

Quality of life in a Brazilian sample of patients with Parkinson's disease and their caregivers

Qualidade de vida de uma amostra de pacientes brasileiros portadores da doença de Parkinson e seus cuidadores

Pedro Schestatsky,¹ Vanessa Cassina Zanatto,² Regina Margis,¹
Eduardo Chachamovich,¹ Mateus Reche,² Rodrigo Gomes Batista,²
Daniele Fricke,¹ Carlos RM Rieder¹

Abstract

Objective: Parkinson's disease is a common neurodegenerative disorder characterized by motor disabilities and increasing dependence on others for daily life activities with consequent impact on patients' and caregivers' quality of life. **Method:** A cross-sectional study was performed in which quality of life was assessed by the WHOQOL-BREF questionnaire in 21 patients with Parkinson's disease and their respective caregivers. **Results:** Significant differences between patients and caregivers were found in physical ($p < 0.001$) and psychological ($p = 0.002$) domains. In the Parkinson's disease group there was a significant inverse correlation between the psychological domain and duration of disease ($p = 0.01$), as well as between social domain and severity of disease ($p = 0.001$). There was a positive correlation between physical domain scores and number of people living in the same house ($p = 0.02$). The only significant finding in the group of caregivers was an inverse correlation between the social domain and the patients' age ($p = 0.04$). **Conclusion:** Duration, severity of the disease and the number of people living in the same house were the most important predictors of quality of life of Parkinson's disease patients. The age of the patients was the only significant predictor found in the caregivers' quality of life. In order to complement our findings, further short-form questionnaires should be validated for Brazilian samples of Parkinson's disease.

Keywords: Quality of life; Parkinson disease; Caregivers; Evaluation studies; Validity

Resumo

Objetivo: A doença de Parkinson é uma enfermidade neurodegenerativa comum caracterizada por disfunção motora e níveis crescentes de dependência para atividades da vida diária, com conseqüente impacto sobre a qualidade de vida dos pacientes e seus cuidadores. **Método:** Foi realizado um estudo transversal avaliando qualidade de vida por meio do questionário WHOQOL-BREF em 21 pacientes com doença de Parkinson e seus respectivos cuidadores. **Resultados:** Diferenças significativas entre pacientes e cuidadores foram encontradas nos domínios físico ($p < 0,001$) e psicológico ($p = 0,002$) do questionário WHOQOL-BREF. No grupo dos pacientes, houve uma significativa correlação inversa entre o domínio psicológico e duração da doença ($p = 0,01$), assim como entre domínio social e gravidade da doença ($p = 0,001$). Houve uma correlação positiva entre domínio físico e número de pessoas vivendo na mesma casa ($p = 0,02$). O único achado significativo no grupo dos cuidadores foi uma correlação inversa entre o domínio social e a idade do paciente ($p = 0,04$). **Conclusão:** Duração, gravidade e número de pessoas vivendo na mesma casa foram os fatores preditores mais importantes sobre a qualidade de vida dos pacientes com doença de Parkinson. A idade dos pacientes foi o único fator preditor encontrado sobre a qualidade de vida dos cuidadores. Outros questionários de aplicação curta devem ser validados para amostras brasileiras de pacientes com doença de Parkinson no sentido de complementar nossos achados.

Descritores: Qualidade de vida; Doença de Parkinson; Cuidadores; Estudos de avaliação; Validade

¹ Service of Neurology, Hospital de Clínicas de Porto Alegre (HCPA), Porto Alegre (RS), Brazil

² Medical School, Universidade Federal do Rio Grande do Sul (UFRGS), Porto Alegre (RS), Brazil

Correspondence

Pedro Schestatsky
Neurology Department
Hospital de clínicas de Porto Alegre
Ramiro Barcelos, 2600
90035-003 Porto Alegre, RS, Brazil
Phone: (55 51) 2101-8520 Fax: (55 51) 2101-8752
E-mail: lonfra@hotmail.com

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Introduction

One of the main objectives of medical care in Parkinson Disease (PD), besides the treatment of motor aspects or increment of survival, is the enhancement of quality of life (QOL).¹ Different aspects of the disease could contribute for the QOL of such patients.²⁻³ There is a positive association between caregiver's emotions and behaviors with clinical relapses in PD.⁴ Thus, caregivers should be also assessed in order to identify the characteristics of and factors associated with the strain they are experiencing. As far as we are concerned, there are no studies evaluating the impact of QOL on PD patients and caregivers simultaneously in South America. The objective of the present study was to examine the QOL by a practical and validated instrument in patients with PD and their caregivers simultaneously. We believe that the identification of determinants of QOL in such population could help us design effective interventions for the improvement of the distress related to the disorder.

