Influencing factors when Living with Parkinson's Disease: A cross-sectional study.

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ABSTRACT

Aims and objectives: To identify the personal and disease related factors that are associated to Living with Parkinson's disease.

Background: Living with Parkinson's disease affects the physical, psychological, social and spiritual areas of the person. Health professionals need to know which factors influence the daily Living with Parkinson's disease, in order to facilitate a positive living.

Design: A multicentre cross-sectional study.

Methods: 324 patients with a Parkinson's disease diagnoses were included in the study through a consecutive cases sampling. Data were collected from January to June 2015, in specialized units of movement disorders of public and private and community centres, from Spain, Argentina, Mexico, Ecuador and Cuba. Nine measures were applied to evaluate personal related factors (age, gender, psychosocial function, satisfaction with life, social support, home economical situation) and Parkinson's disease related factors (duration of disease, motor symptoms, non-motor symptoms). The STROBE checklist was used to ensure quality reporting during the study (see Supplementary File 1). Multiple linear regression analysis was carried out.

Results: Results indicated that social support, followed by satisfaction with life and home economical situation are the only three factors that significantly influence in Living with Parkinson's disease. The rest of the factors analysed did not present significant influence in the daily Living with this neurodegenerative disease.

Conclusion: This study highlights the necessity to put more emphasis on the person and his/her daily Living with the condition and less on symptoms and treatment. Health professionals need to develop person centred interventions that also deal with other elements of the experience of living with a long-term condition like Parkinson's disease.

Relevance to clinical practice: Interventions to foster positive living with Parkinson's disease in clinical practice should integrate strategies to tackle and prevent loneliness and interagency elements to increase community resources and systems of support.

Keywords: Cross-sectional study, Influencing factors, Social support, Satisfaction with life, Long-term condition, Parkinson's disease.

INTRODUCTION

Demographic changes happening in the 20th century in the Western world such as ageing and the increase in life expectancy have produced a significant growth in long-term conditions (LTCs) in the contemporary society. In particular, LTCs have become a leading health related issue (WHO, 2017). Among LTCs, neurodegenerative and progressive disorders like Parkinson's disease (PD) stand out. PD is the second most common neurodegenerative disease, after Alzheimer' disease, affecting 1% of all people over 60 years of age in industrialized countries (de Lau and Breteler, 2006). PD prevalence is increasing and it is expected that the number of people with PD will double by 2030 (Dorsey *et al.* 2007). At present, there is no cure for PD and is a major and increasing burden on patients, families, carers and healthcare systems (Findley, 2007). Medical costs for people with PD are twice those of people without PD. More concretely, the annual costs per patient and per year ranged around $1750 in Canada, $17,560 in Germany or £5,993 in UK (Findley, 2007). Taking into account these numbers, it is clear that management strategies that minimise the impact of disease progression and maximise the daily living are needed to ensure optimal resource utilization and reduce expenses in healthcare systems.

BACKGROUND

PD is a complex and disabling disorder manifested through a combination of specific motor and non-motor symptoms that generate an important psychological and social impact on the person who suffers the disease (Kalia and Lang, 2015, Lees *et al.* 2009, Poewe *et al.* 2017). A recent study of PD patients showed a high proportion of patients reporting non-motor symptoms such as hallucinations, depression or cognitive decline, affecting negatively in their daily living with the disease (Findley, 2007). In this way, throughout the PD course, patients do not only experience a progressive intensification of PD specific symptoms but also have to cope and deal with an increasing limitation in all areas of their daily Living with PD as a consequence of the disease (Haahr *et al.* 2011, Hermanns, 2011).

Living with a LTC like PD has been recently defined as a complex, dynamic, cyclic and multidimensional process that involves key elements, as acceptance, coping or adjustment (REFERENCE BLINDED FOR PEER REVIEW). Living with PD affects the patients' physical state together with other essential aspects in his/her life, such as the psychological, social and spiritual ones (Kang and Ellis-Hill, 2015, Navarta-Sanchez *et al.* 2017).

