Breaking barriers: holistic assessment of ability to work in patients with sarcoidosis

Published Online October 15, 2024 https://doi.org/10.1016/S2213-2600(24)00297-2

> "Variability is the law of life, and as no two faces are the same, no two bodies are alike, and no two individuals react alike and behave alike under the abnormal conditions which we know as disease."[1]
>
> *Sir William Osler*

Sarcoidosis, a relatively uncommon disease, is rarely encountered by disability assessors, leading to a knowledge gap regarding its impact. Patients frequently express dissatisfaction with work capacity assessments, which often do not include input from sarcoidosis experts and tend to focus narrowly on lung function tests (appendix 1 pp 1–2).[2] In addition to the highly variable spectrum of organ-related disabilities, functional impairments, including fatigue, reduced exercise capacity, and cognitive impairment, cause complex disruptions across crucial life domains such as ability to work.[2–5] Difficulties arise when assessing such elusive manifestations that do not have straightforward evaluation and quantitative tests.[6] This Comment, informed primarily by patients with first-hand experience worldwide, patient advocate groups (appendix 1 p 3), clinicians, and the literature, offers a better understanding of the impact of sarcoidosis on the ability to work, and a more realistic approach to the quantification of disease burden.

See Online for appendix 1

The traditional medical approach to sarcoidosis needs to evolve to integrate subjective experiences with objective assessments, especially when evaluating work capacity. This integration is essential to ensure that genuine disability is not overlooked when it is primarily driven by symptoms without supporting objective tools. Endorsing validated scales for fatigue, cognitive impairment or so-called brain fog, and small fibre neuropathy symptoms is desirable, particularly when patients are symptomatic and markers of disease activity are in the normal range.[6–8] Assessing an individual's employment capacity requires a holistic perspective that considers health, personal circumstances, patient wellbeing, and professional capabilities.[2,6,8] As with other diseases, each person with sarcoidosis is unique, necessitating tailored approaches that incorporate patient-reported symptoms and impairment burdens. A collaborative dynamic, rooted in attentive listening, facilitates shared decision making, empowering both patients and clinicians.[9] This approach allows for realistic work-related goals, such as delayed return to work, modified tasks, or even permanent inability to return to work.

The shift from a paternalistic so-called doctor knows best model to an egalitarian alliance between clinicians and those with lived experience has traction in contemporary health care. Such an alliance has a better chance of acknowledging poorly understood disease mechanisms that cannot be quantified or even detected. Enhancing dialogue between patients and health-care providers, focusing on daily life aspects, supports comprehensive and patient-friendly assessments.[10] The figure visually depicts patients' experiences across sarcoidosis associated limitations as well as life areas, aiding structured assessments and fostering awareness from the patient's perspective.[11]

The disease burden of sarcoidosis varies for each patient and is not easily captured by standard measurement tools.[4–7] Open-ended queries about patients' concerns about physical as well as psychological capacity are crucial for assessing work capacity (figure).[11] Clinicians' reliance on objective measures often discounts subjective evidence. Difficulties in objective verification do not invalidate the major symptoms and quality-of-life issues experienced in sarcoidosis.[10] The delivery of effective health and social care requires patients voices to be heard. The social and medical burden of sarcoidosis, which affects work capacity, personal activities, and family life, is greatly underestimated.[12] Diagnostic delays, and the associated fear and uncertainty, impact on patients' self-confidence even before a diagnosis is made. Upon diagnosis, new problems and uncertainties arise about what the future holds. Comorbidities and adverse drug reactions, particularly with glucocorticosteroids, can increase disease burden.[7]

The clinical manifestations of sarcoidosis are categorised based on their activity and severity, including organ dysfunction. Active disease does not necessarily imply a progressive trajectory, fatal prognosis, or immediate need for treatment. The disease course

