Reliability and validity of the Turkish version of Parkinson's Disease Sleep Scale

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Abstract

Objective: The aim of this study was to determine the reliability and validity of the Parkinson's Disease Sleep Scale (PDSS)-Turkish version. 48 patients with idiopathic Parkinson's disease and 48 healthy controls were included in this cross-sectional study. The patients' Unified Parkinson's Disease Rating Scale (UPDRS), Hoehn-Yahr Stage (HYS), and the drugs were recorded. Mini-Mental State Examination was performed in the study population. The professional translation of the PDSS (English to Turkish and Turkish to English) was done by a neurologist and a language educator who was a native English speaker and well versed in Turkish, and it was approved by a certified translation agency as well. PDSS and Epworth Sleep Scale (ESS) tests were performed to 96 subjects. PDSS was repeated 15 days later.

Conclusions: The scale was found to be reliable by the first and second assessment of PDSS to 96 subjects (Cronbach's alpha= 0.721 and 0.77). Intra-class correlation coefficient (ICC) 90%, was found to be high. A statistically significant negative correlation was found between the total ESS and the total PDSS scores when tested in the 96 cases included in the study (rs = -0.306, p = 0.02; rs = -0.340 p = 0.01, respectively). PDSS was found to be reliable and valid in our study with Parkinson's patients who were monitored at our outpatient clinic.

Keywords: Parkinson's disease sleep scale, sleep disorders, Parkinson's disease.

INTRODUCTION

Sleep disturbances are frequently observed in patients with Parkinson's disease, which can be seen in its early stages as well as later in the course of the disease, since neurotransmitters including dopamine, serotonin, and 5HT, which play a role in sleep control^{1,2}, are affected. The scales recommended by the Movement Disorders Society (MDS) for the evaluation of sleep disorders in Parkinson's patients were Parkinson's Disease Sleep Scale (PDSS), Pittsburgh Sleep Quality Index (PSQI), SCOPA Sleep Scale (SCOPA), Epworth Sleepiness Scale (ESS). Inappropriate Sleep Composite Score (ISCS) and Stanford sleepiness scale (SSS) are suggested scales by the MDS.³ The PDSS was first developed in 2002 by Chaudhuri et al. The scale consists of 15 questions interrogating sleep disturbance in Parkinson's disease and each question is scored between 0 and 10 with the visual analog scale (VAS).4

METHODS

This was an observational, cross-sectional study carried out at the Department of Neurology of the Ankara Training and Research Hospital. Forty eight patients with idiopathic Parkinson's disease and 48 healthy controls were included.

The professional translation of the PDSS (English to Turkish and Turkish to English) was done by a neurologist and a language educator who was a native English speaker and well versed in Turkish, and it was approved by a certified translation agency as well.

Subjects

Sixty three patients with Parkinson's disease diagnosed according to the United Kingdom Parkinson's Disease Society Brain Bank Clinical Criteria were included in the study. Fifteen patients did not come for a second visit. There were 48 healthy controls included having similar demographic characteristics with the patient

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group. The study was approved by local Ethics Committee of Ankara Training and Research Hospital. Patients with a history of intracranial mass, aneurysm, arterio-venous malformation, cerebrovascular disease, severe head trauma, severe cognitive decline who are unable to respond to the questions, Parkinson's plus and secondary parkinsonism and depression, and those who refused to participate were excluded from the study. In the control group, those with any neurological diseases, obesity, respiratory function impairment, rheumatologic diseases, and psychiatric disorders were excluded.

The UPDRS total and subgroup scores of the patients, the HYS, and the drugs they were using were recorded. For objective assessment of cognitive status, all participants underwent Mini-Mental State Examination (MMSE), and those with moderate to advanced dementia were excluded from the study. Patients with depression were also excluded who were evaluated according to the DSM-IV depression criteria. Evaluations and testing were performed by the same neurologist. Patients participated in the study and the control group responded to the questions in the Parkinson's Disease Sleep Scale (PDSS), taking the last week into account. The scale was repeated 15 days later. The quality of sleep all night (question 1), difficulties falling and staying asleep (questions 2,3), restlessness (questions 4,5), night psychosis (questions 6,7), nocturia (questions 8,9), motor symptoms at night (questions 10, 11, 12 and 13), benefit from sleeping and well awakening (question 14), and unexpectedly asleep in a daytime (question 15) were assessed with PDSS. For each question in the test, points were given between 0 (symptom very severe) and 10 (symptom free). The total score was 150, indicating there is no complaint about sleep. ESS was also administered to the patient and control groups. There is a total of 8 questions on this scale and the patients respond by giving a score between '0' (no drowsiness) and '3' (high probability of drowsiness) for each question. A total of "10" or more points were considered as daytime sleepiness and "≥15 points" as pathological sleepiness.

