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Review

Scales to Assess Sleep Impairment in Parkinson's Disease: Critique and Recommendations

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Abstract: There is a broad spectrum of sleep disturbances observed in Parkinson's disease (PD). A variety of scales have been applied to the evaluation of PD sleep and wakefulness, but only a small number have been assessed specifically for clinimetric properties in the PD population. The movement disorder society has commissioned this task force to examine these scales and to assess their use in PD. A systematic literature review was conducted to explore the use of sleep scales in PD and to determine which scales qualified for a detailed critique. The task force members, all of whom have extensive experience in assessing sleep in PD reviewed each of the scales using a structured proforma. Scales were categorized into recommended, suggested and listed according to predefined criteria. A total of 48 potential scales were identified from the search and reviewed. Twenty-nine were excluded because they did not meet review criteria or were variations of scales already included, leaving 19 scales that were critiqued and rated by the task force based on the rating criteria. Only six were found to meet criteria for recommendation or suggestion by the task force: the PD sleep scale (PDSS) and the Pittsburgh sleep quality index (PSQI) are recommended for rating overall sleep problems to screen and to measure severity, the SCOPA-sleep (SCOPA) is recommended for rating overall sleep problems both to screen and to measure severity, and for rating daytime sleepiness; the Epworth sleepiness scale (ESS) is recommended for rating daytime sleepiness to screen and to measure severity; the inappropriate sleep composite score (ISCS) is suggested for rating severe daytime sleepiness or sleep attacks to screen and to measure severity; and the Stanford sleepiness scale (SSS) is suggested for rating sleepiness and to measure severity at a specific moment. The task force does not recommend the development of new scales, but emphasizes the need for educational efforts to train physicians in sleep interview techniques and polysomnography. © 2010 Movement Disorder Society

Key words: sleep; Parkinson's disease; rating scales; questionnaires; nocturnal disturbances; daytime sleepiness

INTRODUCTION

Sleep disturbances are common in patients with Parkinson's disease (PD) affecting more than 75% of patients.[1] The sleep disturbances that may occur more frequently in PD than in healthy, age-matched controls

Additional Supporting Information may be found in the online version of this article.

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include insomnia, sleep fragmentation, daytime sleepiness, rapid eye movement (REM) behavior disorder (RBD), sleep apnea syndromes, neuropsychiatric disturbance, motor disabilities, restless legs syndrome (RLS) or periodic limb movements (PLM), and nocturia.[2] As PD advances, nighttime sleep disturbances and daytime sleepiness increase.[3] Daytime sleepiness and sleep attacks (or episodes of sudden sleep onset) can have major impact on everyday function and may cause motor vehicle accidents.[4] It is important that sleep disturbances in PD patients be recognized and assessed.

Sleep can be evaluated by history and scales (sometimes considered to be subjective tools), or by neurophysiological methods such as polysomnography (PSG), the multiple sleep latency test (MSLT),[5,6] and the maintenance of wakefulness test (MWT)[7] (often referred to as objective tools). PSG evaluates nocturnal sleep structure and allows quantification of sleep disturbance, while the MSLT and MWT provide quantitative measures of daytime sleepiness and the ability to remain awake. However, these tests are both costly and time-consuming and require specialized hospital-based settings. There has been intense discussion if this dichotomization into subjective and objective is justified, first of all, because scales reflect real life and in a certain way also try to evaluate objectively, e.g., the probability to fall asleep in certain situations in the ESS.[8] Nevertheless, a sometimes high discrepancy between subjective and objective assessment results in the same patients has been recognized both in insomnia (e.g., sleep state misperception, paradoxical insomnia) or daytime sleepiness.[9,10] While the diagnosis of insomnia is based exclusively on subjective criteria (patient's impairment due to symptoms)[11,12] the use of subjective criteria alone has sometimes been considered insufficient in daytime sleepiness, when lacking awareness may contribute to accidents.[9] In addition, objective tests may not adequately capture the fluctuating nature of some of the sleep disturbances in PD. Hence, more practical and specific tools are needed to screen for sleep disturbance and daytime sleepiness in larger numbers of PD patients. The Movement Disorder Society (MDS) Task Force on Rating Scales for PD therefore commissioned a Sleep Scale Task Force (SSTF) to review and evaluate the existing sleep scales, the appropriateness of their use in PD, and to make recommendations for their use in this patient population (Table 1 shows criteria used). A summary of the findings can be found in Table 2. This task force focused exclusively on night sleep (insomnia, sleep quality, sleep disturbance) and daytime sleepiness. Other specific sleep related diagnoses such as RLS, RBD, sleep apnea were not included.

