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Long-term survival after paediatric cardiac surgery in patients with congenital heart defects

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Objective. To collect reliable and complete data for evaluation of long-term survival after paediatric cardiac surgery.

Methods. All 2439 patients (1125 girls/1314 boys) operated due to congenital heart defects in our institution before the age of 18 years from Jan 1st 1994 to Jan 1st 2009 were included. During the study period nearly 50% of all paediatric cardiac surgery in Sweden was performed at our institution. Patient files were cross-checked as of Jan 1st 2012, against the National Population Registry in Sweden, allowing for reliable and complete data on long-term survival. 23 patients (0.9%) emigrated during the study period and were lost to follow up.

Results. Median age at first surgery was 0.35 years (0-17.8 years). 2135 patients (87.5%) had surgery for biventricular correction and 304 patients (12.5%) had univentricular heart palliations. Median age of survivors at follow up was 12.9 years (3-34.7). 184 deaths (7.5%) occurred with a median age at death of 0.5 years (0-30.1). Median survival time in the deceased patients was 51 days (0-17.1 years) after the last major surgical procedure. 101 deaths (4.7%) occurred after surgery for biventricular correction and 83 (27.3%) after palliation for univentricular heart defects ($p < 0.001$). 51/109 (46.7%) patients died after surgery for classic hypoplastic left heart syndrome or unbalanced atrioventricular septal defect with left ventricular hypoplasia, compared to 32/195 (16.4%) after surgery for other univentricular heart defects ($p < 0.001$). 22 patients had a heart transplantation of whom 6 (0.3%) had previous biventricular and 16 (5.2%) previous univentricular heart surgery. Seven late deaths occurred in patients who received a heart transplant (32%).

Conclusions. Total survival from birth was 92.5 %, with more than 50% of all deaths occurring later than 30 days after the last major surgical procedure, reflecting the need for long-term follow up.

Survival after surgery for biventricular correction was 95.3%, compared to 53.3% after surgery for classic hypoplastic left heart syndrome or unbalanced atrioventricular defect with left ventricular hypoplasia and 83.6% after surgery for all other types of univentricular heart patients.