Parkinsonism and Related Disorders 96 (2022) 1–5

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Living with chronic illness scale in Parkinson's disease: Longitudinal metric properties and meaningful change

Carmen Rodriguez-Blazquez [a], Mayela Rodriguez Violante [b], Tomoko Arakaki [c], Nelida Susana Garretto [d], Marcos Serrano-Dueñas [e], Ivonne Pedroso Ibáñez [f], Leire Ambrosio [g,*]

[a] National Centre of Epidemiology and CIBERNED, Carlos III Institute of Health, Av. Monforte de Lemos, 5, 28029, Madrid, Spain
[b] National Institute of Neurology and Neurosurgery, Movement Disorders Clinic, Insurgentes Sur 3877, Colonia La Fama, 14269, Mexico City, DF, Mexico
[c] Department of Neurology, JM Ramos Mejia Hospital, Urquiza 609, 1221, Buenos Aires, Argentina
[d] Department of Neurology, JM Ramos Mejia Hospital, Urquiza 609, 1221, Buenos Aires, Argentina
[e] Medicine Faculty. Pontifical Catholic University of Ecuador, Avenue 12 De Octubre 1076, Quito 170143 and Movement Disorder and Biostatistics Units, Neurological Service, Carlos Andrade Marín Hospital, Quito, Ecuador
[f] Department of Movement Disorders and Neurodegeneration, CIREN. Ave 25 # 15805, 11300, Cubanacán, Playa, La Habana, Cuba
[g] NIHR ARC Wessex, School of Health Sciences, University of Southampton, Building 67, University Road, SO171BJ, Southampton, United Kingdom

ARTICLE INFO

Keywords:
Living with
Parkinson disease
Responsiveness
Effect size
Minimally clinical important difference
Patient reported outcome
Measurement properties

ABSTRACT

Aim: To analyze the responsiveness and interpretability of the Living with Chronic Illness Scale in patients with Parkinson's disease (LW-CI-PD).
Methods: Longitudinal, international study, with a convenience sample of 153 PD Spanish and Latin-American patients assessed at baseline and one year later. The LW-CI-PD and other clinical measures were applied. For responsiveness, Wilcoxon-Mann-Whitney test of differences, correlation of change between rating scales, standard error of difference, relative change, Cohen's effect size and standardized response mean of LW-CI-PD were computed. The minimally clinical important difference was calculated using anchor- (applying the Patient Global Impression of Severity) and distribution-based methods. A triangulation of interpretability indexes was performed to determine the range of the minimally clinical important difference values.
Results: The LW-CI-PD scored 65.7 (11.7, range: 33–101) at baseline, and 68.6 (10.3, range: 33–102) one year later ($p < 0.001$). Change in LW-CI-PD correlated −0.26 with change in psychosocial status, 0.18 with change in motor function and −0.15 with change in social support. Responsiveness statistics were: relative change = 4.5%; effect size = 0.25; standardized response mean = 0.46. Using PGI-S as anchor, 29 patients worsened, and the value of minimally clinical important difference for worsening in LW-CI-PD total score was 4.7. Minimally clinical important difference values using distribution-based methods were between 4.5 (1 standard error of measurement) and 10.4 (10% of total score), with a mean of 6.9.
Conclusions: Our study suggest the LW-CI-PD is responsive to changes over time. The use of different methods for calculating the minimally clinical important difference allows to determine a range of the real change for the LW-CI-PD.

1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder worldwide, affecting 1% of all people over 60 years of age [1]. PD is a complex and disabling disorder manifested through a combination of characteristic motor signs, such as bradykinesia, rigidity, resting tremor, and postural instability, and non-motor symptoms as, for example, psychiatric disorders, autonomic disturbances, pain, and fatigue [2]. Throughout PD course, patients experience a progressive intensification of signs and symptoms and increasing limitations to the performance of daily activities.

