

# Quality of life in patients with Parkinson's Disease and their caregivers' stress levels

*Qualidade de vida nos portadores de Doença de Parkinson e níveis de estresse em seus cuidadores*

*Elton Gomes da Silva<sup>1</sup>, Karina Cuziol<sup>2</sup>, Maura Aparecida Viana<sup>3</sup>, Elizabeth Maria Aparecida Barasnevicius Quagliato<sup>4</sup>*

## RESUMO

**Introdução.** A qualidade de vida nos pacientes com doença de Parkinson (DP) está relacionada ao estágio da doença e altera também a qualidade de vida dos cuidadores que convivem com eles. **Método.** Foram avaliados consecutivamente 43 pacientes com DP (31 homens) e seus respectivos cuidadores (35 mulheres) para definir se os sintomas da doença influenciam na qualidade de vida dos indivíduos analisados. **Resultados.** Houve correlação significativa entre a qualidade de vida e as medidas de gradação da doença e o stress dos cuidadores, sendo que quanto maior a pontuação nas escalas de estágio da doença, pior a qualidade de vida dos pacientes e seus cuidadores. **Conclusão.** O controle dos sintomas da doença ajuda a melhorar a qualidade de vida dos pacientes e, conseqüentemente, de seus cuidadores.

**Unitermos.** Doença de Parkinson, Qualidade de Vida, Assistência ao Paciente.

Citação. Silva EG, Cuziol K, Viana MA, Quagliato EMAB. Quality of life in patients with Parkinson's Disease and their caregivers' stress levels.

## SUMMARY

**Introduction.** The quality of life in patients with Parkinson's disease (PD) is related to the disease level, which also indicates the caregiver's quality of life. **Methods.** This study comprised 43 patients with PD (31 male) and their respective caregivers (35 female) in order to evaluate if these disease symptoms may change their quality of life. **Results.** There was a statistically significant correlation between quality of life and the disease level and caregiver stress. The higher the score of disease level, the worse the patients and caregivers' quality of life. **Conclusion.** The disease control improves the patients' quality of life and, consequently, the caregivers' quality of life.

**Keywords.** Parkinson Disease, Quality of Life, Patient Care.

Citation. Silva EG, Cuziol K, Viana MA, Quagliato EMAB. Quality of life in patients with Parkinson's Disease and their caregivers' stress levels.

Department of Neurology, Faculty of Medical Sciences, State University of Campinas, State of São Paulo, Brazil (FCM/Unicamp).

1. MD, Neurosurgery student.
2. MD, Surgery student.
3. MD, Neurologist.
4. Adjunct professor, responsible for the Movement Disorders Unit, Unicamp Teaching Hospital.

Support: State of São Paulo Research Foundation (FAPESP)

## Correspondence Address:

Elton Gomes da Silva  
R. Tessália Vieira de Camargo 26  
Departamento de Neurologia/FCM-Unicamp  
Cx. Postal 6111, 13083-970, Campinas, SP  
E-mail: elgosi@yahoo.com.br

Recebido em: 11/03/08  
Revisado em: 12/03/08 a 25/06/08  
Aceito em: 26/06/08  
Conflito de interesses: não

## INTRODUCTION

The Parkinson's disease (PD) is a chronic and degenerative disorder of the Central Nervous System, and may lead to a high degree of incapability and difficulty to write, interfering with the patients' daily functions. Their customs and emotions, as well as the environment where they have lived are changed<sup>1</sup>.

The patients need caregivers to help them from the simplest to the most complex functions, altering their daily routine<sup>2-4</sup>.

Due to these changes, patients and caregivers are exposed to stress, irritability, and psychosomatic disease, as depression, which may affect among 30 and 70% of the patients with PD, damaging their quality of life<sup>5-7</sup>.

The concept of quality of life is subjective and is related to physical, psychological and social comfort<sup>8,9</sup>. While the patient's physical aspect includes medication and symptoms, the disease's stage, time of evolution and comorbidity, the emotional aspect includes felling, belief, expectation and perception of the patient themselves, the disease acceptance, and self-attention<sup>9-12</sup>.