In this context, healthcare professionals and especially nurses need to be aware and adopt a comprehensive approach so that all aspects of the patients, understood as a bio-psycho-social and spiritual being, are individually addressed (Fix *et al.* 2018, WHO, 2018). Nurses play an essential role and need to reconsider daily practice to focus on the person and not just on the disease, symptoms and treatment. Hence, identifying and understanding which factors could affect the person's living experience with PD is necessary to provide care according to the patient individual and unique needs (REFERENCE BLINDED FOR PEER REVIEW, Lees *et al.* 2009, REFERENCE BLINDED FOR PEER REVIEW). Consequently, nurses could develop individualised plans and/or targeted interventions improving the experience of the person with PD.

At present, several studies have been identified in the literature (Kang and Ellis-Hill, 2015, Prizer and Browner, 2012, Soundy *et al.* 2014), which address the patients' experience and perceptions when living with PD. There is also evidence (Hurt *et al.* 2012, McLaughlin *et al.* 2010, Navarta-Sanchez *et al.* 2017) showing the factors (i.e. family support, resources or personal aspects) influencing the psychosocial adjustment or coping with PD. Despite the relevance of these papers, it is important to point out that they all focussed on a single element of the whole process of Living with PD, having a fragmented view of the daily living with a disease. In this sense, despite the existing literature, at present the predictors of the Living with PD and how they interact with each other remain unknown. Therefore, the aim of this study is to identify the personal and PD related factors that are associated to Living with PD.

METHODS

Hypotheses

Based on previous research (Kang and Ellis-Hill, 2015, Zaragoza *et al.* 2014), we hypothesized that highly perceived levels of social support of the patient are related to a positive Living with PD (H1); more satisfaction with life is related to a positive living with PD (H2); a better home economical situation is related to positive Living with PD (H3); being at an initial or less severe stage of PD is related to a positive Living with the condition (H4); and less burden of PD motor and non-motor symptoms is related to a more positive Living with PD (H5).

Study design

This was an international study with an observational and cross-sectional design which took place in five countries (Spain, Argentina, Ecuador, Mexico, Cuba). This research was part of a multidisciplinary research programme called XXX (REFERENCE BLINDED FOR PEER REVIEW), whose general purpose is to design individualized interventions to normalise the experience of living with LTCs for patients and family/carers through the development, implementation and evaluation of individualised multiagency interventions. STROBE checklist for cross-sectional studies was used to ensure quality of this study (see Supplementary File 1).

Participants and setting

Participants (people with PD) were recruited in seven specialized outpatients consultations of movement disorders of the 5 participating countries: Argentina, Ecuador, Cuba, Mexico and Spain from January to June 2015.

A consecutive cases sampling took place and the following inclusion and exclusion criteria were applied during the recruitment. Inclusion criteria: 1) being diagnosed with PD by a neurologist according to international recognized diagnostic criteria (Lees *et al.* 2009); 2) being native Spanish-speaking patients; 3) being able to read and understand the questionnaire; and 4) providing an informed consent. Exclusion criteria: 1) having other type of parkinsonism different to PD; 2) having other concomitant severe systemic condition; 3) presenting cognitive deterioration (diagnosed by the neurologist); 4) having other acute disorders or injuries due to pharmacological effect (e.g., dopamine antagonists), or sensorial deficit (e.g., blindness) potentially distorting the assessment; and 5) refusing to participate or not meeting all inclusion criteria.

Assessments

Socio-demographic data (age, gender, marital status, employment situation and educational level) and PD historic data (age at PD onset, PD duration and PD treatment duration) were collected. In addition, nine measures were applied. All of them had been validated to Spanish, presented adequate reliability and validity values, and were open access or authors had the licence/permission to use them. The applied measures were the following:

Rater-based assessments

The Hoehn and Yahr stage (HY) was used to evaluate the overall severity of the disease. This scale classifies the severity of PD into five stages from 1 (without functional issue) to 5 (wheelchair bound or bedridden unless aided) (Hoehn and Yahr, 1967).