Living with PD does not only affect the patients' physical state but also other aspects in their lives, such as the psychological, emotional, spiritual, and social ones [3–5]. Understanding and evaluating how a person is living with PD is paramount to provide a person-centred care [3,5,6]. Clinical specialists play an essential role in facilitating the

* Corresponding author.
E-mail address: lag1v19@soton.ac.uk (L. Ambrosio).

https://doi.org/10.1016/j.parkreldis.2022.01.007
Received 14 July 2021; Received in revised form 17 December 2021; Accepted 7 January 2022
Available online 13 January 2022

patient's living with PD process and, consequently, improving his/her quality of life and wellbeing [3–5]. More concretely, neurologist and nurse specialists need to have tools that allows assessing how a person is living with PD, in combination with clinical tools that focus on specific signs and disabilities of PD [3,6,7]. At present, the Living with Chronic Illness–PD scale (LW-CI-PD) is the only reliable and valid instrument to evaluate how a person is living with PD [7,8]. The LW-CI-PD scale is an innovative patient-reported outcome measure (PROM) developed in 2016 to evaluate in a comprehensive manner how a person is living with a chronic condition, as PD [7,8]. The scale was originally designed for Spanish-speaking population living with a chronic condition and has been published for Spanish-speaking population in a pilot study carried out in patients living with different high prevalent and prototypical chronic conditions, such as PD, chronic heart failure, chronic obstructive pulmonary disease, or type 2 diabetes mellitus, among others [9]. It is a 26-item PROM to evaluate in a comprehensive manner how the patient is living with PD, in regard to five domains: Acceptance (4 items); Coping (7 items); Self-management (4 items); Integration (5 items); and Adjustment (6 items). Items are scored from 0 (never/nothing) to 4 (always/a lot), except for domain Acceptance, with reverse score (4: never/nothing; 0: always/a lot) ranges from 0 (negative living with PD) to 104 (positive living with PD) [9]. In spite of the excellent psychometric properties of the LW-CI-PD scale through classic test theory approach [7] and Rasch analysis [8], there are not studies addressing its longitudinal psychometrics.

The clinical use of a rating scale requires the analysis of its ability to detect changes (responsiveness) in response to treatment or to the natural progression of the disease and to decide whether this change is detectable and meaningful for patients and clinicians (interpretability). Responsiveness is linked to the precision of a scale, that is, its ability to detect small differences, which is calculated using the standardized error of measurement (SEM) [10]. The more precise an instrument is, the more likely it is to detect small changes. Moreover, there are authors who propose that the detected change must be clinically important, which relates responsiveness with interpretability [11]. Interpretability statistics are based on calculating the minimal important change (MIC) or the minimal important difference (MID). The methodology for calculating them can be classified into two main approximations: techniques based on an external criterion or anchor (anchor-based) and techniques based on the distribution of scores (distribution-based) [12]. Anchor-based techniques compare the change in an item or scale with the change in another scale or a measure that acts as a reference or anchor (for example, a clinical test or a transition question on change in a symptom or condition). Distribution-based approaches use statistical methods that relate the magnitude of the effect to some measure of variability, for example, the standard deviation, the effect size or the SEM. The main advantage of distribution-based techniques is that they offer standardization and allow the interpretation of change when there is not an external criterion or anchor. However, distribution-based methods yield different values from each other, and the cutoff points are arbitrary, so some authors recommend using anchor-based methods or to carrying out a triangulation between the different statistics, assuming that the true value of the MIC is between them [13].

Taking into account these considerations, the aim of the present study was to analyze the responsiveness and interpretability of the LW-CI-PD scale using different techniques to ascertain its longitudinal psychometric properties.

2. Methods

This was an international, longitudinal study carried out on consecutive PD patients. Participant centres were located in Argentina, Cuba, Ecuador, and Mexico. Inclusion criteria were: (1) diagnosis of PD by a neurologist according to international recognized diagnostic criteria [14]; (2) native Spanish-speaking patients; (3) able to read and understand properly questionnaires and (4) having completed baseline and T3 assessments. The exclusion criteria were: (1) parkinsonism other than PD; and (2) concomitant severe condition, including cognitive deterioration previously and formally diagnosed by the neurologist, or disorder influencing the PD manifestations expression or impact.

2.1. Assessments

Data collection process was conducted between November 2018 and September 2019. Participants filled in the scales during regular consult with their neurologist, every 3–4 months, depending on the individualized care regimen prescribed for each patient. Four-time evaluations were conducted per patient (T0 = baseline, T1 = 4 months, T2 = 8 months, T3 = 12 months). Considering that the LW-CI-PD scale is a 26-item scale, a minimum sample size between 130 and 260 people living with PD was estimated for the baseline and consequently evaluations. We estimated a loss <10% which is acceptable for longitudinal studies and does not imply load related to the scale.

