Symptoms in patients with ALS before and after onset of weakness

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Symptoms unrelated to weakness occur in patients with ALS. No studies systematically categorizing such symptoms onset and evolution with disease progression using patient reported questionnaires compared with controls exist. Therefore, these symptoms might be missed during patients' visits. Also it is not known if motor symptoms are the first manifestations, or if there might be other manifestations preceding the most obvious weakness-related symptoms by months or years. In this cross-sectional, retrospective study, we investigated the prevalence of various symptoms and their possible onset prior to weakness in 36 Amyotrophic Lateral Sclerosis (ALS) patients and 38 healthy controls using a newly designed questionnaire. The questions were chosen based on previously published literature and experience of the members of our Muscular Dystrophy Association and ALS Association Clinics. Besides musculoskeletal, symptoms from psychiatric, sleep, sensory, autonomic and extrapyramidal domains were most prevalent in the ALS group compared to controls. The most commonly reported symptoms besides muscle weakness in the ALS group were: muscle cramping and twitching, poor balance, stiffness, slowness of movements and feeling sad or depressed, compared to controls. Occasionally, these symptoms appeared before the onset of weakness although that was not statistically significant. The symptom burden correlated with advanced disease. There was a weak correlation of amount of these symptoms with ALSFRS scores. Our study shows that non-strength related symptoms in ALS patients are more common than in healthy controls and some may occur before onset of weakness. Additional studies are necessary to confirm this data and to further validate our questionnaire as a useful screening tool. The knowledge of various organ systems involved in the disease process would prevent failure to diagnose potentially co-morbid symptoms and improve individualized delivery of care.

Speaker Biography

Alexander Shtilbans is an Assistant Professor of Neurology at the Parkinson's Disease and Movement Disorders Institute of Weill Cornell Medical College and Hospital for Special Surgery. His clinical and research interests are in Neurodegenerative Diseases in general and in Parkinson disease and ALS. Having started out as a Molecular Biologist in Neuroscience, after obtaining his PhD, he had transitioned into Clinical Neurology to work with patients and to better understand the clinical course of the diseases. He has received his Medical degree from Mount Sinai School of Medicine, where he also completed his residency in Neurology and served as a Chief Resident. Subsequently, he has completed his Clinical Fellowship in Movement Disorders at Columbia University. He has a longstanding interest in translational research and currently leads several NIH-funded clinical trials on Parkinson's disease as a Principal Investigator and is involved in studies on Amyotrophic Lateral Sclerosis. He has published in peer-reviewed journals and received awards from the American Academy of Neurology.

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