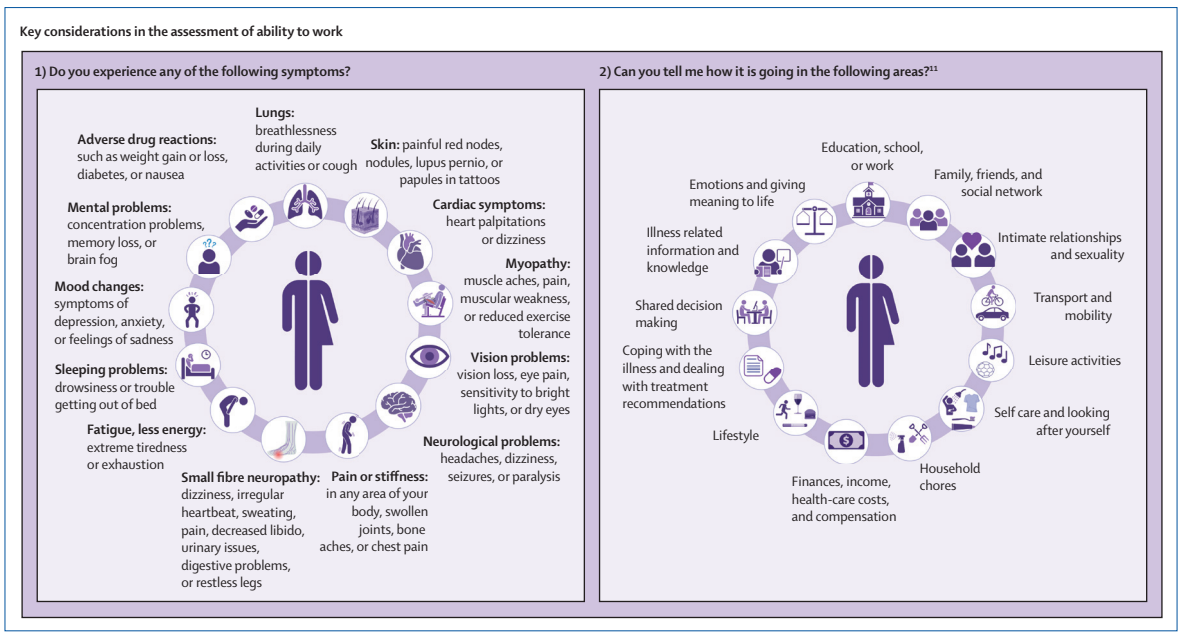

Figure: **Holistic assessment of ability to work in patients with sarcoidosis**
Patients with sarcoidosis often face obstacles in the assessment process of their ability to work. To show the impact of sarcoidosis on the ability to work, key considerations in this assessment are presented. Physical and cognitive functions, including the ability to perform daily activities, are fundamental to the capacity to work in chronic disorders such as sarcoidosis. To support a comprehensive and patient-friendly assessment of limitations and facilitate dialogue between patients and health-care providers, it is essential to offer a holistic view of symptoms and various life areas, recognising the biophysical and social circumstances of each person. Figure created with BioRender.com.

is unpredictable, influenced by clinical presentation, phenotype, treatment efficacy, and whether chronic limitations develop.[7] Not all manifestations respond to pharmacological or supportive therapies like rehabilitation. Furthermore, even in the absence of signs of active inflammation, symptoms such as fatigue can persist for many years.[5–8,13] Although sarcoidosis-related sick leave is common, it is usually temporary. However, one-third of patients might have a prolonged or chronic disease course, necessitating regular assessment of their ability to work. Accurate recognition of sarcoidosis-related limitations should guide these assessments.[5]

Clinicians and work assessors unfamiliar with sarcoidosis might be unable to holistically appreciate all factors contributing to the patient's inability to work.[2,3,13] Assessors often rely on protocols for conditions very different from sarcoidosis, such as chronic obstructive pulmonary disease, focusing on lung function and overlooking critical sarcoidosis-associated symptoms such as fatigue, pain, and cognitive problems. This approach leads to inaccurate assessments. Data is limited, but a Dutch study by Hendriks and colleagues[2] found that 38% of patients with sarcoidosis disagreed with the outcomes of their work fitness assessment, with 75% of them taking further action by appealing their assessment. This finding indicates a substantial flaw of current assessment practices. Similar dissatisfaction has been reported in other countries, including Germany, Denmark, and France.

For individuals with chronic diseases, active participation in life is integral to wellbeing and sense of purpose. These individuals often feel disempowered due to their inability to fully participate in society and contribute actively. Tailored solutions focusing on possibilities rather than limitations, such as flexible work schedules, can help maintain workforce participation. The COVID-19 era validated non-organ-specific symptoms like fatigue and brain fog, recognising their disabling nature and the need for specific support. This recognition has eased the way for a holistic clinical assessment and management approach. Guidelines published in 2023 suggest this holistic approach for patients living with post-COVID-19 condition (also known as long COVID), many of whom share symptoms with sarcoidosis.[14] A thorough assessment incorporating both objective and subjective information is crucial (figure).[5,8] Poorly understood symptom pathophysiology does not preclude future objective findings.