Considering that the patients' relation with their families may not be adequate, the patients' psychomotor capability may be underestimated and completely neglected by their caregivers. Everything may be caused for high levels of stress and default of information about the illness and its treatment, and this may cause deterioration in the quality of life of patients with PD.

Therefore, the family should be informed about the fluctuation in the action of the medication, which may cause discomfort and variation in the patients' humor and temper<sup>13</sup>.

One way to improve the patient's quality of life is to stimulate his living in society, by the family, other people, and other patients. Therefore, the family's role is to stimulate and to facilitate the communication of the patient with PD, avoiding that they

**Table 1.** Frequency of patients and caregivers to every age.

Age (years)	Patients	Caregivers
< 30	0 (0.0%)	4 (9.3%)
30-39	0 (0.0%)	3 (7.0%)
40-49	6 (14.0%)	10 (23.3%)
50-59	11 (25.6%)	15 (34.9%)
60-69	11 (25.6%)	8 (18.6%)
> 70	15 (34.9%)	3 (7.0%)
Total	43 (100%)	43 (100%)

**Table 2.** Frequency of patients in each score of classification of Hoehn & Yahr.

Hoehn & Yahr	Frequency
1.0	0 (0.0%)
1.5	3 (7.0%)
2.0	21 (48.8%)
2.5	9 (20.9%)
3.0	10 (23.3%)
4.0	0 (0.0%)

immure themselves socially and develop depression. Everything should be performed in order to improve the patients' well being<sup>14</sup>.

The objectives of this study were to evaluate the quality of life of patients with PD; measure the caregivers' stress level; and to confront the caregivers' stress levels with the patients' quality of life, relating them to the disease gradation.

## METHOD

During the period July 2003 to July 2004, 43 patients diagnosed with PD and their caregivers were interviewed, consecutively followed up at the Movement Disorders Outpatient Unit of the Department of Neurology, State University of Campinas Teaching Hospital (HC/Unicamp). The PD diagnosis was based on the London Brain Bank criteria<sup>15</sup>.

All patients were evaluated during phase "on", just with effect of antiparkinsonian medication.

The exclusion criteria were having undergone neurosurgery to provisory decrease of the disease symptoms, and presence of dementia.

The disease degree was evaluated by using the following scales: UPDRS (Unified Parkinson's Disease Rating Scale), Hoehn & Yahr scale, and Schwab & England scale<sup>16</sup>.

The patient's quality of life was evaluated by using the PD questionnaire (PDQ-39), which estimated the disease impact on the patient's health and well being, with scores ranging from 37-185 points. The higher is the score, the worse the patient's health is<sup>17</sup>.

The caregivers were defined as the closest people with the patients, helping them in their daily activities, independent of relationship degree<sup>5</sup>. They had their stress levels measured by the Caregiver Stress Scale (CSS), ranging from 25-125 points<sup>18</sup>.

The Research Ethics Committee of the Faculty of Medical Sciences of Unicamp approved this study, and the patients and caregivers were informed as to the evaluation objectives and signed a consent term.

The percentage and average calculations as well as the Chi-Square test were used for statistics when indicated and Spearman Correlation was used to compare the scales' scores, with significance level of  $p < 0.05$ .

## RESULTS

The 43 interviewed patients (72.1% of them were men) presented an average age of  $62.9 \pm 10.7$  years old. The time elapsed at the beginning of symptoms and the interview was  $8.81 \pm 4.28$  years. The caregivers interviewed (81.4% women) had an average age of  $51.0 \pm 13.5$  years old. Table 1 shows the age distribution among the patients and caregivers, with their respective frequency.

The total score at the UPDRS scale was  $63.2 \pm 24.1$ , ranging from 18-146 points. Most patients with PD (48.8%) obtained score 2.0 into the Hoehn & Yahr scale, according to table 2; table 3 shows the frequency of the patients according to the Schwab & England scale.

