UNDERSTANDING THE PATIENT BURDEN OF PAIN AND SYMPTOMS IN SARCOIDOSIS:
Learnings from the Foundation for Sarcoidosis Research (FSR) Patient Registry

Timothy Legenzoff[1], Elliott Crouser[2], Logan Harper[3], Mary McGowan[1], Leslie Serchuck[1], Tricha Shivas[1], Elise Hoover[1]

[1]Foundation for Sarcoidosis Research; [2]The Ohio State University, [3]Cleveland Clinic Foundation

Introduction

- The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since its establishment in 2000, FSR has fostered over $8 million in sarcoidosis-specific research efforts.
- For 25 years, FSR has responded to the voice of those living with sarcoidosis. The FSR Patient Registry seeks to understand the impact of sarcoidosis symptoms and socioeconomic variables on the quality of patients' daily lives.
- The FSR Patient Registry is a comprehensive, patient-driven data resource aimed at improving the lives of those affected by sarcoidosis through research and collaboration.
- Nearly 7,000 participants are enrolled and fill out surveys on demographics, medical and family history, organ involvement, treatments, and how the disease affects quality of life.

Methods

- The FSR Patient Registry, launched in 2015, is an online platform that collects self-reported data from participants living with sarcoidosis (or caregivers on their behalf).
- We analyzed data from the Baseline Questionnaire which captures data on demographics, diagnosis, organ involvement, medications, and validated measures from the PROMIS Adult Pain Interference Short Form 8a and Sarcoidosis Health Questions.
- Responses from 5,083 Registry participants were assessed to characterize the impact of common sarcoidosis-related symptoms.
- We categorized reported pain burden based on response to "How much does pain interfere with your enjoyment of life?" as High Pain Burden ("quite a bit" or "very much") or Low Pain Burden ("not at all," "a little bit," or "somewhat")
- We calculated odds ratios (ORs) and 95% confidence intervals (CIs) for associations between pain burden and participant characteristics.

Conclusions

- The FSR Patient Registry survey data highlight patient features associated with high pain burden, including low socioeconomic status, younger age, female sex, systemic disease manifestations, and indicate pain is associated with current use of medications.
- 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.
- FSR encourages researchers to utilize this valuable dataset for future analyses.

Results

- Registry participants' mean age was 59 years, 70% were female, 76% were White, 16.3% Black/African American and 4.7% Hispanic/Latino.
- Overall, 2224 (44%) of participants reported a high pain burden. These participants indicated a diagnosis most frequently in their lungs, liver, brain/cranial nerves, or central lymph nodes (Figure 1).
- Respondents with high compared to low pain burden were younger at the time of diagnosis (mean age 42 versus 46) and at the onset of symptoms (mean age 39 versus 43) (p<0.0001 for both - Figure 2).
- Compared to participants with low pain participants with high pain burden were (Figure 2):
  - 1.6x more like to be female,
  - 1.6x more likely to be currently taking medication
  - 3.7x more likely to report job loss due to sarcoidosis health effects
  - 2.9x more likely to report an annual household income under $35,000
- There was a statistically significant association between high pain burden an participant-reported Black/African American race (OR=1.2, CI=1.0-1.4, p=0.02)
- When asked about effects of sarcoidosis on daily life, participants reported worries that their sarcoidosis might flare or worsen as their highest burden, followed by shortness of breath when walking short distances or climbing stairs. (Figure 3)
- 2584 (51%) participants reported shortness of breath on exertion either all or most of the time. Among these, 8% reported no lung involvement and instead indicated sarcoidosis diagnosis in their central lymph nodes (n=52, 25%), joints/arthritis (n=32, 16%), or skin (n=30,15%).

