Journal of Clinical Neuroscience 28 (2016) 102–106

Contents lists available at ScienceDirect

Journal of Clinical Neuroscience

journal homepage: www.elsevier.com/locate/jocn

Clinical Study

Duration of disease does not equally influence all aspects of quality of life in Parkinson's disease

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ARTICLE INFO

Article history:
Received 15 April 2015
Accepted 18 September 2015

Keywords:
Disease duration
Health-related quality of life
Parkinson's disease

ABSTRACT

Health related quality of life (HRQoL) is negatively impacted in patients suffering from Parkinson's disease (PD). For the specific components that comprise HRQoL, the relationship between clinical variables, such as disease duration, is not fully characterized. In this cross-sectional study (n = 302), self-reported HRQoL on the Parkinson's Disease Questionnaire (PDQ-39) was evaluated as a global construct as well as individual subscale scores. HRQoL was compared in three groups: those within 5 years of diagnosis, those within 6–10 years of diagnosis, and those greater than 11 years since diagnosis. Non-parametric analyses revealed lower HRQoL with increasing disease duration when assessed as a global construct. However, when subscales were evaluated, difficulties with bodily discomfort and cognitive complaints were comparable in individuals in the 1–5 years and 6–10 year duration groups. Exploratory regression analyses suggested disease duration does explain unique variance in some subscales, even after controlling for Hoehn and Yahr stage and neuropsychiatric features. Our findings show that HRQoL domains in PD patients are affected differentially across the duration of the disease. Clinicians and researchers may need to tailor interventions intended to improve HRQoL at different domains as the disease progresses.

1. Introduction

Health related quality of life (HRQoL) in Parkinson's disease (PD) is a multifaceted construct, encompassing the emotional, physical, and social impacts of the condition [1]. In recent years, HRQoL has emerged as an increasingly important outcome measure for evaluating the efficacy of interventions in PD [2]. Studies of HRQoL in PD have revealed strong associations with several features beyond the core motor symptoms, including depression [3], fatigue [4], and other non-motor symptoms [5]. Given that PD is progressive, with increasing motor and non-motor symptoms over time [6], it stands to reason that disease duration could be strongly correlated with HRQoL. However, some studies have found little relationship between disease duration and HRQoL [7] or found that the relationship attenuates after accounting for other demographic or clinical factors [8]. According to a recent systematic review [3] of 20 studies examining factors influencing HRQoL, disease duration was retained as a significant predictor in only six.

One potential explanation for these discrepant findings is that the association between disease duration and HRQoL might be more complex than a simple direct linear relationship. For example Soh [9] proposed that disease duration contributes to HRQoL via its impact on motor, non-motor, mental, and self-care limitations. However, the fit indices of their structural equation models were not fully desirable. In a similar vein, Visser et al. [10] found that depression and psychological functioning continue to influence HRQoL throughout the course of the disease, while pain and impaired activities of daily living (ADL) are only predictors of HRQoL in early, but not in the later stages of PD.

In addition to a more complex relationship between disease duration and HRQoL, it is also important to point out that the above studies often treated HRQoL as a unitary construct, by using a summary score in their analysis. Because multiple domains of daily life define HRQoL, summary scores alone may miss more focused impacts of the disease on a particular facet of daily existence. This assertion is supported by previous factor analytic

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http://dx.doi.org/10.1016/j.jocn.2015.09.019
0967-5868/

studies that suggest multiple components of HRQoL exist which overlap, but also explain a unique portion of the variance in the global construct [11]. These individual facets of HRQoL may be differentially impacted by disease duration. As an example, a 12 month study of patients with PD found that the Parkinson's Disease Questionnaire (PDQ-39) subscales of stigma, communication and body pain alone changed over the study course, while other subscale scores remained unchanged [12]. In another study, when comparing subscales of treated *versus* untreated early stage PD patients over 18 months [13], six of the eight subscales of the PDQ-39 improved with treatment over the course of 18 months, while all domains declined in the non-treated early PD group. Interestingly, in the treatment group it was mobility and ADL scores that did not change, and the magnitude of decline in the control group was not uniform between domains.