Sociodemographic data, such as gender, age, marital status, employment, and educational level were collected. Also, historical data of PD, such as age at PD onset, disease duration, PD stage, and levodopa daily dose were collected. In addition, the Spanish version of the following clinician-reported outcomes measures were applied: (1) the original Hoehn and Yahr staging (HY) [15]; (2) the Scales for Outcomes in Parkinson's Disease-Motor (SCOPA-Motor) [16]; (3) the Non-Motor Symptoms Scale (NMSS) [17]; and (4) the Clinical Impression of Severity Index for PD (CISI-PD) [18]. See Table 1 for further detail of included scales.

In addition to the LW-CI-PD scale, the Spanish version of the following PROM were applied: (1) Scales for Outcomes in Parkinson's Disease-Psychosocial (SCOPA-PS) [19]; (2) Duke-UNC Functional Social Support Questionnaire (DUFSS) [20]; (3) Patient-Based Global Impression of Severity Scale (PGIS) [21]; and (4) the modified version of the Satisfaction with Life Scale [22] (SLS-6). See Table 1 for further detail of included scales. For all scales, except DUFSS and SLS-6, higher scores denote greater severity or difficulty. Correlations (see Data analysis) considered the different directions scored in each scale.

To ensure homogeneity and reduce possible errors during data collection, a detailed and standard protocol was designed for all centres before starting data collection. Overall, potential participants were approached through the neurologist, who explained the study and after signed informed consent, participants completed the questionnaires during the consult. In total, 9 questionnaires were used during this study. However, 4 of them were applied by the neurologist and the rest were easy and short questionnaires to be answered by the person. The presence of the neurologist may have avoided potential missing data. Overall, the average time for completing the scales was 50 min.

2.2. Ethical aspects

The study was approved by the Ethics Committee of the University of Navarra (approval number 2018.036) and all the participant centres. Signed consent to participate in the study was obtained from all patients after receiving the pertinent information.

2.3. Data analysis

Descriptive statistics (mean, standard deviation (±SD) and frequency and percentages) for characterization of the sample were performed. To compare HY and PGIS results at baseline and follow-up we used chi-square test (χ^2), and for the rest of variables, Wilcoxon-Mann-Whitney test was used. For the LW-CI-PD scale, we compared data from the baseline (T0) and the third follow-up (T3) assessments, and the following statistics were calculated, following the classification by Terwee and colleagues [11]:

Responsiveness is usually calculated with statistics based on the magnitude of change, such as the relative change (CR), expressed as a

Table 1
Main characteristics of included scales.

Included scales[a]	Analysed concept	Items/score
Hoehn and Yahr staging [15]	Global estimation of PD progression	5 level classification
Scales for Outcomes in Parkinson's Disease-Motor (SCOPA-Motor) [16]	PD signs, activities of daily living, and motor complications	21 items in 3 domains: Examination, Activities of daily living, and Motor complications. Each item scores from 0 (normal) to 3 (severe) and the total scale score is 0–75.
Non-Motor Symptoms Scale (NMSS) [17]	Burden (severity and frequency) caused by non-motor symptoms	30 items in 9 domains. Each item is scored for frequency and severity, from 0 (no present) to 12 (maximum frequency and severity). Total scores for the domains and the whole scale can be obtained by the sum of the corresponding items scores.
Clinical Impression of Severity Index for PD (CISI-PD) [18]	Motor signs, disability, motor complications, and cognitive status	4 items: Motor signs; Disability; Motor complications; and Cognitive status. - Items are rated from 0 (normal) to 6 (very severe). The total score runs from 0 to 24.
Scales for Outcomes in Parkinson's Disease-Psychosocial (SCOPA-PS) [19]	Difficulties in psychosocial functioning	11 items Items are scored from 0 (not at all) to 3 (very much), with higher scores denoting greater difficulty. The summary index is obtained by summing up direct item scores transformed into percentage values.
Duke-UNC Functional Social Support Questionnaire (DUFSS) [20]	Perceived social support from the patient perspective, regarding confidant, affective and instrumental support, among others	11 items. Each item varies from 1 (much less than I would like) to 5 (as much as I would like)
Patient-Based Global Impression of Severity Scale (PGIS) [21]	Patient global impression of severity	6 point Likert scale. Each item ranges from 0 (not ill at all) to 5 (extremely ill)
Modified version of the Satisfaction with Life Scale (SLS-6) [22]	Overall satisfaction with life and regarding physical, psychological well-being, social relations, leisure, and financial situation.	6 items. Each item scores from 0 (unsatis- fied) to 10 (totally satisfied).