Figure 1: Organ Involvement by Level of Pain

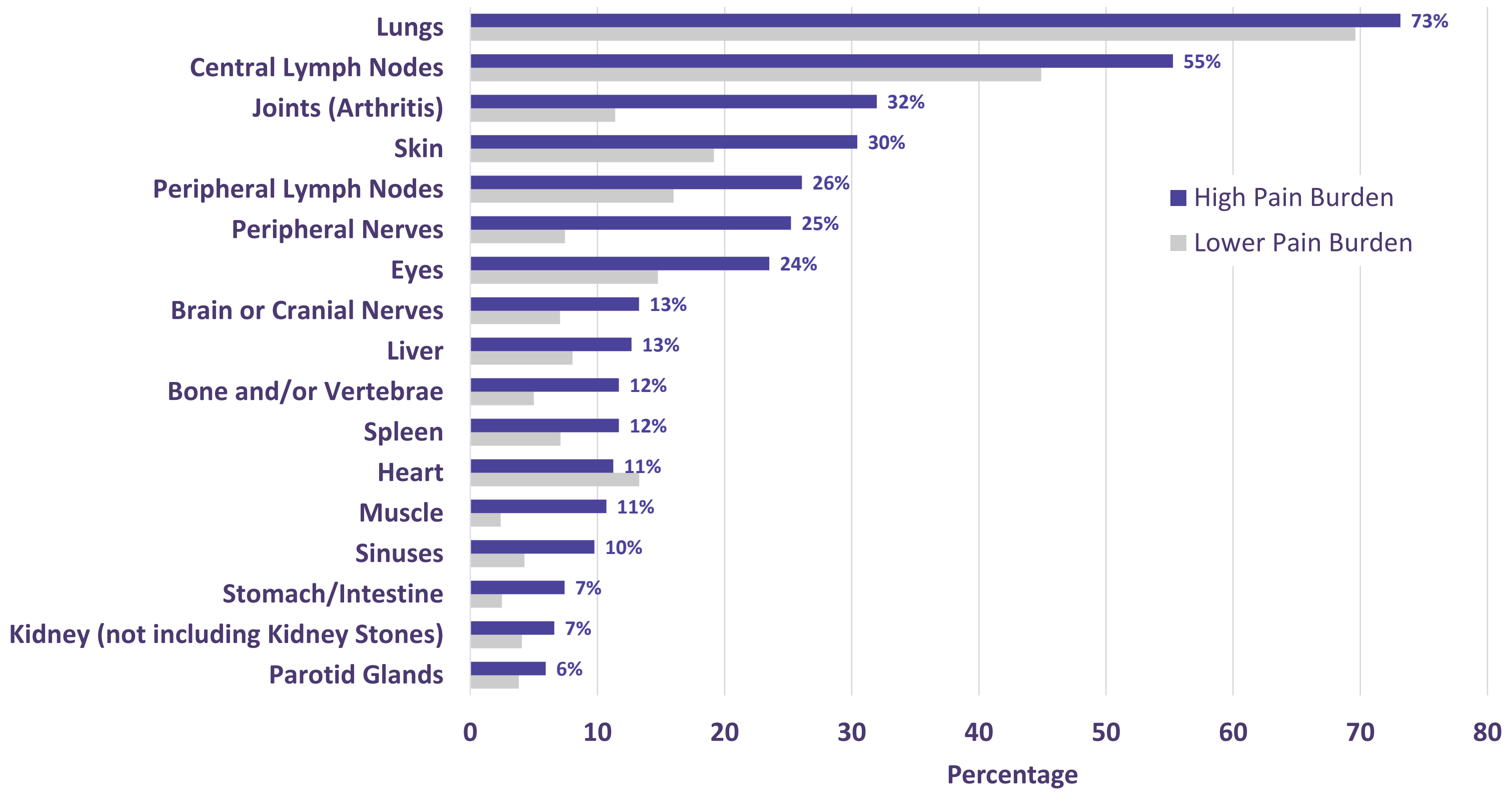


Figure 2: Comparison of Respondents with High Pain Burden to Those Reporting Low Pain Burden

