

Why Do We Miss A Congenital Heart Disease? Pediatricians' Point of View

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Congenital heart disease (CHD) is the most common cause of major congenital anomalies representing a major global health problem. Approximately 1/100 baby is born with CHD, in which one fourth are critical CHD. In Indonesia, five million infants are born each year and 50,000 babies are born with CHD and 12,500 babies are critical CHD. While in some high-income countries prenatal diagnosis is used to detect CHD before birth, in low- and middle-income countries only few children with CHD are early detected.

The proportion of children who missed diagnosis is vary among centers, and much higher in low- and middle-income countries compared to high-income countries. Among 838 children aged less than 18 years with newly diagnosed as CHD at the Dr Sardjito Hospital, Yogyakarta, Indonesia during 1st February 2016 to 31st July 2017, around two-third were missed diagnosis. Patients with cyanotic CHD were lately diagnosed when they discovered after they had initially been discharged home from a birth clinic. Similarly, patients with acyanotic CHD are missed diagnosis when an elective cardiac procedure or an immediate treatment should have already been performed at the initial visit. The reasons of these missed diagnosis of CHD were related to delayed first consultation to a doctor (general practitioner, pediatrician, or other specialists), delayed diagnosis by doctors, delayed referral to the center for CHD care, midwifery care, financial and social factors (any personal, cultural or spiritual beliefs that hinder a proper diagnosis and treatment of CHD). Indeed, lack of awareness among health care workers could be considered as one of the most underlying causes for the delays. Majority of pediatricians receive little or no training in pediatric cardiology because there are very few pediatric cardiac programs in Indonesia. Further, lack of pediatric cardiologists in Indonesia, lack of skilled personnel, and absence of facility for cardiac surgery might contribute to the delays. In order not to miss a CHD, some possible attempts should be made including the improvement of early CHD recognition among health care providers. These include the use of signs and symptoms of CHD particularly in low-income countries including recurrent cough, dyspnea, poor feeding, poor weight gain, excessive sweating, central cyanosis, heart murmur, abnormal chest-xray or electrocardiogram as well as the use of pulse oximetry screening for critical cyanotic CHD.

Among those with missed diagnosis of CHD might present at a late stage and have few benefits from surgical treatment. Mortality in CHD is changing in the last decades with increase in survival among children who have a proper diagnosis and management of CHD in high-income countries, or the presence of those with missed diagnosis that survive particularly in low- and middle-income countries. Complications at the diagnosis of CHD in older children with delayed diagnosis were prevalent. The most common complications among those with missed diagnosis of CHD in our study included congestive heart failure and pulmonary hypertension at 49% and 15.3%, respectively. The management of those late presenters is challenging and requires a comprehensive and multidisciplinary approach focusing on the complexity of CHD and therapeutic options, surgical complexity, neurological factors, physical impairment, psychosocial and economic factors, and clinical point of view. Further, a careful long-term evaluation and follow-up of the present and residual cardiac anomalies need to be taken into account to make a decision concerning problems related to the late presentation of CHD. A proper and smooth transition from pediatric cardiologist and cardiac surgeon to adult cardiologist is necessary. Further, a model of mentoring and supporting physicians and other staff from well-established CHD centers in high-income countries to establish a high-quality referral and cardiac training centers in low-middle income countries should be prioritized.