

Pulmonary sarcoidosis: a multicentre initiative

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Abstract

Sarcoidosis is a chronic systemic disease of unknown aetiology, characterised histologically by granulomatous inflammation. Existing treatment options include either no medication or a mix of first-line, second-line and third-line medication with trade-offs between treating inflammation and quality of life (QoL). A chronic disease course requires long-term treatment with corticosteroids, cytotoxics and other agents that can have a serious impact on the quality of life. Significant grey areas exist in approaches to treatment and thus how care is delivered across different countries and centres. Little knowledge is available regarding outcomes of delivered care in relation to the various treatment options. Therefore, there is a need for standardisation of core outcomes to ensure high-value care delivery for all patients with sarcoidosis globally. Patients suffering from chronic diseases have persistent needs and therefore need ongoing healthcare. Accordingly, patients with complex chronic conditions, such as sarcoidosis, are also the costliest patients, and costs increase with the number of chronic conditions. In patients with sarcoidosis, it has been confirmed they have higher rates of comorbidity and complexity compared with a matched control group (matched for age and gender). Furthermore, it was found that the main comorbidities were pulmonary, liver, autoimmune and neoplastic disease in patients with sarcoidosis compared with controls. It was estimated that commercial payers incurred US\$19 714 annually on healthcare costs spent per patient with sarcoidosis in the USA, with outpatient visits and inpatient admissions as the two main cost drivers. Globally, healthcare providers are driven by similar goals: to improve patient experiences and healthcare outcomes, to become more efficient and to reduce the costs as well as to innovate the way care is provided. As addressed by Porter, value-based healthcare (VBHC) could be a guiding principle in achieving these multiple goals. In particular, transparently sharing treatment outcomes of routine clinical care can help hospitals to learn from each other and improve patient value, defined as outcomes over costs. Sarcoidosis often affects young and middle-aged adults. Patients suffer from a broad range of non-specific symptoms, with high variability in the degree of inflammation as well as organs affected. In more than 90% of the cases, sarcoidosis affects the lungs. Spontaneous remissions occur in approximately two-thirds of the patients, but the disease course is chronic in 10%–30% of the patients. Incidence and prevalence rates reported in the literature are highly variable. The prevalence varies over geographical regions as well as ethnic groups, with the highest sarcoidosis prevalence reported in the Nordic countries and in individuals of African descent. For this study, we aimed to specifically develop a standard set of outcome measures for patients with pulmonary sarcoidosis.

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