

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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Objectives

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

Result

Table 1: Outcome in 135 children with CMP or CHD listed for heart transplantation in Sweden 1989-2009. Infants less than one year old in parenthesis. 11 improved patients were taken off list. Patients who died after being taken off the waiting list due to deterioration were classified as list deaths.

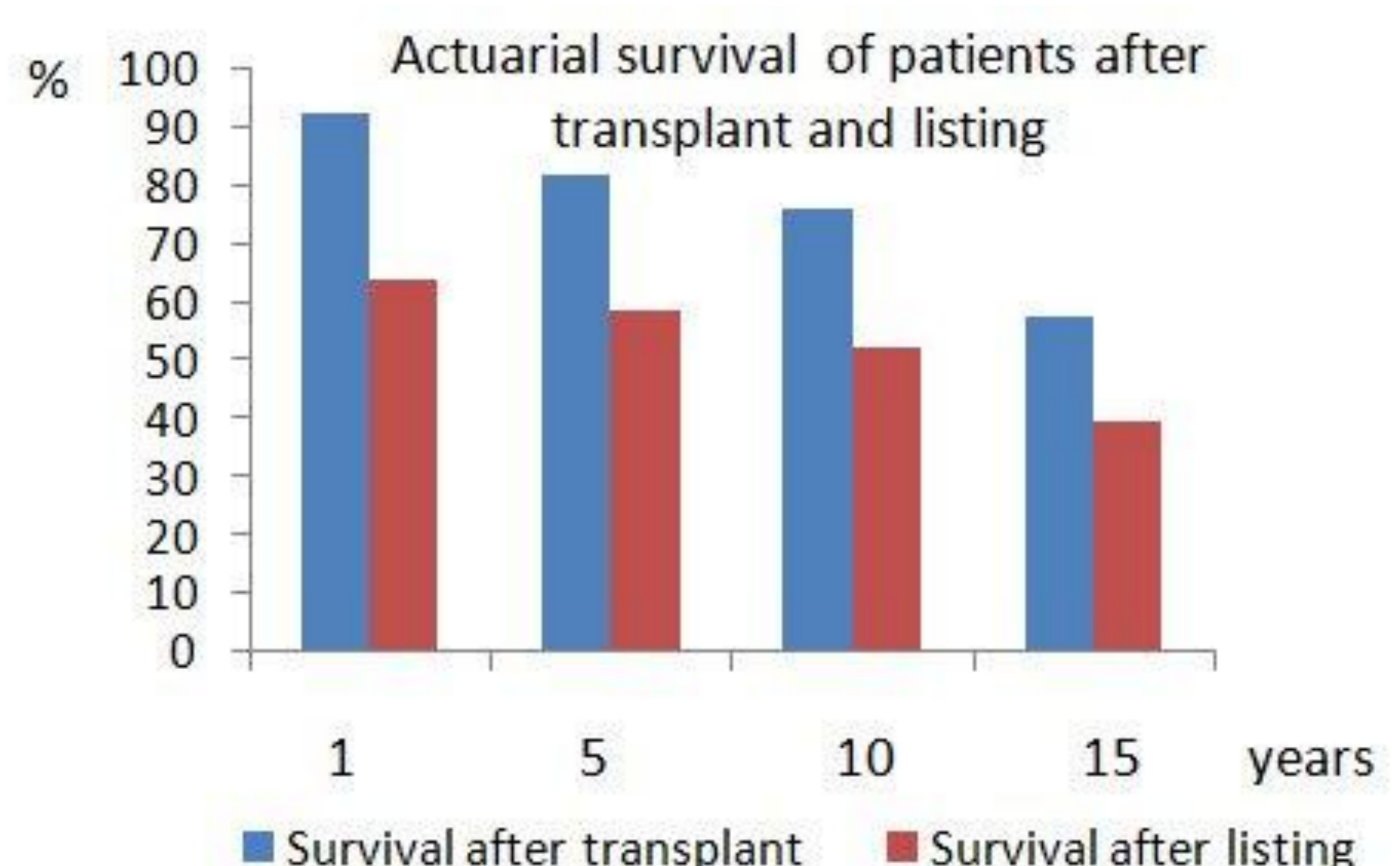
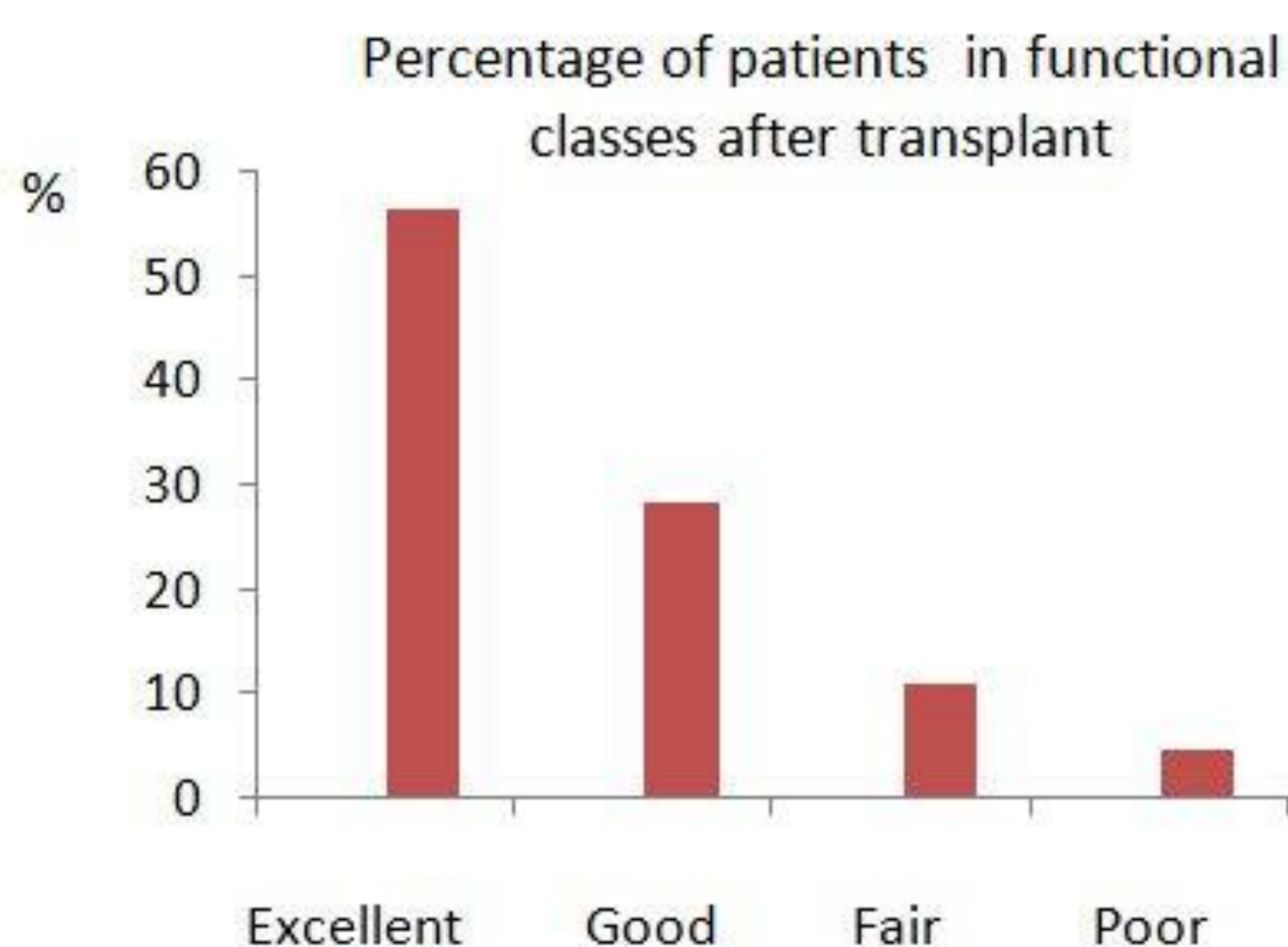
	Listed	Improved	List death	On list	transplanted	Dead after transplant	Alive after transplant
CMP	74 (10)	3(1)	19(2)	1(1)	51(6)	10(1)	41(3)
CHD	61 (24)	8(6)	19(10)	3(0)	31(8)	8(2)	23(6)

