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Adult Congenital Heart Disease in Greece: Need for a Step Forward

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Congenital heart disease (CHD) is common, occurring in ~8 of 1000 live births, with 90% of children born with heart defects surviving to adulthood. This has occurred mainly due to the progress in cardiothoracic surgery over the recent decades and the ongoing improvements in the diagnostic, interventional, and critical care skills of the paediatric and adult cardiologists who care for these patients. Based on the above numbers, is it estimated that every year ~1000 babies with CHD are born in Greece, while there are 40,000-50,000 adolescents and adults with various types of congenital heart lesions in the country. Adult patients have probably outnumbered their paediatric counterparts for the first time. These patients increasingly present to cardiologists' offices for care; therefore, healthcare providers will need to develop a better level of comfort with adult patients with CHD (ACHD).

ACHD patients represent a wide spectrum of disease, from small septal defects and minor valvular lesions to complex anatomies that have been palliated early in life with, sometimes multiple, surgical repairs. The causal and phenotypic heterogeneity of CHD is an issue that influences management, and results in difficulties when it comes to enhancing research opportunities and designing large randomised studies in this population. In fact, current practice in the risk stratification and management of ACHD has been implemented after extrapolation from similarities in the pathophysiology and clinical course to acquired heart disease.¹⁻³

In order to provide these patients with high quality care, there are a number of issues that need to be resolved in our national healthcare system. Firstly, specialty clinics and regional centres of excellence for

the care of ACHD patients are insufficient. These patients should be followed by adult cardiologists specialised in their management. Although every ACHD patient should have a primary care physician, it is at least sad that patients with complex anatomy are managed exclusively by physicians who are not experienced in CHD. Every academic adult cardiology/cardiac surgery centre should have access to a regional ACHD unit for consultation and referral. Governmental agencies and national physician associations are currently trying to define the scope of this national healthcare issue and to determine how best to educate and train current and future generations of cardiologists. Practice nurses, physician assistants, psychologists, and social workers should cooperate closely with the physicians and play an integral role in assessing and providing care for the psychosocial needs of ACHD patients. Finally, when assessing these patients it should not be overlooked that as they grow older, they become more likely to develop coronary artery disease. Traditional cardiovascular risk factors for atherosclerosis also apply to ACHD patients, in whom primary prevention should be as important as in the general population.⁴

An increasingly important problem is the unacceptably high number of patients who are lost to follow up. A recent article demonstrated that 61% of adult patients with CHD in Quebec, Canada, fail to receive cardiac follow up.⁵ Recent guidelines recommend a formal transition process, which should begin by 12 years of age and should be individualised on the basis of the patient's maturity level.⁶ Failure to have guided transition from paediatric to adult care remains a barrier to healthcare access for ACHD patients in Greece. Insufficient education of patients

and caregivers regarding disease nature and follow up might be a limitation in our health system. Now more than ever, there is a need for a structured transitional programme in order to maintain the benefits from early intervention for CHD patients, while close collaboration between adult units and their paediatric counterparts is essential for maximising the potential gains from such endeavours.⁷

The next generation will see important changes in Greek ACHD care. It is, therefore, of major importance to educate adult cardiologists with focused conference meetings, train cardiology residents with rounds in ACHD clinics, and organise high quality research on the basis of national registries and close collaboration between regional centres. These young patients with a complex chronic illness should receive high quality care, where the main goal is to enable them to lead meaningful and productive lives.

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