

PW4-7

First 20 years of paediatric heart transplantation in Sweden: Comprehensive outcome after listing for transplantation and post-transplant results 1989-2009

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Objective: To evaluate, on a national basis, the outcome, including functional class, in the first generation of children with end-stage heart disease due to cardiomyopathy (CMP) or congenital heart disease (CHD) to which heart transplantation was presented as an option.

Methods and results: Records of all 135 Swedish children <18 years (median age 6.5 years, range 1 day-17.6 years) listed for heart transplantation from January 1989 to December 2009 were examined. There were 74 (54.8%) CMP and 61 (45.2%) CHD patients; 34 (25.2%) were <1 year. Since 11 patients improved and were de-listed, follow up data was based on 124 patients. Waiting list mortality was 30.6 % (44.4% in infants). Median waiting time until transplant in 82 surviving patients was 57 days (0-585 days). At median post-transplant follow up of 5.9 years (0.03-20.1 years), mortality was 18/82 (22%) and actuarial survival was 92.4% at one year, 82.1% at 5 years, 76.2% at 10 years, and 57.9% at 15 years. Survival after listing was 63.9% at one year, 58.5% at 5 years, 52.3% at 10 years and 39.5% at 15 years. Post-transplant complications included rejections in 34.1%, malignancies in 12.2%, renal failure in 8.5%, coronary artery vasculopathy in 6.1% and re-transplantation in 4 patients (4.9%). Among 64 survivors 84.3% had an excellent or good functional class whereas, in 15.7%, there were important complications including poor prognosis.

Conclusion A high waiting-list mortality and some post-transplant attrition precluded >50% of this population from reaching adulthood. Functional class in survivors is generally good.