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Children and adolescents with congenital heart defect show equal or even better health related quality of life than healthy controls

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Introduction: Improved treatments for patients with congenital heart disease (CHD) decrease the mortality rate and lead to a growing importance of long-term outcomes like health related quality of life (HRQoL). Although there already exist numerous studies, an influence of CHD on HRQoL is not certain. Especially the results concerning the impact of particular diagnoses are not homogenous, mostly even contradicting.

Methods: The cross-sectional study included 390 patients (143 girls) aged 6 to 17 years (12.7 ± 3.3 years), recruited in the German Heart Centre Munich between July 2014 and December 2015. To evaluate the HRQoL an age-adapted questionnaire (KINDL®) for self-report was used which includes six subcategories: physical, psychical, family-, social-, and school-related well-being as well as self-esteem. The data of the patients were compared to 734 healthy children (346 girls, 13.5 ± 2.1 years), which were examined between 2011 and 2013. Three analyses were performed: (1) comparison of healthy and CHD, (2) comparison of severity class simple ($n=98$), moderate ($n=86$) or severe heart defect ($n=166$), (3) diagnostic subgroup analysis of patients with Aortic Coarctation/Aortic Stenosis (CoA/AS $n=81$), Tetralogy of Fallot/Pulmonic Stenosis (ToF/PS $n=55$), Atrial Septal Defect/Ventricular Septal Defect/Atrioventricular Septal Defect (Shunts $n=63$), Transposition of the Great Arteries (TGA $n=44$), Univentricular Heart (UVH $n=50$). In all analyses the influence of age and sex was controlled by a multivariate regression model.

Results: Current children and adolescents with CHD have a better HRQoL compared to healthy peers (CHD: 78.6 ± 9.7 vs. healthy: 75.6 ± 10.1 ; $p < .001$). Still after correction for sex and age children with CHD present a 2.1 higher HRQoL ($B=2.1$, $p=.001$). In the subcategories family-related well-being ($B=2.4$, $p=.009$), school-related well-being ($B=7.3$, $p < .001$) and self-esteem ($B=3.1$, $p=.005$) they show even higher values. Children with simple, moderate or severe heart defect do not differ in a single domain. There was no difference in-between the diagnostic subgroups, only children with shunts showed worse HRQoL results ($B=-3.1$, $p=.007$).

Conclusion: Children with CHD can cope well with the adverse impact of their disease so that no negative influence on HRQoL is evident. This holds true for all severity classes and almost all diagnostic subgroups.