

## Quality of life of caregivers in Parkinson's disease

Pablo Martínez-Martín<sup>1</sup>, Julián Benito-León<sup>2</sup>, Fernando Alonso<sup>3</sup>, M<sup>a</sup> José Catalán<sup>4</sup>, M. Pondal<sup>5</sup>, I. Zamarbide<sup>3</sup>, A. Tobías<sup>6</sup> & J. de Pedro<sup>1</sup>

<sup>1</sup>Neuroepidemiology Unit, National Center for Epidemiology, Carlos III Institute of Public Health, Madrid (E-mail: pmartinez@isciii.es); <sup>2</sup>Department of Neurology, Móstoles Hospital; <sup>3</sup>Department of Neurology, Pamplona University Teaching Clinic, Navarre; <sup>4</sup>Department of Neurology, San Carlos University Teaching Hospital, Madrid; <sup>5</sup>Department of Neurology, Severo Ochoa Hospital, Leganés; <sup>6</sup>Department of Statistics, Carlos III University, Getafe, Madrid, Spain

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### Abstract

**Objective:** To assess the impact of PD on informal caregivers of patients and identify the main factors related to caregiver strain. **Patients and methods:** Pairs of PD patients and their caregivers. Evaluation by neurologists included the Hoehn and Yahr, Schwab and England, UPDRS (parts 1–3), ISAPD, and Pfeiffer's SPMSQ rating scales. Patients completed the Euro-QoL 5D, PDQ-8, and Hospital Anxiety and Depression Scale. The SQLC was used to assess caregivers' quality of life (QoL), with caregivers, in turn, applying the Euro-QoL and PDQ-8 to assess patients' health-related quality of life (HRQoL). Multiple linear regression models were fitted to ascertain factors linked to the SQLC. **Results:** Significant correlations were in evidence between the following scores: SQLC and clinical rating scales and SQLC and patients' HRQoL. Based on multiple regression analysis, patients' functional state (ADL) proved to be the main predictor of caregivers' QoL. Self- and caregiver-assessed patients' HRQoL also proved to be a relevant factor. **Conclusions:** (1) Patients' functional state was significantly related to caregivers' psychosocial burden; (2) patients' HRQoL proved to be an additional factor linked to caregiver QoL; (3) improvement of patient disability and HRQoL might alleviate caregiver strain.

**Key words:** Assessment, Caregivers, Functional state, Parkinson's disease, Quality of life

### Introduction

Most chronically ill subjects are cared for by an informal support system comprising relatives, friends or other non-professional caregivers. Caring for patients with chronic and disabling diseases means that these types of caregivers bear physical and psychological distress, limitations on their personal and social activities, as well as a financial burden.

The consequences, not only for individuals but also for the health-care system, of the impact exerted by chronic patients on caregivers, merits attention for several important reasons [1]. An example of this is the fact that the caring capacity

of such informal caregivers tends to be a key factor in determining the institutionalization of patients. This is because family caregivers will usually only place patients in a long-term institution when their own caring capacity is overwhelmed by the physical, emotional or economic load. Furthermore, the distress caused by looking after disabled friends and relatives may have major adverse consequences for caregivers' physical and psychological health [2–5].

Caregivers should be assessed in order to identify the characteristics of and factors associated with the strain that they are experiencing. Knowledge of this type may help design effective interventions targeted at improving caregiver

distress. Alleviating the burden and thereby allowing for a better caregiver quality of life, will lead to an ensuing extension of patients' permanency at home and a better quality of care [6–9].

In advanced stages of the disease, patients with Parkinson's disease (PD) present with diverse degrees of disability resulting from physical and mental impairment. As a consequence, persons closest to PD patients are burdened with a strain derived from their role as caregivers of patients with a progressive disease [9–12].

To date, relatively few studies have addressed the topic of caregiver distress or burden in PD. It was this, coupled with the point outlined above, that led us to embark on the present study, which aimed at to assessing the impact of PD on informal caregivers of patients and identify the main factors influencing the magnitude of caregiver strain.

