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Quality of life in Parkinson's disease: validation study of the PDQ-39 Spanish version

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Abstract The present multicenter study evaluated the validity of the PDQ-39 Spanish version (PDQ-39 SV) for assessing health-related quality of life (QoL) in Parkinson's disease (PD). A total of 103 PD patients were evaluated by the Hoehn and Yahr stage and by the following scales: Unified Parkinson's Disease Rating Scale (UPDRS), Schwab and England scale, Pfeiffer's SPMSQ, and Geriatric Depression Scale. The Hospital Anxiety and Depression Scale and the PDQ-39 SV were self-completed by patients. For analysis of data we used descriptive statistics, Cronbach's α , Spearman's rank correlation coefficients, and the Kruskal-Wallis test. The internal consistency of the PDQ-39 SV dimensions was satisfactory (Cronbach's α : 0.63–0.94; item-total correlation: 0.57–0.87, $P < 0.001$), although

Social Support and Cognition items were beneath ideal values. Recorded results for Mobility, Activities of Daily Living, and Communication were highly correlated with PD rating scales ($r_s = 0.49$ – 0.73 , $P < 0.001$). Emotional Well-Being and Body Pain showed their best correlations with mood measures. Cognition was the only dimension significantly correlated with the SPMSQ ($R_s = 0.27$, $P < 0.01$). These data and previous studies indicate that the PDQ-39 is a consistent instrument for evaluation of physical, emotional and psychosocial aspects of QoL in PD patients.

Key words Parkinson's disease · Health-related quality of life · Assessment · PDQ-39 · Internal consistency

Introduction

Parkinson's disease (PD) is a chronic, progressive, disabling disease characterized particularly by motor disturbances. PD patients often also experience emotional, cognitive, sensorial, and autonomic disorders that entail functional and psychosocial impairment of patient's life. Evaluation of PD patients is usually carried out by means of rating scales designed to evaluate physical and mental functioning [7]. These instruments are completed by clinicians and do not provide information about the impact of the disease from the subjective experience of the patient.

In the past two decades, however, interest in health status measures has increased. Self-evaluated emotional, functional and social dimensions of health are now keys to the analysis of outcomes in clinical research and pharmacoeconomics [14]. A number of generic and specific instruments are currently available for measuring health-related quality of life (QoL). Generic instruments are most appropriate for performing health surveys on general populations but may overlook some problems or specific conditions that are infrequent, and that are better evaluated by applying specific tools. QoL in PD patients is clearly disturbed, and some specific questionnaires (PDQ-39, PDQL) have been developed to measure the magnitude of such disturbance [2, 10].

Table 1 Descriptive data of patients (*n* = 103)

	Mean	SD	95% CI	Range	%	
Age	65.85	10.25	–	40 – 84	–	
Sex – Males	–	–	–	–	53.4	
– Females	–	–	–	–	46.6	
Duration of disease (years)	7.76	5.63	–	0.5– 35	–	
SD = Standard deviation; CI = Confidence Interval; UPDRS = Unified Parkinson’s Disease Rating Scale–3.0; SPMSQ = Short Portable Mental Status Questionnaire; HAD = Hospital Anxiety and Depression Scale	Hoehn & Yahr Stage	2.46	0.79	2.30– 2.61	1 – 4	–
	UPDRS	32.64	18.34	29.03–36.25	2 – 85	–
	Schwab & England Scale	75.34	17.96	71.82–78.85	30 –100	–
	SPMSQ	0.54	1.10	0.32– 0.76	0 – 6	–
	Geriatric Depression Scale	5.27	3.68	4.55– 6.0	0 – 15	–
	HAD Scale	13.55	7.58	12.05–15.04	1 – 30	–

The purpose of the present study was to analyse the validity of the PDQ-39 Spanish version (SV), while also providing additional information on the characteristics of this instrument.

Methods and materials

Patients

The study was carried out by 11 neurologists in nine hospitals on 103 patients with the diagnosis of idiopathic PD [6].

Methodology and scales

After patients consented to take part in the study, the following data were recorded: age, sex, duration of disease, treatment, Hoehn and Yahr stage (HY) [4], Unified Parkinson’s Disease Rating Scale version 3.0 (UPDRS) [3], Schwab and England scale (SE) [12], Short Portable Mental Status Questionnaire (SPMSQ) [11], reduced (15-item) Geriatric Depression Scale (GDS) [13], Hospital Anxiety and Depression Scale (HADS) [15], and the PDQ-39 SV.

