Assessment of Sleep and Sleepiness in Parkinson Disease

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Study Objectives: To develop a short and practical scale (SCOPA-SLEEP) that evaluates nighttime sleep and daytime sleepiness. The scale is developed for research in Parkinson disease but may be of value for other somatic diseases.

Design: Postal survey including 4 instruments, the SCOPA-SLEEP night-time sleep (5 items) and daytime sleepiness (6 items), the Pittsburgh Sleep Quality Index, and the Epworth Sleepiness Scale.

Setting: Movement Disorders Center, Department of Neurology, Leiden University Medical Center, Leiden, The Netherlands.

Participants: 143 patients with Parkinson disease and 104 controls.

Interventions: N/A.

Measurements and Results: Reliability of the scale was high: internal consistency of the nighttime sleep and daytime sleepiness scales were 0.88 and 0.91, respectively (Cronbach α), and test-retest reliabilities were 0.94 and 0.89, respectively (intraclass correlation coefficient). Scale scores differed significantly between patients and controls (P < .001). Construct validity was assessed by correlations with scales that

addressed similar constructs. Correlation between the nighttime sleep scale and the Pittsburgh Sleep Quality Index was 0.83 (P < .001), and the correlation between the daytime sleepiness scale and the Epworth Sleepiness Scale was 0.81 (P < .001). Factor analysis revealed 1 factor each for both scales, indicating that the scales measure 1 construct, which justifies the calculation of sumscores. The coefficient of variation of both the nighttime sleep and the daytime sleepiness scale was higher than that of the Pittsburgh Sleep Quality Index and the Epworth Sleepiness Scale, indicating a better ability to detect differences between individuals.

Conclusions: The SCOPA-SLEEP is a reliable and valid instrument for assessing nighttime sleep and daytime sleepiness in patients with Parkinson disease.

Key Words: sleep, sleep initiation and maintenance disorders, disorders of excessive somnolence, sleepiness, SCOPA, clinimetrics, reliability, validity, insomnia, hypersomnia

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INTRODUCTION

INSOMNIA AND HYPERSOMNIA OCCUR FREQUENTLY IN THE GENERAL POPULATION AND INCREASE WITH HIGHER AGE. Several studies found even higher prevalences of both types of sleep problems in patients with Parkinson disease (PD).1-3 Poor nighttime sleep is associated with lower quality of life of patients and their spouses,4-6 while excessive daytime sleepiness may be bothersome or even dangerous. A few studies have reported the occurrence of sleep attacks among patients with PD, potentially causing hazardous situations.⁷⁻⁹ Sleep problems in PD, therefore, merit particular attention, and in order to assess this issue in a longitudinal study, we were interested in a concise, practical, and clinimetric sound instrument that could be used to assess nighttime sleep (NS) problems and daytime sleepiness (DS) in patients with this condition. The questionnaire should be appropriate for both research and clinical practice. However, none of the existing sleep scales matched these objectives. Some scales lacked conceptual clarity and combined scores on items addressing different constructs into a total score (eg, Pittsburgh Sleep Quality Index (PSQI), 10 Parkinson's Disease Sleep Scale¹¹). Other scales had potential problems with face validity and were either too short (Stanford Sleepiness Scale, 12 Karolinska Sleepiness Scale¹³), lacked relevant items (Sleep Problems Scale¹⁴), or asked patients to indicate the chance of falling asleep in situations they possibly did not experience (Epworth Sleepiness Scale¹⁵[ESS]). Still other scales were not suitable for clinical use because they were too long, the calculation of scores was complex (Pittsburgh Sleep Quality Index), or combined continuous and categoric responses (St. Mary's

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No significant financial interest/other relationship to disclose.

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Hospital Sleep Questionnaire¹⁶). Additionally a number of scales were not appropriate because they involved diagnostic instruments (Sleep Disorders Questionnaire¹⁷) or were intended for particular patient groups (eg, narcolepsy) or particular interventions (eg, pharmacologic in the Leeds Sleep Evaluation Questionnaire¹⁸).