In light of these findings, the current study seeks to evaluate differences in HRQoL at the subscale level in a cross sectional study of PD clinical outpatients. Specifically, we sought to evaluate any difference in PDQ-39 subscales across patient groups in the early (0–5 years), middle (6–10 years) and later (11+ years) periods of disease duration. Preliminary analyses to establish any independent relationship with disease duration and domains of HRQOL are also undertaken.

2. Methods

2.1. Participants and data acquisition

All patients with a diagnosis of idiopathic PD in the Plummer Movement Disorders Center of Baylor Scott & White Hospital were asked to complete yearly surveys that include the PDQ-39 as well as various demographic and clinical factors. Pertinent to this survey, individuals were also asked to select their disease duration from several different options: 0–5 years, 6–10 years, 11–15 years, and 15+ years. Given small sample sizes in some of the advanced groups, these were combined into 0–5, 6–10, and 11+ years duration for this study.

The current study retrospectively evaluated the data collected in 2012 with the approval of Baylor Scott & White Hospital's Institutional Review Board. Of the 337 surveys collected in 2012, 35 were incomplete and eliminated from the statistical analysis. For the remaining 302 patients, demographics, disease duration and HRQoL data (measured by PDQ-39) were extracted. On the demographic questionnaire, items such as age were asked in terms of ranges rather than ratio level data. In addition, Hoehn and Yahr (H&Y) [14] ratings or the information necessary to obtain the H&Y score was abstracted from neurology notes and coded by a trained research coordinator. Demographic and clinical variables are found in Table 1.

2.2. Instruments

The PDQ-39 [11] is a 39-item questionnaire in which the frequency of PD-related interference on a number of activities, situations, and symptoms is rated using a 0 (never) to 4 (always) scale. The items are grouped in eight domains: mobility, ADL, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. The scores for each subscale are transformed into a 0–100 scale by summing the raw scores for each item, divided by the maximum possible raw score, and then multiplying by 100 (higher scores mean poorer HRQoL). A Summary Index is also calculated from the mean of the eight domain scores.

In addition to the PDQ-39, patients provided relevant clinical and demographic data in a multiple choice format in an accompanying questionnaire. Pertinent to the current study, patients were asked to endorse whether they were experiencing depression, anxiety, or thinking problems. This information was also utilized in the analyses below and is summarized in Table 1.

2.3. Data analysis

All statistical analyses were completed in Stata 13 (StataCorp, College Station, TX, USA) [15]. Demographic and clinical variables were compared between groups with chi-square tests. Initial analysis of the PDQ-39 variables revealed significantly non-normal distributions. As such, Kruskal–Wallis tests (a non-parametric variant of the analysis of variance) were used to compare the groups on the subscales and summary index of the PDQ-39. Given the multiple comparisons, Bonferroni correction on the omnibus tests was used, with a significance level for each analysis set to $p \leqslant 0.006$ for all analyses. For significant findings, Dunn's test was employed as *post hoc* analyses between the three duration groups [16]. To help determine the potential impact of disease stage and neuropsychiatric covariates on these analyses, exploratory multiple regressions were conducted to evaluate the impact of these variables on HRQoL domains.

Table 1
Demographic and clinical variables for Parkinson's disease patients

Variable	0–5 years		6–10 years		11+ years		Total sample
	%	N	%	N	%	N	%
Male sex	50.21	122	63.41	26	55.56	10	52.32
Age, years							
<50	3.29	8	0.00	0	0.00	0	2.65
51–60	10.29	25	19.51	8	5.56	1	11.26
61–70	32.51	79	36.59	15	38.39	7	33.44
71–80	34.57	84	24.39	10	38.89	7	33.44
81+	19.35	47	19.51	8	16.67	3	19.21
H&Y							
1	25.00	58	21.95	9	0.00	0	23.10
2	71.98	167	63.41	26	64.71	11	70.34
3	3.02	7	4.88	2	17.65	3	4.14
4	0.00	0	7.32	3	11.76	2	1.72
5	0.00	0	2.44	1	5.88	1	0.69
Self-reported:							
Depression	29.10	71	34.15	14	50.0	9	31.02
Anxiety	34.02	83	39.02	16	33.33	6	34.65
Cognitive difficulties	46.31	113	46.34	19	46.34	9	50.00

H&Y = Hoehn and Yahr.