The original English version of the PDQ-39 was kindly provided to the main author (P.M.M.) by its authors (Peto et al.). The questionnaire was translated into Spanish by two bilingual persons (one of them expert in clinical instruments of assessment, the second a layperson). A final joint translation was translated back into English and sent to the PDQ-39 authors for confirmation. When final agreement was found, this version was used for the present study and was named as PDQ-39 SV.

Both HADS and PDQ-39 SV were completed by patients immediately before or after their visit to the clinic. When some kind of help was needed (e.g. due to visual problems), a *neutral* person (different from relatives, caregivers, or physicians in charge) assisted the patient in completing the form.

Statistical analysis

Descriptive statistics were applied to demographic, rating scales, and questionnaire data. Cronbach’s α and item-total correlation (Spearman’s rank correlation coefficients) were used to determine the internal consistency of PDQ-39 SV dimensions. The Kruskal-Wallis test was applied to determine the distribution of mean scores on the domains of PDQ-39 SV according to the HY stage. Convergent validity of PD rating scales and mental status tests against the summary scores of PDQ-39 dimensions was determined by Spearman’s rank correlation coefficients.

A comparison between the results of English [5, 10] and Spanish studies can be presented if appropriate.

Table 2 Mean scores and 95% confidence intervals on dimensions of the PDQ-39 Spanish version

Dimension	Mean	SD	95% CI
Mobility	40.51	30.36	34.54–46.48
Activities of daily living	39.52	27.28	34.12–44.91
Emotional well-being	36.97	26.01	31.88–42.06
Stigma	22.63	26.81	17.38–27.88
Social support	16.26	23.84	11.51–20.98
Cognition	25.12	20.56	21.07–29.16
Communication	21.68	22.12	17.35–26.01
Bodily discomfort	37.21	25.48	32.23–42.20

Table 3 Internal consistency of the dimensions of the PDQ-39*

Dimensions	Peto et al. [10] ^a	Jenkinson et al. [5] ^a	Present study ^b
Mobility	0.94	0.95	0.94
Activities of daily living	0.89	0.90	0.86
Emotional well-being	0.83	0.88	0.87
Stigma	0.80	0.86	0.81
Social support	0.69	0.66	0.63
Cognition	0.70	0.74	0.67
Communication	0.79	0.76	0.72
Body discomfort	0.75	0.72	0.72

* Cronbach’s alpha; ^a Postal survey [5, 10]; ^b Completed at clinic

Results

Table 1 shows the main characteristics of the sample and descriptive statistics of the scales applied in the study. Mean scores, standard deviations, and 95% confidence intervals on the dimensions of PDQ-39 are shown in Table 2.

Table 3 shows the Cronbach’s α of the dimensions included in the PDQ-39. Two sets of data are presented in the table, the first resulting from the present study and the second from studies by Jenkinson et al. [5] and Peto et al. [10]. The results of these three studies were very similar, with raw differences among coefficients ranging from 0.01 to 0.07. Extreme values of α in the present study fluctuated from 0.63 to 0.94. Social Support and Cogni-

Table 4 Item-total correlation of the PDQ-39 domains

ITEM	Peto et al. [10]	Present study
Mobility		
Difficulty doing leisure activities	0.75	0.71
Difficulty looking after your home	0.80	0.80
Difficulty carrying bags of shopping	0.82	0.84
Problems walking half a mile	0.85	0.84
Problems walking 100 yards	0.84	0.79
Problems getting around the house	0.85	0.77
Difficulty getting around in public places	0.88	0.87
Needed to be accompanied when out	0.82	0.81
Frightened or worried about falling in public	0.72	0.76
Confined to the house more than liked	0.81	0.74
Activities of daily living		
Difficulty washing yourself	0.84	0.80
Difficulty dressing yourself	0.87	0.86
Problems doing up buttons or laces	0.84	0.82
Problems writing clearly	0.67	0.73
Difficulty cutting up food	0.84	0.80
Difficulty holding a drink	0.72	0.62
Emotional well-being		
Felt depressed	0.78	0.81
Felt isolated and lonely	0.74	0.75
Felt weepy or tearful	0.71	0.78
Felt angry or bitter	0.73	0.68
Felt anxious	0.75	0.78
Felt worried about the future	0.73	0.70
Stigma		
Felt you had to conceal PD	0.70	0.72
Avoided eating or drinking in public	0.77	0.74
Felt embarrassed by having PD	0.88	0.80
Felt worried by others' reaction to you	0.82	0.72
Social support		
Problems with close relationships	0.79	0.57
Support from spouse or partner	0.79	0.78
Support from friends or family	0.79	0.83
Cognition		
Fallen asleep during day	0.73	0.68
Problems with concentration	0.80	0.79
Felt your memory was bad	0.68	0.70
Distressing dreams or hallucinations	0.69	0.63
Communication		
Difficulty with speech	0.87	0.85
Unable to communicate properly	0.91	0.83
Felt ignored by people	0.73	0.60
Bodily discomfort		
Muscle cramps or spasms	0.85	0.85
Aches and pains	0.85	0.79
Unpleasant hot or cold	0.75	0.72