We, therefore, decided to develop and validate a new scale, the SCOPA-SLEEP, that evaluates both NS and DS. We were especially interested in the performance of this scale in PD in view of future studies, and therefore patients with this condition were involved in the development process. The development of this scale is part of a larger research project on Scales for Outcomes in Parkinson's disease (SCOPA).¹⁹

METHODS

Scale Development

Items in the NS scale were selected from the literature and evaluated whether subjects experienced problems with respect to their nocturnal sleep. It was hypothesized that together these items would reflect a subject's perceived sleep quality. The items were judged by experts and piloted among patients with PD regarding comprehensibility and clarity. Testing was continued until no further problems were encountered and patients understood all items well. The DS scale was developed similarly and evaluated how often a subject had fallen asleep in the daytime, a subject had experienced difficulty staying awake, and whether falling asleep in the daytime was considered a problem. The SCOPA-SLEEP thus consists of 2 parts. The NS subscale addresses NS problems in the past month and includes 5 items with 4 response options. Subjects have to indicate how much they were bothered by particular sleep problems, ranging from 0 (not at all) to 3 (a lot). The 5 items address sleep initiation, sleep fragmentation, sleep efficiency, sleep duration, and early wakening. The maximum score of this scale is 15, with higher scores reflecting more severe sleep problems. One additional question evaluates overall sleep quality on a 7-point scale (ranging from slept very well to slept very badly). The score on this item is not included in the score of the NS scale but is used separately as a global measure of sleep quality. The DS subscale evaluates DS in the past month and includes 6 items with 4 response options, ranging from 0 (never) to 3 (often). Subjects indicate how often they fell asleep unexpectedly, fell asleep in particular situations (while sitting peacefully, while watching TV or reading, or while talking to someone), how often they had difficulty staying awake, and whether falling asleep in the daytime was considered a problem. The maximum score is 18, with higher scores reflecting more severe sleepiness

Participants

Since patients with PD reported more sleep problems than controls in almost all previous studies, the scales would have to be able to detect these differences, and subjects without PD were therefore included as a control group.

Patients

Patients who visited the outpatient clinic of the Department of Neurology of the Leiden University Medical Center and fulfilled the United Kingdom Parkinson's Disease Society Brain Bank criteria for idiopathic PD²⁰ were included. Patients were excluded if they also had other diseases of the central nervous system or were not able to read or understand Dutch.

Table 1—Characteristics of participants					
	Patients	Controls	P		
No.	142	100			
% men	60.5	48.0	.053*		
Mean (SD) age, y	65.6 (10.8)	61.4 (11.2)	.004†		
H&Y 1	4 (2.8 %)				
H&Y 2	57 (40.1 %)				
H&Y 3	52 (36.6 %)				
H&Y 4	26 (18.3 %)				
H&Y 5	3 (2.1 %)				
Mean (SD) disease duration, y	9.9 (5.4)				
Using levodopa, no. (%)	73 (51%)				
Mean (SD) levodopa dose in users, mg	665 (361)				
Using dopamine-receptor agonists, no. (%)	60 (42%)				
Using levodopa + dopamine agonists, no. (%)	54 (38 %)				
Using sleep medication, no. (%)	27 (19%)	7 (7%)	< 0.001 ¹		
H&Y refers to Hoehn and Yahr score. $*\chi^2$ test $\dagger t$ test					

Table 2—Reliability of sleep scales in patient group						
	Cronbach α	Item-total*	ICC sum†	K _w items‡		
SCOPA-NS (nighttime sleep)	0.88	0.48-0.85	0.94	0.82-0.94		
1: difficulty falling asleep		0.48		0.90		
2: been awake too often		0.77		0.82		
lying awake too long		0.85		0.86		
4: waking too early		0.72		0.83		
5: had too little sleep		0.77		0.90		
Overall sleep quality	N/A	N/A	N/A	0.91		
Pittsburgh Sleep Quality Index	0.77	0.27-0.71	§	§		
SCOPA-DS (daytime sleepiness)	0.91	0.55-0.88	0.89	0.49-0.82		
1: falling asleep unexpectedly		0.88		0.79		
2: falling asleep while sitting		0.86		0.78		
3: falling asleep while watching TV		0.82		0.81		
4: falling asleep while talking		0.55		0.78		
5: difficulty staying awake		0.76		0.82		
6: falling asleep considered a problem		0.64		0.49		
Epworth Sleepiness Scale	0.86	0.56-0.71	8	8		

^{*}Corrected item-total correlations

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Controls

Subjects without PD who were able to read or understand Dutch were eligible as controls, provided that they had no history of diseases of the central nervous system.