The Clinical Impression of Severity Index-PD (CISI-PD) was used to evaluate the global impression of PD severity in four areas: motor signs, disability, motor complications and cognitive status. Each item is rated on a range of 0 (normal, no affectation) to 6 (very severe affectation). The total score ranges from 0 to 24 (Martinez-Martin *et al.* 2006, Martinez-Martin *et al.* 2009a).

The Scales for Outcomes in Parkinson's Disease-Motor (SCOPA-Motor) was used to measure patients' motor symptoms generated by PD. It is a 21 item scale grouped into three sections: examination, activities of daily living, and motor complications. The score for each item varies from 0 (normal, no affectation) to 3 (severe affectation) and the total scale score ranges from 0-75 (Marinus *et al.* 2004, Martinez-Martin *et al.* 2005).

The Non-Motor Symptoms Scale (NMSS) was used to evaluate the burden of non-motor symptoms in PD. It is a 30-item scale, with nine domains: cardiovascular, sleep/fatigue, perceptual problems/hallucinations, attention/memory, gastrointestinal tract, urinary, sexual function and miscellaneous. The score for each item varies from 0 (no presence of symptom) to 12 (maximum frequency and severity of symptom). The total score for the domains and the whole scale can be obtained by the sum of the corresponding items scores (Chaudhuri *et al.* 2007, Martinez-Martin *et al.* 2009b).

Patient-reported assessments

The SCOPA-PS was used to evaluate the psychosocial functioning of the patient during the preceding month. It is a self-reported 11-item questionnaire where each item is scored from 0 (not psychosocial problems at all) to 3 (maximum level of problems). The summary index is obtained by summing up direct item scores transformed into percentage values (Marinus *et al.* 2003, Martinez-Martin *et al.* 2009c).

The Duke-UNC Functional Social Support Questionnaire (DUFSS) was used to evaluate the social support of the patients' from his/her perspective. The DUFSS is a self-reported measure that comprises 11 items that evaluate diverse dimensions of social support as confidant, affective and instrumental support. The score for each item varies from 1 (much less than I would like) to 5 (as much as I would like). Total score ranges from 11 (lowest level of support 'much less than I would like') to 55 (highest level of support 'as much as I like') (Ayala *et al.* 2012, Broadhead *et al.* 1988).

The Satisfaction with Life Scale (SLS) is a 7-item self-reported questionnaire. For this study, a modified version of the SLS was used because the original version was specific for a student population. In this way, a modified version with 6-item scale (SLS-6) was used to evaluate the degree of overall satisfaction with life (item 1) and regarding five areas: physical, psychological wellbeing, social relations, leisure, and financial situation. Each item rated on a 0 (totally unsatisfied with life) to 10 (totally satisfied with life) point Likert scale (REFERENCE BLINDED FOR PEER REVIEW, Mazaheri and Theuns, 2006).

The self-rated home economical situation (SEH) is a generic and analogical visual measure with 10 tracts, scored from 0 (very poor home) to 10 (very rich home).

Finally, the Living with Chronic Illness Scale (EC-PC) is a new scale to evaluate the process of Living with a LTC, as PD. The EC-PC is a 26-item scale with five domains: 1-Acceptance (4 items); 2-Coping (7 items); 3-Self-management (4 items); 4-Integration (5 items); and 5-Adjustment (6 items). Items are scored on a 5-point scale ranging from 0 (never/nothing) to 4 (always/a lot), except for domain 1-Acceptance that ranges upside down (4: never/nothing; 0:

always/a lot). Total score ranges from 0 (negative Living with PD) to 104 (positive Living with PD). The psychometric properties of this scale have been published elsewhere (REFERENCE BLINDED FOR PEER REVIEW).