[a] In this study the Spanish version of each scale was used.

percentage, and the effect size (ES), that transform score change into standardized values that can be easily interpreted using cutoff points [23].

- Responsiveness as the ability of LW-CI-PD to detect change in general: calculated with Wilcoxon-Mann-Whitney test of differences, and the standard error of measurement (SEM) at T0. The SEM, that marks the threshold for a true change, was calculated using the formula displayed in the Supplementary table.
- Responsiveness as the ability of LW-CI-PD to detect clinically important change, obtained using effect size statistics: Cohen's effect size (ES) and standardized response mean (SRM). The formulas for Both indexes are displayed in the Supplementary table. They are interpreted in the same way: 0.20–0.49 represents a small change, 0.50–0.79, moderate, and ≥0.80, large [13].
- Responsiveness as the ability of LW-CI-PD to detect a real change in the concept being measured: using correlation of change between the LW-CI-PD and the rest of rating scales with Spearman's rank correlation coefficients.
- The minimal important change (MIC) was calculated using anchor-(according to the PGIS, using those values ≥1-point of change from T0 to T3) and distribution-based methods: half a standard deviation (1/2 SD), 10% of total maximum score of the scale and subscales and 1 SEM at baseline [24]. Following Revicki and colleagues [24], a triangulation of interpretability indexes was performed to determine the range of the MIC values.

IBM SPSS 22.0 (Armonk, NY: IBM Corp) was used for all analyses.

3. Results

From 169 PD patients completed the baseline, the final sample was composed by 153 PD patients that completed the baseline and the third follow-up assessment (Table 2). As estimated the loss was <10% between baseline and T3. Two thirds of the sample (67%) were men. At baseline, mean age was 66.2 years old (±10.5; range: 30–84), age at PD onset was 56.6 years old (±10.5; range: 23–80), and disease duration was 9.6 years (±6.4; range: 1–28). Most patients were in HY stages 2 (57, 37%) and 3 (59, 39%), and were taking a mean of 707.80 levodopa equivalent daily dose (LEDD) (±369.7; range: 0–1900). At third follow-up, 135 (88%) patients remained in the same HY stage than at baseline, and 11 (7%) worsened ($p < 0.001$). Mean LEDD at follow-up was 763.7 (±348.9; range 0–1800; $p < 0.001$).

Mean LW-CI-PD score in T0 was 65.7 (±11.7) and in T3 was 68.6 (±10.3) ($p < 0.001$). There were significant differences in all LW-CI-PD subscales mean scores between T0 and T3 (Table 3). The rest of applied rating scales also showed significant differences in mean scores in T3 in comparison to T0 (Table 3).

Responsiveness statistics are displayed in Table 4. SEM was 3.67 for LW-CI-PD total score and ranged from 0.85 to 1.75 for domains. The ES of LW-CI-PD total was 0.25, ranging 0.10–0.43 for domains. Finally, the SRM of the total score was 0.46, with values from 0.16 to 0.49 in the

Table 2
Characteristics of the sample at baseline (N = 153).

Variable		N	%
Sex	Men	103	67.3
	Women	50	32.7
Marital status	Single	27	17.6
	Married	103	67.3
	Widow	14	9.2
	Divorced/other	9	5.9
Employment	Employee	100	65.4
	Retired	22	14.4
	Home care	14	9.2
	Unemployed	17	11.1
Educative level	Primary or less	63	41.2
	High school/secondary	59	38.6
	University	26	17.0
	Other	5	3.3
HY	1	11	7.2
	2	57	37.3
	3	59	38.6
	4	20	13.1
	5	6	3.9
	Range	**Mean**	**SD**
Age	30–84	66.16	10.51
Age at PD onset	23–80	56.60	10.53
Disease duration	1–28	9.61	6.43
LEDD	0–1900	707.80	369.71

PD: Parkinson's disease; LEDD: levodopa equivalent daily dose; SD: standard deviation.

