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1996-2017: a humanitarian action for 3000 children with congenital heart diseases from developing countries

Gouton M. (1,2), Saint-Picq M. (1), Lucet V. (1), Bical O. (1), Leca F. (1)
(1) : Mécénat-Chirurgie Cardiaque - Paris - France
(2) : Institut Mutualiste Montsouris - Paris - France

Objectives:
Mécénat-Chirurgie Cardiaque is a humanitarian association whose mission is to enable children suffering from cardiac malformations to come to France to access the care that is not available in their native countries. Since its creation in 1996, near 3000 children were managed by MCC. The purpose of this study is to analyse the follow-up of this cohort.
Methods:
We reviewed all patients managed by our humanitarian organisation since 1996, and analysed long-term survival.
Results:
2984 children were entrusted, from 66 different countries, mainly from sub-Saharan Africa: 70%, but also from North Africa: 11%, the Middle East 8%, South-East Asia: 8%, Eastern Europe: 5%.
Mean age at arrival in France was 7 years old.
The diagnoses, made by the cardiologists in the countries of origin of the children, had to be confirmed and sometimes corrected at the arrival in France.
The encountered heart diseases were tetralogy of Fallot 25%, VSD 17%, acquired valvular diseases 16%, complex congenital heart disease: single ventricle, pulmonary atresia with VSD, DORV, D-TGV 5% each, truncus arteriosus 2%.
11 children died before surgery. 223 children were withdrawn for surgery, mainly because of pulmonary hypertension or overly complex heart disease, or because of venial disease. 2750 children underwent surgery or intervention. Post-operative mortality has been 2.3%.
After a mean follow-up of 4.4 years, 401 children were lost to follow-up.
At last follow-up, 288 children were dead at a mean age of 10.5 years old. Mean delay until death was 2.3 years. Survival rate at 5 and 10 years was 89% and 84% in operated children, and 74% and 62% in non-operated children respectively. Survival rates at 5 and 10 years were: Fallot 95.4%-94.9%; VSD 94.9%-91.1%; acquired valvular diseases 77.9%-68.5%; single ventricle 78.2%-71.7%.
Conclusion:
With low operative mortality for often very severe heart disease, and good long-term follow-up (87%), the management of children from countries without cardiac surgery is justified by a similar survival to that of Western cohorts - except for acquired valvulopathies, presumably because of the difficulty of anticoagulant treatment. Thus our humanitarian action must continue, and improve for an optimal management of the disinherited populations.