Characteristics of patients with progressive supranuclear palsy (PSP) in US health insurance claims data

Progressive supranuclear palsy (PSP) is a rare and progressive neurodegenerative tauopathy characterized by vertical supranuclear gaze palsy and postural instability. PSP affects approximately 6 per 100,000 persons in the United States [1,2] and the majority of studies of PSP have been in small, clinic-based samples. In order to obtain a better understanding of this rare disease, researchers in the Safety and Benefit Risk Management department at Biogen identified a cohort of PSP patients in a United States health insurance claims database, Truven Health MarketScan®. The study objectives were to describe the demographic characteristics, comorbidities and medications of PSP patients.

Applying a combination of International Classification of Diseases (ICD) version 9 and 10 diagnostic codes from 2012-2017, 630 patients met the case definition for PSP out of approximately 38 million patients. A little over half of PSP patients were male and the mean age was 71.9 years. The most frequent comorbidities in patients with PSP were nervous system disorders (96.6%), connective tissue diseases (92.0%), eye disorders (85.2%), and non-traumatic joint disorders (84.8%). In the 12 months prior to the index date, many patients had diagnoses of Parkinson's disease, gait abnormalities, muscle weakness, falls, dysphagia, and urinary tract infections. The most frequently prescribed medications were anti-infectants (83.8%), drugs for movement disorders (78.8%), anti-depressants (66.9%), and narcotic analgesics (65.1%).

This is one of the largest studies of PSP patients in the United States using real world data. The findings confirm that PSP is a rare disease with a high burden of comorbidities and prescription medication utilization, underscoring the complexity of the disease. The identification of comorbidities frequently diagnosed prior to the PSP diagnosis may assist with the earlier identification of patients. This study contributes to further knowledge of this rare and devastating disease.

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[1] Fleury, V., P. Brindel, N. Nicastro and P. R. Burkhard (2018). "Descriptive epidemiology of parkinsonism in the Canton of Geneva, Switzerland." Parkinsonism Relat Disord.
[2] Schrag, A., Y. Ben-Shlomo and N. P. Quinn (1999). "Prevalence of progressive supranuclear palsy and multiple system atrophy: a cross-sectional study." Lancet 354(9192): 1771-1775.