Table 3
Scores of applied instruments at baseline and follow-up (N = 153).

	Baseline (T0)		Follow-up (T3)		
	Mean	SD	Mean	SD	p[a]
SCOPA Motor Exploration	15.65	7.38	15.95	7.22	0.207
SCOPA Motor ADL	7.65	4.67	7.76	4.72	0.388
SCOPA Motor Complications	3.75	3.19	3.85	3.23	0.207
SCOPA Motor total	27.05	13.89	27.56	13.87	0.002
NMSS total	53.84	39.77	55.49	43.22	<0.001
CISI-PD total	10.01	4.60	10.29	4.69	0.008
SCOPA-Psychosocial total	11.41	6.94	12.09	6.80	<0.001
SLS-6 total	33.14	11.61	32.59	11.79	<0.001
DUFSS total	30.67	8.32	27.99	7.90	<0.001
Acceptance	9.11	3.56	8.60	3.45	<0.001
Coping	18.90	3.60	20.43	3.40	<0.001
Self-management	10.41	2.76	10.96	2.39	<0.001
Integration	13.37	3.06	14.28	2.65	<0.001
Adjustment	13.90	4.14	14.33	4.10	<0.001
LW-CI-PD total	65.68	11.71	68.61	10.33	<0.001

SD: standard deviation; SCOPA: Scales for Outcomes in Parkinson's disease; NMSS: Non-Motor Symptoms Scale; CISI-PD: Clinical Impression of Severity Index for Parkinson's disease; SLS-6: Satisfaction with Life Scale, 6 items; DUFSS: Duke-UNC Functional Social Suport Scale; LW-CI-PD: Living with Chronic Illness–Parkinson's disease scale.
[a] Wilcoxon-Mann-Whitney test.

Table 4
Responsiveness statistics of the LW-CI-PD.

	SEM	ES	SRM
Acceptance	1.59	0.14	0.23
Coping	2.22	0.43	0.49
Self-management	1.61	0.20	0.25
Integration	1.68	0.30	0.38
Adjustment	2.03	0.10	0.16
LW-CI-PD total	4.54	**0.25**	**0.46**

SEM: standard error of measurement at baseline; ES: effect size; SRM: standardized response mean.

domains.

The change in LW-CI-PD total and subscales showed low correlation coefficients with the change in the rest of applied scales (Table 5). Change in LW-CI-PD total score correlated −0.26 with change in SCOPA-PS and change in domains Acceptance and Integration correlated 0.29 and −0.28, respectively, with change in DUFSS.

For interpretability (Table 6), MIC of LW-CI-PD reached values from 4.5 (as per SEM) to 10.4 (10% of total score), with a mean of 6.9. Using the PGIS as an anchor, 29 (19%) patients worsened from baseline to follow-up, with a difference of 4.76 points in LW-CI-PD total score.

Table 6
Interpretability statistics of the LW-CI-PD.

	1/2 SD baseline	10% total	SEM	Mean[a]
Acceptance	1.78	1.6	1.6	1.66
Coping	1.80	2.8	2.2	2.27
Self-management	1.38	1.6	1.6	1.53
Integration	1.53	2	1.7	1.74
Adjustment	2.07	2.4	2.0	2.17
LW-CI-PD total	**5.86**	**10.4**	4.5	6.93

SEM: standard error of measurement at baseline.
[a] Based on Revicki et al. Journal of Clinical Epidemiology 2008; 61:102–109.

4. Discussion

This is the first study on the responsiveness and interpretability of the LW-CI-PD rating scale, complementing the satisfactory psychometric properties of this scale for assessing how PD patients live with their illness [7,8]. The relevance of analyzing the longitudinal metric attributes of a scale in clinical settings is substantial: a scale with good longitudinal properties allows clinicians to evaluate changes in the patient's health status, to identify the direction and magnitude of change, and to determine if the estimated change is clinically relevant and meaningful for the patient.

The LW-CI-PD showed a significant worsening in scores over time, as did most applied rating scales except the SCOPA-Motor. Moreover, 19% patients perceived a worsening in their status, as per the PGIS. The results of the test of differences show that the LW-CI-PD is responsive to changes over time.

