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Clinical profile and follow-up data of patients included in the European Registry for ICD and CRT devices in Pediatrics and Adults with Congenital Heart Disease (Euripides): An Interim Report

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Introduction: The European Registry for ICD and CRT Devices in Pediatrics and Adults with Congenital Heart Disease (Euripides) has been founded as an initiative of the AEPC, ESC and the German Competence Network Congenital Heart Disease in 2007.
Methods: Demographic and medical data including indication and implantation details as well as obligatory yearly follow-up of treatment efficacy, complications and therapy termination were prospectively entered into the registry since 2007 using a pseudo-anonymized web-based data entry.
Results: A total of 72 ICD and 25 CRT patients from 12 centres (8 European countries) aged median 13.8 (IQR 9-17.5) years at implantation have been included. Of the ICD patients 33% had congenital heart disease, 14% had hypertrophic cardiomyopathy and 31% suffered from primary electrical disease. 40% of the indications were primary preventive. CRT was aimed at resynchronization of the systemic/sub-pulmonary/single ventricle in 88/4/8% of patients. 33% of the CRT patients were in NYHA class III or IV and 67% had prior conventional pacemaker implantation. At least one yearly follow-up was entered in 51% of all eligible patients yielding a median (IQR) follow-up period of 1.1 (IQR 0.9-2.0) years. In the ICD group actuarial freedom from adequate/inadequate therapy was 81.5/97.1 % at 1 year. Of the CRT patients 91 % were regarded clinical long-term responders. 9 surgical system revisions have been necessary in 7/72 ICD patients (9.7 %) with an actuarial freedom from revision of 83 % at 1 year.
Conclusions: Euripides is the only registry enabling prospective follow-up of ICD/CRT therapy in paediatric/congenital heart disease worldwide. Data entered allow for detailed analysis of therapy indications, efficacy and complications. Major problems are slow data volume growth and low adherence to annual follow-up reports. (JJ was supported by a grant of the Internal Grant Agency of Ministry of Health of the Czech Republic NT 12321-3/2011)