All coefficients were significant ($P < 0.001$)

tion were beneath the ideal values that should exceed 0.70 [1, 9].

Item-total correlation of the PDQ-39 domains and parallel data from the study by Peto et al. [10] are shown in

Table 4. Differences greater than 0.10 were observed in only two items (Problems with Close Relationships and Felt Ignored by People).

Correlation between each scale of PDQ-39 and the other scales and questionnaires assessing motor, functional, cognitive and emotional status from the clinical point of view, are displayed in Table 5. The dimensions Mobility, Activities of Daily Living, and Communication showed strongest correlations with PD rating scales ($r_s = 0.49-0.73$, $P < 0.001$) and depression measures ($r_s = 0.43-0.60$, $P < 0.001$). Emotional well-being was highly correlated ($r_s = 0.69-0.74$, $P < 0.001$) with depression and anxiety scales. Cognition was the only PDQ-39 SV dimension significantly correlated with the SPMSQ ($R_s = 0.27$, $P < 0.01$). Body Pain was best correlated with anxiety and depression self-measures (both, $R_s = 0.41$, $P < 0.001$).

Finally, mean scores of the PDQ-39 SV dimensions broken down by HY stage are displayed on Table 6. No HY stage V patient entered the present study. The Kruskal-Wallis test indicated significant trends of dimensions of the PDQ-39 SV across the HY stages, although this effect was weaker for Stigma, Social Support, and Cognition domains.

Discussion

The demographic characteristics of the present series of patients did not differ statistically from those in the clinic-based study by Jenkinson et al. [5]. Some differences to be highlighted in both studies were the absence of patients in HY stage V in the Spanish sample and the significant lower mean scores (Table 2) of two domains Stigma ($P < 0.05$) and Cognition ($P < 0.01$; Student's t test). On the other hand, the internal consistency of the PDQ-39 dimensions (determined by Cronbach's α) were similar and indicative of acceptable reliability [1, 9]. Social support appeared as the less consistent dimension ($\alpha < 0.70$) in both studies and in that reported by Peto et al. [10] (Table 3).

An additional test of internal consistency was performed by calculation of the item-total correlation. Coefficients ranked from 0.57 (Problems with Close Relationships) to 0.87 (Difficulty Getting Around in Public Places; all, $P < 0.001$; Table 4). Only two items, Problems with Relationships and Felt Ignored by People, showed differences that may deserve some emphasis (> 0.10) compared with the study by Peto et al. [10]. Therefore it may be concluded that the PDQ-39 possesses satisfactory internal consistency in both the English and the Spanish versions.

The clinical assessment of patients with PD is usually carried out by means of rating scales that vary widely in metric characteristics, length, and efficiency [7]. Nowadays, PD patients in clinical practice and clinical trials are probably evaluated more frequently with the HY, UPDRS, and SE. Three dimensions of PDQ-39 SV – Mobility, Activities of Daily Living and Communication – were highly

Table 5 Correlations between the summary scores of the PDQ-39 SV dimensions against other rating scales and questionnaires*

Dimensions	HY	UPDRS	SE	SPMSQ	GDS	HAD	
						A	D
Mobility	0.69	0.63	-0.73	NS	0.47	0.49	0.60
Activities of daily living	0.67	0.66	-0.67	NS	0.43	0.43	0.52
Emotional well-being	0.44	0.42	-0.47	NS	0.69	0.74	0.70
Stigma	0.30	0.31	-0.33	NS	0.37	0.39	0.41
Social support	0.32	0.39	-0.34	NS	0.28	0.26	0.39
Cognition	0.27	0.32	-0.25	0.27	0.31	0.43	0.48
Communication	0.54	0.49	-0.54	NS	0.47	0.59	0.51
Bodily discomfort	0.28	0.28	-0.29	NS	0.20	0.41	0.41