Implicit Problems when Using Rating Scales for Sleep in PD (sPD)

The Multiple Types of Sleep Disorders

The multifactorial and multidimensional nature of sleep disturbances in PD precludes using a single instrument to assess sleep. Further, medications as well as the occurrence of motor symptoms, fatigue, cognitive impairment, depression, and medication side effects in PD may confound the outcome of sleep scales that were developed for a non-parkinsonian population. It is therefore necessary to identify whether the scale focuses on insomnia, daytime sleepiness, or other specific sleep disturbances reported in PD (which were not the focus of this task force). For PD patients, not only specific sleep disorders but various nocturnal motor and psychiatric problems contribute to the nighttime disturbance.

Patient and Caregiver Awareness and Perception of Sleep and Sleepiness

In PD,[9] as in narcolepsy,[13] it has been shown that patients may be unaware of experiencing brief naps. It is therefore necessary to interview the caregiver whenever possible. Conversely, in insomnia, the phenomenon of sleep state misperception[14] refers to a subject thinking he or she has been awake all night, but the bed partner (or objective PSG) confirm the contrary. Several other sleep items cannot be assessed by the patient alone (e.g., snoring and apneas are not perceived, and patients are often unaware of RBD unless it causes them injury) and so assessment with the bed partner or caregiver is useful. It should always be specified if someone other than the patient contributed to answering scale questions.

Overlap in Symptoms

Fatigue is sometimes confounded with daytime sleepiness. Both fatigue[15] and daytime sleepiness[16–18] are frequent in PD. Lack of motivation can be mistaken for a lack of alertness, and apathy may be misinterpreted as sleepiness. Autonomic failure is a pervasive problem in PD. Rarely, a syncopal episode due to orthostatic hypotension may be confused with dozing by patients or their caregivers.[19] Finally, depression is also a common feature of PD, and both hypersomnia and insomnia are associated with depression.

Problems of Assessment in PD with Cognitive Impairment

Between 30 and 40% of patients suffer from cognitive decline associated with PD.[20] This limits the use of

TABLE 1. *Definition of the three categories*

Category	Criteria
"recommended"	(1) Scale has been applied to PD populations (2) Other groups beyond the original developing group have published data[a] of the scale in its clinical use (3) Psychometrical studies are available, that concluded the scale valid and reliable
"suggested"	(1) Scale has been applied to PD populations (2) Only one other criteria (2) or (3) from the above recommended category applies
"listed"	(1) Scale has been applied to PD populations, but no further criterion met

[a]Data needed to be published in full papers, no abstracts included.

self-assessment scales in these patients, and a caregiver or bed partner is required to help answer questions about the patient's sleep habits and sleep disturbances.

Timing of Assessment

The majority of rating scales for sleep in PD (sPD) will specify a particular time period that should be considered when responding to the scale questions. For example, the ESS specifies that the questions should be addressed to include "in recent times". Some rating scales are designed to assess sleepiness at that moment. An example of this is the Stanford sleepiness scale (SSS), which inquires about immediate sleepiness and can be used to measure the differences in sleepiness in which a state-dependent change may be anticipated. An example would be patients with motor fluctuations in which sleepiness may vary depending on whether the patient is "on" or "off". Sleep scales that cover a longer time span (such as "in recent times") rely on recall memory; diary-type questionnaires—such as the sleep and awakening quality scale (SSA),[21] which are administered upon awakening each day—could provide a more accurate picture of reality (see Supporting Information).