The SEM is a measure of precision of the scale (ability to detect small differences) and represents the value for a minimally detectable change [25]. Based on our results, a change over 4.5 points in LW-CI-PD total score is deemed as a true change. According to the ES and SRM, however, the detected change in LW-CI-PD was small. This can be due to the short follow-up period, or to the fact that the scale is measuring a relatively stable aspect of the disease. This is the case for related constructs such as coping styles [26].

The change in LW-CI-PD total score and domains showed low correlations with the change in the rest of applied scales. This means that changes in motor and non-motor status in PD patients have a little impact on how the patient live with his or her disease. Only variations in social support (DUFSS) and psychosocial adaptation to the disease

Table 5
Correlations of change in LW-CI-PD and change in related variables.

	Acceptance	Coping	Self-management	Integration	Adjustment	LW-CI-PD total
Coping	−0.20*					
Self-management	−0.13	0.61**				
Integration	−0.27**	0.67**	0.58**			
Adjustment	−0.22**	0.55**	0.38**	0.45**		
LW-CI-PD total	0.04	0.88**	0.72**	0.76**	0.63**	
LEDD	−0.05	0.13	0.06	0.16*	0.08	0.08
SCOPA Motor Exploration	−0.16	0.18*	0.15	0.24**	0.08	0.18*
SCOPA Motor ADL	0.08	−0.03	0.04	0.08	−0.06	0.01
SCOPA Motor Complications	−0.06	0.14	0.05	0.13	0.13	0.18*
SCOPA Motor total	−0.03	0.12	0.12	0.18*	−0.01	0.15
NMSS total	−0.05	0.18*	0.20*	0.13	0.13	0.14
CISI-PD total	0.03	0.00	−0.04	0.08	0.09	0.04
SCOPA-Psychosocial total	−0.04	−0.232*	−0.28**	-.20*	−0.12	−0.26**
SLS-6 total	0.07	−0.04	−0.07	0.06	0.07	0.02
DUFSS total	0.29**	−0.21**	−0.21**	−0.28**	−0.10	−0.15

Spearman's rank correlation coefficients, *p < 0.01; **p < 0.05.
LW-CI-PD: Living with Chronic Illness-Parkinson's disease scale; LEDD: levodopa equivalent daily dose; SCOPA: Scales for Outcomes in Parkinson's Disease; NMSS: Non-Motor Symptoms Scale; CISI-PD: Clinical Impression of Severity Index for Parkinson's disease; SLS-6: Satisfaction with Life Scale, 6 items; DUFSS: Duke-UNC Functional Social Suport Scale.

(SCOPA-PS) are related to variations in the LW-CI-PD. This result was also identified with other long-term conditions, such as type 2 diabetes mellitus [27] or COPD [28] showing that living with a long term condition as PD is much more influenced by person's related factors, as psychological and social factors rather than the disease *per se* [3]. Each person with 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 healthcare and social care services, focusing on the factors that directly influence in living with PD, as for social support and satisfaction.

MIC refers to changes regarded as minimally important by patients or clinicians, and anchor- and distribution-based methods are used to determine it, although with different results as showed in this study [29]. For distribution-based methods, some authors have proposed that 1 SEM, ½ SD at baseline or 10% of total score are good estimates of MIC [24]. Using these calculations, the MIC for LW-CI-PD fluctuated between 4.5 (1 SEM) and 10.4 (10% total score), with a mean of 6.9. While the anchor-based techniques are preferred over the distribution-based methods, some caveats should be considered. The anchor should be interpretable and strongly associated to the studied instrument. In this study, using the PGIS as anchor, the value of MIC was 4.76, greater than the SEM, suggesting that this change is beyond measurement error. This way, we could conclude that the real value of MIC for LW-CI-PD would be between 4.76 and 6.9.

The present study is part of a bigger and ambitious research project with the general aim to achieve a standardized and unique self-reported scale in Spanish-speaking population to evaluate the process of living with one or more than one chronic condition, such as PD. Concretely, this study is a continuation of previous published PD validation study in Spain and South America [7,8]. Based on emerged satisfactory results, the LW-CI-PD scale could become the only available person centred tool that captures the individual perception of daily living with PD cross-culturally in Spanish countries. However, the scale is expanding internationally and as part of international networking the English version of the LW-CI-PD scale has already been developed and validated in PD population. To continue testing the scale, future studies include the validation of the scale in other contexts and conditions, as well as with other types of analysis.

