Decreasing quality of life associated with increased organ involvement in sarcoidosis: learnings from the Foundation for Sarcoidosis Research (FSR) Patient Registry

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INTRODUCTION
Understanding which organs affected by sarcoidosis contribute to patient quality of life (QOL) changes is crucial to shared decision making in the clinic. The FSR-SARC Patient Registry, comprised of over 7,000 individuals, collects longitudinal data to understand the impact of sarcoidosis symptoms and disease course on QOL directly from those impacted by sarcoidosis.

OBJECTIVES
Understand QOL changes over time for patients specifically as measured by the Sarcoidosis Health Questionnaire (SHQ), a scale of 1–7 with higher scores indicating better QOL.

MATERIALS AND METHODS
Participants who completed the FSR Patient Registry baseline and annual update surveys at least one year apart were included in analyses. We modeled SHQ scores, total (T) and subdomains Daily Functioning (DF), Physical Functioning (PF), and Emotional Functioning (EF), at follow-up adjusting for age at baseline, sex at birth, race, years between baseline and follow-up, and respective SHQ baseline score.

RESULTS
999 individuals were included in the analysis. Mean age at follow-up was 58 years, 69% were female, 72% were White, 10% African American, and 86% reported residing in the United States. 49% reported one or two organs affected by sarcoidosis at baseline, with 19% reporting five or more. At follow-up (average of 4 years later) 54% reported at least one additional organ diagnosed with sarcoidosis. Reported new organ involvement was significantly associated with decreased QOL scores across all SHQ domains, most notably in new lung diagnoses (0.61 points lower for SHQ-T and 1.3 points lower for SHQ-PF than those without new lung involvement), new bone diagnoses (0.80 points lower for SHQ-DF than those without new bone involvement), new diagnoses in the joints (0.42 points lower) and new brain/cranial nerves or eye involvement (0.38 and 0.40 points lower for SHQ-EF, respectively).

CONCLUSION
The FSR-SARC Patient Registry collects valuable QOL data that, when paired with longitudinal patient-reported disease progression, can provide insights into the burden of sarcoidosis and inform resource development.

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