The public health burden of cardiomyopathies: A call for action

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The public health burden of cardiomyopathies: A call for action

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Related article
by Mizia-Stec et al.

Cardiomyopathies (CMs) are defined as myocardial disorders in which structural or functional abnormalities of the myocardium occur in the absence of conditions that can explain them. In recent years, tremendous progress on understanding of molecular background, genetic architecture and diagnostic strategies has dispelled the concept of CMs as rare entities. Indeed, they are now recognized as a major health burden and an important cause of heart failure, arrhythmias, and sudden cardiac death [1]. However, the clinical course of CMs patients is not always straightforward. Based on phenotype, genotype, and comorbidities patients may remain asymptomatic or experience multiple exacerbations. The variable expression of CMs has influenced epidemiological studies, underestimating the true prevalence. In addition, most of information come from studies conducted at tertiary centers and are affected by referral bias. Finally, studies describing clinical trajectories and contemporary management of CMs are lacking. In this issue of the Polish Heart Journal, Mizia-Stec and colleagues [2] publish a cross-sectional, nationwide, retrospective study providing novel insights on treatment pathways of CMs patients. Authors gathered data from the national healthcare provider’s sample using International Classification of Diseases 10th revision (ICD-10) codes, including information on hospitalizations, either elective or urgent due to exacerbation of the disease, and
outpatient care, either at tertiary centers or as first-line care. 65383 CMs patients accessed to the public health system in Poland between 2016 and 2021. They were stratified into three subgroups according to Charlson Comorbidity Index (CCI) score. Across the CCI score spectrum, male sex was prevalent, and as predictable, age increased in parallel with CCI score. Conversely, the higher the CCI score, less steps were taken in the health system. In addition, more comorbid patients were mostly hospitalized and had the lowest rate of third-level outpatient care. Interestingly, authors identified hospitalization as a crucial step in diagnostic work-up in majority of patients. In fact, 93.4% of patients was diagnosed with CM during hospitalization (mostly urgent), whereas only 3.3% and 3.0% received a diagnosis in tertiary centers and first-line care, respectively. Additionally, outpatient diagnostic rates were further reduced in patient with CCI >5. Subsequent interactions with the health system were scarce. Indeed, among hospitalized patients, one-third was not registered again whereas one-fifth died. Most of patients who had a second contact with the health system were hospitalized whereas referral to tertiary care had the lowest rate. Despite the novelty and the significance of the study there are some limitations that readers shall consider. CMs diagnosis relied on ICD-10 codes, which may be erroneously recorded or otherwise not necessarily confirm the diagnosis. However, authors correctly mitigated this limitation excluding patients with codes concerning ischemic heart disease. Second, since the period 2016–2021 include the outbreak of COVID-19 pandemic, its impact on hospitalizations and outpatient visits cannot be excluded. Finally, interpretation of data derived from such an heterogenous cohort including different CM phenotypes must be made with caution. In this regard, we eagerly await the analysis focusing on hypertrophic (HCM) and dilated phenotypes. Furthermore, this work offers some points of reflection. As indicated by CCI, patients included in this study had several comorbidities and an higher score accounted for worse outcomes. A recent analysis of EURObservational Research Programme Cardiomyopathy registry designed by the European Society of Cardiology evaluated the association between common cardiovascular risk factors and severity of HCM phenotype [3]. Although the study was not intended to assess the impact of traditional risk factors on outcomes, authors reported significant associations between obesity, hypertension, and diabetes with left ventricular hypertrophy, higher New York Heart Association class, higher left ventricular outflow tracts gradients and atrial fibrillation. Collectively, CMs pose a major clinical burden on healthcare systems due to increasing prevalence and severe prognosis. Similar data were observed either in cohorts including different CM phenotypes or exclusively obstructive HCM [4, 5]. The increasing number of hospitalizations and surgical procedures translates in increased costs. In addition, the frequent diagnostic delays further heighten the financial burden [6]. Furthermore, since CMs have heterogenous trajectories, there is a need for lifelong follow-up and implementation of a framework between primary care and third-level centers [7, 8]. Indeed, a
previous analysis from the Sarcomeric Human Cardiomyopathy Registry, demonstrated that most of events, especially heart failure and atrial fibrillation, occur after the fifth decade, whichever was the age at diagnosis [7]. The importance of continued follow-up and communication between different levels of care was recently highlighted by Garmany et al. [8] 2058 patients evaluated at Mayo Clinic reported high rates of hospitalizations and cardiac-related procedures away from tertiary care, emphasizing the need for continuity of care, especially for patients deemed at high risk. It is clear that CMs represent a major health burden that require multiple interventions at different levels: 1) Management of CMs is no longer a prerogative of CMs specialists. Clinicians need to be aware of CMs as possible underlying cause of using a “cardiomyopathy-mindset” as suggested by the recent comprehensive European Society of Cardiology guidelines [9]; 2) Patients and caregivers education is of pivotal importance for a shared decision-making; 3) Finally, implementation and consolidation of infrastructure incentivizing research and continuity of care is paramount to address the unmet needs of this complex population.

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