## Methods

### *Hypothesis*

In PD, the following factors are associated with impairment of caregivers' quality of life (QoL):

- (1) patient-related factors, such as age, sex, duration of disease, disability, motor impairment, emotional disorder and self-perception of poor state of health;
- (2) caregiver-related factors, such as age, sex, continuity of care to patient, educational level and perception of patients' poor state of health.

### *Design*

Observational, cross-sectional, one-point-in-time evaluation, multicentre study. Eligible subjects were consecutive patients with clinical diagnosis of PD and a stable non-professional caregiver.

### *Patients and caregivers*

Patients were included if they had a diagnosis of idiopathic PD certified by neurologists with competence in movement disorders. Both sexes and any level of severity were allowed. The permissible age range at assessment was 40–80 years. 'Caregiver' was defined as the person who usually cohabited

with the patient and who was in some way directly involved in the patient's care or impacted by the patient's health problem (even though the patient was not in need of care). Patients were community-dwelling, thus excluding professional caregivers and carers belonging to social support networks.

Pairs were included in the study on condition that both patients and their respective main caregivers were literate ('able to read, understand and answer the questionnaires'). A further requirement was that eligible patients were not to present with any co-morbidity that might impede assessment strictly focused on PD.

Sixty-four of a total of 72 consecutive pairs of patients-caregivers (88.88%) returned the questionnaires. Complete evaluation was ultimately obtained for 62 caregivers (96.87%) and 57 patient-caregiver pairs (89.06%).

### *Evaluations*

The following assessments were carried out:

- (1) *Neurologists* informed patients and caregivers about the study and made their evaluation at a regular follow-up visit at clinics (65%) or during a visit to a local PD Association (35%). They applied the Unified Parkinson's Disease Rating Scale (UPDRS-Version 3.0, including the modified Hoehn & Yahr [HY] classification and Schwab & England ADL Scale [SES] but excluding the Section 4 – Complications) [13]. Additional measures were the Intermediate Scale for Assessment of Parkinson's Disease (ISAPD) [14] and Pfeiffer's Short Portable Mental Status Questionnaire (SPMSQ) [15].
- (2) *Patients* completed the validated Spanish versions of the EuroQoL (EQ-5D) [16, 17], Parkinson's Disease Questionnaire – 8 items [18, 19], and the Hospital Anxiety and Depression Scale (HADS) [20, 21].
- (3) *Caregivers* were helped by neurologists to complete the Spanish version of the Scale of Quality of Life of Caregivers (SQLC) [22, 23] during the visit, in a private setting with no patients present. In addition, they provided proxy evaluations of patients' health-related quality of life (HRQoL) by means of the EQ-5D (except for the visual analogue scale rating, "health state today") and the PDQ-8.

In addition, data on demographic aspects of patients and caregivers, duration of disease, educational level of caregivers, size of and number of residents per dwelling were also recorded.

### Instruments

*UPDRS-3.0* – The UPDRS is a four subscale combined scale (mental state, activities of daily living, motor examination, and complications). The first three subscales are devoted to assessing manifestations of PD, and items are uniformly scored (ranging from 0 = normal to 4 = severe), while part four – Complications – possesses a heterogeneous scoring system [13, 24].

Two further instruments are attached to the UPDRS, namely: (1) a modified Hoehn & Yahr Staging [25], an *ad hoc* ordinal scale that is applied to gauge the course of disease over time; and (2) the Schwab & England Scale [26], a measure of functional independence providing scores that, though expressed as a percentage, are on an ordinal scale.

Ratings are neurologist-based, and scores are obtained by interview and examination. Thanks to its design, the UPDRS allows for partial and total scores. It is currently used as a standard reference scale in clinical practice and research. A recent overview of its characteristics and application has recently been carried out by an *ad hoc* Task Force of The Movement Disorders Society [27].