Data collection

All measures were completed during the consultation with the neurologist, from January to June 2015. The neurologist completed the rater-based assessments and in addition, the participants filled in the patient-reported assessments. In order to ensure homogeneity in all the participating countries and reduce possible errors during data collection, the principal investigator of the project developed a data collection protocol with the following steps: presentation of information about the research programme and in particular this study; clarification of doubts; reading out load instructions measuring scales completed with the neurologist and their items and answers, selecting the answer chosen by the patient; reading out load instructions of the self-reported scales and giving participants time to complete them. The average time to complete the self-reported scales was 45 minutes.

Ethical considerations

The study was approved by the Institutional Review Board of the XXX and the other participating countries (IRB No.: 071/2014). Patients gave their consent to participate voluntarily after receiving the pertinent oral and written information. All data and information about the participants' identity were handled in full confidentiality throughout the research process. No ethical conflicts emerged.

Data analysis

Data were analysed using Stata 14 (StataCorp, College Station, Texas 77845 USA). Descriptive statistics (central tendency measures, proportions) were used to determine the socio-demographic and disease related factors of the participants. Besides, Spearman rank correlation coefficient (r_s) was used for testing the associations between the EC-PC and the rest of assessments. Spearman rank correlation coefficient was used because the origin of the main data was ordinal and because the distribution of scores from the main variables was not normal. The criterion values were: negligible/weak $r_s < 0.35$, moderate $r_s = 0.35 - 0.50$ and strong $r_s > 0.50$ (Juniper *et al.* 1996).

To identify the factors that could influence Living with PD multiple linear regression models were used for the EC-PC total and the domain related scores. Before, assumptions of normality, homoscedasticity, independence of errors and absence of multicollinearity were checked and, subsequently, some variables were discarded (HY, CISI-PD, SCOPA-Motor Examination, SCOPA-PS). Six regression models were built. The respective dependent variables were EC-PC total score and the five domains. The independent (explanatory) variables for all models were: age, gender, duration of studies, duration of PD, ability for activities of daily living and motor complications (SCOPA-Motor), non-motor symptoms burden (NMSS), satisfaction with life (SLS-6), social support perceived by the patient (DUFSS) and, home economical situation (SEH).

The method of entry of variables was simultaneous to check the effect of each explanatory variable in each model in order to make these effects comparable, taking into account that multicollinearity was previously discarded.

A p-value of 0.05 or lower was considered statistically significant.

Rigour

To ensure the rigour of the study, we administered instruments validated in a Spanish population with excellent psychometric properties. In particular, the EC-PC is a reliable instrument with satisfactory Cronbach's alpha ($\alpha \geq 0.70$) in patients living with PD. Besides, validity showed satisfactory in convergent, internal and known-groups validity coefficients (REFERENCE BLINDED FOR PEER REVIEW). In addition, Guba and Lincoln (1981) criteria of trustworthiness were used to ensure rigour in quantitative research. To ensure truth-value patient-reported assessments were included and a standardized protocol was used in all participating centres. ~~For promoting applicability, statistically representative sample size was used based on the literature (Stebbins, 2012).~~ The data of this study emerged form the validation study of the EC-PC (REFERENCE BLINDED FOR PEER REVIEW). The characteristics of the sample can be considered representative of the PD population attended in specialized movement disorder units (male predominance, advanced age, middle PD duration and all HY stages). Also, the study was carried out in five different Spanish spoken countries in order to ensure the applicability of the results in this population. A minimum of 50 patients per centre was requested, considering that basic psychometric attributes of the EC-PC could be tested on this sample size, if it was convenient (Terwee *et al.* 2007). Consistency was fulfilled including researchers with high expertise in measures related to PD and in the phenomenon of Living with LTCs. Also, rigour was ensured developing a structured protocol for all the researchers in order to standardized the study. Neutrality was promoted following a systematic methodology and including external experts from XXX research group (REFERENCE BLINDED FOR PEER REVIEW).