Comparing scores at the Hoehn & Yahr scale, it was found statistical significance between the genders ( $p = 0.0031$ ), with average score for men equal to 2.44 and average score for women was 1.96. There was not statistical significance on the scores of the other disease gradation scales related to the patients' gender, as well as the caregivers' age or gender.

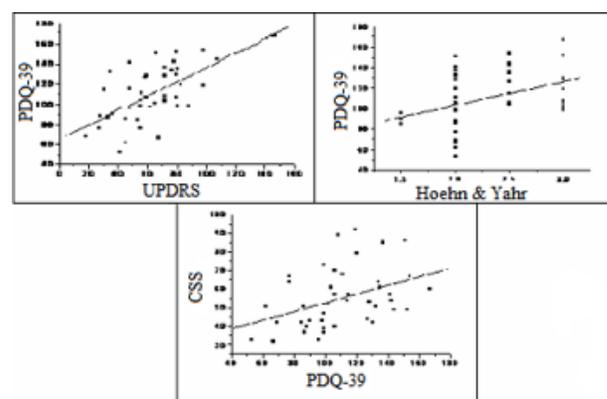
The average score into the PDQ-39 scale was  $110.3 \pm 27.0$  points, ranging from 53-167 points. According to evaluation using the PDQ-39 scale, 37.2% of the patients felt embarrassed because of the disease, and 39.5% had difficulties on accepting the disease.

The evolution of symptoms was feared by 39.5% of the patients. They also felt safe at the relationship with their caregivers in 48.8% of the cases. The feeling of depression or discouragement was seen in 51.2% of the patients.

The average score into the CSS was  $55.1 \pm 15.6$  points, ranging from 32-92 points. The CSS

**Table 3.** Frequency of patients for each classification into the Schwab & England scale.

Schwab & England	Frequency
40%	2 (4.7%)
50%	8 (18.6%)
60%	8 (18.6%)
70%	9 (20.9%)
80%	14 (32.6%)
90%	2 (4.7%)



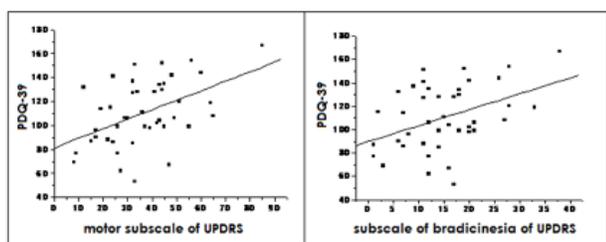
**Graphic 1.** Comparison between scales UPDRS vs. PDQ-39, Hoehn & Yahr vs. PDQ-39, and PDQ-39 vs. CSS

showed that 55.8% of the caregivers accepted the patients' diagnosis, furthermore, all of them had no embarrassed to talk about the disease; 46.5% were aware of the dependency of patients on them to perform several activities. Concerning the caregivers' health, 83.7% of them did not suffer injuries associated with the patient care, besides that, 86% felt well supported by health professionals. There was not statistical significance between the CSS and the caregivers' gender ( $p = 0.6847$ ) or age ( $p = 0.8912$ ).

A comparison among every score of the UPDRS, Hoehn & Yahr, Schwab & England, PDQ-39 or CSS, related with the time since at the beginning of the symptoms of PD, did not show statistical significance for Kruskal-Wallis test.

Using the Spearman's correlation, the comparison among the scales showed statistical significance: UPDRS vs. PDQ-39 ( $p = 0.0001$ ,  $r = 0.6057$ ); Hoehn & Yahr vs. PDQ-39 ( $p = 0.0031$ ,  $r = 0.4412$ ); PDQ-39 vs. CSS ( $p = 0.0017$ ,  $r = 0.4646$ ). Others comparisons did not show statistical significance. The relation between the statistical significance scales is shown in graph 1 – the largest is the disease gradation (UPDRS and Hoehn & Yahr), largest the PDQ-39 degree is; the worse is the disease grade, the more caregiver is stressed.