TABLE 2. *Summary of recommended and suggested scales*

Scale	N° of items/ self-completed (yes/no)	Type of disorder assessed	Information from partner/caregiver	Presence or severity, proposed cut-off	Timing of assessment	State*
PDSS	15/Y	Nocturnal disturbance and excessive daytime sleepiness	No, although they are allowed to help.	Weighted towards severity No cut-off published	Over previous week	Recommended for overall sleep impairment as a screening tool and as a measure of severity
PSQI	19/Y	Sleep quality	Five extra items (not added in score)	Presence and severity cut-off 5	Over previous month	Recommended for overall sleep impairment as a screening tool and as a measure of severity
SCOPA-SLEEP	12/Y	Sleep quality, daytime sleepiness, night time sleep disturbances	No, but could be helpful for daytime sleepiness	Presence/severity cut-off 5/6 suggested to distinguish good from bad sleepers	Over previous month	Recommended for overall sleep impairment as a screening tool and as a measure of severity
ESS	8/Y	Daytime sleepiness presence and severity	Not required for original scale. Caregiver score may vary from patient score	Presence/severity Cut-off 10/11 for pathological sleepiness	In recent times	Recommended for daytime sleepiness as a screening tool and as a measure of severity
ISCS	6/N	Risk of sudden onset of sleepiness while driving	Not required (but could be useful)	Presence and severity of excessive daytime sleepiness cut-off 1		Suggested for severe daytime sleepiness/sleep attacks as a screening tool and as a measure of severity
SSS	1/Y	General level of daytime sleepiness	No	Severity of sleepiness at a specific moment, no cut-off proposed	Specific moment in time/current	Suggested for daytime sleepiness as a screening tool and as a measure of severity

*Recommended, Applied to PD population, used in clinical studies beyond the group who developed the scale, studied clinimetrically with satisfactory results; Suggested, meets two of the three criteria; Listed, meets only one of the three criteria.

Further details on the reason for recommendation level for each scale given in the text.

Use of Scales for Different Study Purposes

Sleep scales have been used extensively in studies of PD. The choice of scale for clinical assessment or a particular research study largely depends on the specific aims of the study, and the area of sleep disturbance relevant to a particular study design. Some scales [such as the ESS and the Pittsburgh sleep quality index (PSQI)] with validated cut-offs are used to categorize patients as healthy or unhealthy and may be used to screen for general sleep disturbances; other scales, such as the Parkinson's disease sleep scale (PDSS), are intended to screen for the presence of many different sleep disorders found in PD patients and provide a general impression of their severity.[22] In addition, sleep scales are applied as an outcome measure to evaluate the response of a specific treatment, but only limited data are available for this use and this needs to be addressed in further studies.

SUBJECTS AND METHODS

Organization and Critique Process

The MDS Task Force on Rating Scales for PD Steering Committee appointed a task force of seven members to review the sleep scales that have been used in PD. The SSTF members include neurologists, sleep specialists, epidemiologists and a biostatistician from Europe and North America, all have extensive experience in assessing sPD.

Selection of Scales

The methods for this study are modeled on methodology used previously in a study on depression in PD,[23] and the rating of scales was based on the criteria used in recent task forces assessing apathy and anhedonia,[24] psychosis[25] or anxiety[26] in PD. A literature search was performed using Medline and PubMed. The keywords used in the search included: "(sleep OR sleepiness) AND (Parkinson OR parkinsonism OR Parkinson's OR Parkinson disease) AND (scale OR measure OR questionnaire)". All manuscripts (n = 214) published before March 20, 2007 were retrieved from Medline using these terms. These manuscripts were then thoroughly screened by the chair of the writing committee in order to ascertain whether a sleep scale or questionnaire had been used in each study, or whether scales contained at least one sleep item. As the objective of the task force was to examine sleep scales in PD, a specific literature search for the terms restless legs syndrome (RLS), RBD and other sleep disorders was not performed. From this search, a list of the sleep scales used in PD was drawn up with the corresponding studies in which these scales were reported. A total of 48 potential scales and questionnaires were identified. These were thoroughly screened by the task force and discussed in a phone conference with all members. Twenty scales were excluded at this step, because they focused on a different topic (e.g., quality of life instrument) and contained only one sleep item or question. Other exclusion criteria comprised data sets specifically created for one specific study (e.g., a set of three or four questions put together for an individual study objective only), or scales not in English. Twenty-eight scales were sent out to the task force members for full review. From those, another seven turned out not to meet inclusion criteria (e.g., unavailability of the total scale, published in abstract form only), a further two were considered to be variations of already included scales and thus were combined for further analysis. For final review, 19 scales were included. For analysis of each scale, a template was used modeled on the previous task forces. Only peer-reviewed papers on scales that had been used in PD patients were included for review.

