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Llagostera-Reverter, Irene; López-Alemany, Mario; Sanz-Forner,
Rosana; González-Chordá, Víctor M; Orts-Cortés, María Isabel
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ORIGINALES

Quality of life and self-care in patients with Parkinson in a regional hospital: descriptive study

Calidad de Vida y Autocuidado en enfermos de Parkinson de un hospital comarcal: estudio descriptivo

Irene Llagostera-Reverter¹

Mario López-Alemany¹

Rosana Sanz-Forner¹

Víctor M González-Chordá²

María Isabel Orts-Cortés³

¹ Nurse, Vinaroz District Hospital, Vinaroz, Castellón de la Plana. Spain. llagosterairene@gmail.com

² Department of Nursing, Jaume I University, Castellón de la Plana. Spain.

³ Department of Nursing, University of Alicante, Investén-isciii. CIBER of Frailty and Healthy Ageing, Alicante. Spain.

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ABSTRACT:

Objectives: To determine the level of self-care and quality of life in a sample of patients in the early stages of Parkinson's disease and identify the most highly affected dimensions of self-care and quality of life. To study the relationship between non-motor symptoms and these outcome measures.

Method: A cross-sectional study was conducted in a sample of 21 patients with stage I or II Parkinson's disease as defined by the Hoehn Yahr Scale. We studied the level of self-care, quality of life, non-motor symptoms and perceived health status. Descriptive, inferential and correlation analyses were performed using SPSS v.20.

Results: Mean sample age was 71.86 (SD±8.93) years old, and 52.4% were males. The mean score for self-care was 1.14 (SD±0.35), and the most highly affected dimension was medication use, with 61.9% of the sample presenting complete autonomy, while for quality of life it was 17.28 (SD±7.75), and the most highly affected dimension was bodily discomfort (m=35.03; SD±19.61). We observed a correlation between non-motor symptoms and quality of life ($r=0.246$; $p=0.022$), but not between non-motor symptoms and self-care ($r=0.010$; $p=0.662$).

Conclusions: Our sample presented an acceptable level of self-care and quality of life. The most highly affected quality of life dimensions were bodily discomfort followed by cognitive impairment, and non-motor symptoms were related to the level of quality of life. It is important to consider these aspects when designing therapeutic education interventions targeting patients with Parkinson's disease.

Key words: Parkinson's disease; quality of life; self-care; non-motor symptoms.

RESUMEN:

Objetivos: Determinar el grado de autocuidado y la calidad de vida en una muestra de pacientes con Enfermedad de Parkinson en estadios iniciales y conocer las dimensiones de autocuidado y calidad de vida más afectadas. Estudiar la relación entre los síntomas no motores con estas medidas de resultado.

Metodología: Estudio observacional transversal realizado en una muestra de 21 enfermos de Parkinson grado I, II de la escala Hoehn Yahr. Se estudió el nivel de autocuidados, calidad de vida, síntomas no motores y nivel de salud percibido. Se realizó análisis descriptivo, inferencial y de correlación con el paquete estadístico SPSS v.20.

Resultados: La edad media de la muestra fue de 71,86 ($dt \pm 8,93$) años, el 52,4% eran hombres. El nivel medio de autocuidados fue de 1,14 ($dt \pm 0,35$) siendo la dimensión más afectada el uso de medicamentos con una autonomía completa del 61,9% y 17,28 ($dt \pm 7,75$) para la calidad de vida siendo la dimensión más afectada el discomfort corporal ($m=35,03$; $dt \pm 19,61$). Se observó correlación baja entre los síntomas no motores y la calidad de vida ($r=0,246$; $p=0,022$), pero no entre los síntomas no motores y el autocuidado ($r=0,010$; $p=0,662$).

Conclusiones: El nivel de autocuidados y calidad de vida de la muestra estudiada es adecuado. Las dimensiones de calidad de vida más afectadas son el discomfort corporal seguida por el deterioro cognitivo y los síntomas no motores están relacionados con el nivel de calidad de vida. Es relevante considerar estos aspectos en el desarrollo de intervenciones de educación terapéutica dirigidas a pacientes con Parkinson.