The average score of the patients at the UPDRS motor subscale was of  $36.3 \pm 16.2$  points, while the bradykinesia subscale was of  $15.0 \pm 8.2$  points. Using Spearman's correlation, the comparison among these subscales and PDQ-39 showed statistical significance to the motor subscale ( $p = 0.0021$ ;  $r = 0.4556$ ) and to the bradykinesia subscale ( $p = 0.0250$ ;  $r = 0.3416$ ), according to the graph 2, where the worse is the disease symptoms, a largest score of PDQ-39 is seen and the worse patient symptoms is.



**Graphic 2.** Comparison between UPDRS motor and bradykinesia and PDQ-39 subscales.

There was not statistical significance between motor and bradykinesia subscales and the CSS.

## DISCUSSION

According to the literature, PD affects both genders similarly<sup>11,19</sup>, with the exception of other two and our studies<sup>20,21</sup>, where there was male predominance among patients. An epidemiological comparison related to gender is not possible, once the patients were picked for this study and treated at a tertiary health service<sup>22</sup>.

In this study, there was a female predominance among the caregivers, as the preview literature<sup>11,21</sup>; however, the average age was lower than in other studies, without statistical significance in comparison with other variables. Other studies showed that male caregivers were more fragile when the illness had lowest dimension<sup>23,24</sup>, which was not seen in this study.

Similarly to other studies<sup>6,11,20,21,25,26</sup>, the patients obtained scores 2.0 and 3.0 at the Hoehn & Yahr scale regarding the disease gradation. The score at the PDQ-39 scale was the same in all studies.

When the motor symptoms get worse, there was a decrease in the patients' quality of life, which implies the need to control the disease, but the patients' clinical picture did not influence significantly on the caregivers' well being.

The male patients had a small degree at the Hoehn & Yahr scale. Perhaps, they have taken lower drug dosages than females because of their fewer complaints; the doses of medication are reduced for them, even with severe degree of the disease. However, this relation cannot be confirmed because this situation was not studied in this work.

Comparing both scales, there was statistical significance between the disease gradation (UPDRS and Hoehn & Yahr) and worsening of the patients' quality of life, which led more stressed the caregivers, according to other studies<sup>6,11,21,25,26</sup>.

The increase of motor symptoms had statistical significance in comparison with the decrease

of patients' quality of life, but this did not change the stress score among the caregivers. Therefore, the disease clinical worsening was not the cause of the increase of caregivers' stress, as observed at the caregiver proportion who accepted well the patients' diagnosis, according to the study by Happe & Berger<sup>21</sup>. This same study observed an increased severity of motor symptoms related to the worsening of caregivers' sleep, which was not seen in this study.

Despite of reports in literature about family destruction caused by the disease<sup>10,24,27</sup>, in this study, patients and caregivers had good structure, psychological support, and clarification about the disease.

The family support is vital to insert the patient in the society, and they should participate in it, improving quality of life and decreasing depression symptoms, which have still harmful consequences for the caregiver.