RESULTS

A total of 324 patients with PD were included. Socio-demographic and PD related characteristics of the sample are shown in Table 1. Most of patients in the sample were married, retired and had primary or secondary education level. Most of patients (85.8%) were in intermediate HY stages (55.25% stage 2; 30.56% stage 3), although all stages were represented. There were no missing data and the average scores of included measures were, overall, at indicative levels of moderate to mild of their respective constructs. Part of the descriptive statistics for PD related variables and assessments in the study, and for the EC-PC were mentioned in a previous manuscript (REFERENCE BLINDED FOR PEER REVIEW) (Tables 2 and 3).

According to the correlation coefficient values, DUFSS showed strong association ($r_S = 0.61$) with EC-PC total score. A moderate correlation was identified between EC-PC and SLS-6 ($r_S = 0.46$). Moderate correlations ($r_s = 0.32$-0.48) were also identified between EC-PC domains and the other assessments: NMSS with domain 1-Acceptance; SCOPA-PS with domain 1-Acceptance; DUFSS with domain 5-Adjustment; and SLS-6 with domain 1-Acceptance, 4-Integration, and 5-Adjustment. All these correlations were significant ($p < 0.001$). Weak or negligible correlations were found between EC-PC and the clinician-based PD assessments (Table 3).

Table 4 shows the results from the multiple linear regression analysis. In addition, the analysis of the residuals concluded that a normal distribution could not be discarded and there was no heteroscedasticity. Social support (DUFSS), satisfaction with life (SLS-6) and home economical situation (SEH) showed a significant and independent influence on the process of Living with PD (EC-PC). According to the standardized coefficients, the variable showing the greatest effect was DUFSS (beta = 0.51), followed by SLS-6 (beta = 0.26) and SEH (beta = -0.16). Additionally, these three measures (DUFSS, SLS-6, SEH) also presented independent and selective association with different domains of the EC-PC: DUFSS presents significant association with domains 2-Coping, 3-Self-Management, 4-Integration and 5-Adjustment, while domain 1-Acceptance showed strong association with SLS-6, but not with DUFSS or SEH. Years of education and motor symptoms (SCOPA-M) did not present a significant effect in the analysed models. The rest of the measures included in the study showed a p value > 0.05.

DISCUSSION

Results in this study could establish some basic notions for a more comprehensive approach of PD management, showing key factors that influence the experience of Living with PD and including a specific measure in this regard (EC-PC). To our knowledge, this is the first study that analyses and reports on the factors that influence in Living with a LTC, in particular with PD.

One of the key results in this study showed a clear positive association between patients' social support perception and Living with PD. Furthermore, our subsequent multiple linear regression analysis confirmed this influence and we can state that social support is the most influencing factor of Living with PD confirming hypothesis 1 of this study.

The identification of social support as a star factor when it comes to PD is not new in the literature and from a qualitative and quantitative perspective this has been intuited before (Dunk *et al.* 2017, Kang and Ellis-Hill, 2015) with a special focus on the support given by nurses (Kang and Ellis-Hill, 2015, Wang *et al.* 2014). However, our results are novel as this association has never been determined with Living with PD from a quantitative perspective. Living with a LTC as a phenomenon bears complexity and should not be simplified to processes like self-management or acceptance of the diagnosis, which are inner parts of the former (REFERENCE BLINDED FOR PEER REVIEW). This is illustrated in the other associations presented in table 4 as all domains but Acceptance were clearly influenced by the perceived social support and non-motor symptoms influenced significantly the level of acceptance of the condition. This indicates that establishing strong and positive personal networks for social support could facilitate positive living with PD in terms of illness work, adjustment, emotional support and feelings of burden (Kennedy *et al.* 2015, Koetsenruijter *et al.* 2015, Vassilev *et al.* 2016). Further research could look at the effectiveness of these strategies for people with PD and also family-carers and also explore other possibilities of social support that are beyond the family itself, fostering a conceptual change to understand families not only as providers but also recipients of such support.