Palabras clave: Enfermedad de Parkinson; Calidad de vida; Autocuidado; Síntomas no motores.

INTRODUCTION

Parkinson's disease (PD) is the second only to Alzheimer's as the most prevalent neurodegenerative disorder in Spain⁽¹⁾, affecting between 87,833 and 396,976 people⁽²⁾. Furthermore, prevalence is related to population ageing and management of the disorder is complex, rendering PD a major health and social problem⁽³⁾. Onset usually occurs between 55 and 60 years of age, with a higher incidence among men. Although the average life expectancy of a patient with PD is generally the same as for the general population, complications may arise in the latter stages of the disease that can lead to death⁽⁴⁾.

The cardinal symptoms of PD are tremor, rigidity, slowness of movement and postural instability. For many years, PD was only thought to affect the motor system. However, it has since been found to affect other neurons over time, giving rise to non-motor symptoms that disrupt and damage the autonomic, limbic and somatosensory systems and cause severe alterations in behaviour and mood. Despite advances in neurology, the aetiology of PD remains unclear; nonetheless, genetic and environmental factors, such as early exposure to agrochemicals, are now known to play a role in its pathophysiology⁽⁵⁾.

Studies have demonstrated that patients with PD present impaired quality of life compared with the general population, as a result of motor and non-motor symptoms that affect their ability to function and contribute to their deterioration⁽⁶⁾. Some authors have emphasised the prevalence of non-motor symptoms, their rate of underdiagnosis and their impact on quality of life, since these are the main cause of morbidity and the primary reason for institutionalisation and hospitalisation⁽⁷⁾, entailing high health costs.

More than 60% of patients with PD are in the early stages⁽⁸⁾. Consequently, therapeutic education interventions with these patients may help prevent or delay worsening of symptoms and improve their quality of life through self-care. Further research is required to determine the areas of quality of life that are most affected in the early stages of PD and to measure these patients' needs and perceptions of their own well-being, in order to design therapeutic education interventions that target their self-care needs. Promoting self-care will enable these patients to exercise greater

control over their health and microenvironment and achieve better overall well-being and a higher quality of life⁽⁹⁾.

The primary aim of this study was to determine the level of self-care and quality of life in a sample of patients in the early stages of Parkinson's disease and identify the most highly affected dimensions of self-care and quality of life. A further goal was to study the relationship between non-motor symptoms and self-care and quality of life.

METHOD

Design and setting

We conducted a cross-sectional study between July 2014 and June 2015 to determine the quality of life and self-care in patients with Parkinson's disease attending the neurology service of a district hospital (HUCV) in the province of Castellón. We used the STROBE guide to design and conduct the study⁽¹⁰⁾.

Population and sample

The target population consisted of patients diagnosed with PD (ICD-9-332) and attending the HUCV neurology service (N=162). Using purposive sampling, we included patients aged 50-85 years old in the early stages of PD (stages I or II on the Hoehn Yahr Scale⁽¹¹⁾), who obtained a score greater than 60 on the Barthel index⁽¹²⁾ and greater than or equal to 70% on the Schwab & England Activities of Daily Living Scale⁽¹³⁾. We excluded subjects who did not want to participate and those who presented intellectual disability (Pfeiffer Scale)⁽¹⁴⁾.

In line with the results of the GRANMO programme, a sample of 27 subjects was considered sufficient, establishing a 95% confidence interval, an accuracy of 20%, a percentage of the population of patients in the early stages of PD of 50% and a 20% replacement rate.

Variables and instruments

Sociodemographic variables included age, sex, educational level (no formal education, basic education, post-compulsory secondary education, university education), marital status (married, single, separated/divorced, widowed) and occupational status (active, unemployed, retired).