Statistical analysis

Test-retest reliability was examined with ICC, while internal consistency with Cronbach's alpha. PDSS was compared between patients and controls for validity, and compared with the ESS and assessed by the Spearman correlation coefficient (rs).

RESULTS

Forty eight patients and 48 controls who had completed both pre- and post-tests were included in the statistical analysis. The demographic and clinical characteristics of the patient group are shown in Table 1. In the control group, 26(54.2%) were female and 22 (45.8%) were male, and the mean age was 68.69 ± 79.3 years. There was no statistically significant difference between the patient and control group in terms of gender and mean age (p = 0.101 and p = 0.653, respectively). The mean MMSE score was 26.7 ± 2.03 (22-30) in the patient group and 28 ± 1.41 (25-28) in the control group, which was statistically significant (p<0.001).

When the total PDSS scores of the patient and control group were examined, the mean score of the patients in the first practice was 109.8 ± 26.9 points and it was 105.8 ± 30.8 points at the repeat of the test. The control group scored a mean of 126.7 ± 11.9 points in the first assessment and 125.9 ± 12.4 points in the test's repetition. The total PDSS score of the patients was lower than that of the control group (p<0.001). In addition, it was statistically significant (p < 0.001) and 93% safe when the first and second assessment of the scale were compared. In the first and second assessment of the scale, the patient and control group had comparable scores for 7th, 8th, 12th and 14th questions, however they had obviously different scores for 3rd, 11th and 15th questions (Figure 1, 2).

In the internal consistency analysis of PDSS, Cronbach's alpha was found as 0.721 in the first assessment of the test, and the internal consistency was found to be 0.771 in the second assessment. When the scale was repeated, the consistency was found to be higher. When the effects of the questions on the reliability on the scale were examined on 96 cases, Cronbach's alpha increased to 0.727 after removal of the 7th question from the scale, Cronbach's alpha increased to 0.731 after removal of the 8th question, and to 0.726 after removal of the 15th question at the first assessment of the scale and the consistency of the test was increased. At the second assessment of the test, when the 7th question was removed from the scale, Cronbach's alpha increased to 0.776 and it increased to 0.783 after removal of the 8th question, and the consistency of the test increased (Table 2).

For reproducibility analysis of the scale, the intra-class correlation coefficient was checked and a high value of 90% was found for PDSS (Table 3).

Variable			Value
Patient number (n) Gender			48
	Female	n (%)	17 (35.4%)
	Male	n (%)	31 (64.4%)
Age			±
-		mean±SD	69.50±8.28
		Range	44-84
Disease duration (month)		C	
		mean±SD	34.4±38.7
		Range	4-240
HYS		n (%)	
		1	27 (28%)
		2	14 (14.6%)
		3	6 (6.3%)
		4	1 (1.0%)
UPDRS		mean±SD	~ /
	UPDRS1		3.6±5.7
	UPDRS2		9.1±5.4
	UPDRS3		15.2±12.8
	UPDRS4		0.7 ± 2.4
	UPDRStotal		2.8±19.8
Treatment		n (%)	
	Levodopa		11 (22.9%)
	Dopamine agonist(DA)		12 (25.0%)
	Levodopa +DA		21 (43.6%)
	Untreated		4 (8.3%)
MMSE		mean±SD	26.7±2.03
		Range	22-30

Table 1: The demographic and clinical characteristics of the patient group

 Table 2: Internal consistency in the extraction of each item for the first and second assessment of the scale

