperative status in neonates with critical CHD even in a low-resource setting.<sup>[26]</sup> However, none of the studies showed a reduction in mortality. An interesting analysis reported the varied referral pattern in India.<sup>[27]</sup> Warrier

et al. reported an abysmally low awareness (2.2%) of fetal echocardiography even among parents visiting a tertiary care center in a metro city.<sup>[28]</sup>

Numerous case reports in fetal echocardiography are reported from India due to the sheer numbers of fetal scans performed. Most of the case reports focused on the diagnosis of unusual lesions, [29-32] early pick up of difficult lesions, [33,34] or diagnosis of associated noncardiac lesions. The use of newer modalities such as 4D fetal echocardiography and spatiotemporal image correlation (STIC) imaging [36] would further help enhance the imaging quality and delineation of the anomalies.

Most of the impactful research papers from India are the works of a handful of dedicated researchers. Almost all the fetal echocardiography studies are from tertiary care centers and are confounded by referral bias and often report remarkably high yields and accuracy. The results may be substantially different in primary and secondary care settings. There are no prospective population-based studies on fetal cardiac diagnosis in India. The scope for research in fetal cardiology is immense in India. The talented pool of researchers should come together, identify focus areas, and generate multicentric data that could take fetal cardiac science forward.

## TRAINING IN FETAL ECHOCARDIOGRAPHY IN INDIA

Most of the Indian experts had their training in fetal echocardiography either in Europe, America, or Australia. However, we now have fetal cardiology centers of excellence in India, which can train the next generation of experts. However, accredited fellowships in fetal cardiology are limited, and most of the training is informal. PCSI has constituted fellowship training in fetal cardiology, and the first batch of fellows have received their certification. More such courses, which are accredited by regulatory agencies, are needed.

#### **CONCLUSIONS**

The major roadblocks to universal access to antenatal diagnosis of CHD in India include lack of awareness, low resources, late referrals, and low utilization of services. The key towards developing a successful fetal cardiology program is "an all-inclusive approach" and developing an in-utero referral network for prenatal diagnosis, referral, counseling, and planned peripartum care. The availability of fetal cardiology services and research and training opportunities have increased several folds in the past decade. Fetal cardiology in India is at crossroads. It is time for everyone in the field to come together and give a thrust and direction to the field in India, so that we may reach the destination sooner than later.

"Direction determines destination."-Jim Rohn.

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