Self-care and quality of life variables

- Self-care was measured using the *Escala de Valoración de la Autonomía para el Autocuidado* (Self-Care Autonomy Scale, Spanish initials: EVAA). This rates autonomy on a scale of 1 to 10 where the higher the score, the lower the degree of autonomy⁽¹⁵⁾.
- Quality of life was measured using the Parkinson's Disease Questionnaire (PDQ-39). This yields a score between 0 and 100 where the higher the score, the better the individual's perceived quality of life⁽¹⁶⁾.
- Non-motor symptoms were measured using the Non-Motor Symptoms Scale (NMSS) for Parkinson's disease. This yields a score between 0 and 360 where a value close to 0 indicates fewer non-motor symptoms⁽¹⁷⁾.
- Perceived health status was measured using the EuroQoL-5D (EQ-5D) instrument, where scores range between 1 (better health status) and 0 (death)⁽¹⁸⁾.

Data collection

Subjects were recruited and data collected between January and March 2015. Patients with PD were identified from the neurology service database, and medical records were consulted to select subjects who met the inclusion criteria.

Data were collected during patients' appointments at the neurology service. Patients who did not have an appointment already scheduled during the data collection period were contacted by telephone. Patients received a telephone call to remind them of their appointment.

Two nurses collected data during interviews using an *ad hoc* data collection spreadsheet. A pilot study was conducted with 5 subjects to confirm that the procedure functioned correctly. Average interview duration was 30 minutes.

Ethical considerations

This study was approved by the HUCV and the Ethics Committee at Jaume I University, and observed the ethical principles of the Declaration of Helsinki. All subjects received prior information and were asked to give their informed consent for data processing. Personal data were anonymised by assigning a specific code, and confidentiality was maintained in line with Articles 11.1.e) and 11.6 of Organic Law 15/1999 on the Protection of Personal Data.

Statistical analysis

A descriptive analysis was performed of all variables according to their nature. A comparison of means or medians was performed using the Mann Whitney U-test and the Kruskal-Wallis test. The relationship between mean scores for non-motor symptoms and self-care and quality of life was analysed using Pearson's correlation coefficient. The level of statistical significance was $p=0.05$. Statistical analysis was performed using SPSS v.20.

RESULTS

A total of 27 subjects met the inclusion criteria. One was excluded as it was not possible to establish contact, four refused to participate and one was lost during the study, leaving a final sample of 21 subjects. Table 1 gives a summary of the sociodemographic variables.

Table 1. Description of sociodemographic variables

	m	SD
Age	71.86	8.93
Children	2.1	1.41
	n	%
Sex		
Male	11	52.4
Female	10	47.6
Marital status		
Married	15	71.4
Single	1	4.8

Widowed	5	23.8
Occupational status		
Active	1	4.8
Unemployed	0	0
Retired	20	95.2
Educational level		
No formal education	4	19
Basic education	12	66.7
Post-compulsory secondary education	2	9.5
University education	1	4.8

m: mean; SD: standard deviation

The EVAA scale yielded a mean score for self-care of 1.14 ($SD \pm 0.35$), with 85.7% ($n=18$) of the sample obtaining a functional autonomy level of 1 and 2 (greater degree of autonomy). The most highly affected dimension was medication use, whereby 61.9% ($n=13$) showed complete autonomy, 23.8% ($n=5$) needed stimulus/supervision, 9.5% ($n=2$) required help and 4.8% ($n=1$) presented total dependence. For mobility, 76.3% ($n=16$) presented complete autonomy, 14.3% ($n=3$) needed stimulus/supervision and 9.5% ($n=2$) required help. We found significant differences between educational level and the items nutrition-food ($p=0.008$), nutrition-hydration ($p=0.001$) and grooming-hygiene ($p=0.008$) (Table 2).

Table 2. Description of EVAA and its items and relationship with sociodemographic variables

	n	%	Sex	Educational level	Occupational status	Marital status
EVAA						
Functional autonomy levels 1 and 2	18	85.7				
Functional autonomy levels 3 and 4	3	14.3	0.48	0.84	0.68	0.08
Nutrition-food						
Complete autonomy	19	90.5				
Help	2	9.5	0.94	0.00	0.74	0.79
Nutrition-hydration						
Complete autonomy	20	95.2				
Stimulus/supervision	1	4.8	0.34	0.00	0.82	1
Medication use						
Complete autonomy	13	61.9				
Stimulus/supervision	5	23.8	0.71	0.89	0.34	0.10
Help	2	9.5				

