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Evaluation of knowledge level of adolescents and adults with congenital heart disease: Effectiveness of a structured CHD education program in adolescents

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Background Adolescents with congenital heart disease (CHD) constitute a growing population of individuals for whom a well-planned and well-executed ''transition process'' is essential. Transition program should include education about medical conditions and promote skills in decision-making and self-care. To improve their level of health related knowledge, a structured education program was implemented in a transition CHD program. This study aimed 1/to evaluate level of knowledge of adolescents who received structured CHD education as compared to adults who did not, 2/to evaluate whether patients who received structured education improve their knowledge.

Methods and results 42 adolescents (16 ± 2 years old, 21 girls) were included in a structured CHD education program and were compared to 22 adults (33 ± 7, 6 women) with CHD who have never followed education program. Knowledge in adolescents was assessed before and after the educational program using questionnaire exploring specific issues related to CHD. A same questionnaire was used in non-educated adult patients. The mean total knowledge score in the educated adolescent group was significantly higher as compared to the non-educated adult with CHD (score = 15.6/20 ± 3.6 vs. 12.5 ± 4.5, $P < 0.01$). Provision of structured CHD education and female sex were determinant of higher levels of knowledge. A significant improvement of knowledge was observed in adolescents group after CHD education program (range of increase was 23 to 44%). This result was not influenced by age, sex, education level, socio-economic status of parents and disease complexity, and persists at 10 months mean follow-up.

Conclusion A structured education program was associated with a higher level of knowledge, above all in male CHD patients. Education at transition period has a significant impact on the adolescent knowledge. Structured education program should improve adult CHD understanding of their heart condition, and could prevent potential complications.

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Long-term experience with heart transplantation in children and patients with congenital heart disease

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Methods Retrospective single-centre analysis of long-term post-transplant outcome, with chart collection of clinical and paraclinical data [this study assessed the long-term outcome of heart (HTx) and heart-lung transplantation (HLTx) in patients with congenital heart disease (CHD) and children with non-congenital cardiac or pulmonary disease.]

Results From 1984 to 2013, 111 first-HTx, 5 HLTx and 6 re-HTx were performed (62 males), in patients aged 11.7 ± 8.2 y: 96 (79%) aged < 18 y. Cardiopathy included 61 cardiomyopathies (50.8%), 50 CHD (41.7%), 6 retransplants (5%). HLTx included 1 Eisenmenger, 1 PPHT, and 2 pulmonary diseases. Patients with cardiomyopathy were younger than CHD (8.7 y vs. 14.9 y). Seventeen (14%) patients had circulatory mechanical support as bridge to transplant. Acute rejection occurred more frequently within the first year post-transplant or > 5th year in non-compliant teenagers. Overall, 33 patients died (27%), 3.5 ± 4.6 y post-Tx (1 day to 16.4 y, med 1.5 months), due to early multivisceral failure in 6 (18%), pulmonary hypertension in 3 (9%), acute rejection in 7 (21%), graft coronary disease in 6 (18%), sepsis in 5 (15%) and miscellaneous in 6. Graft coronary disease occurred in 15 (12.4%): 4 had re-HTx, 6 died and 5 are alive. Five lymphoma occurred, 4 months to 14 y after HTx, cured in 4 (1 died). Patients survival was 85% at 1 y, 81% at 5 y, 70% at 10 y and 61% at 20 y post-transplant. Graft survival rates were respectively 82%, 68% and 52% at 5 y, 10 y and 20 y post-transplant. Survival did not differ with pretransplant disease, age, gender, pre-transplant mechanical support. Mortality was higher in patients with coronary disease (40%) than those free from (25%).

Conclusion Long-term prognosis after HTx and HLTx is favourable. Graft coronary disease is the main cause of failure, less frequent than in the adult non-CHD heart-transplanted population.

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Risk markers of cardiac events in patients with Marfan syndrome diagnosed during childhood

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