Recruitment

Questionnaires were sent to eligible patients. An introductory letter provided information on the goal of the study and asked patients to provide the names of 2 persons, 1 man and 1 woman, who would consent to participate as control subjects. The age difference between the patient and his or her controls was not to exceed 10 years. The introductory letter emphasized that only the names of persons who explicitly expressed their willingness to participate were to be provided. Partners were not eligible as controls, since nocturnal sleep problems of patients could affect the partner's sleep pattern. 6.21 Relatives of patients were not excluded. Response was interpreted as consent to participate. The study was approved by the medical ethics committee of the Leiden University Medical Center.

Scale Evaluation

A postal survey was sent to potential participants. The included questionnaires were the SCOPA-SLEEP (appendix), the PSQI,10 and the ESS. 15 Eight additional questions were used to evaluate the use of sleep medication, sleep initiation time (minutes), time awake per night (hours), actual duration of NS (hours), duration of daytime sleep (minutes), and how often subjects had planned naps, unplanned naps, or fallen asleep quite unexpectedly in the past month. Response options for the latter 3 questions ranged from not at all to every day. The PSOI, ESS, and the 8 additional questions were included to assess the construct validity of the SCOPA-SLEEP. The PSQI and the ESS were included because they are frequently used and have previously been used in studies involving patients with PD. The PSQI evaluates several aspects of NS and consists of 19 self-rated questions and 5 questions rated by the bed partner or roommate. 10 The latter 5 questions are used for clinical information only and are not tabulated in the scoring of the PSQI. Scores are first grouped in 7 domains and next recoded to a 0 to 3 scale. The 7 domains include subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction. Both the total score and the subscale scores can be used. The total score has a maximum of 21, with higher scores reflecting greater problems. The developers advise a cutoff score of 5/6 to separate good from bad sleepers.10

The ESS evaluates DS. In this scale, the individual is asked to rate the chance of dozing off in 8 different situations. ¹⁵ There are 4 response options, ranging from 0 (would never doze) to 3 (high chance of dozing). The maximum score is 24, with higher scores reflecting more severe sleepiness. Healthy controls usually have scores of 10 or less. Scores greater than 10 are considered indicative of excessive sleepiness. ²² Scores of 16 or greater indicate a high level of DS but are by themselves not diagnostic of a particular sleep disorder. ¹⁵

Participants were asked to complete the questionnaires within 1 week. After 2 weeks, nonresponders were contacted by telephone, and the investigator inquired whether the subject still considered participating. Patients who returned their questionnaires within 1 week were asked to complete the SCOPA-SLEEP a second time 2 weeks later, for the evaluation of the test-retest reliability. Information from the questionnaires of participating patients was combined with information from patient records (ie, disease severity, disease duration, and medication use) to assess known-groups validity. Disease severity was evaluated at each control visit and assessed by the Hoehn and Yahr (H&Y) staging system.²³ An H&Y 1 is the mildest stage with only unilateral symptoms, whereas H&Y 5 is the

[†]Intraclass correlation coefficient (ICC) for the total score, calculated over 2-week interval

[‡]Weighted kappa (K_W) of items, calculated over 2-week interval

[§]Reproducibility not assessed for this scale

SCOPA-NS refers to Scales for Outcomes in Parkinson's disease-Nighttime Sleep subscale; SCOPA-DS, Scales for Outcomes in Parkinson's disease-daytime sleepiness subscale; N/A, not applicable

most severe stage in which patients are wheelchair-bound or bedridden. Comorbidity was assessed by means of a standard questionnaire, evaluating the 22 most common diseases. This questionnaire includes an extra question in which respondents are asked to indicate the presence of other diseases.

Statistical Analysis

Data were entered and analyzed with SPSS for Windows 10.0 (SPSS Inc. Chicago, III).

Questionnaires were excluded if they had more than 20% of values missing.

Data Quality and Score Distribution

The quality of the data was considered acceptable if item scores were missing in less than 10% of the patients²⁴ and item-total correlations in the patient group exceeded 0.20.²⁵

Reliability

Internal consistency of the scales was assessed with Cronbach α . Test-retest reliability for individual items was assessed with a weighted kappa (K_w ; quadratic weights), whereas an intraclass correlation coefficient (ICC) was used for the total score.

