Quality of life of children with congenital heart diseases: a multi-center controlled cross-sectional study


Pediatric and Congenital Cardiology Department, University Hospital, Montpellier, France (1).
Pediatric and Congenital Cardiology Department, St-Luc University Hospital, Brussels, Belgium (2).
Pediatric and Congenital Cardiology Department, La Timone University Hospital, Marseille, France (3).
Department of Public Health, Aix-Marseille University, EA 3279 Research Unit, Marseille, France (4).
Clinical Research and Epidemiology Unit, University Hospital, Montpellier, France (5).
Clinical Investigation Center, University Hospital, Montpellier, France (6).
Laboratory of physiology and experimental medicine of heart and muscles, INSERM U1046 Research Unit, Montpellier, France (7).

Objectives: To assess health-related quality of life (QoL) in children with congenital heart diseases (CHD) with a validated questionnaire in comparison with control children.

Methods and Results: we prospectively recruited 282 children with CHD aged 8 to 18 in two tertiary care centers (France and Belgium) and 180 same-age controls in randomly selected French schools. Children's QoL was self-reported with the Kidscreen-52 questionnaire and reported by parents with the Kidscreen-27. QoL scores of each dimension were compared between CHD and controls and between the classes of disease severity defined by Uzark et al.

Both centers were comparable for most demographic and clinical data. Age- and gender-adjusted self-reported QoL scores did not differ between CHD children and controls except for physical well-being (mean±SEM: 45.97±0.57 vs 50.16±0.71, p<0.0001), financial resources (45.72±0.70 vs 48.85±0.87, p=0.01) and peers/social support (48.0±0.72 vs 51.02±0.88, p=0.01). Parent-reported scores were lower in CHD children for physical (p<0.0001), psychological well-being (p=0.04), peers/social support (p<0.0001) and school environment (p<0.0001). Similarly, the severity of the disease had an impact on physical well-being (p<0.001), financial resources (p=0.05) and peers/social support (p=0.01) for the self-reported dimensions, and on physical well-being (p<0.001), psychological well-being (p<0.01), peers/social support (p<0.001) and school environment (p<0.01) for the parent-reported dimensions. However, in multivariate analysis, disease severity was not significantly associated with self-reported QoL.

Conclusions: Self-reported QoL of children with CHD was similar to that of same-age healthy children in 7 out of 10 dimensions but parents-reported QoL was impaired in 4 out of 5 dimensions.