*ISAPD-2.1* – This is a combined scale for PD, targeted mainly at assessing functional state and complications. The first part includes two sections: (1) evaluation of activities of daily living (ADL) (11 items), and (2) examination of mobility (2 items). The second part evaluates dyskinesias (amplitude and duration) and off-periods (duration and disability) [14]. In the ISAPD, all items are scored from 0 = normal to 3 = severe.

Ratings are neurologist-based and scores are obtained by interview and examination. While the ISAPD has occasionally been applied in clinical practice and research, it has not yet been used by independent authors [28].

*Pfeiffer's SPMSQ* – This is a short, 10-item instrument, purpose-designed to detect and approximate the severity of cognitive impairment [15]. It explores memory (short- and long-term), orientation (time, place and self), and basic calculations. It is rated by interview.

The SPMSQ is hardly influenced by educational level and, as a result, proves quite useful and reliable for screening general and elderly populations. Five errors or more are indicative of moderate or severe impairment. A validated Spanish version is available [29]. It was applied in this study to monitor the cognitive state of patients. Scores were transformed by counting the number of correct (as opposed to incorrect) responses.

*EQ-5D* – This is a preference-based, self-administered HRQoL measure. It contains a descriptive part comprising five dimensions with three possible levels of severity (1 = no problem; 2 = some/moderate problems; and 3 = many/severe problems), which generate 243 health status profiles (245, when *unconsciousness* and *death* are added) ranging from the best (11 111) to the worst (33333). A preference value for each profile can be calculated by means of the visual analogue scale (EQ-5D VAS) and time trade-off methods (EQ-5D TTO) [17, 30]. These values range from 1.0 to 0.0, where 1 is assigned to 'perfect health state' and 0 to death. Both types of values, calculated for every possible health status and standardized for the general Spanish population, are available (Euro-QoL User's Guide) and were applied in the present study. The instrument also includes a visual analogue scale on which patients rate their own current health status (from 100 = best imaginable to 0 = worst imaginable), a question designed to categorize the evolution of subjects' state of health in the previous year, and a section about the respondent's socio-demographic data.

*PDQ-8* – The PDQ-8 is a self-administered, short-form questionnaire, made up of 8 items, each of which represents one domain of the PDQ-39 [18, 31]. Scores for each item run from 0 (no problem) to 4 (continuous problem/ unable to do it). The PDQ-8 Summary Index (PDQ-8 SI) is calculated as the total score for the 8 items divided by the maximum possible score ( $\Sigma$  of scores/ 32) and is expressed as a percentage. The lower the index, the better the HRQoL.

*HADS* – This self-administered scale, simultaneously evaluates anxiety (HADS-A) and depression (HADS-D). It was designed to identify mood disorders in non-psychiatric outpatients attending hospital consulting rooms. The authors sought to prevent the presence of somatic items weighting as mood problems (e.g., bradykinesia scoring as

slowness linked to depression). It consists of 14 items (7 for assessment of anxiety and 7 for assessment of depression) scoring from 0 (no problem) to 3 (extreme problem). Scores of  $\geq 11$  points for a subscale are indicative of mood disturbance (anxiety or depression). The psychometric properties of the HADS in PD patients have been recently reviewed [32].

*SQLC* – Glozman's *SQLC* attempts to quantify the impact of disease on caregivers' professional (4 items), social and leisure activities (5 items), as well as the strain stemming from the responsibilities entailed in caring daily for patients (7 items) [22]. Its double system of rating (items and sub-items) and variable ranking of scores tends to make application a little complex. With this scale, the lower the score, the more severe the impact on caregivers. Four degrees of caregiver distress can be determined: none, 141–149 points; mild, 140–100 points; moderate, 99–86 points; and severe, less than 85 points. A Spanish version of the *SQLC* has been occasionally used for evaluation of caregivers looking after PD patients [23, 33]. In our experience, the *SQLC* has shown satisfactory internal consistency ( $\alpha > 0.80$ ; item-dimension correlation:

