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.

MATERIALS AND METHODS

Participants who completed the FSR Patient Registry baseline and annual update surveys at least one year apart were included in analyses (N=1,038). 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.

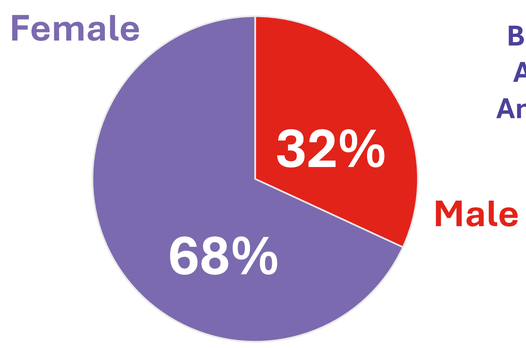
OBJECTIVE

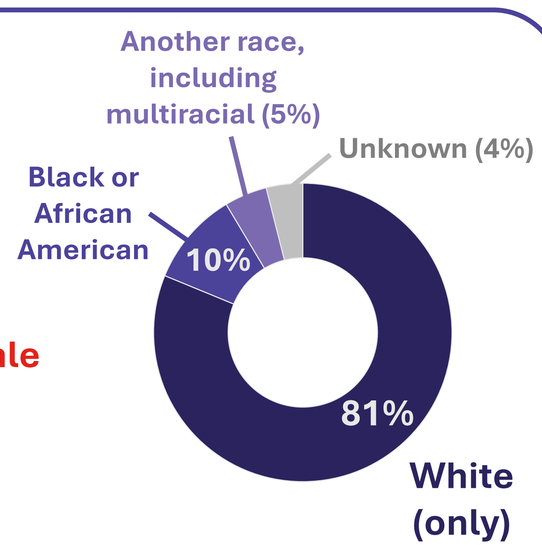
Understand QOL changes over time for patients specifically as measured by the Sarcoidosis Health Questionnaire (SHQ), a scale of 1–7 with higher scores indicating better QOL.

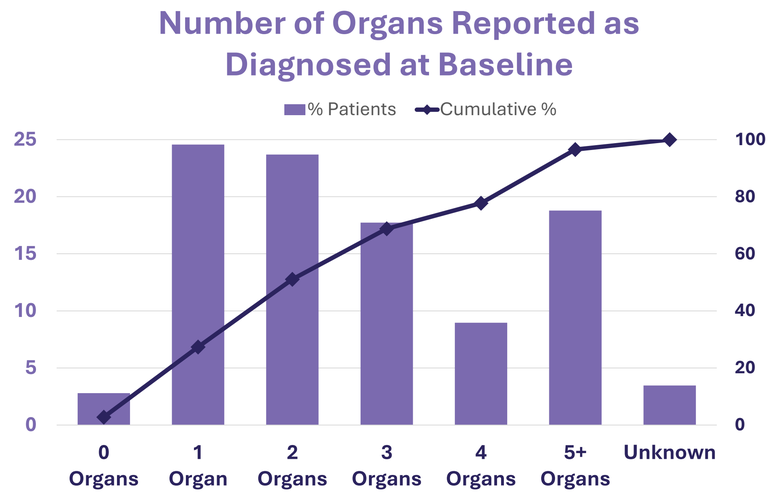
RESULTS

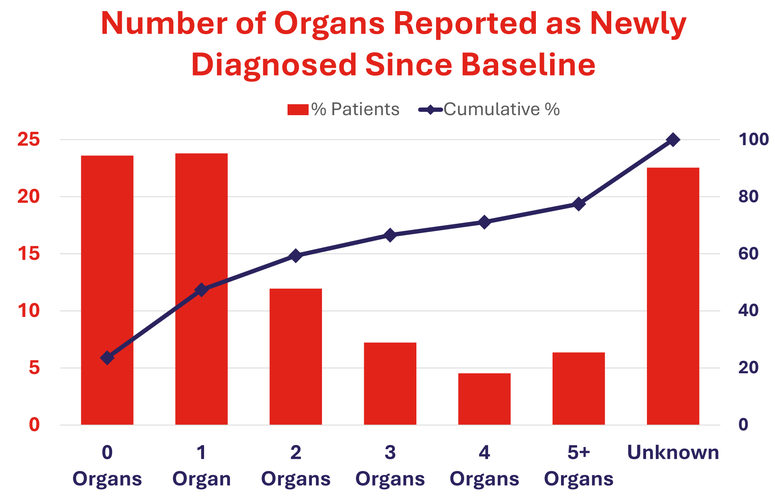
Baseline completed: June 2014–December 2024
Follow-Up completed: December 2020–March 2026