Validity

Age, disease severity, and male-female ratio of responders were compared with those of nonresponders, using t tests, Mann-Whitney U tests, and χ^2 tests, respectively. Independent samples t tests were used to compare scores of patients and controls, and scores of patients who were on medication (levodopa, dopamine-receptor agonists, or sleep medication) versus those who were not. The significance threshold was set at .05. Construct validity of the SCOPA-SLEEP was assessed by calculating the correlation between this scales and scales that addressed similar constructs, using Pearson correlation coefficient (r). This coefficient was also used to explore the relation with disease duration. Spearman corre-

Table 3—SCOPA-SLEEP item scores* Patients Controls P value P value adjusted† Nighttime Sleep 0(1)0(1).959‡ .771 1. Difficulty falling asleep < .001‡ 2. Been awake too often 1(2) 1(1).003‡ 3. Lying awake too long 1(2) 0(1)< .001‡ < .001‡ < .001‡ 4. Waking too early 1(2) 0(1)< .001‡ 5. Had too little sleep < .001‡ < .001‡ 1(2)0(1)Overall sleep quality (0-6) 2(2)1(1)< .001† < .001† Daytime Sleepiness 1. Falling asleep unexpectedly 1(2) 0(1)< .001‡ < .001‡ < .001‡ 2. Falling asleep while sitting 1(2) 0(1)< .001‡ 3. Falling asleep watching TV < .001‡ < .001‡ 1(1)0(1)< .001‡ < .001‡ 4. Falling asleep while talking 0(0)0(1) 5. Difficulty staying awake 1(1) < .001‡ < .001‡ 6. Sleepiness problematic 0(0)< .001‡ < .001‡ 0(1)Other Sleep Parameters < .001‡ 27 (19) 7(7).002! 1. Using sleep medication, no. (%) 534! 71 2. Sleep initiation time, min 22 19 3. Time awake per night, h 1.9 0.6 .006¶ .005 4. Actual sleep per night, h 7.0 .001¶ 6.3 .007 5. Sleep in daytime, min 34 11 < .001¶ < .001‡ 6. Planned naps. no. (%) 2(3)0(2)7. Unplanned naps, no. (%) 1(2)0(1)< .0011 8. Unexpected sleep, no. (%) 0(1)0(0)< .001‡

lation coefficient (r_s) was used if the correlation involved subscales of the PSQI and the 'global sleep quality' item. Known-groups validity was assessed by comparing the NS and DS scores of patients with different disease severity, using analysis of variance (ANOVA). To discriminate groups of patients with different disease severity, patients were classified as mild (H&Y 1 and 2), moderate (H&Y 3), or severe (H&Y 4 and 5). Stages 1 and 2 on the one hand, and 4 and 5 on the other hand, were collapsed because patients in H&Y stages 1 and 5 were underrepresented, a common finding in studies involving patients with PD. A principal component factor analysis with orthogonal rotation was performed to explore the underlying structure of the scales. Coefficients of variation (CV) were calculated to assess the discriminative properties of the scale. The CV are calculated by dividing the SD of the score by the mean of the score. Higher values for CV indicate a better ability to detect differences between individuals.

RESULTS

Response Rate and Sample Characteristics

A postal survey was sent to 185 patients with PD and 112 controls; 143 patients returned their questionnaires. One questionnaire had more than 20% of the data missing and was excluded. Thus 142 usable questionnaires remained, constituting a response rate of 76.7%. Of the controls, 104 returned their questionnaires; 4 questionnaires were excluded because the age difference with the corresponding patient was more than 10 years. Therefore, 100 usable questionnaires (89.3 %) from controls were available for analysis. Of the 60 patients who returned their questionnaires within 1 week, 56 completed the SCOPA-SLEEP a second time. One questionnaire was subsequently removed from the analysis because too much data was missing, leaving a response rate of 91.7% (Table 1).

Differences between responders and nonresponders in the patient group were not significant for disease severity and age, but the proportion of women among the nonresponders was significantly higher (P < .05). The mean disease duration of the patients was 9.9 (SD 5.4) years. Disease severity was mild in 61 patients (43.0%), moderate in 52

(36.6%), and severe in 29 (20.4%). The male-female ratio did not differ significantly between patients and controls (P = .053), but controls were significantly younger (Table 1). None of the controls reported a sleep disorder in the comorbidity questionnaire.