significant for 11 items [ $p < 0.001$ ]; non-significant for items 4 and 10), adequate distribution of scores (difference between mean and median  $< 6$  points; floor and ceiling effects = 1.47%), cross-sectional precision (standard error of measurement on  $\alpha = 8.57$ ), and sensitivity to caregiver strain related to disease severity as measured by HY staging (Kruskal–Wallis,  $p < 0.0001$ ). Convergent validity with PD variables such as disease duration, HY stage, mental (cognitive and emotional) and motor status has proved significant ( $p = 0.001$  to  $p < 0.0001$ ). Age, type of relationship with patient, and educational level of caregiver failed to correlate with *SQLC* score. In contrast, an association was found with caregiver gender (more strain for females,  $p = 0.02$ ). The scale is 'filled in by the caregiver in the course of an interview with the physician, who explains, as necessary, the meaning of the items' [22]. Table 1 displays the main characteristics of the assessments applied.

#### Data analysis

Descriptive statistics (mean, standard deviation, range, 95% confidence interval) were obtained as

**Table 1.** Assessments applied in the study

Scale	Purpose of the evaluation	Rater	Administration
Hoehn and Yahr Staging	Course and severity of PD	Neurologist	Examination
Schwab and England Scale	Functional independence	Neurologist	Interview
Unified PD Rating Scale			
Section 1 – Mental state	Cognition, thought, mood	Neurologist	Interview
Section 2 – ADL	Disability	Neurologist	Interview
Section 3 – Motor exam.	Motor signs	Neurologist	Examination
Intermediate Scale (ISAPD)			
ADL section	Disability	Neurologist	Interview
Motor examination	Motor signs	Neurologist	Examination
Motor complications	Dyskinesias, fluctuations	Neurologist	Interview and examination
Pfeiffer's SPMSQ	Orientation, memory, basic calculation	Neurologist	Interview
EuroQoL	Generic health-related QoL	Patient	Self-administered
PDQ-8	Specific health-related QoL	Patient	Self-administered
Zigmond's HADS	Anxiety and depression	Patient	Self-administered
Glozman's <i>SQLC</i>	Quality of life of caregivers	Caregiver	Self-administered <sup>a</sup>
EuroQoL by proxy	Generic health-related QoL	Caregiver	Self-administered
PDQ-8 by proxy	Specific health-related QoL	Caregiver	Self-administered

<sup>a</sup> With neurologist-based help and supervision.

PD: Parkinson's disease. ADL: Activities of Daily Living. ISAPD: Intermediate Scale for Assessment of Parkinson's Disease. PDQ-8: Parkinson's Disease Questionnaire-8 items. HADS: Hospital Anxiety and Depression Scale. *SQLC*: Scale of Quality of Life of Caregives.

required. We applied the Mann–Whitney or Kruskal–Wallis test to compare the distribution of scores for independent samples, and Spearman’s rank correlation coefficient to test the association between the SQLC and the other measures. The level of agreement between patient and caregiver for EQ-5D preference values and the PDQ-8 SI was determined by means of the intraclass correlation coefficient (ICC).

Multiple linear regression models were fitted to ascertain the major SQLC determinants. Three models were considered. A first model was fitted including only patient-related variables, such as sex and age, duration of disease, measures of disability (SES, UPDRS – Section 2, ISAPD-ADL), motor examination (UPDRS – Section 3, ISAPD-Exam), mood (HADS-A, HADS-D), and health state perception (PDQ-8 SI, EQ-5D VAS, EQ-5D TTO). In the second, only caregiver-related variables were considered, namely, age, sex, educational level, continuity of care, and perception of patients’ health status (PDQ-8 SI-C, EQ-5D VAS-C, EQ-5D TTO-C). PD severity, as determined by means of HY

staging, was excluded due to its influence on the other disease-related variables. Variables were included in both the above models following a stepwise procedure, with the variables finally selected being those that attained a conservative individual statistical significance level ( $p < 0.1$ ). Goodness-of-fit for selected models was assessed by reference to maximization of the adjusted determination coefficient ( $R^2$ ) and minimization of the mean squared error (MSE). Finally, these two models for patient- and caregiver-related variables, respectively, were combined into a multiple linear regression model, in order to assess the type of variables which had a major impact on caregivers’ quality of life.

