Assessment of quality of life in families with a child after staged treatment for hypoplastic left heart syndrome (HLHS) – one center experience.

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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. Our hospital is one of the biggest centers for HLHS treatment in Poland.

AIM: The aim of the study was to assess the quality of life of our HLHS patients and their families.

METHODS: Mothers of 57 children with HLHS; 40 boys and 17 girls (age 4-16 years) completed the questionnaire to assess quality of their children’s life and impact of child’s illness on the family. All children were operated at our institution. In 20 families (35%) child with HLHS was the only child, in 32 families (56%) child with HLHS was the first child. HLHS was diagnosed prenatally in 21 cases (37%) and in 18 (32%) the child was born at our institution.

RESULTS: Limited physical activity in HLHS patients was reported in 80%, but only 8 patients (14%) attend to rehabilitation, emotional problems in 25%, educational in 9%. Development estimated as normal was reported in 89%; 79% of patients attend to normal schools or kindergartens. Good tolerance of frequent hospitalizations was reported in 75% of cases. 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 parents and religious faith were considered most helpful. Only 7 (12%) mothers looked for professional psychological care. 94% responders assessed familial atmosphere as good, in 67% child’s illness strengthened parental marriage. Impact of child’s illness on family material situation was assessed as significantly negative in 79%. In 59% of families the father is the only working parent.

CONCLUSIONS: In majority 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 but child’s illness is a reason of strong parental stress and indicates material problems. Increasing number of HLHS survivors indicates the need for continuation studies concerning neurodevelopmental outcome, quality of life and family functioning.