Health-Related Quality of Life in Children with Surgical Therapy of Congenital Heart Disease

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Background: Although survival of children with congenital heart disease (CHD) has improved significantly, their health-related quality of life (HRQoL) is less inquired, particularly in relation to surgical therapy. Since 2009, HRQoL has been assessed in part with DISABKIDS questionnaire (DCMG12), and recorded in the Swedish national registry of congenital heart disease (SWEDCON).

Methods: A retrospective SWEDCON survey of 365 children (147 girls and 218 boys; age 9-18 years). The majority (n=345) had biventricular heart (BVH), while the remaining (n=21) had univentricular heart (UVH). Cardiac surgery ± catheter therapy was pursued in 218 children. NYHA class and indices of cognitive function (learning ability) were available in 359 children. HRQoL from DISABKIDS was expressed as total score (TS; range from 0 to 100 highest). TS data are given as median / interquartile range (25-75 percentiles). Kruskal Wallis or Mann-Whitney test, when appropriate, were used as statistical analyses.

Results: DISABKIDS was answered by 340 children. In the whole cohort, TS was high (95/ 88-100) without any difference in gender (p=0.78) or age (p=0.1). There was no difference in TS between BVH and UVH children (p=0.57). In the BVH cohort, TS was lower in those with previous surgery than in those without (95/83-100 and 98/90-100 respectively; p=0.008). Children with ≥ 3 surgeries (n=32) had the lowest TS (81/69-93; p < 0.001), needed more often aid in school (p =0.024) and had more frequently NYHA ≥ 2 (p= 0.006 vs NYHA 1). As much as 96 % children without surgery (n=138) attended regular school and were classified in NYHA1. In those with surgery (n=154), 79 % attended regular school and 81% were in NYHA 1 (p<0.001 versus nonsurgical cohort).

Conclusion: Overall, children with biventricular CHD have high HRQoL. Cardiac surgeries appear to have cumulative adverse effect on HRQoL, learning ability and NYHA. Further larger studies are warranted to validate these findings and to assess the efficacy of putative interventions in improving HRQoL in this cohort.