## Results

Mean age ( $\pm$  standard deviation) of patients was 67.01 ( $\pm$  7.91; range: 45–79) years; a breakdown by sex showed that 58% were females. They were in HY stage 2.6 ( $\pm$  0.74). Duration of disease was 10.47 ( $\pm$  6.16) years and duration of follow-up by

**Table 2.** Descriptive statistics of patient-related variables

	Mean	SD	Min.	Max.	95% CI.	
Age at onset of PD	56.33	9.34	39	75	–	
Age at evaluation	67.01	7.91	45	79	–	
Duration of disease	10.47	6.16	1	30	–	
HY	2.60	0.74	1	5	2.41	2.78
SES	69.68	21.23	0	100	64.38	75.00
UPDRS						
Section 1 (Mental)	3.57	2.46	0	9	2.96	4.19
Section 2 (ADL)	16.29	8.50	3	45	14.17	18.42
Section 3 (Motor)	18.10	10.51	5	56	15.05	21.15
ISAPD						
ADL section	13.08	6.85	0	33	11.36	14.79
Motor examination	2.12	1.67	0	6	1.70	2.54
Complications	6.11	6.65	0	23	4.44	7.77
SPMSQ	9.51	1.16	5	10	9.22	9.80
EQ-5D Index VAS	0.58	0.21	0.03	1	0.53	0.63
EQ-5D Index TTO	0.60	0.28	–0.39	1	0.52	0.66
PDQ-8 Sum. Index	33.50	20.94	0	93.75	28.26	38.73
HADS – anxiety	7.54	3.90	1	18	6.57	8.52
HADS – depression	7.86	0.52	1	17	6.81	8.90

SD – standard deviation; Min. – minimum; Max. – maximum; 95% CI – 95% confidence interval. HY–Hoehn and Yahr Staging; SES – Schwab and England Scale; UPDRS–Unified Parkinson’s Disease Rating Scale; ISAPD–Intermediate Scale for Assessment of Parkinson’s Disease; SPMSQ–Pfeiffer’s Short Portable Mental Status Questionnaire; EQ-5D-VAS, -TTO–Health state value of the EuroQoL by visual analogue scale and time trade-off method, respectively; HADS–Hospital Anxiety and Depression Scale.

neurologist was 5.7 ( $\pm$  5.04) years. Table 2 gives a detailed description of measures applied to patients. As measured by item 1 of the UPDRS and the SPMSQ, two patients showed moderate cognitive impairment, though neither was considered demented by their respective neurologists and caregivers. According to the same measures, three additional patients could be said to have had mild cognitive impairment.

Caregivers' age was 58.84  $\pm$  14.90 years. Two thirds of caregivers were females, 73% were spouses, and 22% sons or daughters. Caring for patients was permanent in 86% of the cases. Caregivers' educational level proved to be as follows: 17%, no formal education; 38.1%, elementary level; 28.57%, high school; 15.87% university or equivalent. Twenty per cent were receiving treatment for mood disorder (antidepressants [9.52%], anxiolytics [6.35%] or a combination of the two [4.76%]).

Mean SQLC score was 113.82  $\pm$  21.08 (range, 53–141; 95% CI: 108.46–119.17). Distribution of SQLC scores by degree of disease severity based on HY classification (early = 1–2; middle = 2.5–3; late = 4–5) [9] showed a significant downward trend (125.60  $\pm$  15.66; 107.88  $\pm$  18.10; and 91.87  $\pm$  22.80, respectively) indicating significantly worse QoL among caregivers as the severity of the disease among patients rose (Kruskal–Wallis test,  $p = 0.0001$ ).

Evaluation of HRQoL by patients themselves and caregivers, using the EQ-5D and the PDQ-8, showed a substantial degree of agreement beyond chance (ICC = 0.77–0.82) between patients and caregivers.