Method

We studied patients diagnosed with PD⁵ in the movement disorders clinic of a university hospital in southern Brazil from December 2003 to November 2004. All patients who met no exclusion criteria and agreed to participate in the study were consecutively examined in a cross-sectional design. Exclusion criteria were as follows: 1) vascular, pharmacological or atypical parkinsonism; 2) presence of other psychiatric diseases non-related to PD; 3) abusive use of alcohol or illicit drugs; 4) Mini-Mental Score Examination (MMSE) lower than 24 points; and 5) PD patients who lived alone or who were not accompanied by their usual caregivers for more than three consecutive consultations. We also examined their respective caregivers, consisting of individuals who were considered by the patients as the most usual caretaker in their daily lives.

Patients who met criteria for the study were scheduled for clinical assessment through a questionnaire on general information about PD, including disease severity as measured by the Hoehn & Yahr Scale (HYS)⁶ and QOL aspects. Quality of life was assessed as per WHOQOL-BREF, which was administrated in a face-to-face basis and recorded by an experienced psychiatrist. The WHOQOL-BREF questionnaire consists of 26 items, whose mean application time is approximately 5-10 minutes. Two questions assess global QOL and the rest of the instrument approaches more specific aspects that include social, physical, psychological and environmental domains. Higher scores indicated better quality of life in each

domain. This questionnaire was originally elaborated by the WHOQOL Group⁷ and it has been modified to a shorter version which was validated in a Brazilian sample by Fleck et al.⁸ Since it is based on the WHO concept of quality of life, it emphasizes the role of the subjective perception instead of more objective approaches used in other instruments. WHOQOL-BREF is characterized as a generic quality of life assessment instrument, which is capable of detecting the impact of determined conditions in a broad way, in contrast to more specific quality of life measures. All patients and controls gave their informed consent for the study, which was approved by the Ethical Committee of our institution.

Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 10.0 for Windows. Comparisons between WHOQOL-BREF scores were performed using Student's t-test for paired samples, while correlations between continuous variables were performed using the Pearson's correlation coefficient. A p value < 0.05 was considered to indicate statistical significance.

Results

Twenty-one patients aged 32 to 86 years were studied (mean age = 65.76 ± 11.07), 76.2% being male. There were no refusals to participate in the protocol. The average duration of disease was 6.78 ± 4.46 years. The mean score on the HYS was 2.55 ± 1.06 and the mean score of the MMSE was 26.52 ± 1.86. The mean amount of antiparkinsonian medications used was 2.95 ± 1.71. None of the patients lived alone. The mean number of people living in the same dwelling was 2.8 ± 1.23 people. Caregivers aged 23 to 70 years (mean age = 50.70 ± 16.26), being 90.4% female. Concerning the nature of relationship, 52.1% of the caregivers were wife or husband, 25.9% sons or daughters, 12% siblings and 10% did not have any familial connection with the patient (professional caregiver).

Significant differences between patients and caregivers were found in physical (p < 0.001) and psychological (p = 0.002), but not for social and environmental domains (p = 0.3 and p = 0.9, respectively).

In Table 1, WHOQOL-BREF parameters of patients with PD and caregivers are shown in relation to our main outcome variables. In the PD group there was a statistically significant inverse correlation between psychological domain and duration of disease (r = -0.55; p = 0.01), as well as between social domain and HYS (r = -0.7; p = 0.001). On the contrary, there was a positive correlation between physical domain scores

Table 1 - Correlations between WHOQOL-BREF values and other variables in patients and caregivers (Pearson correlation)