Scale Evaluation

Data Quality and Score Distribution

The quality of the data was good. None of the items had missing values in more than 10% of the patients, indicating good acceptability. All item-total correlations exceeded 0.20. Patients used the full score range in both scales. Twenty-five patients (17.7%) had a score of 0 in the NS scale, whereas 2 patients (1.4%) scored 15. Seventeen patients (12.1 %) had a score of 0 in the DS scale, whereas 1 patient (0.7%) scored 18.

Reliability

Cronbach α for the NS subscale was 0.88, with corrected item-scale correlations ranging from 0.48 to 0.85 (Table 2). Test-retest reliability for the total score of this scale was 0.94 (ICC), whereas the K_w for items ranged from 0.82 to 0.90. Cronbach α for the DS subscale was 0.91, with corrected item-scale correlations between 0.55 and 0.88. The ICC for the total score of DS was 0.89, with the K_w for items ranging from 0.49 to 0.82.

^{*}Data are expressed as median (interquartile range) unless otherwise indicated

[†]Univariate analysis of variance, adjusted for age and sex

[‡]Mann-Whitney U test

[§]All controls scoring 0

 $[\]chi^2$ test*

 $[\]P t$ test

Validity

The scores on all items of both parts of the SCOPA-SLEEP differed significantly between patients and controls, with the exception of item NS1 (difficulty falling asleep) (Table 3). Responses to 7 of the 8 additional questions also differed significantly between patients and controls (all P values < .001). The 1 exception again concerned sleep initiation, with both groups indicating similar amounts of time before falling asleep. Sumscores of patients and controls differed significantly on all included sleep scales (Table 4). The correlation between NS and the PSQI total score in the patient group was 0.83 (P < .001) and the correlation with the separate subscales of the PSOI ranged from 0.38 to 0.73 (all P values < .001). The correlation between NS and the global sleep quality score was 0.85 (P < .001), whereas this was 0.78 (P < .001) for the PSQI with the global score. The correlation between the DS scale and the ESS in the patient group was 0.81 (P < .001). No significant differences were found in the scores of patients grouped by disease severity for any of the 4 scales (ANOVA). The relation with disease duration displayed similar results, with low and insignificant correlations. There were no significant differences in any of the 4 scale scores between patients who used levodopa and those who did not. We also found no significant correlation between the levodopa dose and any of the scale scores in those patients that took levodopa. Scores on both scales that evaluated DS were higher for patients taking dopamine-receptor agonists, with differences reaching significance in the ESS (8.8 vs 5.9; P =.04) but not in the DS (5.9 vs 4.1; P = .07). Subjects who used sleep medication had significantly higher NS and PSQI scores in both the patient and the control group (P < .001), but differences in DS and ESS scores were not significant.

If the proposed PSQI cutoff value (5/6) was used to discriminate between good and bad sleepers, 106 subjects (29 controls and 77 patients, ie, 43.8% of the total sample) were considered poor sleepers. Using this PSQI cutoff as an external criterion for the NS subscale resulted in an area under the receiver operating characteristic (ROC) curve of 0.90, with an optimal cutoff at 3/4, yielding a sensitivity of 0.82 and specificity of 0.84. Since we considered the proportion of subjects with poor sleep by this criterion in both groups exceptionally high, we also used responses to the global sleep quality item as a criterion. This revealed that only 32 subjects (3 controls, 29 patients) actually considered themselves poor sleepers, a finding that agrees better with the literature. 1,26,27 If this global item was used to separate patients who slept badly (scores 4-6) from those who did not (scores 0-3), the best cutoff point for the NS subscale was 6/7, with an area under the ROC curve in patients of 0.94. This cutoff value showed a sensitivity of 0.97 and a specificity of 0.80. Using this same global sleep quality criterion for the PSQI suggested that a cutoff of 8/9 would be more appropriate, both in patients and in all subjects, resulting in an area under the ROC curve of 0.91, with a sensitivity of 0.93 and a specificity of 0.76.