Attentive, open-minded history-taking and active listening alongside acknowledging the impact of symptom-related disability is essential for assessing ability to work. Comprehensive evaluations must consider information from treating clinicians and patient self-reports. Where work assessors do not have an adequate clinician statement for evaluations, we advocate for involvement of sarcoidosis expert in pre-evaluations of patients' ability to work.[5,8] Specialist consultations can clarify patients' needs, such as temporary work cessation with gradual return and provide insights into living with sarcoidosis, limitations, outcomes, and treatment responses, aiding personalised evaluations and necessary adjustments.[7] We propose that work capacity queries require referral to a sarcoidosis specialist. Expert clinicians can provide authoritative statements on symptom validity, pre-empting symptom dismissal and distinguish symptoms unrelated to sarcoidosis that might necessitate interventions for other conditions. Specialists integrate sarcoidosis and non-sarcoidosis morbidity, assisting in overall evaluations. Specialists articulate potential improvements with management strategies and anticipated response times. Expert input supports viewing symptoms as sarcoidosis consequences, aiding sensible, personalised evaluations. Expanding international networks of sarcoidosis experts will enhance ability to work assessments.

See **Online** for appendix 2

In summary, assessing ability to work in sarcoidosis requires a patient-centred holistic, expert, multidisciplinary approach that reflects the experience of an individual living with the disease and should complement available evidence. In recognising that the impact of sarcoidosis extends beyond pulmonary function tests, involving fatigue, cognitive issues, pain, and broader functional limitations, we can contribute to more equitable evaluation processes that acknowledge the multifaceted nature of this condition. There is a need for guidelines that accurately reflect the lived experience of patients with sarcoidosis. Despite cultural differences in disability claim approaches, our outlined strategy is universal.

MD is the chair of the ild care foundation (no honoraria) and the emeritus president of the World Association for Sarcoidosis and Other Granulomatous Disorders (WASOG). A-MR has received honoraria for lectures from Boehringer Ingelheim, Hoffman La Roche, Irish Lung Fibrosis Association, and Aerogen; travel support for attending meetings from Boehringer Ingelheim, Hoffman La Roche, iMyoS, and the Interstitial Lung Disease Interdisciplinary Network. LAS has received grants from aTyr Pharmaceuticals, Kinevant Pharmaceuticals, Horizon Pharmaceuticals, Kadmon Pharmaceuticals, US Department of Defence, University of Pittsburgh, and the Scleroderma Research Foundation; honoraria for lectures from Janssen – Johnson & Johnson Pharmaceuticals and the Eastern Pulmonary Conference; travel support for attending meetings from the International Myositis Society for travel to Global Conference on Myositis, the European Respiratory Society for travel to an Annual Conference, the American College of Rheumatology for travel to annual conference Scleroderma Foundation for participation in annual patient conference, and The Myositis Association for participation in an annual patient conference and the Eastern Pulmonary Conference; compensation for Participation on a Data Safety Monitoring Board from Argenx Pharmaceuticals and National Institutes of Health; is the chair of Myositis International Health and Research Collaborative Alliance (a non-profit organization), a chair of the Nominating Committee of The Myositis Association Medical Advisory Board, a Board Member of the Steffens Scleroderma Foundation, and a member of the Medical Scientific Advisory Board of the Scleroderma Foundation. PS has received consulting fees from Novartis; honoraria for consultancy activities from Novartis and for lectures from Chiesi; compensation for participation in Scientific Advisory Board from CSL Behring and Merck; is chair of the European Respiratory Society (ERS) Assembly 12.03 Sarcoidosis and other granulomatous disorders, and treasurer and executive committee member of WASOG. MV has received lecture fees from Boehringer Ingelheim and Chiesi Pharmaceuticals; compensation for participation on a Data Safety Monitoring Board from Xentria Pharmaceuticals; is secretary of the ERS Assembly 12.03 and other granulomatous disorders, and secretary and executive committee member of WASOG. AUW is the president of the WASOG. MD, A-MR, and LAS were responsible for initial conceptualisation. MD was responsible for the project coordination, administration, and supervision. MD, A-MR, LAS, PS, MV, and AUW formed the ability to work writing committee and were responsible for writing of the original draft, reviewing and editing of the manuscript. Representatives of the sarcoidosis community, who are listed in appendix 2, endorsed and coauthored this Comment and participated in the conceptualisation process. All authors accept responsibility to submit for publication. Organisations who have endorsed the initiative described in this Comment are listed in appendix 1 (p 3).

