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Guidelines

Recommendations to organize care for adults with congenital heart disease in the Czech Republic



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ABSTRACT

This paper was formed by the Expert committee for congenital heart disease (CHD) in adults – a division of Czech Society of Cardiology (ČKS). It was designed as an appendix to *National cardiovascular programme ČKS* created in 2013 and was based on *Recommendations for organization of care for adults with congenital heart disease and for training in the subspecialty of 'Grown-up Congenital Heart Disease' in Europe: a position paper of the Working Group on Grown-up Congenital Heart Disease of the European Society of Cardiology* created in 2014 [1].

Aims of this paper are: To optimize medical care in all its aspects for adults with CHD in the Czech Republic, to facilitate easy transition between paediatric and adult medical care, to enable research in the field in order to create evidence based care, to support training of regional cardiologists and other specialists who are involved in monitoring adult patients with CHD, to help with communication with national institutions, to provide information for other medical workers and patients, to consolidate resources.

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Introduction

Incidence of CHD is 6–8 per 1000 newborns. Progress of paediatric cardiology and cardiac surgery dating back to 8th decade of previous century led over time to significant increase in long-term survival of patients with CHD. Today about 90% of patients with CHD grow into adulthood [2]. The estimated prevalence of all CHDs is 12/1000 in children and 5/1000 in adults, the estimated prevalence of critical/severe CHDs is 1.45/1000 in children and 0.38/1000 in adults [3], while each year the absolute number of adults with CHD increases by 5% [4]. Total number of adults with CHD in the European Union is estimated around 2.3 million (for comparison total number of adults with ischaemic heart disease is 24 million) [5].

If we extrapolate above mentioned data, we should end up with around 53,000 adults with CHD (including atrial septal defects and bicuspid aortic valve) in the Czech Republic, 4000 of these would have a severe CHD. At the moment three complex centres specializing in CHD in the Czech Republic register 9000 adult patients diagnosed with CHD. Frequency of hospitalizations of adult patients with CHD has increased by 81.5% between 2003 and 2010 and mean age at time of hospitalization has increased from 53.5 years to 57.5 [6]. This increase of hospitalizations of adults with CHD has even overcome number of hospitalizations of children with CHD [7].

Due to significant decrease in early mortality in patients with CHD the modern medical care now encounters and has to deal with long-term complications of CHD such as chronic heart failure, high risk of infective endocarditis, higher occurrence of arrhythmias, pulmonary hypertension, valve

defects and complications during pregnancy. Wide range of CHD can be categorized as a rare disease (occurring in less than 5/10,000 people) [8]. Population of adult patients with CHD is and will always be relatively small but at the same time it is and will be very heterogeneous in spectrum of CHD and their particular complications and subsequent management. These guidelines in combination with super-specialized multi-disciplinary medical care are in accord with *National strategy for rare diseases for years 2010 to 2020*. This means that implementation of these guidelines into medical care should increase efficiency of diagnostic and treatment process of rare diseases (in our case CHD) and should provide all patients with rare disease with indicated and high-quality medical care and help them with social incorporation [9].

Organization of care

System of medical care for adults with CHD in Czech Republic should be a continuation of the well working system of medical care for children with CHD. Specialized care for children with CHD is covered by one complex cardiac centre (Children's Heart Centre, University Hospital Motol, Prague) with a long-term stable outcome of 400–500 surgical interventions each year. This centre is directly connected to a nation-wide network of paediatric cardiologists and also closely cooperates with neonatology and paediatric units in the whole Czech Republic [10].

Follow-up observation of adult patients is to be similarly managed by a network of specialized centres for CHD in adults (CHD centres), complex cardiovascular centres (with a

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