Health Related Quality of Life for School-Age Hypoplastic Left Heart Syndrome Survivors: A Single Center Study

Oberhuber R.D. (1, 2), Huemer S. (1), Mair R. (1), Sames-Dolzer E. (1), Kreuzer M. (1), Tulzer G. (1)
Kepler University Hospital, Children's Heart Center Linz, Austria (1);
University of Education of Upper Austria, Linz, Austria (2)

Introduction:
Neurological and radiological research results show an abnormal neurological development in patients treated for hypoplastic left heart syndrome (HLHS). Thus, the aim of this study was (1) to survey the quality of life scores in comparison with healthy children and children with other heart diseases (mild, moderate, and severe heart defects, heart defects in total) and (2) to find out to what extent children with HLHS are successful in integrating socially into daily school life.

Methods:
Children with HLHS (ages 6.3 -16.9) under compulsory education requirements who were treated at our clinic between 1997 and 2009 (n=74), were surveyed. 41 children and 44 parents were examined prospectively by psychologists according to Pediatric Quality of Life Inventory, a health-related quality-of-life measurement (HRQOL).

Results:
The results of the self-assessments of health-related quality of life (HRQOL) on a scale of 1 – 100 showed a wide range, from a minimum of 5.00 (social functioning) to a maximum of 100 (physical health-related summary scores, emotional functioning, school functioning), with a total score of 98.44. Adolescent HLHS patients rated themselves on the same level as healthy youths and youths with different heart diseases.

Conclusion:
The results show that HLHS patients ages 6-16 can be successfully supported and assisted in their psychosocial development even if they show low quality of life scores as well as varying physical and psychosocial parameters.