PDSS item	Cronbach alfa (1st assessment)	Cronbach alfa (2nd assessment)	
1. Sleep quality	0.691	0.751	
2. Difficulties falling asleep	0.694	0.759	
3. Difficulties staying asleep	0.686	0.748	
4. Restlessness in arms and legs	0.713	0.746	
5. Fidgeting	0.689	0.751	
6. Distressing dreams	0.712	0.763	
7. Distressing hallucinations	0.727	0.776	
8. Nocturia	0.731	0.783	
9. İncontinence	0.708	0.761	
10. Numbness or tingling	0.690	0.748	
11. Painful cramps in arms or legs	0.697	0.744	
12. Early awakening	0.714	0.761	
13. Tremor on waking	0.707	0.758	
14. Tired and sleepy after waking	0.710	0.754	
15. Unexpectedly asleep in daytime	0.726	0.770	

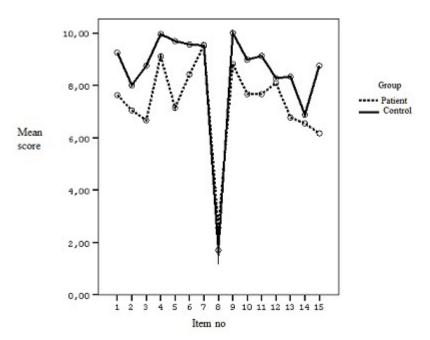


Figure 1. Mean score of each question in the first practice of the patient and the control group

The total PDSS score of Parkinson's patients did not differ between males and females (p = 0.501, p = 0.741). The total PDDS score was not significantly related with disease duration (p=0.241, p=0.491), total UPDRS score (p=0.862, p=0.949), UPDRS1 score (p=0.829, p=0.909), UPDRS2 score (p=0.799, p=0.958), UPDRS3 score (p=0.303, p=0.404), UPDRS4 score (p=0.213, p=0.626) or HYS (p=0.338, p=0.336).

There was no significant relationship between total scale score and age (p = 0.301, p = 0.288), MMSE score (p = 0.186, p = 0.128). No significant relationship was found when PDSS total scores were evaluated according to current treatment (Table 4) in the patient group(p = 0.234 p = 0.584).

A statistically significant negative correlation was found between the ESS total score and the correlation coefficient = -0.306, p = 0.02, and

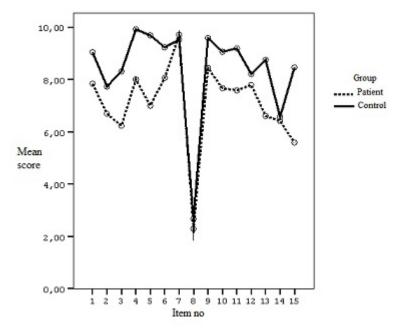


Figure 2. Mean score of each question in the test repetition of the patient and control group.

PDSS Item	rs	р	ICC
1. Sleep quality	0.897	0.000	0.872
2. Difficulties falling asleep	0.895	0.000	0.863
3. Difficulties staying asleep	0.846	0.000	0.839
4. Restlessness	0.778	0.000	0.581
5. Fidgeting	0,852	0.000	0.815
6. Distressing dreams	0.853	0.000	0.708
7. Distressing hallucinations	0.781	0.000	0.713
8. Nocturia	0.767	0.000	0.769
9. Incontinence urine due to 'off' period	0.607	0.000	0.638
10. Numbness or tingling	0.853	0.000	0.811
11. Painful cramps in arms or legs	0.819	0.000	0.926
12. Early awakening	0.856	0.000	0.924
13. Tremor on waking	0.810	0.000	0.806
14. Tired and sleepy after waking	0.794	0.000	0.832
15. Unexpectedly asleep in daytime	0.870	0.000	0.927
16. PDSS total	0.937	0.000	0.906

Table 3: Test and re-test reliability of the PDSS

rs, Spearman correlation coefficient; ICC, intra-class correlation coefficient

Spearman correlation coefficient = -0.340, p = 0.01, respectively). In addition, a statistically significant, inversely proportional relationship was found between ESS and PDSS 15th question (p < 0.001, and p < 0.001).