Table 3 shows the Spearman rank correlation coefficients between SQLC and patient-related variables. No significant association was in evidence between SQLC and patients' age or age at disease onset. Similarly, patients' gender had no significant influence on SQLC scores (Mann–Whitney test).

The association between SQLC scores and caregiver-related variables was statistically significant for EQ-5D VAS-C ( $r = 0.49$ ;  $p = 0.0001$ ), EQ-5D TTO-C ( $r = 0.50$ ;  $p = 0.0001$ ), and PDQ-8 SI-C ( $r = -0.57$ ;  $p < 0.0001$ ), but not for caregivers' age or educational level, size of dwelling (surface area) or number of residents per dwelling. There was a trend towards lower SQLC scores for female caregivers (Mann–Whitney test;  $p = 0.019$ ).

**Table 3.** Correlation between SQLC score and patient-related variables

	<i>r</i>	<i>p</i>
Duration of PD	−0.39	0.0016
Hoehn and Yahr Stage	−0.67	<0.0001
Schwab and England Scale	0.71	<0.0001
UPDRS – mental state	−0.45	0.0002
ADL	−0.65	<0.0001
Motor examination	−0.50	0.0004
ISAPD – ADL	−0.73	<0.0001
Motor examination	−0.68	<0.0001
Complications	−0.51	<0.0001
Pfeiffer's SPMSQ	0.38	0.0020
EQ-5D VAS	0.46	0.0002
EQ-5D TTO	0.47	0.0001
PDQ-8	−0.60	<0.0001
HADS – anxiety	−0.37	0.0033
HADS – depression	−0.42	0.0006

*r*: Spearman rank correlation coefficient.

SQLC–Scale of Quality of Life of Caregivers; PD–Parkinson's disease; UPDRS–Unified Parkinson's Disease Rating Scale; ADL–Activities of Daily Living section; SPMSQ–Short Portable Mental Status Questionnaire; EQ-5D-VAS, -TTO–Health state value of the EuroQoL by visual analogue scale and time trade-off method, respectively; HADS–Hospital Anxiety and Depression Scale.

Major determinants of Glzman's SQLC scale, based on multiple regression analysis of patient-related variables, were sex and disease duration (though only marginally associated:  $p = 0.097$  and  $p = 0.118$ , respectively), ISAPD-ADL ( $p < 0.001$ ), and PDQ-8 SI ( $p = 0.002$ ). This model explained 56.7% of SQLC variability. For caregiver-related variables, PDQ-8 SI-C ( $p = 0.007$ ) and EQ-5D TTO-C ( $p = 0.037$ ) were the main determinants of SQLC scores. However, this model only explained 36.1% of SQLC variability (Table 4). Combination of patient- and caregiver-related variables showed the only statistically significant association to be that between the SQLC and ISAPD-ADL ( $p = 0.001$ ), which explained 57.3% of variability (Table 4).

## Discussion

Most patients suffering chronic and disabling diseases are assisted by non-professional caregivers, usually relatives or friends. Informal caring for these patients currently represents considerable

**Table 4.** Multiple regression models fitted to assess determinants of the quality of life of caregivers (SQLC)

	Regression model for patient variables			Regression model for caregiver variables			Regression model for combination of patient and caregiver variables		
	$\beta$ (se)	<i>t</i>	<i>p</i> -value	$\beta$ (se)	<i>t</i>	<i>p</i> -value	$\beta$ (se)	<i>t</i>	<i>p</i> -value
Sex	7.077 (4.189)	1.69	0.097				5.121 (4.623)	1.11	0.273
Duration	-0.528 (0.332)	-1.59	0.118				0.546 (0.367)	-1.49	0.144
ISAPD-ADL	-1.563 (0.364)	-4.30	<0.001				-1.461 (0.432)	-3.38	0.001
PDQ-8 SI	-0.256 (0.103)	-2.50	0.002				-0.188 (0.144)	-1.30	0.199
PDQ-8 SI-C				-0.427 (0.153)	-2.79	0.007	-0.057 (0.157)	-0.36	0.718
EQ-5D TTO-C				20.988 (9.789)	2.14	0.037	7.933 (8.445)	0.94	0.352
[Intercept]	110.335 (3.024)	36.48	<0.001	112.902 (2.333)	48.38	<0.001	111.072 (3.259)	34.09	<0.001
Adjusted <i>R</i> <sup>2</sup>	56.7%			36.1%			57.3%		
MSE	13.908			17.432			14.297		

