

SARCOIDOSIS: AN ORPHAN DISEASE NEEDS TO BE ADOPTED

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Sarcoidosis, a multi-organ granulomatous disorder, continues to remain an elusive entity. It is generally under diagnosed and overshadowed by the presence of tuberculosis, a close mimic (1). Although potentially a curable disease, diagnostic delays may adversely impact not just the lungs but other bodily organs as well. In April 2016, US Senate Resolution 443 designated April 2016 as “National Sarcoidosis Awareness Month” and stated a few facts as “Many sarcoidosis patients struggle to find knowledgeable physicians and emotional support resources relating to sarcoidosis; and treatment options for sarcoidosis are limited due in part to the lack of informative research and funding specific to sarcoidosis.” Sarcoidosis is a challenge for both the clinician and the patient. For a clinician, timely and accurate diagnosis is of utmost essence, whereas for patients, it is a matter of understanding a disease which is not heard before they encounter it. The disease sarcoidosis is abundant with diagnostic imprecision, unfavorable outcomes, therapeutic after effect and a great deal of psychological stress but lacks any clinical and therapeutic model or dedicated specialty clinics for its better management.

The prevalence of sarcoidosis varies with respect to countries and ethnicity. African Americans are the commonest affected ethnic group in the United States and have a prevalence four times that of for

Caucasians (2.4% vs 0.85% respectively) (2). The reported prevalence of sarcoidosis in India is estimated to be 10-12 cases per 1,000 new registrations in a respiratory unit at Kolkata and 61.2/100,000 new cases at a center in New Delhi (3). However, these figures are unlikely to be a true representation as sarcoidosis is usually unidentified due to the high burden of tuberculosis here. Real figures are anticipated to be much higher. At the All India Institute of Medical Sciences, a tertiary referral health care center at Delhi, approximately 100 new cases of pulmonary sarcoidosis are being diagnosed every year. The number is quite noticeable for a disease otherwise considered rare.

Regarding diagnosis of sarcoidosis, clinicians usually lack any confident explanation about disease cause and course to satisfy the anxiety of patients. Patients make themselves to read and search as much information as possible to give them the understanding and knowledge of the disease so as to obtain some security and trust that they are receiving the appropriate treatment and care to prevent any further damage to their health. However, self-gathered knowledge might be catastrophic for their mental health. For sarcoidosis patient care, it is advisable that clinicians should also include mental as well as emotional health in their treatment protocol.

Disease course in sarcoidosis is generally self-limiting but many patients face an uncertain future with chronic illness. Complete remission is not always certain and if, it is only possible with the long course of steroids treatment. To survive with a disease of unexplained reasons and unpredictable outcomes is physically as well as psychologically tiring. There are studies that have examined the psychiatric

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aspect of sarcoidosis and the results are really concerning. Depression, perceived stress, anxiety, fatigue and decreased quality of life are on the higher side in patients with sarcoidosis (4-8). All the reverberations associated with this disease necessitated the establishment of multispecialty center as well as a dedicated sarcoidosis patient care facility for catering their symptomatic and psychometric aspect.

Almost no country has such clinical setups that exclusively deal with the problems of sarcoidosis patients. Apart from a nationwide survey of pulmonary sarcoidosis clinics in the United States, no other study reported the status of sarcoidosis clinics in any part of the world. In this study, a minority of academic medical centers were found to have a dedicated sarcoidosis clinic, and the minority of dedicated sarcoidosis clinics used a concurrent multidisciplinary model (9). In India, sarcoidosis is gaining recognition slowly but of course is not privy to speciality treatment. The disease-specific clinical model usually proves beneficial for improved disease management. We believe that the health care providers should create a standard multidisciplinary model for evaluation, diagnosis, and treatment of sarcoidosis which will improve the outpatient care of disease bearer.

Although lacking in clinical model, UK and USA both have support and welfare groups that are helping sarcoidosis patients through their education programs, fund raising awareness camps, and other clinical facilities. Additionally, these organizations are also filling the research gaps by encouraging funding to acclaimed research groups. Foundation of Sarcoidosis Research (FSR); Bernie Mac Foundation in USA and Sarcoidosis and Interstitial Lung Disease (SILA or Sarcoidosis UK) in the UK are the awareness groups working in this direction.

In India as well as in other countries, we also need similar groups so we can make people aware of the disease and its outcomes. There is a need to es-

tablish a platform that can give people confidence to sustain with the disease, a platform where people can share their struggle with the disease and inspire others to tackle it. Through such organization, we can also assemble clinical and research groups together to find actual prevalence of sarcoidosis and to arrange funds for better research in this field.

Sarcoidosis, a disease without consistent definitions and practice patterns requires special consideration rather a casual approach. Multidisciplinary clinical model and in-person support groups may work favorably to cure the disease and to inform the public about the disease so the patients do not go through undue trauma. Furthermore, extensive research is indeed required to find some breakthroughs which will provide answers to etiology, diagnosis, treatments and a cure for the disease.

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