DISCUSSION

Assessment of sleep disturbances is important since it negatively affects the quality of life of a patient with Parkinson's disease. PDSS is prepared for this purpose and can be applied at the bedside. PDSS was first published by Chaudhuri *et al.*⁴ in 2002. Then the Spanish version was published⁵ in 2004, the Chinese version⁶ in 2008, the Portuguese⁷ and Japanese versions⁸ in 2009, and the Italian version⁹ in 2012. This scale was revised in 2011 by Trenkwalder *et al.* The major change in this revision was the replacement of the VAS score by Likert type with five categories

of responses, from 0 (never) to 4 (very often), in the evaluation of the questions. In terms of the questions, the sleep apnea question was placed as the 15th question in the PDSS, where the daytime sleepiness and sleep episodes were questioned previously.^{10,11} The first PDSS is preferred in many clinical trials.¹²⁻¹⁶ We aimed to validate the Turkish version of the sleep scale using the first version of PDSS on the MDS-Recommended Rating Scales list, which we think is practical to use in our Parkinson's disease and movement disorders outpatient clinic.

In our study, patient selection was made based on the study in which the sleep scale was first developed. The number of patients was limited since it was a single-centered study and the exclusion criteria of studying only patients accepting second visits 15 days later.

There was no significant relationship between PDSS total score and HYS in our study. According

Treatment	n	PDSS total 1st	PDSS total 2nd
Levodopa	11	112,4±26,5	108,6±29,5
Dopamine agonist (DA)	12	121,9±16,4	116,2±24,8
Levodopa+DA	21	100,0 ±30,9	98,0± 36,0
Untreated	4	117,2±16,0	108,5±14,7

Table 4: Treatment and PDSS total scores in patient group

to the exclusion criteria, patients with moderate and advanced dementia were not included which may have caused most patients to be in an early stage of the disease. The low number of patients in advanced stages of the disease might make it difficult to establish this possible relationship. A similar finding was found in the studies of Martinez et al. and Gang et al.5,9In other validation studies with PDSS and PDSS-2 showed significant correlation between HYS and PDSS total score.^{4,10,17,18} However, when studying the relationship with UPDRS, Martinez et al.found a poor score on the scale, especially in relation to UPDRS4.5 Whereas in our study, we did not find a significant relationship between scale and UPDRS subgroups. UPDRS4 is a question of treatment complications and non-motor complications such as sleep disturbances. For this reason, positive answers to these questions by subjects having complaints regarding sleep will increase the correlation. Although cognitive state was different between two groups, there was no significant relationship between total scale score and MMSE score.

A statistically significant inverse correlation was found between the ESS and PDSS scale applied to both groups. This is because the high score from ESS is associated with sleep disturbance, while the low score from PDSS indicates sleep disturbance. There was also a significant negative correlation between the ESS and the 15th question of the PDSS in the study. While ESS shows excessive daytime sleepiness, 15th item of the PDSS is about unexpected sleep episodes during the day, and the low score from this question points out a pathological situation, whereas the ESS has the opposite situation. This contributes to the negative correlation between the two tests mentioned.

In the internal consistency analysis of PDSS, Cronbach's alpha value was found to be better than the normal in the test and the repetition of the test for the groups (Cronbach's alpha = 0.721, Cronbach's alpha = 0.771). This shows that there is an internal consistency. In the light of these results, the scores determined were close to each other, but different in the first assessment and the repetition of the test. This might be because repeating the test may increase the patient compliance. On the other hand, patients' awareness about their sleep related complaints may have increased after the first assessment of the test. Test-retest reliability (ICC) for the total PDSS score of the scale was found to be 90% in our study, which is consistent with the 94% ICC value of Chadhuri and Martinez et al.

When the contribution to the internal consistency of the questions in the scale was examined, it was noticed that the internal consistency of the test increased when the 7th question (hallucinations at night) was removed from the scale for the first and second assessment. According to the item total correlation, the 7th problem was found to have the least contribution to the scale in terms of measuring the desired condition. The missing side of the problem may be that patients might misunderstood the hallucination at night question as 'distressing dreams' and this confusion might have led to this result.

The way to correct this is to find a suitable item questioning for the same answer, or to change the item while adapting to Turkish. In the test assessment and repetition, it was found that the internal consistency had increased when the 8^{th} question was removed from the scale. In addition, the lowest score assignment to this item in the patient and control groups (Figures 2 and 3) might be due to the fact that nocturia is not directly related to the primary symptoms of Parkinson's disease.