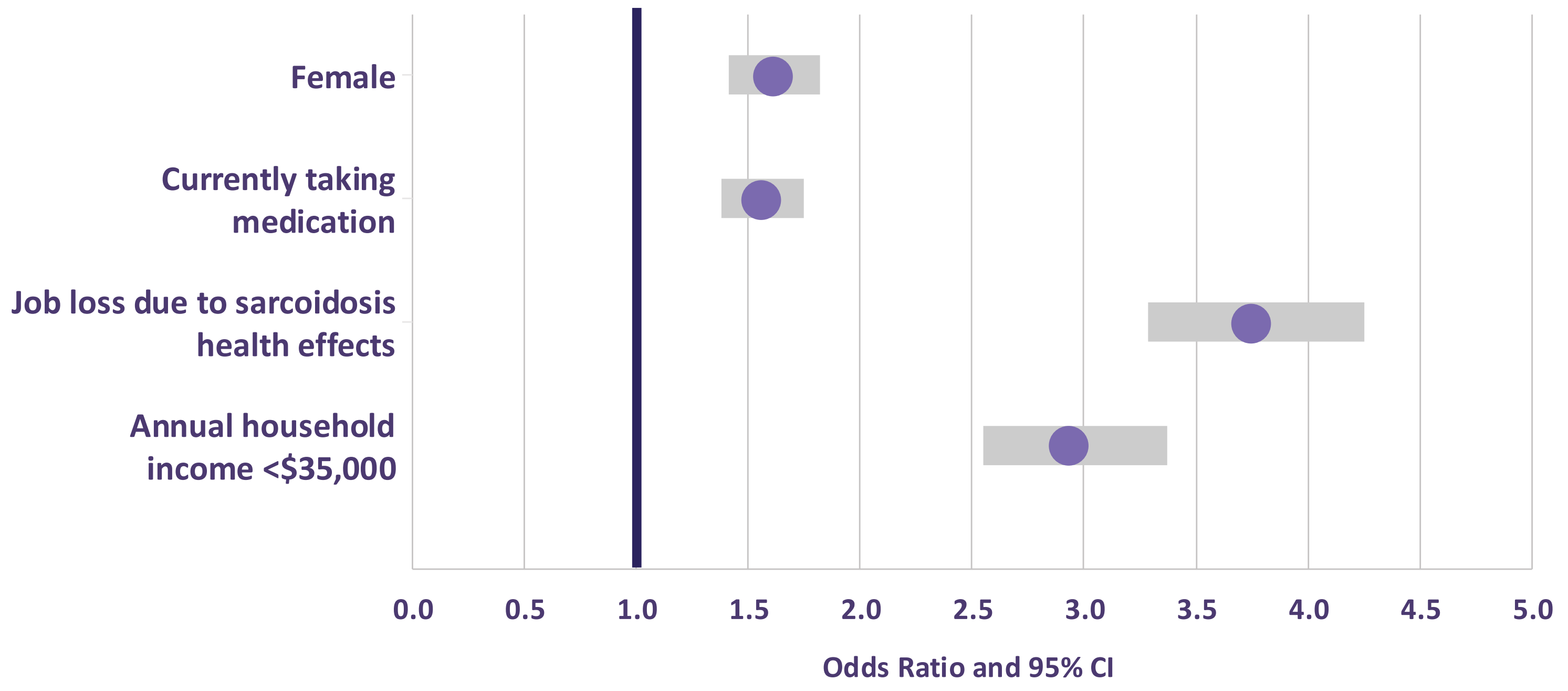
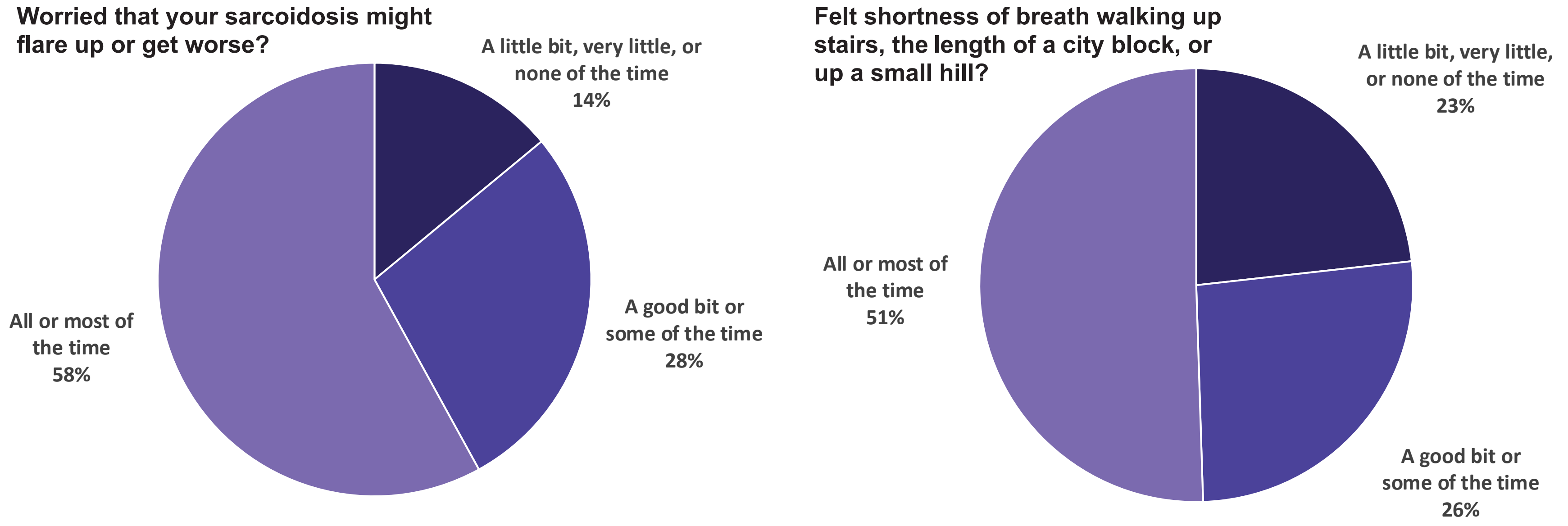


Figure 3: Top Reported Effects of Sarcoidosis on Daily Life


Worried that your sarcoidosis might flare up or get worse?

Felt shortness of breath walking up stairs, the length of a city block, or up a small hill?

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Corresponding Author Information:

Elise Hoover
elise@stopsarcoidosis.org

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Registry