Some limitations should be considered in this study, such as the relatively low sample size, the short follow-up for capturing changes in PD status as well as other anchors other than PGIS could produce different MIC values. In fact, the use of the Patient Global Impression of Change (PGIC) would have been desirable, although the use of indexes of severity status such as the PGIS and the HY for the progression of the disease is common in PD patients. Finally, we acknowledge that one year is a short period to detect disease progression. This was due to logistic as well as management issues. However, this study also has some strengths as it is the first study showing the responsiveness and interpretability of the LW-CI-PD scale.

In conclusion, in the light of our findings, the LW-CI-PD scale can be deemed as potentially responsive to changes over time. It could be, thus, useful in clinical trials and routine clinical practice to measure how the patients adapt to the disease, respond to treatment, and live with a progressive long term condition such as PD.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.parkreldis.2022.01.007.

References

[1] European Parkinson's Disease Association, EPDA. About Parkinson's, 2018. Available at: http://www.epda.eu.com/about-parkinson-s/what-is-parkinson-s/. (Accessed 7 April 2021).

[2] A.J. Lees, J. Hardy, T. Revesz, Parkinson's disease, Lancet 373 (2009) 2055–2066.

[3] L. Ambrosio, M.C. Portillo, C. Rodriguez-Blazquez, J.M. Rojo, P. Martinez-Martin, Influencing factors when Living with Parkinson's Disease: a cross-sectional study, J. Clin. Nurs. 28 (2019) 3168–3176.

[4] M.V. Navarta-Sanchez, N. Caparros, M. Riverol, S. Diaz de Cerio, M.E. Ursua, M. C. Portillo, Core elements to understand and improve coping with Parkinson's disease in patients and family carers: a focus group study, J. Adv. Nurs. 73 (2017) 2609–2621.

[5] M. Kang, C. Ellis-Hill, How do people live life successfully with Parkinson's disease? J. Clin. Nurs. 24 (2015) 2314–2322.

[6] G.M. Fix, C.V. Lukas, R.E. Bolton, J.N. Hill, N. Mueller, S.L. LaVela, B.G. Bokhour, Patient-centred care is a way of doing things: how healthcare employees conceptualize patient-centred care, Health Expect. 21 (2018) 300–307.

[7] L. Ambrosio, M.C. Portillo, C. Rodríguez-Blázquez, M. Rodríguez-Violante, J. C. Martínez-Castrillo, V, et al., Living with chronic illness scale: international validation of a new self-report measure in Parkinson's disease, NPJ Parkinsons Dis. 2 (2016) 1–6.

[8] L. Ambrosio, C. Rodriguez-Blazquez, A. Ayala, M.J. Forjaz, Rasch analysis of the living with chronic illness scale in Parkinson's disease, BMC Neurol. 20 (2020) 1–7.

[9] L. Ambrosio, M.V. Navarta-Sanchez, A. Meneses, C. Rodriguez-Blazquez, Living with Chronic Illness Scale: pilot study in patients with several chronic diseases, Atención Primaria 52 (2020) 142–150.

[10] Scientific Advisory Committee of the Medical Outcomes Trust, Assessing health status and quality-of-life instruments: attributes and review criteria, Qual. Life Res. 11 (2002) 193–205.

[11] C.B. Terwee, F.W. Dekker, W.M. Wiersinga, M.F. Prummel, P.M.M. Bossuyt, On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation, Qual. Life Res. 12 (2003) 349–362.

[12] K.W. Wyrwich, J.M. Norquist, W.R. Lenderking, S. Acaster, Industry Advisory Committee of International Society for Quality of Life Research (ISOQOL). Methods for interpreting change over time in patient-reported outcome measures, Qual. Life Res. 22 (2013) 475–483.

[13] R.D. Crosby, R.L. Kolotkin, G.R. Williams, Defining clinically meaningful change in health-related quality of life, J. Clin. Epidemiol. 56 (2003) 395–407.

[14] A.J. Lees, J. Hardy, T. Revesz, Parkinson's disease, Lancet 373 (2009) 2055–2066.

