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Complex ACHD patients – 15 years of care in a specialized tertiary care

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In response to the increasing number of adults with congenital heart disease (ACHD), the first specialized tertiary care facility in Hungary developed in 2000. Patients with a complex severity (severe and moderate lesions) have been rigorously followed in our centre. Objectives. To characterize the major features of this largest tertiary ACHD centre in Hungary, with a focus on ambulatory care, hospital admissions and mortality data of those patients with complex disease. Methods: Prospectively collected data were analyzed from our database. Results: A total number of 1391 patients (mean age 31 ± 18 years) have complex congenital lesions (moderate, 30%; severe, 70%). Eighty-three percent of these patients had undergone one or more reparative surgeries. Age at transfer from pediatric to adult care has decreased over a 15 years period from 25-30 to 18-20 years. Compared with year 2000, by 2015 the number of new patients /year increased from 30 to 116; the outpatient visit/week has been 15 times higher, and the overall hospital admissions 7 times higher. Whether in 2000 hospital admissions meant mostly surgical interventions for residual lesion, nowadays the major issues are arrhythmias, heart failure, and pulmonary hypertension. Lapse of follow-up (> 3 years) has been present in 16% of patients with severe and 14% in moderate lesions. Overall, 52 complex patients died. Conclusions: This study gives an insight in the current trends in complex ACHD patients care, characterized by increasing number of patients, more committed patients to specialized follow-up, and better survival.