Marjolein Drent, Anne-Marie Russell, Lesley Ann Saketkoo, Paolo Spagnolo, Marcel Veltkamp, Athol U Wells, on behalf of representatives of the sarcoidosis community
m.drent@ildcare.nl

Interstitial Lung Diseases Center of Excellence, Department of Pulmonology, St Antonius Hospital, Nieuwegein, Netherlands (MD, MV); Department of Pharmacology and Toxicology, Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, Netherlands (MD); ild care foundation research team, 6711 NR Ede, Netherlands (MD); Institute of Clinical Sciences, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK (A-MR); Birmingham Regional NHS ILD and Occupational Lung Disease Service, University Hospitals Birmingham NHS Foundation Trust, UK (A-MR); Department of Health and Care Professions, Faculty of Health and Life Sciences, University of Exeter, Exeter, UK (A-MR); New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center, New Orleans, LA, USA (LAS); University Medical Center, Comprehensive Pulmonary Hypertension Center and Interstitial Lung Disease Clinic Programs, New Orleans, LA, USA (LAS); Tulane University School of Medicine, New Orleans, LA, USA (LAS); Louisiana State University Health Sciences Center, Division of Pulmonary Medicine, New Orleans, LA, USA (LAS); Respiratory Disease Unit, Department of Cardiac, Thoracic, Vascular Sciences and Public Health, University of Padova, Padova, Italy (PS); Division of Heart and Lungs, University Medical Center, Utrecht, Netherlands (MV); Royal Brompton Hospital, Imperial College London, London, UK (AUW); World Association for Sarcoidosis and Other Granulomatous Disorders, Padova, Italy (MD, A-MR, LAS, PS, MV, AUW)

1 Osler W. On the educational value of the medical society. *NEJM* 1903; **148:** 275–79.
2 Hendriks CMR, Saketkoo LA, Elfferich MDP, De Vries J, Wijnen PAHM, Drent M. Sarcoidosis and work participation: the need to develop a disease-specific core set for assessment of work ability. *Lung* 2019; **197:** 407–13.
3 Gerke AK, Judson MA, Cozier YC, Culver DA, Koth LL. Disease burden and variability in sarcoidosis. *Ann Am Thorac Soc* 2017; **14** (suppl 6)**:** S421–28.
4 Elfferich MD, Nelemans PJ, Ponds RW, De Vries J, Wijnen PA, Drent M. Everyday cognitive failure in sarcoidosis: the prevalence and the effect of anti-TNF-alpha treatment. *Respiration* 2010; **80:** 212–19.

5 Drent M, Costabel U, Crouser ED, Grunewald J, Bonella F. Misconceptions regarding symptoms of sarcoidosis. *Lancet Respir Med* 2021; **9:** 816–18.

6 Voortman M, Hendriks CMR, Elfferich MDP, et al. The burden of sarcoidosis symptoms from a patient perspective. *Lung* 2019; **197:** 155–61.

7 Drent M, Crouser ED, Grunewald J. Challenges of sarcoidosis and its management. *N Engl J Med* 2021; **385:** 1018–32.

8 Moor CC, Kahlmann V, Culver DA, Wijsenbeek MS. Comprehensive care for patients with sarcoidosis. *J Clin Med* 2020; **9:** 9.

9 Veenendaal HV, Chernova G, Bouman CM, Etten-Jamaludin FSV, Dieren SV, Ubbink DT. Shared decision-making and the duration of medical consultations: A systematic review and meta-analysis. *Patient Educ Couns* 2023; **107:** 107561.

10 Saketkoo LA, Russell AM, Jensen K, et al. Health-related quality of life (HRQoL) in sarcoidosis: diagnosis, management, and health outcomes. *Diagnostics (Basel)* 2021; **11:** 11.

11 Been-Dahmen JMJ, Beck DK, Peeters MAC, et al. Evaluating the feasibility of a nurse-led self-management support intervention for kidney transplant recipients: a pilot study. *BMC Nephrol* 2019; **20:** 143.

12 Harper LJ, Gerke AK, Wang XF, et al. Income and other contributors to poor outcomes in U.S. patients with sarcoidosis. *Am J Respir Crit Care Med* 2020; **201:** 955–64.

13 Drent M, Strookappe B, Hoitsma E, De Vries J. Consequences of sarcoidosis. *Clin Chest Med* 2015; **36:** 727–37.

14 Davis HE, McCorkell L, Vogel JM, Topol EJ. Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 2023; **21:** 133–46.