Inclusion for Review

Scales at least used once in PD were included. Exclusion from review were non-English language scales, scales mentioned in review but not used in an original study, data sets only created for the sake of a specific study, as were data sets and questionnaires not available to the task force or not fully published (e.g., abstract only). Furthermore, scales that did not focus on sleep but on other topics such as quality of life (QoL) and contained no more than one or two sleep items were also excluded. For more details on inclusion and exclusion criteria see Supporting Information 1.

Criteria for Rating

The three criteria for final recommendations were: (1) Use in PD; (2) Use by groups other than the investigators who originally developed the scale; (3) Satisfactory clinimetric results (validity, reliability, sensitivity). Scales that met all 3 criteria are designated as recommended; those that meet criterion 1 and either criteria 2 or 3 are suggested; those that meet only criterion 1 are listed. Definitions for recommended, suggested, listed are given in Table 1.

RESULTS

Reviewed Scales

A total of nineteen scales were reviewed and attributed to the categories recommended, suggested or

listed as indicated above. Of these, six scales met the criteria for recommended or suggested, as appropriate for assessing sleep and/or daytime sPD: the PDSS,[22] the PSQI,[27] the SCOPA-sleep (SCOPA),[28] the Epworth sleepiness scale (ESS),[29] the inappropriate sleep composite score (ISCS), and the SSS.[30] Table 2 gives a brief summary of the six recommended or suggested scales, an extensive review is provided in Supporting Information 2. The remaining 13 scales, catergorized as listed are shown in Table 3 of Supporting Information 3.

PARKINSON'S DISEASE SLEEP SCALE (PDSS)

Constructs Being Measured

The PDSS is a self-rated scale designed to measure nocturnal problems, sleep disturbance and excessive daytime sleepiness in PD over the previous week.[22] The PDSS can be used to screen for daytime sleepiness and can also be used to ascertain the prevalence of general "sleep disturbance" in PD. The scale consists of 15 questions, addressing 15 commonly reported symptoms associated with nocturnal phenomena occurring in PD patients. Several of the items in the PDSS are not related to sleep per se, but to nocturnal disability impacting sleep. Each item is rated on a visual analogue scale (VAS) from 0 (severe and always present) to 10 (not present). The item scores are summed. Thus maximal scores reflect optimal sleep. Although the scale is brief, PD patients often require instruction on the VAS measure to ensure accurate reporting.

No cut-off score was reported in the original article.[22] The mean scores for the healthy controls were >5 on every item. The PD patients included in the study showed a mean score ≤ 5 for only one item (nocturia). One study has since used a cut-off of <5 for each item to indicate substantial sleep disturbance.[31] The current version of the scale does not use the subject's summed score, although a sum score has been calculated in treatment trials where the total score ranges from 150 (no sleep problems) to 0 (severely affected on all items). The use of a profile constituted of individual items rather than a summed score is based on the observation that some items will improve with the patient's condition, while others will not.

Clinimetric Properties (for More Extensive Details See Supporting Information 2)

Robust test-retest reliability has been shown (intraclass correlation coefficient [ICC] 0.94, lower 95% confidence limit 0.89, ICC range for individual items 0.61–0.99),[22,32] and good internal consistency (Cronbach's alpha, 0.77) with a significant item-total correlation for 11 items.[32] The incidence of floor and ceiling responses is low (1%).[32]

The PDSS has been extensively used in the PD population and differentiates between PD subgroups in early and advanced stages of the disease. Individual items accurately distinguish PD patients from healthy controls, and items of the PDSS correlate with PSG. In comparison to other scales, which do not address at all the multidimensional nature of sleep problems in PD, the PDSS makes the attempt to account for these. The PDSS has been applied to monitor treatment effects and demonstrated sensitivity to change.