$\beta$ —regression coefficient; *s*—standard error of regression coefficient; *t*—*t*-value defined as  $\beta$ /*s*; MSE—mean squared error; ISAPD-ADL—Subscale Activities of Daily Living from the Intermediate Scale for Assessment of Parkinson's Disease PDQ-8 SI—PDQ-8 Summary Index; PDQ-8 SI-C—PDQ-8 Summary Index by caregivers (evaluation by proxy of patients' health-related quality of life); EQ-5D TTO-C—Health preference value from EuroQoL-5D time trade-off method by caregivers (evaluation by proxy of patients' health-related quality of life).

savings for health-care systems in terms of resources and cash. In many countries, however, this situation will be challenged in 20–50 years' time, due to: (1) the increase in the 'parent support rate' (number of persons aged  $\geq 85$  per 100 persons aged 50–64 years), which by 2050 is projected to be around 28/100 in the USA (triple the 1990 figure); and (2) the fact that looking after the oldest-old will be problematic for their caregivers, who by that time will be 60–80 years old and might also be suffering from physical or mental disease and/or disability [1, 34]. The consequences of this new situation may be of enormous importance for health policy and social welfare.

Attention should therefore be paid to identifying factors influencing caregiver burden and distress, so as to decrease the impact of the disease on same and, by extension, on the patients themselves (influence of caregiver attitude on patient management and institutionalization).

PD is a chronic and progressive disorder, with components of physical and mental impairment and disability. The importance of the caregiver's role in looking after PD patients has gradually become recognized.

A search in Medline (access June 1, 2003), using the descriptors, 'caregivers [AND] Parkinson' unearthed over 20 papers published since 1986 and addressing aspects more or less specifically related to caregivers of PD patients. Half these papers had

appeared from January 2001 through June 2003. The settings, sample sizes, design and objectives of these studies are very diverse, rendering a combined review of the literature difficult. With respect to the present study, special mention should however be made of those papers targeted at identifying determinants of caregiver strain or burden, namely: severity of PD [9]; patients' functional state, caregivers' depressive symptoms and perceived social support [12, 34]; patients' depression, functional and cognitive impairment, agitation, aberrant behaviour and psychosis [10, 12, 35–38]; duration of disease, as the main predictor of depressive symptoms among spouse-caregivers [39]; and sleep disturbances of caregivers linked to their caregiving commitment [40]. Other studies focused on aspects such as financial burden or the effect of interventions on patients and caregivers [41–44].

The impact of the disease on caregivers is present across all stages of disease [9] and affects the entire sample [22, 33]. In line with previous studies [9, 33], caregivers QoL registered a significant downward trend in response to rises in disease severity.

Correlation analysis displayed a significant association between SQLC scores and disease stage (HY), ADL (ISAPD, UPDRS), motor examination (ISAPD, UPDRS), motor complications (ISAPD), and HRQoL (PDQ-8) ( $r = 0.53$ – $0.70$ ,

$p < 0.0001$ ). Disease stage and disability were identified as predictors of caregiver burden in prior studies [9, 10, 12, 34]. To our knowledge, however, the other associations have never been previously explored.

Duration of disease, mental state (cognitive, emotional) and general HRQoL (EQ-5D) also displayed a statistically significant correlation with SQLC, albeit at a lower level ( $r = 0.37$ – $0.47$ ,  $p = 0.003$ – $0.0001$ ) (Table 3). Previous studies also reported a relationship between caregiver burden on the one hand, and duration of disease [39] or patients' mental disorders [35–38], on the other.

