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

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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 than 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.