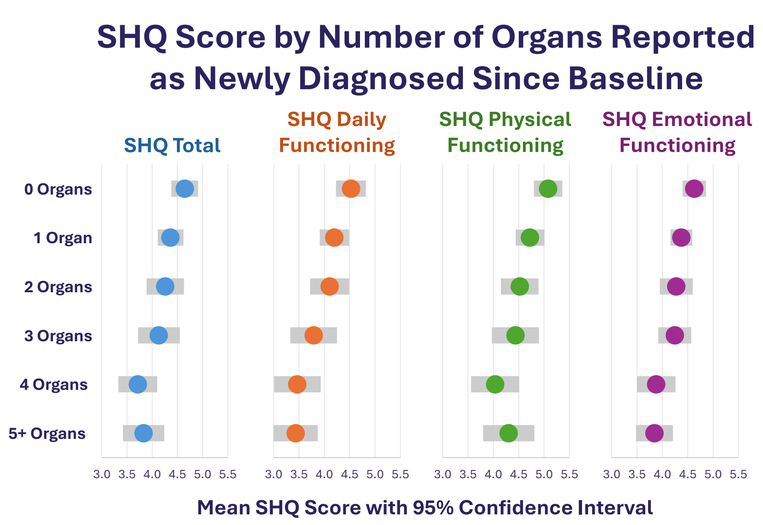
	Overall (N=1,038)	
Age at Baseline completion, mean (SD), years	54.4	(10.1)
Disease duration at Baseline completion, median (IQR), years	4.0	(9.8)
Time between Baseline and Follow-Up, mean (SD), years	4.1	(2.6)
Age at Follow-Up completion, mean (SD), years	58.5	(10.1)
Disease duration at Follow-Up completion, median (IQR), years	8.5	(11.4)

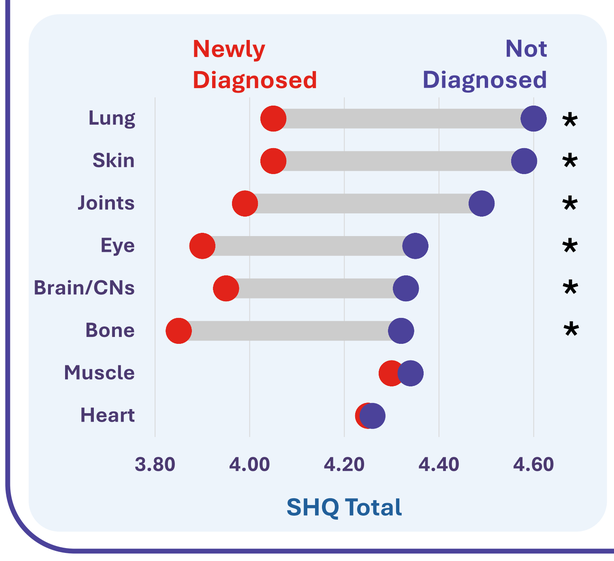


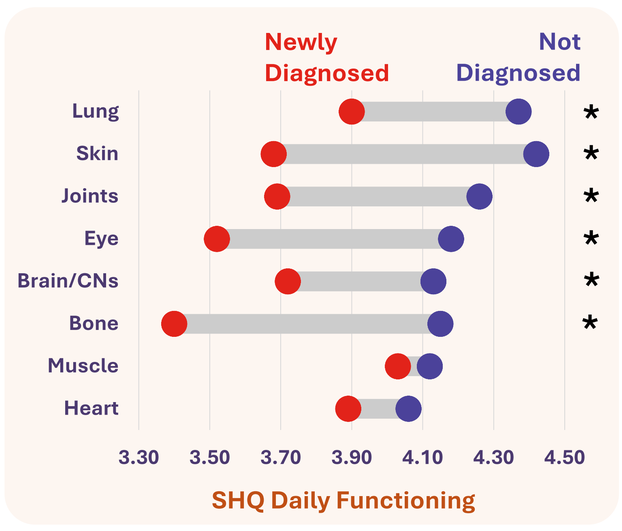


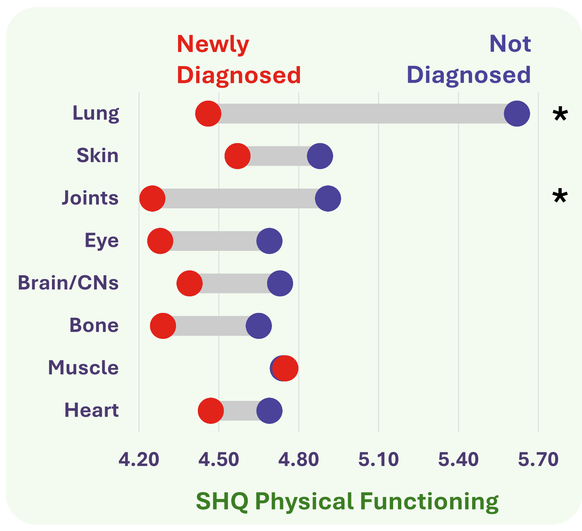


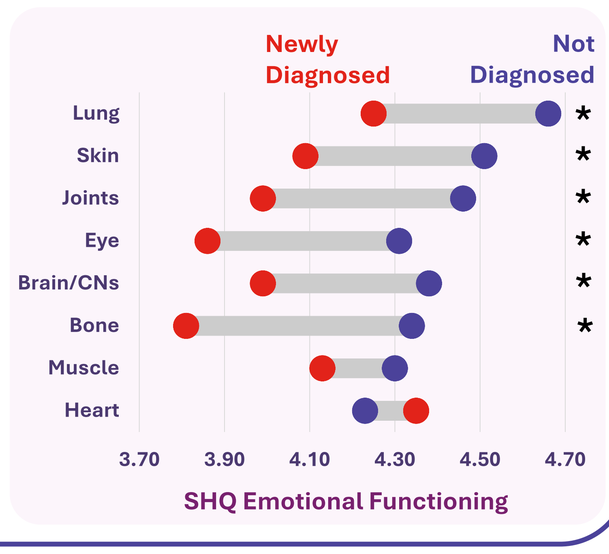












CONCLUSIONS

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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RESOURCES

FSR-SARC 10-Year Registry Report

FSR-SARC Patient Registry Data

FSR-SARC Patient Registry Website