Similarly, caregiver-rated patient HRQoL (using proxy EQ-5D and PDQ-8) correlated significantly with total SQLC scores ( $r = 0.49$ – $0.57$ ;  $p \leq 0.0001$ ). No other independent variables, such as patients' age or sex, age at disease onset, duration of disease, caregivers' age or educational level, or housing-related variables were associated with impairment of caregivers' QoL. There was a trend towards lower SQLC scores among female caregivers (Mann–Whitney test;  $p = 0.019$ ), a relevant finding taking into account that, in the present study, around two thirds of caregivers were females. Female caregivers may experience more stress than do male caregivers, as a consequence of a heavier workload (household tasks) [45, 46].

Multiple regression analysis of patient-related variables showed four variables (sex, disease duration, ISAPD-ADL, and PDQ-8 SI) to be linked to caregiver burden – explaining 56.7% of the SQLC variability – though only two of these (ISAPD-ADL, and PDQ-8 SI) attained a consistent level ( $p < 0.001$  and  $p = 0.002$ , respectively).

In the case of caregiver-related variables, only patients' perceived HRQoL (by proxy HRQoL) could be considered to be related to SQLC (PDQ-8 SI-C and EQ-5D TTO-C,  $p = 0.007$  and  $0.037$ , respectively), yet this model explained only 36.1% of SQLC variability.

Finally, when independent variables from patients and caregivers were combined, only the ISAPD-ADL showed a significant link ( $p = 0.001$ ) to caregiver strain, explaining over 57% of SQLC variability (Table 4).

In the present study, therefore, level of patient disability – as determined by means of a scale rating activities of daily living – proved to be the most significant factor associated with caregiver strain.

These results are in agreement with previous studies by Caap-Ahlgren et al. [12] and Edwards and Scheetz [34], which found patients' functional state to be a predictor or determinant of caregivers' psychosocial burden. Other studies obtained different results. Aarsland et al. [10] found that mental symptoms – such as depression, cognitive impairment, agitation, abnormal behaviour, and delusions – were the most consistent predictors of caregiver distress in PD. Meara et al. [36] highlighted the level of depression expressed by patients as an important determinant of carer distress and mood disorder. Thommessen et al. [37] encountered a similar type and level of psychosocial burden in spouses caring for patients with dementia, stroke and Parkinson's disease, identifying patients' cognitive functioning as the most relevant factor influencing caregiver burden. Patients sleep disturbances increased the burden of caregivers in the study by Happe et al. [38] and two related factors, severity and disease duration, were found to be associated with caregivers' depression by Carter et al. [9] and Fernandez et al. [39], respectively.

A remarkable finding of the present study was the identification of patients' HRQoL (both self- and proxy-assessed) as a factor possibly associated with caregivers' QoL, as shown by the corresponding multiple regression models (Table 4). A speculative explanation might be that the impact of the disease on the patient, as captured by the HRQoL measures, may be expressed by the patient and perceived by the caregiver in a global manner. It seems logical then that such a perception should exert an important influence on caregiver state, particularly when one recalls that 95% of all caregivers in this sample were first-degree relatives.

This study's limitations lie in its cross-sectional design, which limits 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 bars any generalization of the conclusions. Taking into account these limitations, the results may be summarized as follows: (1) patients' basic ADL-related functional state is significantly associated with caregivers' psychosocial burden; (2) patients' HRQoL (both self- and proxy-assessed) also appears to be a relevant factor linked to caregivers' QoL; and (3) patients' and caregivers' demographic characteristics are not significantly related to caregivers' QoL.



Accordingly, improvement in patients' functional state and HRQoL could alleviate patients' individual suffering as well as the strain exerted on their respective caregivers. Such relief might, in turn, serve to help patients being cared for in the community, and thereby delay institutionalization [1, 34, 40, 41, 44].

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*Address for correspondence:* Dr.P. Martínez Martín, Centro Nacional de Epidemiología, Instituto de Salud Carlos III, Unidad de Neuroepidemiología, C/ Sinessio Delgado 6, 28029 Madrid, Spain  
 Fax: +34-91-3877815  
 E-mail: pmartinez@isciii.es.