

Favorable outcome after heart transplantation in children: 18 years' experience of the Dutch national transplantation program

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OBJECTIVES: Heart transplantation (HTx) in children is concentrated in one center in the Netherlands. The objective of the study was to evaluate the outcome of a national pediatric heart transplantation program.

METHODS: A retrospective, single-center, descriptive study of all children listed for heart transplantation in the Netherlands between 1999 and 2017.

RESULTS: In total, 69 children were listed for HTx at a median age of 10.3 years (IQR 2.5-13.1). The underlying diagnoses included dilated cardiomyopathy (n=43, 62%), restrictive cardiomyopathy (n=8, 12%) and congenital heart disease (n=3, 4%), and 15 (22%) had another etiology. At HTx listing, (n=52, 75%) patients were hospitalized. Forty-seven (68%) children were successfully transplanted at a mean age of 10.5 ± 4.8 years. Outcome after HTx was favourable, 5-years survival was 95% (n=43) Three children died after a mean of 4.0 ± 3.5 years after HTx, one in the 1st year from infectious complications after treatment for severe cellular rejections, two at adolescent age due to graft failure after rejections related to non-adherence. One patient underwent successful retransplantation. Twenty-two (32%) children on the waiting list were not transplanted: 16 (25%) died, 8 of whom on mechanical circulatory support (MCS), which was available in our program as of 2007. One patient was delisted with improved cardiac function after 9 months on MCS, and 4 patients were still listed at the end of the study. Overall, the functional outcome after HTx was favorable: all children returned to school, and participated in age-appropriate physical activities. In the majority of the recipients, graft function has been good at follow-up. The most important transplantation-related complications were post-transplant lymphoproliferative disease (n=8, 13%), cardiac allograft vasculopathy (n=3, 6%) and infections: Epstein-Barr virus infection (n=15, 32%) and Cytomegalovirus infection (n=10, 15%). No hemodialysis or kidney transplantation was needed.

CONCLUSION: A national approach allowed an adequate base for a pediatric heart failure - and transplantation program. We report favorable outcomes, in line with international standards. Heart transplantation is a viable option for a selected group of children with end-stage heart failure and without alternative treatment options. Currently, insufficient donor availability remains the critical limitation for transplantation.