Adult Congenital Heart Disease (ACHD): A Crack of Our Medical System

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Improved medical and surgical treatment facilities for children suffering from congenital heart disease have resulted in a growing population of patient reaching adulthood. One million people over the age 20 years suffer from congenital heart disease in USA. Population of adult CHD is growing at rate of 5% per year in USA and the number of patient with congenital heart disease are more in the age group over 20 year than less than 20 years[1-2]. The annual number of hospitalizations of adults with CHD more than doubled in the US between 1998 and 2005. During that same period of time, hospitalization for adults with complex CHD increased 60%[1]. Current estimates of the ever expanding populations of adults with congenital heart disease are 1.2 million in Europe and over 1 million in the USA alone[3].

Adult CHD cases has the chance to slip through the cracks of our medical system as many of them are too old to be cared by paediatirc cardiologist and unfortunately most of the adult cardiologists are not trained in congenital heart disease[4].

So it is important to identify congenital heart diseases in adult and to be treated through a separate program. Many adults with uncorrected or previously palliated congenital heart disease has more options available now as reasonable addition, alternative better treatment of choice when further medical or surgical treatment is required.

Commonly encountered cardiac defects in adolescents and adults are limited. Common acyanotic congenital heart disease in the adult population are primarily left to right shunts such as atrial septal defect (ASD), patent ductus arteriosus (PDA), patent foramen ovale (PFO), ventricular septal defects (VSD) etc. Obstructive and other left sided lesions are aortic stenosis (AS), Coarctation of the aorta (CoA), subaortic stenosis and Mitral valve prolapse. Common right sided lesions are pulmonary stenosis (PS), sub pulmonary stenosis, supra pulmonary stenosis, tricuspid stenosis and regurgitation, ebstein anomaly etc. The most common form of cyanotic congenital heart disease in adult is tetralogy of Fallot (ToF). Other complex conditions in adults are univentricular heart, corrected transposition of the great arteries (C-TGA), single ventricle, persistent truncus arteriosus (PTA) etc. Most of these patients will also need to undergo catheterization, percutaneous intervention and surgeries. Results of all these treatment options are excellent in adult population[1,5-7].

Currently interventional cardiology of adult congenital heart disease (ACHD) is well established field on its own in most of the countries along with other options[5]. Every paediatric program is forwarding their cases to adult program as well as newly diagnosed cases are being added. The wide variation in clinical presentation, novelty of cardiovascular pathologies and potential for concomitant multiple organ system involvement contributed to situations atypical for standard adult or paediatirc laboratories and programs. Long term follow up is also needed for ACHD cases. They also need advices for job selection, lifestyle, insurance, marriage, conception, pregnancy and also support for treatment of other diseases under other specialty. These concerns, combined with a desire to produce separate data for ACHD to determine their outcome need a consideration for separate ACHD program in Bangladesh[4,6-10].

In paediatric cardiac center of combined military hospital (CMH) Dhaka and in Labaid cardiac hospital, about fifty cases under follow up are reaching adulthood per year. Every day in OPD clinic of both hospitals, about 8-10 cases of ACHD report for work up either as new case or as previously treated case[10].

As paediatric cardiology service was initiated in Bangladesh in 1998, many simple form of congenital heart diseases compatible with survival were missed from detection in childhood and now they are coming as new cases when incidentally detected for other reason or for the appearance of symptoms itself. All these cases are being treated by paediatirc cardiologists for few reasons:

1. ACHD service is not available in Bangladesh yet as separate specialty
2. Children under care of paediatirc cardiologist don't like to change their familiar environment and caring staff when they reach adulthood.
3. Adult cardiologists are not trained in congenital heart disease so they do not understand the complex nature of disease and follow up guidelines.

Currently we are getting large number of ACHD patients from following sources:

1. Medical test for recruitment in Armed forces.
2. Medical test for admission in Medical colleges and other higher studies including foreign courses.

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3. Incapability of attending and passing physical fitness test in military services.
4. Antenatal check up of pregnant women who experience unusual dyspnea.
5. Pre anesthetic check up prior to other surgery.
6. Incidental murmur during auscultation of precordium for other reasons.
7. Postoperative and post interventional follow up cases.
8. Eisenmenger syndromes resulted from complications of previous untreated shunt lesions.
9. Incidental diagnosis of PFO secondary to stroke, Migraine and neurological complications.
10. Pace maker check up of postsurgical cases during child hood and cases with congenital complete heart block.

As considerable progress has been made over the last decades in the diagnosis and treatment of CHD, over 90% of children born with this condition are expected to survive into adulthood. Population of ACHD cases requiring interventions are also increasing tremendously. The appropriate training program for the physicians who seek to perform ACHD is still unclear. The profile of the interventional cardiologists for ACHD may vary from specific ACHD interventionalist, paediatirc interventionalist and structuralist. Alternative option is, a paediatirc cardiologist trained in interventions may be able to expand their expertise to adult patient[11]. Last option is playing vital role in Bangladesh so far[11,12].

When adult congenital heart disease cases are evaluated, office set up, staffing, ambience, style are different from that of a child. They also need special care and advice in selecting job, sexuality, exercise. Women need advice regarding conception and pregnancy. Considering above factors, we need a separate subspecialty with separate course and training program to deal with all problems of being an adult and having congenital heart disease.

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