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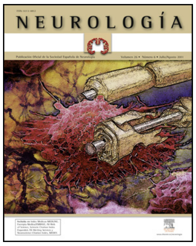

ORIGINAL ARTICLE

# Factors associated with the quality of life of subjects with Parkinson's disease and burden on their caregivers☆

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**KEYWORDS**
Quality of life;
Caregiver burden;
Primary caregiver;
Parkinson's disease;
Motor symptoms;
Non-motor symptoms

## Abstract

*Introduction:* Parkinson's disease affects the quality of life of the individual with the disease in addition to creating a burden on the caregiver. Factors related to these effects include motor and non-motor aspects of the disease, as well as traits inherent to the caregiver.

*Methods:* We evaluated subjects with Parkinson's disease using the following instruments: Quality of Life Questionnaire PDQ-8, Movement Disorders Society Unified Parkinson's Disease Rating Scale part I to IV (MDS-UPDRS), and Hoehn and Yahr staging. The Zarit Burden Inventory was used to assess all primary caregivers. Major demographic and clinical variables were also recorded.

*Results:* A total of 250 subjects with Parkinson's disease were included, of whom 201 had a primary caregiver. In the multivariate analysis, predictors of poor quality of life for a subject with Parkinson's disease were the MDS-UPDRS I score ($\beta = .39$, $P < .001$), MDS-UPDRS II score ($\beta = .21$, $P < .001$), and MDS-UPDRS III score ($\beta = .07$, $P = .004$). Regarding caregiver burden, the MDS-UPDRS II score ($\beta = .54$, $P = .007$) was the most influential factor.

*Conclusions:* The present study shows a relationship between quality of life for the subject with Parkinson's disease and the caregiver's perceived burden. However, the factors that determine each situation appear to be distinct.

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**PALABRAS CLAVE**
Calidad de vida;
Carga en el cuidador;
Cuidador primario;
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Síntomas motores;
Síntomas no motores

## Factores asociados a la calidad de vida de sujetos con enfermedad de Parkinson y a la carga en el cuidador

### Resumen

*Introducción:* La enfermedad de Parkinson impacta en la calidad de vida del sujeto que la presenta, pero también ocasiona una carga para el cuidador. Los factores relacionados con estos efectos incluyen aspectos motores y no motores de la enfermedad, así como características inherentes al cuidador.
*Métodos:* Se evaluó a sujetos con enfermedad de Parkinson mediante los siguientes instrumentos: cuestionario de calidad de vida PDQ-8, escala unificada de la enfermedad de Parkinson de la Sociedad de Trastornos del Movimiento parte I a IV (MDS-UPDRS) y estadio de Hoehn y Yahr (HY). A los cuidadores primarios, se les aplicó el inventario de carga del cuidador de Zarit. Adicionalmente, se registraron las principales variables demográficas y clínicas.
*Resultados:* Se incluyó a 250 sujetos con enfermedad de Parkinson, de los cuales 201 contaban con un cuidador primario. En el análisis multivariado los factores predictores de una peor calidad de vida del sujeto con enfermedad de Parkinson fueron la puntuación de la MDS-UPDRS I ($\beta = 0{,}39$, $P < 0{,}001$), puntuación de la MDS-UPDRS II ($\beta = 0{,}21$, $P < 0{,}001$) y puntuación de la MDS-UPDRS III ($\beta = 0{,}07$, $P = 0{,}004$). En lo que respecta a la carga en el cuidador, la puntuación de la MDS-UPDRS II ($\beta = 0{,}54$, $P = 0{,}007$) fue el que más influyó.
*Conclusiones:* El presente estudio muestra una relación entre la calidad de vida del sujeto con enfermedad de Parkinson y la percepción de carga del cuidador. No obstante, los factores que determinan cada una de estas parecen ser distintos.

## Introduction

Parkinson's disease (PD) is the second most frequent neurodegenerative disease after Alzheimer disease. As PD progresses, quality of life decreases for PD patients due to motor disability and increased non-motor symptoms.[1] The increased disability and symptoms in advanced stages of the disease will require a primary caregiver who will assist the patient with some activities of daily living.[2]

Caregivers play a key role in preserving an acceptable quality of life and some independence for PD patients, and caregiver presence has been reported to decrease morbidity and mortality rates in PD.[3] This role is generally filled by a relative, partner, or close friend. As the disease follows its natural course, caring for the patient frequently becomes the caregiver's main activity.[4]

It is therefore possible to state that the care provided to PD patients is directly related to caregiver burden. Caregiver burden is defined as the extent to which caregivers perceive that their state of health, social life, and economic status have suffered as a result of caring for PD patients.[5] Non-motor symptoms including apathy, depression, impulse control disorder, and cognitive impairment, together with motor complications and falls, add to the burden borne by the caregiver.[6]

The main aim of this study is to analyse the relationship between caregiver burden and PD patients' quality of life in PD patients, as well as the factors determining these 2 parameters, in a population attended by one of Mexico's centres of reference.

## Subjects and methods

We performed a transversal analytical study which included consecutive patients diagnosed with PD according to criteria published by the United Kingdom Parkinson's Disease Society Brain Bank.[7] These patients were attended at the movement disorders clinic at Instituto Nacional de Neurología y Neurocirugía (Mexico) between June 2012 and May 2013. The primary caregiver was defined as the person closest to the PD patient, whether or not the two are related, who assists with daily activities or provides emotional support. An additional requirement was spending at least 10 hours a day with the PD patient.[8]

We recorded the following demographic data: sex, age, level of education, dominant hand, and place of residence for both patients and caregivers. Clinical variables analysed in PD patients included age at onset of non-motor symptoms, age at diagnosis, and years of disease progression. All subjects with PD were assessed using the Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS)[9] and the Hoehn and Yahr (HY) staging scale.[10]

The MDS-UPDRS is a clinical instrument composed of 4 sections. Parts I and II assess the impact of non-motor and motor symptoms, respectively, on experiences of daily living. Part III refers to motor examination and part IV focuses on motor complications. Part I includes a questionnaire assessed by a rater as well as a self-administered questionnaire.

HY stages are used to determine disease severity based on the location of the involvement, functional capacity, postural stability, and gait. PD severity was categorised as mild (HY 1 and 2), moderate (HY 3), or severe (HY 4 and 5).

Patients were also administered the Spanish-language version of the PD quality of life questionnaire (PDQ-8). PDQ-8 is a short form of the PDQ-39. This questionnaire includes 8 items that assess the frequency of different events related to quality of life. Score is obtained by calculating a single summary index extracted from