Satisfaction with life was the second most important influencing factor (after social support) in Living with PD. In this way, hypothesis 2 of this study was confirmed and evidence in this field was corroborated. A previous study carried out in a PD population (Gustafsson *et al.* 2015) showed a possible correlation between low levels or lack of satisfaction with life and increased depression feelings with a special interest in the influence of unemployment in the levels of satisfaction in people with PD. However, as mentioned before ours is the first study that confirmed statistically this direct and significant influence in patients' daily Living with PD as a whole. The direct association with specific domains of Living with PD only showed significance for Acceptance, Integration and Adjustment. These results although logical should not be overlooked as they have clear implications for the unfounded direction of care pathways and priorities for PD management nowadays, which need to include personal based aspects as underpinning elements for quality of care and more essentially satisfaction with life as final patients' outcomes.

Surprisingly, the moderate relationship between home economical situation and Living with PD does not confirm our hypothesis 3. Results showed that a better home economical situation is related to a negative Living with PD. This result was unexpected and there are not previous papers that could explain it. The correlation of EC-PC with the SHE can be loose, a tangible fact which depends on many factors. However, the economical situation at home can be a factor influencing the life with a disease. Due to this reason, the SHE was included in the regression models despite its trivial correlation with the dependent variable, and it appeared as a significant, although weak predictor. Same association was found between the home economic situation and the coping and self-management domains of Living with PD. This demonstrates that access to material resources does not ensure a better experience of living with a neurodegenerative condition like PD. A proposed explanation of this result is that people with a medium-high home economical status could have higher life expectations and therefore, considered Living with PD more detrimental. Thereby, those people with a lower home economic status may be more prone to finding benefits in the condition and valuing other aspects in their daily living (Mavandadi *et al.* 2014, Zaragoza *et al.* 2014). Furthermore, we did not find any relationships of the home economic situation and any of the other independent variables in this study that could clarify this further. Therefore, more research is needed in this regard looking at other potential influential relationships between the socioeconomic status and other variables like the sense of coherence people living with PD have (Antonovski, 1987), which could contribute to understanding how people find meaning in living with PD and make sense of or challenge their resources, identities, skills and feelings of satisfaction towards a more positive adjustment.

Finally, another key result of this study is that Living with PD is not influenced by disease related factors. That means that PD duration, stage of PD and motor symptoms have a negligible or a weak impact on the daily Living with PD. In this way, established hypotheses for this study (H4-H5) were not confirmed. The only domain that was influenced by the non-motor symptoms was acceptance and this could support the need to work on acceptance at the initial stages of the diagnosis when patients could also learn how to manage symptoms. Nevertheless, at other stages of PD symptoms do not have a key role as demonstrated in this study. Our result questions the orientation of self-management programmes for PD, PD clinical guidelines, care pathways and the professional approach of the condition, which unfortunately, keep focusing on the management of the symptoms (https://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions/parkinson-s-disease#evidence-summaries). PD motor and non-motor symptoms are important but show a partial picture of the daily experience with PD and the increase of systems of support for the patient and the family could result in better management and ultimately, quality of life.

Limitations

Due to the cross-sectional design and the specific cultural context of the study population the results must be interpreted with caution. However, an important strength is that Spanish speaking-population is the second most spoken language in the world, after Chinese, with 399 million of speakers (Ethnologue, 2015). Therefore, the inclusion of patients from five different countries supports the consistency of the results at least for this cultural and linguistic setting. Besides, the patients included in the study were also considered representative of the PD population attending movement disorder units, with over 85% of patients in mild or moderate levels of severity. A low percentage of patients with a higher level of severity were included in the study because frequently PD patients with higher levels present cognitive deterioration that was an exclusion criterion.