[15] M.M. Hoehn, M.D. Yahr, Parkinsonism: onset, progression, and mortality, Neurol. 17 (1967) 427–442.

[16] J. Marinus, M. Visser, A.M. Stiggelbout, J.M. Rabey, P. Martinez-Martin, U. Bonuccelli, et al., A short scale for the assessment of motor impairments and disabilities in Parkinson's disease: the SPES/SCOPA, J. Neurol. Neurosurg. Psychiatry 75 (2004) 388–395.

[17] K.R. Chaudhuri, P. Martinez-Martin, R.G. Brown, K. Sethi, F. Stocchi, P. Odin, et al., The metric properties of a novel non-motor symptoms scale for Parkinson's disease: results from an international pilot study, Mov. Disord. 22 (2007) 1901–1911.

[18] P. Martinez-Martin, M.J. Forjaz, E. Cubo, B. Frades, J. de Pedro Cuesta, ELEP Project Members, Global versus factor-related impression of severity in Parkinson's disease: a new clinimetric index (CISI-PD), Mov. Disord. 21 (2006) 208–2014.

[19] J. Marinus, M. Visser, P. Martinez-Martin, J.J. Van Hilter, A.M. Stiggelbout, A short psychosocial questionnaire for patients with Parkinson's disease: the SCOPA-PS, J. Clin. Epidemiol. 56 (2003) 61–67.

[20] W.E. Broadhead, S.H. Gehlbach, F.V. de Gruy, B.H. Kaplan, The Duke-UNC functional social support questionnaire, measurement of social support in family medicine patients, Med. Care 26 (1998) 709–723.

[21] P. Martinez-Martin, C. Rodriguez-Blazquez, M. Alvarez, T. Arakaki, V. Campos Arillo, P. Chana, et al., Parkinson's disease severity levels and MDS-Unified Parkinson's Disease Rating Scale, Parkinson, Park. Relat. Disord. 21 (2015) 50–54.

[22] L. Ambrosio, M.C. Portillo, C. Rodríguez-Blázquez, J.C. Martínez-Castrillo, M. Rodríguez-Violante, M. Serrano-Dueñas, V. Campos-Arillo, N.S. Garretto, T. Arakaki, M. Álvarez, I. Pedroso-Ibáñez, A. Carvajal, P. Martínez-Martín, Satisfaction with Life Scale (SLS-6): first validation study in Parkinson's disease population, Park. Relat. Disord. 25 (2016) 52–57.

[23] J. Cohen, Statistical Power Analysis for the Behavioral Sciences, second ed., Academic Press, New York, 1988.

[24] D. Revicki, R.D. Hays, D. Cella, J. Sloan, Recommended methods for determining responsiveness and minimally important differences for patient-reported outcomes, J. Clin. Epidemiol. 61 (2008) 102–109.

[25] K.W. Wyrwich, F.D. Wolinsky, Identifying meaningful intra-individual change standards for health-related quality of life measures, J. Eval. Clin. Pract. 6 (2000) 39–49.

[26] M.H. Nilsson, F. Oswald, S. Palmqvist, B. Slaug, Coping styles among people with Parkinson's disease: a three-year follow-up study, Behav. Sci. (Basel). 10 (2020) 190.

[27] J. Caro-Bautista, C. Rodriguez-Blazquez, D. Perez-Marchon, E. Timonet, G. Carvajal, A. Fuentes-Ramirez, S. Corchon, M. Aranda-Gallardo, L. Ambrosio, Validation of living with chronic illness scale in a type 2 diabetes mellitus population, Health Qual. Life Outcome 19 (2021) 1–10.

[28] S. Corchon, C. Rodriguez-Blazquez, G. Carvajal, A. Fuentes-Ramirez, M.I. Ruiz de Ocenda, N. Caparros, E. Timonet, M.V. Navarta-Sanchez, L. Ambrosio, International psychometric validation of the living with chronic illness scale in Spanish-speaking patients with chronic obstructive pulmonary disease, BMJ Open 11 (2021), e039973.

[29] B. Barrett, R. Brown, M. Mundt, Comparison of anchor-based and distributional approaches in estimating important difference in common cold, Qual. Life Res. 17 (2008) 75–85.