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**Quality of life in families with a child after staged treatment for hypoplastic left heart syndrome (HLHS)**

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**BACKGROUND:** In spite of increasing number of survivors with HLHS after staged Norwood operation - data about quality of life in this group of patients and their families is limited.

**AIM:** The aim of the study was to assess the quality of life of children with HLHS and their families.

**METHODS:** Mothers of 52 children with HLHS completed the questionnaire to assess subjectively quality of their children's life and impact of child's illness on the family. All children (age 3-15 years) were operated at our institution.

**RESULTS:** Problems in physical activity in HLHS patients were reported in 69 %, emotional problems in 25%, educational in 12%, problems in psychomotoric development were reported in 31%. 89% of analyzed patients attend to normal schools or kindergartens, and in 100% they are accepted by peers and teachers. Good tolerance of frequent hospitalizations was reported in 75% of estimated patients. Child illness is connected with strong parental stress (73%), and negative emotions like sadness (41%), fear and helplessness (42%). Own family support, support groups of families with the same problem and religious faith were considered as most helpful. 94 % responders assessed familial atmosphere as good, in 81% child's illness strengthened parental marriage, good relations among siblings and HLHS patients were reported in 77%. Only in 29% the need of limitation in family activity was reported. Impact of child's illness on family economic situation was assessed as significantly negative in 79%.

**CONCLUSION:** Patients with HLHS are active members of the society, they attend to normal schools and kindergartens although their physical activity is limited. The family functioning is good although child's illness is a reason of strong parental stress and indicates familial economic problems. Increasing number of HLHS survivors indicates the need for continuation studies concerning neurodevelopmental outcome, quality of life and family functioning in this group of patients.