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Prospective FU in various subtypes of cardiomyopathies: insights from the EORP Cardiomyopathy Registry of the ESC

Authors:
J.R. Gimeno Blanes¹, P.M. Elliott², L. Tavazzi³, M. Tendera⁴, J.P. Kaski⁵, C. Laroche⁶, A. Maggioni⁶, A. Caforio⁷, P.H. Charron⁸, ¹Hospital Clinico Universitario Virgen de la Arrixaca - Murcia - Spain, ²Barts and the Heart Hospital NHS Trust, Cardiology - London - United Kingdom, ³GVM Care and Research, E.S. Health Science Foundation, Maria Cecilia Hospital, Cardiology - Cotignola - Italy, ⁴Medical University of Silesia, Cardiology - Katowice - Poland, ⁵Great Ormond Street Hospital for Children, Cardiology - London - United Kingdom, ⁶European Society of Cardiology, EURObservational Research Programme - Sophia-Antipolis - France, ⁷University of Padova, Cardiology - Padua - Italy, ⁸Hospital Pitie-Salpetriere, Centre de R&type de Maladies Cardiaques H&type de Maladies Cardiaques de l’Enfant - Paris - France.

On behalf: EORP Cardiomyopathy and Myocarditis Registry Investigators

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Background: The EORP Cardiomyopathy Registry is a prospective, observational, multinational registry of consecutive patients with cardiomyopathies. The objective of this report is to describe the outcomes at one year of follow-up of adult patients (>18 years old) enrolled in the registry.

Methods: A total of 3,208 patients (median age: 55.0 (43.0; 64.0) years, males: 65.1%) were recruited at baseline. Follow-up data at 1 year were obtained in 2,713 patients (84.6%), including 1,420 with hypertrophic (HCM), 1,105 dilated (DCM), 128 arrhythmogenic right ventricular (ARVC) and 60 restrictive cardiomyopathy (RCM).

Results: Improvement of symptoms (NYHA, chest pain, syncope) was globally observed over time (p<0.001 for each). Additional invasive therapeutics were performed during follow-up: implantation of ICD (primary prevention) (N=109 patients, 5.2%), pacemaker (N=28, 1.2%), heart transplant (N=30, 1.1%), ablation for atrial or ventricular arrhythmia (0.5% & 0.1%). The proportion of patients with history of AF increased from baseline to FU in 3.6% (from 28.2% to 31.8%). ICD therapy at 1 year was delivered more frequently in ARVC then in DCM, HCM and RCM (11.4%, 9.0%; 8.1%, 0% respectively for primary prevention). Major cardiovascular events (MACE) occurred in 29.3% of RCM, 10.5% of DCM, 7.9% of ARVC and 5.3% of HCM. MACE were globally higher in index patients compared to relatives (10.8% vs 4.4%, p<0.001).

When considering geographical areas, MACE were higher in East Europe (13.1%) and lower in South Europe (5.3%) (univariate); heart transplant was higher in West Europe (2.40%) and lower in South Europe (0.25%) (univariate).

Conclusions: Despite symptomatic improvement in most cases, there is still a significant burden of arrhythmic and heart failure events in patients with cardiomyopathies. Outcomes were different not only according to cardiomyopathy subtypes but also in relatives versus index patients.