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Determinants of Quality of Life in Patients with Atypical Prarkinsonian Syndromes: 1-Year Follow-Up Study

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Abstract : Background: A group of atypical parkinsonian syndromes (APS) includes a variety of rare neurodegenerative disorders characterized by reduced life expectancy, increasing disability, and considerable impact on health-related quality of life (HRQoL). Aim: In this study we wanted to answer two questions: a) which demographic and clinical factors are main contributors of HRQoL in our cohort of patients with APS, and b) how does quality of life of these patients change over 1-year follow-up period. Patients and Methods: We conducted a prospective cohort study in hospital settings. The initial study comprised all consecutive patients who were referred to the Department of Movement Disorders, Clinic of Neurology, Clinical Centre of Serbia, Faculty of Medicine, University of Belgrade (Serbia), from January 31, 2000 to July 31, 2013, with the initial diagnoses of 'Parkinson's disease', 'parkinsonism', 'atypical parkinsonism' and 'parkinsonism plus' during the first 8 months from the appearance of first symptom(s). The patients were afterwards regularly followed in 4-6 month intervals and eventually the diagnoses were established for 46 patients fulfilling the criteria for clinically probable progressive supranuclear palsy (PSP) and 36 patients for probable multiple system atrophy (MSA). The health-related quality of life was assessed by using the SF-36 questionnaire (Serbian translation). Hierarchical multiple regression analysis was conducted to identify predictors of composite scores of SF-36. The importance of changes in quality of life scores of patients with APS between baseline and follow-up time-point were quantified using Wilcoxon Signed Ranks Test. The magnitude of any differences for the quality of life changes was calculated as an effect size (ES). Results: The final models of hierarchical regression analysis showed that apathy measured by the Apathy evaluation scale (AES) score accounted for 59% of the variance in the Physical Health Composite Score of SF-36 and 14% of the variance in the Mental Health Composite Score of SF-36 ($p<0.01$). The changes in HRQoL were assessed in 52 patients with APS who completed 1-year follow-up period. The analysis of magnitude for changes in HRQoL during one-year follow-up period have shown sustained medium ES (0.50-0.79) for both Physical and Mental health composite scores, total quality of life as well as for the Physical Health, Vitality, Role Emotional and Social Functioning. Conclusion: This study provides insight into new potential predictors of HRQoL and its changes over time in patients with APS. Additionally, identification of both prognostic markers of a poor HRQoL and magnitude of its changes should be considered when developing comprehensive treatment-related strategies and health care programs aimed at improving HRQoL and well-being in patients with APS.

Keywords : atypical parkinsonian syndromes, follow-up study, quality of life, APS
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