## REFERENCES

1. Quagliato LB, Viana MA, Quagliato EMAB, Simis S. Alterações do olfato na doença de Parkinson. *Arq Neuropsiq* 2007;65(3A):647-52.
2. Anderson R, Bury M. Living with chronic illness: the experience of patients and their families. London: Allen & Unwin, 1988, 88-116.
3. Jacoby A, Backer GA, Smith DF, Dewey ME, Chadwick DW. Measuring the impact of epilepsy: the development of a novel scale. *Epi Res* 1993;16:83-8.
4. Price B. Illness cares: the chronic illness experience. *J Adv Nurs* 1996;24:275-9.
5. Lima SSP, Quagliato EMAB, Cagliari LC, Souza EAP. Linguagem e isolamento social no Mal de Parkinson. *Rev Soc Bras Fonoaudiol* 1997;1(2):5-13.
6. Gray A, McNamara I, Aziz T, Gregory R, Bain P, Wilson J, et al. Quality of life outcomes following surgical treatment of Parkinson's disease. *Mov Disord* 2002;17(1):68-75.
7. Silva EG, Viana MA, Quagliato EMAB. Pain in Parkinson's disease: analysis of 50 cases in a clinic of movement disorders. *Arq Neuropsiquiatr* 2008;66(1):26-9.
8. Souza EAP, Guerreiro MM. Qualidade de vida. In: Guerreiro CAM, Guerreiro MM. *Epilepsia*. São Paulo: Lemos, 1996,191-9.
9. Souza EAP. Questionário de qualidade de vida na epilepsia: resultados preliminares. *Arq Neuropsiquiatr* 2001;59(3A):540-4.
10. Martínez-Martín P. An introduction to the concept of "Quality of Life in Parkinson's disease". *J Neurol* 1998;245[S1]:S2-S6.
11. De Boer AGEM, Sprangers MAG, Speelman HD, De Haes HCJM. Predictors of Health Care Use in patients with Parkinson's disease: a longitudinal study. *Mov Disord* 1999;14(5):772-9.
12. Salgado PCB, Souza EAP. Qualidade de vida em epilepsia e percepção de controle de crises. *Arq Neuropsiquiatr* 2001;59(3A):537-40.
13. Cardoso F. Principais perguntas sobre parkinsonismo e doença de Parkinson. *Beija-flor-São Paulo* 2000;47:6-8.
14. Schrag A, Jahanshahi M, Quinn N. How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. *Mov Disord* 2000;15(6):1112-8.
15. Hughes AJ, Daniel SE, Kilford L, Lees AJ. Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinicopathological study of 100 cases. *J Neurol Neurosurg Psychiatr* 1992;55(3):181-4.
16. Fahn S, Elton RL, and members of the UPDRS Development Committee. Unified Parkinson's disease rating scale. In: Fahn S, Marsden CD, Goldstein M, Calne DB (eds). *Recent Development in Parkinson's disease*. New Jersey: Florham Park, 1987,153-63.
17. Jenkinson C, Fitzpatrick R, Peto V, Greenhall R, Hyman N. The Parkinson's Disease Questionnaire (PDQ-39): development and va-

- Validation of Parkinson's disease summary index score. *Age Ageing* 1997;26(5):353-7.
18. McRae C, Sherry P, Roper K. Stress in family functioning among caregiver of persons in Parkinson's disease. *Parkinson Rel Dis* 1999;5:69-75.
19. Zhang Z, Roman GC. Worldwide occurrence of Parkinson's disease: an updated review. *Neuroepidemiol* 1993;12:195-208.
20. Lee KS, Merriman A, Owen A, Chew B, Tan TC. The medical, social and functional profile of Parkinson's disease patients. *Singap Med J* 1994;35(3):265-8.
21. Happe S, Berger K. The association between caregiver burden and sleep disturbances in partners of patients with Parkinson's disease. *Age and Aging* 2002;31:349-54.
22. Silva EG, Viana MA, Quagliato EMAB. Diagnóstico de síndromes parkinsonianas em uma clínica brasileira de distúrbios do movimento. *Rev Neurocienc* 2005;13(4):173-7.
23. Hankin BL, Abramson LY. Development of gender differences in depression: an elaborate cognitive vulnerability-transactional stress theory. *Psychol Bull* 2001;127:773-96.
24. Pasetti C, Ferrario SR, Fornara R, Picco D, Foglia C, Galli J. Caregiving and Parkinson's disease. *Neurol Sci* 2003;24:203-4.
25. De Boer AGEM, Wijker W, Speelman JD, De Haes JCJM. Quality of life in patients with Parkinson's disease: development of a questionnaire. *J Neurol Neurosurg Psychiatr* 1996;61:70-4.
26. Hobson P, Holden A, Meara J. Measuring the impact of Parkinson's disease with Parkinson's disease Quality of Life Questionnaire. *Age and Aging* 1999;28:341-6.
27. Mc Rae C, O'Brien C, Treed C. Quality of life among persons receiving neural implants surgery for Parkinson's disease. *Mov Disord* 1996;11: 605-6.