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What determines quality of life in pre-school aged children with single ventricle congenital heart disease – Surgery, Hemodynamics, Bayley Scales or Brain Volumes?

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Objectives: Little is known about health-related quality of life (HRQoL) in pre-school age in children with congenital heart disease (CHD) undergoing Fontan palliation. We aimed on HRQoL in preschoolers with single ventricle (SV) CHD by determining patient-related, clinical variables, and their impact of HRQoL with various dimensions of daily functioning.

Methods: Prospective two-center cohort study in children without genetic comorbidity undergoing Fontan palliation for SV CHD at 26.3±3.4 (mean±SD) years of age. HRQoL was assessed by parental report of the Preschool Pediatric Cardiac Quality of Life Inventory (P-PCQLI) one year later at 3-4 years, compared to normative data of children with mixed types of CHD using linear multivariable regression analysis. The influence of hemodynamics determined by catheter measurements, cerebral findings by magnetic resonance imaging, and neurodevelopmental outcome by the Bayley scales III, all assessed before Fontan palliation on later HRQoL were also determined.

Results: 46 children were evaluated with the HRQoL at an age of 38.9±3.6 years. Total HRQoL score was comparable to children with mixed CHD at 41.7±3.3 years. Perioperative variables (summarized in a surgery severity score) were significant determinants of HRQoL at that age, explaining a variability for the total score of 24%, for the physical score of 28% and for the social score of 18%. The surgery severity score and preterm birth predicted the therapy HRQoL (adjusted R2=0.22), whereas preterm birth was the only predicting variable for functional HRQoL (R2=0.15). Pre Fontan hemodynamics and brain volumes showed mild univariate correlations with HRQoL subscores, but were not significant in multivariable analysis (i.e. determining < 10% variability for physical score). The Bayley scales III as well as the presence and type of cerebral lesions on MRI were not predictive for HRQoL at pre-school age.

Conclusions: Despite substantial health-related burden, pre-schoolers with SV CHD are reported to have a good HRQoL. Perioperative risk factors have a stronger impact on HRQoL at pre-school age compared to pre Fontan hemodynamics, brain volumes and neurodevelopmental outcome assessments. In future, reports on patient-individual self-rated HRQoL at school age are needed to determine the impact of the analyzed factors on follow up at school age.