Three controls and 38 patients had an ESS score of at least 11, where-as none of the controls and 16 of the patients scored 16 or higher. Using the cutoff value of 10/11 to separate persons with excessive DS from those without indicated an optimal cutoff value of 4/5 for the SCOPA-

Table 4—Sumscores of patients and controls*

	Patients	Controls	P adjusted†	CV‡
SCOPA – NS	4.9 (4.0)	2.8 (2.7)	< .001	0.82
Pittsburgh Sleep Quality Index	7.2 (4.3)	4.5 (3.3)	< .001	0.70
SCOPA – DS	5.2 (4.1)	2.1 (2.0)	< .001	0.79
Epworth Sleepiness Scale	7.9 (5.3)	4.1 (3.2)	< .001	0.67

^{*} Data are expressed as mean (SD) unless otherwise indicated.

SCOPA-NS refers to Scales for Outcomes in Parkinson's disease-Nighttime Sleep subscale; SCOPA-DS, Scales for Outcomes in Parkinson's disease-daytime sleepiness subscale

†Univariate analysis of variance, adjusted for age and sex

Coefficient of Variation, ie, the SD of the score divided by the mean of the score; higher values of CV indicate better ability to detect differences between individuals

DS. The area under the ROC curve was 0.93, with a sensitivity of 0.90 and a specificity of 0.82.

Factor analysis on the SCOPA-NS revealed 1 factor, accounting for 68.1% of the variance. For the DS subscale, 1 factor emerged, explaining 69.1% of the variance. The factor analysis of the PSQI was performed on the 7 subscales, which produced 2 factors accounting for 58.7% of the variance, with the sleep-pattern–related items (quality, duration, efficiency, and latency) loading on 1 factor, and daytime dysfunction and sleep disturbances loading on the other. The ESS also revealed 2 factors, together explaining 63.4% of the variance. Items that addressed the more private situations at home (items 1, 2, 5, and 7) loaded on 1 factor, whereas items that evaluated more public situations (car, public places, talking to someone; items 3, 4, 6, and 8) loaded on the other

The CV of both the NS and the DS scales were higher than those of the PSQI and the ESS (Table 4).

DISCUSSION

We developed a short questionnaire for the assessment of sleep problems consisting of 2 scales—1 that evaluates NS and 1 that assesses DS—and assessed its performance in a population of patients with PD. The scales displayed good acceptability, and substantial floor and ceiling effects were absent. Both scales revealed good internal consistency and reproducibility, indicating reliability for both scales. The high reliability of the scales allows the use at the level of the individual patient.²⁸ Patients with PD had significantly higher scores than controls on both scales. Correlation with other scales that address similar constructs was high, giving support to the construct validity of the SCOPA-SLEEP. The factor analysis revealed 1 factor for each SCOPA-SLEEP scale, indicating that the scales each measure 1 construct, therewith justifying the calculation of sumscores. The CV of both SCOPA scales were higher than those of the PSQI and the ESS, indicating a better ability to detect differences between individuals. Responsiveness of the SCOPA scales, however, remains to be evaluated.

Assessment of NS

Studies in other populations have shown that the PSOI has adequate reliability and validity. 10,29-32 For internal consistency, this was confirmed by the results of our study. The scale has previously been used in PD. 33-35 Some comments regarding the PSQI are in order, however. First, the content validity of the PSQI may be questioned, especially with respect to use in PD. The PSQI evaluates daytime dysfunction, but problems in this area can be caused by PD as well as other diseases and do not necessarily relate to nocturnal sleep problems. The score on the daytime dysfunction scale is made up of 2 items, ie, enthusiasm to get things done (which could be affected by PD but also by other diseases such as depression) and trouble staying awake (which could be caused by PD or by the effect of antiparkinsonian medication). Second, the incorporation of trouble staying awake and taking sleep medication in the total score is questionable. These items address a clearly different construct than the other items that evaluate aspects of sleep pattern. This is partially confirmed by the factor analysis, in which daytime dysfunction (together with sleep disturbances) loads on 1 factor, whereas the other, sleep-pattern-related items (quality, duration, efficiency, and latency) load on the other. Third, calculating the total score of the PSQI is time consuming, which makes it less suitable for clinical application. These arguments favor the use of the SCOPA-NS in patients with PD. Additionally, if the PSQI is used in patients with PD, a higher cutoff may be more appropriate.