CONCLUSIONS

The results in this study illustrate the need to place the emphasis on the person and in his/her daily living with the disease, and not just on the disease. Each person with a LTC, as PD, must be seen as a unique and unrepeatable person, independently of the stage or the severity of the disease. Therefore, it is necessary to incorporate multidisciplinary and individualized interventions in nowadays health services, focusing on the factors that directly influence in Living with PD, as for social support, satisfaction and economic status. Consequently, possible negative aspects of the daily Living with PD as lack of support, loneliness or dissatisfaction with life could be prevented and a more positive living achieved. So, this study advocates the necessity to put the comprehensive needs of people and communities, at the centre of health systems, empowering people to have a positive living and active role in their own health. Future research in other settings and countries is needed to confirm the generalizability of these findings. Besides, person centre interventions or individualized healthcare plans could be implemented in clinical practice, incorporating non-pharmacological or PD specific measures that address the factor(s) that are paramount in the daily Living with a LTC. In this regard, PD programmes that mobilise and optimize the use of community resources, increase personal networks and social support seem to be the direction for the management of neurodegenerative conditions.

RELEVANCE TO PRACTICE

Elements related to the perceived social support of the person with Parkinson's disease and satisfaction with life play a key role in the living with a LTC like PD. Besides, Living with PD is not influenced by disease related factors, namely duration, stage, or specific motor symptoms. Consequently, research based interventions operationalised in clinical practice require a change of direction to tackle and prevent loneliness and include interagency elements. This could lead to finding community resources and systems of support, which could sustain management programmes for neurodegenerative conditions in nowadays healthcare systems.

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REFERENCE BLINDED FOR PEER REVIEW

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IMPACT STATEMENTS

What does this paper contribute to the wider global clinical community?

- Interventions to foster positive living with Parkinson's disease should integrate strategies to tackle and prevent loneliness and interagency elements to increase community resources and systems of support
- Parkinson's disease programmes that mobilise and optimize the use of community resources, increase personal networks and social support seem to be the direction for the management of neurodegenerative conditions

Table 1. Characteristics of the sample

Demographical variables	Response options	Patients with PD (n = 324)
Gender	Male	171 (52.78%)
	Female	153 (47.22%)
Age	---	66.67 ± 10.68 years (range: 36-94 years)
Marital status	Married	215 (66.36%)
	Single	19 (5.86%)
	Widower	55 (16.98%)
	Separated	29 (8.95%)
	Others	6 (1.85%)
Employment situation	Retired	139 (42.90%)
	Laboral inability	18 (5.56%)
	Full time	28 (8.64%)
	Part time	49 (15.12%)
	House keeper	57 (17.59%)
	Unemployed	24 (7.41%)
	Temporary dismissal	2 (0.62%)
	Others	7 (2.16%)
Educational level	Postgrads studies	6 (1.85%)
	University studies	70 (21.60%)
	Secondary studies	103 (31.79%)
	Primary studies	103 (31.79%)
	Can read and write	16 (4.94%)
	Others	26 (8.02)
Age at PD onset	---	56.90±10.91 years (range: 24-84 years)
Duration of PD	---	9.76±5.71 years (range: 1-28 years)
Duration of treatment for PD	---	8.82±5.64 years (range: 0-28 years)

PD: Parkinson's Disease.

Mean ± Standard Deviation

Table 2. Descriptive statistics for appliqued assessments

	Number of items	Theoretical range /Observed rage	Mean	SD
SCOPA-Motor	21	0-75/ 1-68	22.34	11.26
CISI-PD	4	0-24/ 0-24	7.61	4.00
NMSS	30	0-360/ 0-243	60.36	46.76
SCOPA- PS	11	0-33/ 0-29	9.71	6.49
DUFSS	11	1-55/ 1-44	27.66	10.00
SLS-6	1	0-10/ 0-10	6.75	1.96
EC-PC	26	0-104/ 22-104	62.45	18.57

SD: Standard Deviation.
PD: Parkinson's Disease.
SCOPA-Motor: The Scales for Outcomes in Parkinson's Disease-Motor. CISI-PD: Clinical Impression of Severity Index-PD. NMSS: Non-Motor Symptoms Scale. SCOPA-Psychosocial: Scales for Outcomes in Parkinson's Disease-Psychosocial. DUFSS: Duke-UNC Functional Social Support Questionnaire. SLS-6: Satisfaction with life Scale- 6 items. EC-PC: Living with Chronic illness-PD Scale.

