

Quality of Life in Patients After Staged Operation For Hypoplastic Left Heart Syndrome (HLHS) and Their Families - One Center Experience

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BACKGROUND: Improvement in results of staged palliation for HLHS necessitates assessment of quality of life in this group of patients and their families.

AIM: To assess the quality of life of children with HLHS and their families.

METHODS: Mothers of 98 children with HLHS (73 boys – 75%) completed the questionnaire to assess quality of their children's life and impact of child's illness onto the family. All children (age 3-17 years) were operated at our institution (43 were after Glenn anastomosis and 55 after Fontan completion at the time of study). In 26% child with HLHS was the only child in family.

RESULTS: Development estimated as normal was reported in 94% of patients with HLHS. 84% of patients attend to normal schools or kindergartens. Physical activity comparable with peers was reported in only 19%. Limited physical activity and exercise intolerance were reported in 81 %, emotional problems in 25%, educational in 9%.. Good tolerance of frequent hospitalizations was reported in 75% of cases.

Child illness was connected with strong parental stress (93%), but 91% of responders estimated that they successfully cope with the problem. Family support, support groups of parents and religious faith were considered as most helpful. Only 12% of mothers looked for professional psychological care. 94 % responders assessed familial atmosphere as good, in 85% child's illness strengthened parental marriage, but in 18% of families mother was the only parent. Impact of child's illness on family material situation was assessed as significantly negative in 79%. In 50 % of families the father is the only working parent. 98% of responders would not change anything in their choice of the method and place of treatment.

CONCLUSIONS:

1. Patients with HLHS are active members of the society, they attend to normal schools and kindergartens although their physical activity is limited
2. The family functioning is good but child's illness is a reason of strong parental stress and indicates material problems.
3. Increasing number of HLHS survivors indicates the need for continuation studies concerning neurodevelopmental outcome, quality of life, career planning and social functioning.