Assessment of DS

Studies in other populations have shown that the internal consistency of the ESS is adequate. 15,36-38 The scale has been shown to discriminate successfully between healthy controls and patients with sleep disorders,

but test-retest reliability has not been assessed among patients and therefore remains uncertain.^{37,39} Responsiveness of this scale has not yet been assessed.³⁹ The ESS has frequently been used in PD.^{8,9,33,40-47} Two additional comments regarding the use of the ESS are needed. First, patients are asked to rate the chance of dozing, without actually having to have had the experience of dozing off in that particular situation. Three of the situations described in the ESS (sitting inactive in a public place, as a passenger in a car for an hour without a break, and in a car while stopped for a few minutes) may actually be experienced infrequently by the more severely affected or older patients, which may further compromise the patient's appraisal of the situation. Second, in both the patient and the control group, 2 factors emerged, suggesting that the scale does not measure 1 construct. The SCOPA-DS may therefore be preferred in this population, since it does not have the aforementioned objections.

The first disease-specific sleep scale in PD, the Parkinson's Disease Sleep Scale,11 was published very recently and evaluates various aspects of nocturnal sleep problems. Unfortunately, this publication appeared after we finished our data collection, and hence this scale was not included in our study. A direct comparison of these 2 disease-specific scales would have produced valuable information. The Parkinson's Disease Sleep Scale includes 15 items that evaluate overall sleep quality (1 item), insomnia (2 items), potential reasons for sleep disturbances (6 items), motor symptoms (4 items), sleep refreshment (1 item), and daytime dozing (1 item). Patients indicate on a 10-cm visual-analog scale how well they slept or how often the described items applied to them, based on their experience during the past week. On face value, the scale appears to measure various constructs. A thorough clinimetric evaluation has not yet been published. Internal consistency and factor analysis were not reported, thereby ruling out the possibility of judging whether the calculation of sumscores is justified. The reproducibility of this scale seems adequate but was only assessed in 15 patients. The relation with other scales was assessed only by calculating the correlation between 1 item of this scale (unexpectedly falling asleep during the day) and a scale that addresses DS (ESS) but not with scales that evaluate nocturnal sleep problems.

In conclusion, sleep problems occur frequently in PD and deserve appropriate attention. The SCOPA-SLEEP scale is a valid, reliable, and short scale that can be adequately used to evaluate sleep problems in this population. Items in the SCOPA-SLEEP are not disease-specific, and therefore this instrument may also be applicable to other populations. Future studies that assess its performance in other populations are recommended.

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APPENDIX

SCOPA-SLEEP SCALE

Aim of the Questionnaire

By means of this questionnaire, we would like to find out to what extent *in the past month* you have had problems with sleeping. Some of the questions are about problems with sleeping *at night*, such as, for example, not being able to fall asleep or not managing to sleep on. Another set of questions is about problems with sleeping *during the day*, such as dozing off (too) easily and having trouble staying awake.

First read these instructions before you answer the questions!

Place a cross in the box above the answer which best reflects your situation. If you wish to change an answer, fill in the 'wrong' box and place a cross in the correct one. If you have been using sleeping tablets, then the answer should reflect how you have slept while taking these tablets.

NS: Nighttime Sleep Problems

response options: not at all - a little - quite a bit - a lot

In the past month, ...

- have you had trouble falling asleep when you went to bed at night?
- 2. ... to what extent do you feel that you have woken too often?
- 3. ... to what extent do you feel that you have been lying awake for *too long* at night?
- 4. ... to what extent do you feel that you have woken up *too early* in the morning?
- 5. ... to what extent do you feel you have had too little sleep at night?

Overall, how well have you slept at night during the past month?

<u>response options</u>: very well – well – rather well – not well but not badly - rather badly – badly - very badly

DS: Daytime Sleepiness

response options: never - sometimes - regularly - often

- 1. How often in the past month have you fallen asleep unexpectedly either during the day or in the evening?
- 2. How often in the past month have you fallen asleep while sitting peacefully?
- 3. How often in the past month have you fallen asleep while watching TV or reading?
- 4. How often in the past month have you fallen asleep while talking to someone?
- 5. In the past month, have you had trouble staying awake during the day or in the evening?
- 6. In the past month, have you experienced falling asleep during the day as a problem?