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A population based study of survival and lifestyle assessment after staged surgical management of hypoplastic left heart syndrome in Croatia – 12 years study: Does the fact that surgery is performed in developed European centers but rest of care in small country effects survival and quality of life?

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Introduction: Since, all children born in Croatia with anatomy of hypoplastic left heart syndrome (HLHS) are operated in centers in Western Europe but the rest of care, including preoperative transport, postoperative and care after hospital discharge is performed in Croatia, we tried to evaluate our results and to test if the fact that surgery is performed abroad but rest of care here, effects interstage and late survival and quality of life.

Methods: All children with HLHS born in Croatia from 2002 – 2011, who underwent stage surgery were included and followed till July 2013. year. Patient status was determined from review of interinstitutional medical records and direct patient contact. To determine quality of life and functional status of survivors, symptom-limited cardiopulmonary exercise test was performed and the Pediatric Quality Of Life Inventory (PedsQL) Version 4.0 was completed.

Results: 62 patient were treated. The 1,2,5 and 10 - year survival for the entire cohort was 61.3, 54.8, 53.2,51.6 % respectively. The majority of deaths (50%) occurred at the time of stage I surgery, 43% at stage II, and one late death after Fontan procedure. The median age at stage I surgery was 12 days, 14.5 % were older than 14 days, one had less than 3 kg, 9.7 % had prenatal diagnoses. The median age at stage II surgery was 124 days (22 to 281). The Fontan procedure was performed in 28 patients, with median age of 37.9 months (14.3 to 57.8) and mean follow up 49.2 months (24 – 127). We determined no significant association between anatomic subtype, prenatal diagnoses, type of stage I anastomosis (Sano vrs Blalock Tausig), older age at stage I operation and survival. 93% of survivals fulfilled PedsQL and showed satisfactory physical, psychosocial, emotional and school functioning. 52% of patients with Fontan procedure older than 4 years, performed cardiopulmonary exercise test with mean peak oxygen uptake 30.1 ml/kg/min (range 24 to 37).

Conclusion: Our results showed that survival and quality of life is satisfactory and isn't effected with the fact that surgery is performed in developed centers but rest of care in small country as Croatia.