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Pulmonary Hypertension in Adult Congenital Heart Disease: From Registry to Policy

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Abstract

Pulmonary hypertension (PH) is a chronic disease characterized by vasoconstriction and cell proliferation in the pulmonary vasculature and defines as an elevation of mean pulmonary arterial pressure more than 25 mmHg as assessed by right heart catheterization. According to the classification of pulmonary hypertension by World Symposium of Pulmonary Hypertension (WSPH) 2013, PH is divided into five groups. Pulmonary Arterial Hypertension (PAH) is group 1 of PH Classification. The clinical classification of PH into five groups is according to their similar clinical presentation, pathological findings, hemodynamic characteristics and treatment strategy. Congenital heart disease is one of disease that associate with the development of PAH.
The Jogjakarta Congenital Heart Disease-Pulmonary Hypertension (COHARD-PH) study is a registry of Adult Congenital Heart Disease (ACHD) and PH in Dr. Sardjito Hospital Yogyakarta Indonesia, which is a national referral hospital in the region. The COHARD-PH has been conducted since 5 years ago and until currently there are 696 ACHD patients enrolled. The population of COHARD-PH registry is predominantly woman patients and young age with less than 40 years old. Most of the patients have already suffered from PH (70%) that is diagnosed by right heart catheterization (RHC). The utility of RHC itself to diagnose PAH, based on guideline, is only available in our hospital in the region.
The high prevalence of ACHD in Yogyakarta region and surrounding area coming to our hospital due to PH sign and symptom is a concern. The region with limited facility to diagnose and availability of drugs urges us to make strategy to detect the CHD in the earliest. A preventive policy such as screening of CHD as early as possible so that the case finding will increase and a proposal to the government to fully provide the availability of PH drugs in those affected. The strategies may be effective in reducing morbidity and mortality of the disease and also increasing quality of life for the patients.

Keywords: Pulmonary Arterial Hypertension, Adult Congenital Heart Disease, government policy, registry