In this study, we found that PDSS is valid and reliable in patients with idiopathic Parkinson's disease. The use of this test in Parkinson's patients with sleep complaints can reveal sleep disturbances and can help in the treatment of the disease. It can be used with other scales in the follow-up of Parkinson's patients.

DISCLOSURE

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Conflicts of interest: None

REFERENCES

- 1. Olanow CW, Schapira AH, Roth T. Waking up to sleep episodes in Parkinson's disease. *Mov Disord* 2000;15(2):212-5.
- Schapira AHV, Chaudhuri KR, Jenner P. Non-motor features of Parkinson disease. *Nat Rev Neurosci* 2017;18(7):435-50.
- Högl B, Arnulf I, Comella C, et al. Scales to assess sleep impairment in Parkinson's disease: critique and recommendations. Mov Disord 2010;25(16):2704-16.
- Chaudhuri KR, Pal S, DiMarco A, et al. The Parkinson's disease sleep scale: a new instrument for assessing sleep and nocturnal disability in Parkinson's disease. J Neurol Neurosurg Psychiatry 2002;73:629-35.
- Martínez-Martín P, Salvador C, Menéndez-Guisasola L,*et al.* Parkinson's disease sleep scale: Validation Study of a Spanish Version. *Mov Disord* 2004;19(10):1226-32.

- Pellecchia MT, Antonini A, Bonuccelli U, et al. Observational study of sleep-related disorders in Italian patients with Parkinson's disease: usefulness of the Italian version of Parkinson's disease sleep scale. *Neurol Sci* 2012;33(3):689-94.
- Uemura Y, Nomura T, Inoue Y, et al. Validation of the Parkinson's disease sleep scale in Japanese patients: a comparison study using the Pittsburgh sleep quality index, the Epworth sleepiness scale and polysomnography. J Neurol Sci 2009;287(1-2):36-40.
- Margis R, Donis K, Schonwald SV, et al. Psychometric properties of the Parkinson's disease sleep scale Brazilian version. *Parkinsonism Relat Disord* 2009;15(7):495-9.
- Wang G, Cheng Q, Zeng J, et al. Sleep disorders in Chinese patients with Parkinson's disease: validation study of a Chinese version of Parkinson's disease sleep scale. J Neurol Sci 2008;271(1-2):153-7.
- Trenkwalder C, Kohnen R, Högl B, *et al.* Parkinson's disease sleep scale-validation of the revised version PDSS-2. *Mov Disord* 2011;26(4):644-52.
- Zea-Sevilla MA, Martínez-Martín P. Rating scales and questionnaires for assessment of sleep disorders in Parkinson's disease: what they inform about? J Neural Transm 2014;121(1):33–40.
- Cui SS, Du JJ, Fu R, *et al*. Prevalence and risk factors for depression and anxiety in Chinese patients with Parkinson disease. *BMC Geriatr* 2017;17(1):270.
- Aroxa FH, Gondim IT, Santos EL, et al. Acupuncture as adjuvant therapy for sleep disorders in Parkinson's disease. J Acupunct Meridian Stud 2017;10(1):33-38.
- Tholfsen LK, Larsen JP, Schulz J, et al. Changes in insomnia subtypes in early Parkinson disease. *Neurology* 201; 24;88(4):352-8.
- Panisset M, Stril JL, Belanger M, et al. Openlabel study of sleep disturbances in patients with Parkinson's disease treated with rasagiline. Can J Neurol Sci 2016;43(6):809-14.
- Kwon DY, Koh SB, Lee JH, *et al.* The KMDS-NATION Study: Korean movement disorders society multicenter assessment of non-motor symptoms and quality of life in Parkinson's disease NATION study group. *J Clin Neurol* 2016;12(4):393-402.
- Arnaldi D, Cordano C, Accardo DJ, et al. Parkinson's disease sleep scale 2: application in an Italian population. *Neurol Sci* 2016;37:283-8.
- Kovacs N, Horva K, Aschermann Z, et al. Independent validation of Parkinson's disease sleep scale 2nd version (PDSS-2). Sleep Biol Rhythms 2016; 14:63-73.

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