Temporal Trends in Health-Related Quality of Life and Health Status in Individuals Living with Neurosarcoidosis: A Nationwide Registry Study

Balaban D.[1], Greenfield, J.[2,3], Moss B.[4], Bilodeau, P.A.[1], Shivas T[5], Roberts J.I.[2,3]

[1]Division of Neuroimmunology & Neuroinfectious Disease, Department of Neurology, Massachusetts General Hospital, Harvard Medical School, Boston MA USA
[2]Department of Clinical Neurosciences, Hotchkiss Brain Institute, University of Calgary, Calgary AB Canada
[3]Department of Community Health Sciences, University of Calgary, Calgary AB Canada
[4]Sarcoidosis Center, Cleveland Clinic, Cleveland, OH USA
[5]Foundation for Sarcoidosis Research, Chicago, IL USA

BACKGROUND: It is unclear whether treatment advances in neurosarcoidosis over the past decade have meaningfully improved patient outcomes.

METHODS: We conducted a repeated cross-sectional study using the Foundation for Sarcoidosis Research – Sarcoidosis Advanced Registry for Cures (FSR-SARC) database to examine health-related quality of life (HRQL) and health status trends in people with neurosarcoidosis (pwNS) from 2014-2024. We included patients aged 18 years or greater with neurosarcoidosis. The primary outcome measures were improvement in the Patient-Reported Outcomes Measurement Information System Ability to Participate in Social Roles and Activities Short form 8a (PROMIS-APS) score by a minimal clinically important difference (MCID) of 2 T-score points and improvement in the Sarcoidosis Health Questionnaire (SHQ) by 0.5 standard deviations, a MCID we defined. Higher scores indicate better functioning for PROMIS-APS and SHQ. Multivariable linear regression was used to adjust for age, sex, income, geography, pulmonary involvement, skin involvement, and disease duration since diagnosis. Local ethics committee approval was obtained.

RESULTS: 1059 patients were included. The median age was 59.7 (range 23.4 – 93.7), 73.3% were female, 73.1% were white, 16.7% were black, 88.1% were from the United States, 26.3% were high income (>$85,000 USD), 50.0% had university educations or higher, and 40.0% were unable to work due to disability. Median age at diagnosis was 44.0 (range 18 – 80), 66.4% had central neurosarcoidosis, 82.9% had pulmonary involvement, 71.5% had skin involvement, and 63.2% had ocular involvement. Corticosteroid use trended downward over time (50.6% in 2014-2016, 41.4% from 2021-2024) and steroid-sparing therapy use trended upward over time (48.8% in 2014-2016, 57.4% in 2021-2024). Using univariable linear regression (ULR), PROMIS-APS T-scores significantly improved over 10 years (1.69, 95% CI 0.07 – 3.31) but did not meet the MCID. With MLR, the effect was no longer significant but trended towards improvement (1.49, 95% CI -0.22 – 3.20). PROMIS-APS showed a floor effect, with ~15% achieving the worst score. Using ULR and MLR, SHQ significantly improved over 10 years (MLR 0.19, 95% CI 0.04 – 0.35) but did not meet the MCID (0.419). The SHQ did not demonstrate a floor effect.

CONCLUSION: While one HRQL measure (Sarcoidosis Health Questionnaire) significantly improved over time, neither measure met the pre-defined threshold for clinically meaningful change, despite improved guidance on disease recognition, corticosteroid use, and increased steroid-sparing use over time. Further study is necessary to understand the drivers of improved HRQL in people with neurosarcoidosis.