Subjects and Methods

- Study group:** All 135 children listed for heart transplantation in Sweden from January 1989 until December 2009. 11 children improved and were de-listed.
- The organisation of listing for donation, organ procurement and follow up in Sweden has been within the Scandiatransplant Network (Aarhus, Denmark). The medical records of the 135 children listed for transplantation were examined by authors from the respective heart transplant centres in Lund and Gothenburg, Sweden.
- The functional classes were designated:
 - Excellent** in the absence of coronary arterial vasculopathy, malignancy, diabetes mellitus, symptomatic infections or arrhythmias, motor or neurological impairment, renal failure (glomerular filtration rate < 30 ml L// 1.73 m²) or pulmonary disease and in the presence of good graft function as well as social and emotional adjustment.
 - Good** if there were sequelae or complications according to above which did not affect daily life.
 - Fair** if complications or sequelae affected daily life but did not have a severe impact on prognosis or very symptomatic.
 - Poor** if complications were very symptomatic and/or the prognosis was dismal.

Table 2: Complications of patients that occurred after transplantation.

COMPLICATION	No	%
Rejection	28	34.1
Neuro- or motor impairment	10	12.2
Orthopaedic	5	6.1
Epstein-Barr virus	11	13.4
Gastrointestinal	10	12.2
Cytomegalovirus	10	12.2
lymphoma	8	9.8
other malignancies	2	2.4
renal failure (GFR < 30 ml/1.7 m ²)	7	8.5
mental, psychiatric, social disorders	9	10.9
coronary arterial vasculopathy	5	6.1
diabetes	3	3.7
pulmonary problems	5	6.1
haematologic/immunologic	6	7.3
symptomatic arrhythmias	5	6.1
heart failure	2	2.4
re-transplantation	4	4.8



Conclusions

A high waiting list mortality of 30.6% and some attrition prevented > 50% from reaching adulthood. 84% of survivors had a good or an excellent functional class.