Status	WHOQOL-BREF domains	Patient's age		Duration of disease		HYS		MMSE†		Number of habitants		Number of medications	
		r	p	r	p	r	p	r	p	r	p	r	p
Patients (n = 21)	Physical	0.29	0.1	-0.43	0.06	-0.09	0.6	0.22	0.2	0.5	0.02*	0.03	0.8
	Psychological	0.1	0.6	-0.55	0.01*	-0.33	0.1	0.006	0.8	0.37	0.09	-0.07	0.7
	Social	-0.74	0.07	-0.2	0.3	-0.7	0.001*	-0.007	0.5	0.1	0.6	0.001	0.8
	Environmental	-0.12	0.5	-0.38	0.09	-0.19	0.4	-0.156	0.8	0.08	0.7	-0.02	0.6
Caregivers (n = 21)	Physical	-0.26	0.2	0.24	0.3	0.31	0.6	-0.072	0.07	0.008	0.9	0.21	0.6
	Psychological	-0.18	0.4	-0.11	0.6	-0.1	0.9	-0.179	0.1	0.03	0.8	0.36	0.7
	Social	-0.43	0.04*	-0.01	0.9	-0.05	0.5	-0.24	0.6	-0.16	0.4	0.18	0.7
	Environmental	0.45	0.8	-0.25	0.2	-0.34	0.7	-0.94	0.09	-0.16	0.4	0.12	0.1

* = Statistically significant; † = 45 patients and 45 caregivers were included in the analysis; HYS = Hoehn and Yahr scale; MMSE = Mini-Mental Score Examination

and number of people living in the same house ($r = 0.5$; $p = 0.02$). The only statistically significant finding in the group of caregivers was an inverse correlation between social domain and the patients' age ($r = -0.43$; $p = 0.04$).

Discussion

This is the first South American study simultaneously evaluating the QOL of patients with PD and their caregivers, through the WHOQOL-BREF instrument. In our study, the caregivers, mostly women, presented significant differences in the physical and psychological domains, but not in social and environmental domains, when compared to patients. Interestingly, when patients with MMSE < 24 points were included, the affected domains changed to the social and environmental ones (data not shown). This might be explained by the fact that poor cognition could spare the patients from suffering with obvious physical and psychological matters. The psychological domain is considered one of most importance for QOL in patients with PD.³ Furthermore, depressive symptoms, much more prevalent in PD patients than in the general population, are determinant in psychological domain scores.⁹ This fact corroborates our findings of lower scores in the psychological domain in our patients when compared to caregivers and may be related to the association of PD itself and the development of depressive symptomatology in the course of the illness.

QOL of PD patients was not affected by their age. Older patients with retired life style and slower working pace may find it easier to accept the disease and problems associated with it and hence feel much less distressed. At the present work, the patients' age proved to be the most significant factor associated with caregiver strain. However, these results are not in accordance with previous studies,¹⁰⁻¹¹ in which the patients' functional state was the best predictor or determinant of caregivers' psychosocial burden. On the other hand, Aarsland et al. found that mental symptoms – such as depression, cognitive impairment, agitation, abnormal behavior, and delusions – were the most consistent predictors of caregiver distress in PD.¹² Regarding cognitive impairment our findings did not show significant correlation with any WHOQOL-BREF domains, even when patients with MMSE scores lower than 24 points were included (Table 1). In fact, this relative disparity of findings is in accordance with Martinez and Martin, who observed numerous comparative studies that have revealed great differences in results of evaluations accomplished with patients compared to medical staff and family members.¹ Another explanation for the few discrepancies in the results is based on the fact that our caregivers were younger than the caregivers of other studies^{4,13} and this could have overestimated their QOL scores. The same phenomenon was observed by Habermann, when analyzing patients' wives with similar age range of our study.¹⁴

Longer duration of disease was significantly associated with lower scores in the psychological domain, which is probably related to increased risk of major depression in PD patients with longer course.⁹ The severity of the motor symptoms, measured through HYS was inversely correlated with social functioning ($r = -0.7$; $p = 0.001$). This is in accordance with Behari et al., who also reported a decreased social behavior and decreased interaction in patients with advancing disease and physical disabilities.³

This study's limitations lie in its cross-sectional design, what restricts the interpretation of the results in terms of cause and

effect, as well as in the size and specific characteristics of the sample, something that prevents any generalization of the conclusions. Taking into account these limitations, the results may be summarized as follows: 1) PD patients with normal cognition and HYS between 1-3 have indeed worse QOL scores in comparison with their caregivers in the physical and psychological domains; 2) duration, severity of the disease and the number of people living in the same house were the most important predictors in the QOL of PD patients on the psychological, social and physical domains, respectively; and 3) the age of the patients with PD was the only significant predictor found in the caregivers' QOL, specifically in the social domain. In order to complement our findings, further short-form questionnaires^{2,15} should be validated for Brazilian samples with PD.

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