* Spearman's rank correlations ($n = 103$): > 0.20 , $P < 0.05$; > 0.25 , $P < 0.01$; 0.33 , $P < 0.001$

HY: Hoehn & Yahr Staging [4]; UPDRS: Unified Parkinson's Disease Rating Scale [3]; SE: Schwab & England Scale [12]; SPMSQ:

Short Portable Mental Status Questionnaire [11]; GDS: Geriatric Depression Scale [13]; HAD: Hospital Anxiety (A) and Depression (D) Scale [15]

Table 6 Mean scores and statistical significance (Kruskal-Wallis test) on the PDQ-39 SV dimensions by the categories of Hoehn and Yahr

Dimensions	I ($n = 14$)	II ($n = 50$)	III ($n = 28$)	IV ($n = 11$)	P
Mobility	13.40 ± 19.40	29.64 ± 27.48	57.14 ± 18.14	81.13 ± 10.45	0.001
Activities of daily living	9.22 ± 10.86	32.03 ± 24.48	57.59 ± 20.32	64.77 ± 13.86	0.001
Emotional well-being	19.64 ± 20.17	31.33 ± 23.88	48.36 ± 24.60	55.68 ± 24.81	0.001
Stigma	5.80 ± 8.30	20.75 ± 26.65	31.25 ± 29.46	30.68 ± 27.02	0.05
Social support	3.57 ± 9.64	15.27 ± 24.87	20.37 ± 23.94	26.51 ± 26.82	0.05
Cognition	11.16 ± 9.23	24.94 ± 18.56	28.57 ± 25.08	36.93 ± 18.63	0.05
Communication	2.97 ± 5.27	17.00 ± 17.73	33.03 ± 25.10	37.87 ± 21.52	0.001
Bodily discomfort	18.45 ± 26.80	37.16 ± 23.94	43.75 ± 20.49	44.69 ± 32.76	0.01

correlated with these scales ($r_s = 0.49$ – 0.73 , $P < 0.001$) and with scales assessing depression and anxiety ($r_s = 0.43$ – 0.60 , $P < 0.001$; Table 5). These results agree with those by Jenkinson et al. [5] and differ partially from a pilot study conducted with a similar methodology on 50 patients [8] in which the domain Cognition occupied the position that Communication held here. In the study by Jenkinson et al. [5] Social Support was unrelated to PD scales (HY and Columbia scale) and Emotional Well-Being ($r_s = 0.27$, $P < 0.05$), and Cognition ($r_s = 0.40$, $P < 0.001$) showed correlations with HY that differed significantly from ours (Table 5).

The highest correlation of Emotional Well-Being was with the measures of depression and anxiety ($r_s = 0.69$ – 0.74 , $P < 0.001$) both in the present and in the pilot studies [8]. Cognition was the only domain of the PDQ-39 SV related to the measure of cognitive status by means of the SPMSQ ($r_s = 0.27$, $P < 0.01$), but its relationship was even better ($r_s = 0.43$ – 0.48 , $P < 0.001$) with the state of mind assessments. Also, Body Pain showed its highest correlations with anxiety and depression (Table 5).

In summary, the most highly correlated domains of the PDQ-39 with PD rating scales are Mobility and Activities of Daily Living, followed by Communication and Cognition. Emotional Well-Being, Stigma and Bodily Discomfort are correlated mainly with depression and anxiety measures. Cognition and Social Support yielded irregular results.

QoL measures should not be equated with disability measures. Furthermore, the subjective patient's evaluation of the impact of disease on his life may differ from the physician's rating. These principles must be kept in mind in interpreting comparisons of the two points of view. Low correlations in these circumstances may indicate differences in perception of the disturbance. Such a finding may be interesting since the presence or authentic relevance of a trouble may go unnoticed in clinical evaluation until a QoL measurement. On the other hand, high correlations indicate the coincidence in the evaluation by physicians and patients on this aspect.

The PDQ-39 may be considered a consistent instrument both in the English and in the Spanish versions. A study to determine the test-retest reliability and convergent validity of the PDQ-39 SV with a generic instrument (SF-36) is underway at present. Responsiveness of the questionnaire is awaiting future studies.

Physical, functional, emotional, cognitive, and social aspects of the QoL in patients with PD are clearly represented and assessed through the domains of the PDQ-39. The use of QoL measures in PD is further justified since disturbances in some of these dimensions may be barely perceived by clinical ratings.

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