Total dependence	1	4.8				
Symptoms						
Complete autonomy	19	90.5	0.48	0.07	0.68	0.79
Help	2	9.5				
Activities of daily living						
Complete autonomy	19	90.5	0.94	0.78	0.74	0.08
Help	2	9.5				
Mobility						
Complete autonomy	16	76.2				
Stimulus/supervision	3	14.3	0.14	0.08	0.58	0.05
Help	2	9.5				
Rest and sleep						
Complete autonomy	18	85.7	0.60	0.17	0.68	0.70
Stimulus/supervision	3	14.3				
Grooming and hygiene						
Complete autonomy	19	90.5	0.94	0.00	0.74	0.79
Stimulus/supervision	2	9.5				
Defecation						
Complete autonomy	21	100	1	1	1	1
Urination						
Complete autonomy	20	95.2	0.34	0.23	0.82	0.79
Help	1	4.8				
Leisure activities						
Complete autonomy	17	81	0.23	0.84	0.62	0.08
Stimulus/supervision	4	19				
Use of resources						
Complete autonomy	20	95.2	0.29	0.23	0.82	1
Help	1	4.8				

EVAA: Escala de Valoración de la Autonomía para el Autocuidado (Self-Care Autonomy Scale)

The mean score for quality of life measured using the PDQ-39 scale was 17.28 ($SD \pm 7.75$), and the most highly affected dimensions were bodily discomfort ($m = 35.03$; $SD \pm 19.61$) followed by cognitive impairment ($m = 26.78$; $SD \pm 18.75$). No significant differences were detected between the sociodemographic variables and mean scores for quality of life (Tables 3 and 4).

The mean score for perceived health status, measured using the EQ-5D scale, was 0.67 ($SD \pm 0.13$) and the most highly affected dimensions were anxiety/depression, with a mean of 1.90 ($SD \pm 0.53$), followed by mobility with a mean of 1.48 ($SD \pm 0.51$). The EQ-5D index presented a mean of 75.48 ($SD \pm 15.24$). No significant differences were detected between the sociodemographic variables and perceived health status ($p < 0.05$) (Table 5).

The mean score for non-motor symptoms, assessed using the NMSS scale, was 41.33 ($SD \pm 20.58$). The domain of urinary function showed the highest mean, at 7.95 ($SD \pm 6.67$), while the cardiovascular system domain presented the lowest mean, at 0.95 ($SD \pm 1.20$). The correlation between non-motor symptoms and quality of life was

low ($r=0.246$; $p=0.022$), while that between non-motor symptoms and self-care was negligible ($r=0.010$; $p=0.662$).

DISCUSSION

Spain is posed with the challenge of chronicity. More than 20% of the population rendered dependent by chronic disorders are affected by neurological diseases. Health care for the chronically ill must change to focus on preventing the complications that arise from these disorders, adopting a holistic, integrated and multidisciplinary approach(19). Parkinson's disease is a chronic, progressive disorder associated with a high burden of disability that escalates health care needs(20). One important factor in the quality of life (QoL) of patients with Parkinson's disease is their stage on the Hoehn Yahr Scale, since the step from stage II to III entails a significant decline in QoL and an increase in non-motor symptoms. This change affects patients with PD more than age itself(21). Consequently, the design and implementation of educational interventions in the early stages, based on the most severely affected areas of quality of life and self-care, can help improve patient autonomy and QoL.