Table 3. EC-PC correlations with other scales

	EC-PC Total score	EC-PC domains				
		Domain 1- Acceptance	Domain 2- Coping	Domain 3- Self-Management	Domain 4- Integration	Domain 5- Adjustment
Hoehn & Yahr	-0.09	-0.17	-0.05	-0.02	-0.13	-0.02
CISI-PD	-0.16	-0.25	-0.07	-0.03	-0.14	-0.15
SCOPA-M	-0.08	-0.27	-0.01	0.07	-0.03	-0.14
NMSS	-0.32	-0.36	-0.23	-0.18	-0.24	-0.19
SCOPA-PS	-0.25	-0.40	-0.09	-0.08	-0.23	-0.24
DUFSS	0.61	0.12	0.61	0.57	0.57	0.36
SLS-6	0.46	0.43	0.29	0.28	0.33	0.48

CISI-PD: Clinical Impression of Severity Index-PD. SCOPA-M: The Scales for Outcomes in Parkinson's Disease-Motor. NMSS: Non-Motor Symptoms Scale. SCOPA-PS: Scales for Outcomes in Parkinson's Disease-Psychosocial. DUFSS: Duke-UNC Functional Social Support Questionnaire. SLS-6: Satisfaction with Life Scale- 6 items. EC-PC: Living with Chronic illness-PD Scale.

Table 4. Multiple linear regression models

Independent Variables*	**Dependent variables in each model**					
	EC-PC Total score *Beta* (CI 95%)	**Domain 1- Acceptance** *Beta* (CI 95%)	**Domain 2- Coping** *Beta* (CI 95%)	**Domain 3- Self-Management** *Beta* (CI 95%)	**Domain 4- Integration** *Beta* (CI 95%)	**Domain 5- Adjustment** *Beta* (CI 95%)
Adj R-squared	0.48	0.22	0.41	0.33	0.37	0.25
Age						-0.11 * (-0.12 – -0.00)
Gender		-0.16 ** (-2.46 – -0.56)				
Duration of PD					0.15 * (0.03 – 0.22)	
SLS-6	0.26 *** (1.56 – 3.35)	0.29 *** (-0.52 – 0.05)		0.12 * (0.03 – 0.44)		0.34 *** (0.67 – 1.40)
NMSS	-0.10 * (-0.08 – -0.002)	-0.19 ** (-0.03 – -0.01)			-0.11 * (-0.02 – 0.00)	
DUFSS	0.51 *** (0.79 – 1.10)		0.58 *** (0.33 – 0.48)	0.52 *** (0.16 – 0.23)	0.55 *** (0.21 – 0.30)	0.21 *** (0.07 – 0.19)
SEH	-0.16 *** (-2.59 – -0.75)		-0.19 *** (-1.09 – -0.38)	-0.16 ** (-0.54 – -0.11)		

CI 95% = Confidence interval 95%

* $p<0.05$; ** $p<0.01$; *** $p<0.001$

PD: Parkinson's Disease. Independent variables with at list one significant result. The complete list of independent variables was: age, gender (Male = 0, Female = 1), duration of studies, duration of PD, Disability and Motor complications (SCOPA-Motor), Non-motor symptoms burden (NMSS), Satisfaction with life (SLS-6), Social support perceived by the patient (DUFSS), and Home economical situation (SEH).

Duration of studies, disability and motor complications did not reach statistical significance (p >0.05) in any model.

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	6, 7
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	6
		(*e*) Describe any sensitivity analyses	7
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	7
Outcome data	15*	Report numbers of outcome events or summary measures	8
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear	n/a

		which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	6, 7
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7
Discussion			
Key results	18	Summarise key results with reference to study objectives	8
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	8
Generalisability	21	Discuss the generalisability (external validity) of the study results	11
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	n/a

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.