

Resource Utilization in a US-based Sample of Patients with Sporadic Inclusion Body Myositis (sIBM)

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Background

SIBM is a progressive, idiopathic inflammatory myopathy characterized by atrophy and weakness of proximal and distal muscle groups, knee extensors, wrist and finger flexors; and dysphagic processes are frequently involved. Progressive weakness results in loss of independence and need for assistive devices and supportive care. There is a dearth of information on the socioeconomic burden of sIBM in the United States.

Objectives

To better characterize the socioeconomic burden of individuals with sIBM in the United States.

Methods

Registered participants of The Myositis Association 2013 and 2014 Annual Patient Conferences with a confirmed clinical diagnosis of sIBM were invited to participate in studies to better characterize the socioeconomic burden in this population via a direct mail letter or email following IRB approval. Two cross-sectional studies were conducted wherein participants completed a paper or web-based version of the Skeletal Muscle Activity and Resource Tool for Sporadic Inclusion Body Myositis (SMART-sIBM), a measure of self-reported resource utilization designed to characterize out-of-pocket expenses and non-reimbursable items not captured by health care systems. A subset of participants partook in both studies, providing longitudinal data.

Results

In total, 102 sIBM patients participated across both data collection efforts; 31 contributed to longitudinal data. Overall, mean age was 67.2 years (range 49 – 88), and most (62%) participants were male, Caucasian (94%) and well educated (72% with at least some college). Average number of years since diagnosis and years since first symptoms were 5.3 ± 4.3 (range 0 – 18) and 11.3 ± 6.4 , respectively.

Approximately one-third of participants reported being ambulatory without an assistive device; the remaining noted use of an aid/brace (37%), power mobility for long distances (17%), power mobility most of the time (7%), and/or inability to walk or stand (4%). Average number of falls per month and healthcare visits because of falls were <1 (range 0 – 4) and 0.71 ± 1.8 (range 0 – 12), respectively. All participants reported need for frequent health care visits, and 80% indicated need for house/vehicle modifications and purchase of assistive equipment to accommodate sIBM-related disabilities. More than one-third (36%) of participants required paid help with household tasks, and 60% relied on help from unpaid caregivers (87% spouse). Nearly half (42%) reported changes in job status because of sIBM-related functional limitations.

Conclusions

Results of this study, which provides socioeconomic data for the first time in a US-based sample of patients with sIBM, demonstrate a high resource utilization and financial burden experienced by sIBM patients in the United States.