Table 3. Description of PDQ-39 and its dimensions and relationship with sociodemographic variables

	PDQ-39			Mobility			ADL		
	m	SD	p	m	SD	p	m	SD	p
Sex									
Male	15.72	8.55	0.27	14.09	17.72	0.30	14.39	12.96	0.79
Female	19.00	6.79		22.25	17.69		15.80	11.03	
Educational level									
No formal education	18.07	9.73	0.80	24.37	20.65	0.56	22.92	7.22	0.67
Basic education	16.26	7.40		14.64	14.34		11.58	11.42	
Post-compulsory secondary education	22.62	11.52		31.25	40.66		12.50	0.00	
University education	17.76			12.50			37.50		
Marital status									
Married	15.99	8.36	0.74	14.16	15.83	0.31	12.47	11.43	0.28
Single	17.76			27.50			25.00		
Widowed	21.05	5.68		27.50	22.57		20.83	12.14	
Occupational status									
Active	13.40		0.50	5.00		0.46	16.67		0.89
Retired	17.47	7.91		18.62	17.96		14.98	12.10	

m: mean; SD: standard deviation; PDQ-39: Parkinson's Disease Questionnaire; ADL: activities of daily living

Table 3 (continuation). Description of PDQ-39 and its dimensions and relationship with sociodemographic variables

	Emotional well-being			Stigma		
	m	SD	p	m	SD	p
Sex						
Male	17.42	18.71	0.58	5.11	8.76	0.27
Female	21.67	16.41		12.50	18.63	
Educational level						
No formal education	18.75	18.16	0.63	0.00	0.00	0.63
Basic education	18.45	16.72		11.16	16.66	
Post-compulsory secondary education	33.34	29.46		9.37	13.26	
University education	8.33			6.25		
Marital status						
Married	20.83	18.16	0.53	8.33	15.43	0.78
Single	0.00			0.00		
Widowed	19.17	15.76		11.25	13.55	
Occupational status						
Active	29.17		0.57	0.00		0.55
Retired	18.96	17.65		9.06	14.69	

m: mean; SD: standard deviation; PDQ-39: Parkinson's Disease Questionnaire; ADL: activities of daily living

Table 4. Description of PDQ-39 and its dimensions and relationship with sociodemographic variables

	Social support			Cognitive impairment		
	m	SD	p	m	SD	p
Sex						
Male	5.30	17.58	0.44	31.82	17.33	0.09
Female	11.25	17.12		21.25	9.41	
Educational level						
No formal education	18.75	23.93	0.61	18.75	17.68	0.56
Basic education	5.95	16.48		29.02	15.03	
Post-compulsory	6.25	8.84		21.87	4.42	

secondary education					
University education			37.50		
Marital status					
Married	7.22	19.12		27.92	15.99
Single			0.76	37.50	0.54
Widowed	12.50	12.50		21.25	11.35
Occupational status					
Active				25.00	
Retired	8.54	17.55	0.64	26.87	15.19

m: mean; SD: standard deviation; PDQ-39: Parkinson's Disease Questionnaire

Table 4 (continuation). Description of PDQ-39 and its dimensions and relationship with sociodemographic variables

	Communication			Bodily discomfort		
	m	SD	p	m	SD	p
Sex						
Male	3.03	5.62	0.61	34.09	21.55	0.82
Female	5.00	10.54		36.08	18.34	
Educational level						
No formal education	6.25	12.50	0.82	11.04	15.26	0.03
Basic education	4.17	7.84		39.88	17.04	
Post-compulsory secondary education				50.00	11.78	
University education				33.33		
Marital status						
Married	2.22	4.95	0.16	36.11	20.81	0.93
Single				33.33		
Widowed	10.00	13.69		32.16	19.80	
Occupational status						
Active			0.63	33.33		0.93
Retired	4.17	8.33		35.12	20.12	

m: mean; SD: standard deviation; PDQ-39: Parkinson's Disease Questionnaire

Table 5. Description of EQ-5D and its dimensions and relationship with sociodemographic variables

	m	SD	Sex	Educational level	Occupational status	Marital status
EQ-5D	0.67	0.13	0.45	0.96	0.86	0.58
Mobility	1.48	0.51	0.29	0.83	0.34	0.31
Self-care	1.19	0.40	0.91	0.08	0.62	0.63
Activities of daily living	1.33	0.48	0.54	0.72	0.48	0.13
Pain/discomfort	1.33	0.48	0.37	0.28	0.83	0.89
Anxiety/depression	1.90	0.54	0.29	0.82	0.29	0.31
EQ-5D index	75.48	15.24	0.13	0.66	0.67	0.18

m: mean; SD: standard deviation; EQ-5D: EuroQoL-5D Health Questionnaire

Quality of life and the capacity for self-care were close to good in our sample. The most highly affected dimensions of self-care in our study were medication use and mobility, whereas other studies have found that patients with PD require more help to carry out activities of daily living⁽¹⁹⁾. In addition, other studies have obtained a higher quality of life⁽²²⁾; however, these included patients in all stages of PD, whereas we only included patients in the early stages, and they also analysed much larger samples using different scales.

