Understanding the patient burden of pain and symptoms in sarcoidosis: learnings from the Foundation for Sarcoidosis Research (FSR) Patient Registry

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BACKGROUND

For 25 years, the Foundation for Sarcoidosis Research (FSR) has responded to the voice of those living with sarcoidosis. The FSR-SARC Patient Registry seeks to understand the impact of sarcoidosis symptoms and socioeconomic variables on the quality of patients' daily lives.

METHODS

The FSR-SARC Registry, launched in 2015, is an online platform that collects self-reported data from participants living with sarcoidosis (or caregivers on their behalf). The Baseline Questionnaire captures data on demographics, diagnosis, organ involvement, medications, and validated measures from the PROMIS Adult Pain Interference Short Form 8a and Sarcoidosis Health Questionnaire. Responses from 5,083 Registry participants were assessed to characterize the impact of common sarcoidosis-related symptoms.

RESULTS

Registry participants' mean age was 59 years, 70% were female, 76% were White, 16.3% Black/African American and 4.7% Hispanic/Latino. Participants who reported a high burden of pain (responded "quite a bit" or "very much"; n=2224 (44%)) indicated a diagnosis most frequently in their liver (87%), parotid glands (84%), brain/cranial nerves (80%), or bone/vertebrae (79%). Respondents with high compared to low pain burden were younger at the time of diagnosis (mean age 43 versus 46) and at the onset of symptoms (mean age 39 versus 43) ($p<0.0001$ for both). Additionally, participants with high pain burden were 1.6 times more likely to be female (CI 1.4-1.8), 1.55 times more likely to require immune modulating medications (1.4-1.7), 3.74 times more likely to report job loss due to sarcoidosis health effects (3.3-4.2) and 2.93 times more likely to report an annual household income under $35,000 (2.5-3.4) compared to those with low pain burden (all with a $p<0.0001$). No statistically significant variation by race or ethnicity was found. When asked about effects of sarcoidosis on daily life, participants reported worries that their sarcoidosis might flare or worsen as their highest burden (36%), followed by shortness of breath when walking short distances or climbing stairs (32%). While 79% of participants reporting high burden of shortness of breath had pulmonary sarcoidosis involvement, 21% reported no lung involvement and instead indicated sarcoidosis diagnosis in their central lymph nodes (52%), joints/arthritis (33%), or skin (30%).

CONCLUSION

The FSR-SARC Registry survey data highlight patient features associated with chronic pain, including low socioeconomic status, younger, female sex, systemic disease manifestations, and indicates pain is associated with reliance on immune modulating treatments. Likewise, dyspnea is

common and often dissociated from reported lung involvement. These results underline a pressing need to advance understanding of the consequences and drivers of patient-reported symptoms.

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