

Quality of life in Parkinson's disease

Qualidade de vida na doença de Parkinson

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Quality of life (QoL) can be defined as a general sense of well being which is determined by multidimensional factors related to the individual, social interactions and the environment in the context of a given culture and value system. It also relates to the individuals own perception of their position in life in relation to their goals, expectations and concerns, and therefore should be truly judged by the individuals themselves^{1,2}. Although health status has been considered to be a key factor in determining QoL, several authors have found low level of agreement between reports from individuals with chronic diseases and their caregivers regarding health-related QoL (HRQoL) estimations. This is particularly true with respect to Parkinson's disease (PD), which is a multifaceted and symptomatically complex neurodegenerative condition³.

PD is the second most common neurodegenerative disorder and is characterized by the classical motor symptoms (resting tremor, bradykinesia, rigidity, postural instability) and non-motor symptoms, some of which may precede clinical diagnosis by several years. Non-motor symptoms include autonomic dysfunction (constipation, urinary), cognitive decline (memory and attention), psychiatric disorders (depression, anxiety), sleep disturbances (vivid dreams, REM behavior disorder) and fatigue, among others. HRQoL in PD is determined by motor and non-motor symptoms and by the effects of treatment as well (efficacy and side effects)⁴. As the disease progresses, patients with PD are particularly prone to deterioration of HRQoL as a result of both increased motor disability and the burden of non-motor symptoms. Among motor symptoms, the main determinants are disease severity, motor complications of treatment, postural instability, and gait disturbances⁵. Among non-motor symptoms, depression has been recognized as the main HRQoL determinant but other symptoms such as anxiety, cognitive impairment, fatigue, sleep disorders, pain and dysautonomia are also major contributors to low HRQoL in PD⁶.

Several rating scales have been used to assess disease severity and HRQoL in PD. The most widely used include: Hoehn and Yahr staging (HY), Non-MotorSymptoms Scale (NMSS), MDS-UPDRS, Parkinson's Disease Questionnaire (PDQ-39) and its eight item-short version (PDQ-8). The NMSS include the following domains: cardiovascular, sleep/fatigue, mood, perceptual, attention/memory, gastrointestinal, urinary and sexual function. The MDS-UPDRS is composed of four subscales: Part I, non-motor experiences of daily living; Part II, motor experiences of daily living; Part III, motor examination; and Part IV, motor complications. Items are scored on a five-point scale, ranging from 0 (normal) to 4 (severe), and the total score is obtained for each section. The PDQ-8 has eight items scoring from 0 (never) to 4 (always) and provides judgments about the impact of PD on physical, mental and social domains. The summary index (SI) is expressed as the percentage of the sum of item scores on the maximum possible score (32 points). Higher scores mean worse HRQoL⁷.

In the article by Moreira et al.⁸, in this issue, the authors address a less investigated aspect of PD-related QoL, which relates to the potential changing impact in QoL at different stages of PD. In this cross-sectional study, data were collected from 100 patients rated between 1 and 3 on the HY scale. Patients were classified as having mild PD (MIG) or moderate PD (MOG). The evaluation included clinical history, demographic data and clinical/functional information obtained by applying the UPDRS (ADL and motor examination sections) and PDQ-39. The main results have disclosed important aspects that could go unnoticed during routine patient care. The MOG group had greater impairment in ADL section of the UPDRS but was particularly relevant in the increased drooling, need for assistance with personal hygiene and

more frequent freezing episodes. QoL evaluation by PDQ-39 showed higher means in seven of the eight items in the MOG group. Greater disease duration and lack of support from friends and family members were associated with reduced QoL in both groups. Rather surprisingly, mean motor impairment was not statistically significant between the two groups but when each item was considered individually, significant differences were observed in resting tremor and bradykinesia. Moreover, non-motor symptoms pose additional burden as disease progresses. Anxiety and concern about the future were more important in the MOG group corroborating previous findings that depressive symptoms are critical determinants of lower QoL^{3,6}.

It has become increasingly clear from this and other studies that, in addition to the contribution of motor symptoms in determining QoL in PD, for many patients, the major burden of having the disease derives from the effects of non-motor symptoms. The use of tools to specifically assess non-motor aspects of PD, such as the NMSS and the UPDRS section I (non-motor aspects of daily living) has proved to be of help as a means to quantify symptoms severity. Indeed, reliance on the UPDRS motor score as the sole instrument to assess PD and the effect of treatments should be replaced by a more comprehensive approach capable to efficiently assess the whole complexities posed by the ever changing progressive character of PD.

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