The results of our study indicate that functional status in the initial stages of PD affects certain QoL dimensions through a self-care deficit, coinciding with Jones⁽²³⁾, who suggested that the areas with greatest impact on QoL as a consequence of loss of functionality are those related to physical function, social support and cognitive status. In our study, the least affected QoL dimension was communication, while the most affected was cognitive status. It should be noted that we did not consider concomitant diseases such as arthritis, diabetes or circulatory problems in our study, although these exert a negative effect on the cognitive and functional status of patients with PD⁽²⁴⁾.

No significant differences were observed in the level of QoL depending on the sociodemographic variables studied. Some authors⁽²⁵⁾ have suggested that a lower educational level may benefit QoL in subjects with PD due to greater ease in accepting the disease. However, these results do not coincide with our findings. Furthermore, the severity of PD may have a greater impact on QoL in terms of physical function, mobility and activities of daily living, but psychological adjustment to the disease also exerts a direct influence on QoL.

Our results for non-motor symptoms do not coincide with those reported by other authors⁽²⁰⁾, since the correlation with quality of life was low and was not significant with self-care. It is probable that these results were due to our small sample size. We also observed a higher prevalence of urinary symptoms in our sample, whereas the literature indicates that sleep disorders/fatigue and mood/cognitive impairment are the most frequent symptoms^(23, 26); in our study, these occupied second and third place. Yang⁽²⁷⁾ has calculated that depression affects one in three people with PD, and has claimed that this is exacerbated by the presence of non-motor symptoms, which are very prevalent in the early stages of PD⁽²⁸⁾ and exert a major negative influence on QoL.

Interventions with chronically ill patients should be aimed at enabling them to become active patients who are aware of their illness and adopt a more proactive role. The overall objective of therapeutic education is to help users overcome a self-care deficit so that they can better respond to the demands of self-care entailed in the process of managing their chronic disease and thus enhance their quality of life. The capacity for self-care is promoted by actions that enable patients to recognise, treat and manage their own health problems autonomously, in the knowledge that the health care system is close at hand. It is necessary to implement various actions that promote the concept of self-care and foster the acquisition of this capacity among the population in general and patients in particular. People must be helped to manage their treatment plan (drugs, diet, etc.), to lead the most autonomous and satisfactory life as possible and to learn how to manage the emotional effects of their disease⁽²⁹⁾. This would increase patient satisfaction, enhance daily QoL and improve disease management, besides reducing resource consumption (visits, emergencies, hospitalisation) due to decompensation or complications. To achieve this, it is essential to determine educational needs and identify those aspects of the disease that require most attention.

Our results should be interpreted with caution since the study focused on a specific service and analysed a small sample that was not recruited through random sampling. Consequently, it is difficult to generalise the results. Nevertheless, we did attain the number of subjects necessary according to the sample size calculation performed. It should also be noted that we focused on patients in the early stages of PD, since these are more amenable to educational interventions. In addition, this was a descriptive study and thus did not allow for the verification of hypotheses. Despite these limitations, our findings are useful because they facilitate the design of educational interventions aimed at improving self-care and quality of life based on the needs of this group of patients.

CONCLUSIONS

Our sample presented an acceptable level of self-care and QoL. The main self-care dimensions affected were medication use and mobility. Meanwhile, the most highly affected QoL dimensions were bodily discomfort followed by cognitive impairment. The correlation between non-motor symptoms and quality of life was low but significant, whereas we found no correlation between non-motor symptoms and level of self-care. An analysis of the dimensions affected in self-care, QoL and non-motor symptoms is important when designing educational interventions in patients with PD.

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