Overall Assessment

The scale is in the public domain and, in addition to appearing in the original article,[22] it is widely available in review articles and chapters on sPD. It has been translated into Spanish[32] and Japanese[33] and validated in these languages. The PDSS, while particularly valuable for sleep screening purposes in PD, has not been designed as a diagnostic tool for PD-specific sleep disorders but to screen for nocturnal disturbance in PD. Due to its structure it is also useful for assessing severity of sleep disorders in PD. It has not been designed for, and is not sufficient to screen for specific sleep disorders in PD, such as sleep apnea, RBD or RLS. Based on its wide use beyond the group who has designed the scale, and available clinimetric studies even in PD, and its sensitivity to change, it meets criteria for a Recommended scale for the use in PD to assess nocturnal sleep impairment.

PITTSBURGH SLEEP QUALITY INDEX (PSQI)

Constructs Being Measured

The PSQI is a self-rating questionnaire designed to evaluate sleep quality, and to examine sleep habits and disturbances during the previous month. It consists of 19 questions that are combined to form seven component scores (subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction), each of which can be scored from 0 to 3 (no difficulty to severe difficulty), yielding a possible maximum score of 21, with higher scores indicating more severe difficulties in the different areas. A further five questions are available to be answered by the bed partner or roommate, and provide clinical information but do not contribute to the final score.

The PSQI has been used to evaluate the occurrence of sleep disturbance in the general PD population,[34–36] and in specific disorders associated with PD including RLS,[37] dementia,[38] excessive daytime sleepiness,[39] depression and anxiety[40] and hallucinations.[41] The PSQI has also been used to compare sleep quality of PD patients before and after treatment.[42–45]

Clinimetric Properties (for More Extensive Details See Supporting Information 2)

A Cronbach's alpha of between 0.80 and 0.83 has been reported for the PSQI in different studies and different populations,[27,46] indicating a high degree of internal consistency and internal homogeneity. Its Pearson's correlation coefficient for test-retest reliability was 0.87[47] and it has been shown to be stable over time.[27,48] Significant positive correlations between PSQI estimates and PSG results were not found, but the PSQI is highly correlated with the SCOPA-SLEEP scale. A global cut-off score >5 distinguishes between "good" and "poor" sleepers with good sensitivity and specificity. The PSQI has been reported to be sensitive to change.

Overall Assessment

The PSQI has been used in healthy groups[49] and different patient,[48,50,51] and cultural populations, including PD.[52,53] It is in the public domain. The PSQI can be used to screen for the presence of an important sleep alteration, and to rate severity. Based on its widespread used in and outside the PD population, and available clinimetric data the PSQI meets criteria to be recommended for use in PD to assess overall sleep abnomalities. Nevertheless, the PSQI is limited in its use in PD because it is heavily weighted towards sleep habits with inadequate coverage of sleep disturbances and daytime sleepiness. Some items of the PSQI are ambiguous and may be confusing.

SCOPA-SLEEP

Constructs Being Measured

The SCOPA (scales for outcomes in PD) is a short, practical self-rating scale designed to evaluate sleep quality and daytime sleepiness in patients with PD[28] but has not been widely used. The SCOPA includes three subscales: a nighttime scale (NS), a single-item quality of sleep scale and a daytime sleepiness scale (DS), and also incorporates the concept of sleep attacks (or sudden onset of sleep).

The NS is a five-item scale with four response options that address nighttime disturbances that occurred in the previous month. Subjects indicate the extent to which they were disturbed on a scale of 0 (not at all) to 3 (very much). The five items include 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.

In addition, quality of sleep is assessed using an additional question that evaluates overall sleep quality on a seven-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 but is used separately as a global measure of sleep quality.

The DS subscale evaluates daytime sleepiness in the past month and includes six items with four response options, ranging from 0 (never) to 3 (often). Subjects indicate how often they fell asleep unexpectedly, fell asleep in particular everyday situations, 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. The suggested cut-off score on the DS subscale is four to five.

Clinimetric Properties (for More Extensive Details See Supporting Information 1)

The reliability of both subscales was judged as good in evaluations: The internal consistency of the NS was demonstrated in the original study[28] where the Cronbach alpha was 0.88 (corrected item scale correlations, 0.48–0.85), and 0.84 in the Spanish study.[54] The Cronbach alpha of the DS was 0.91 (corrected item scale correlations 0.55–0.88) in the original study[28] and 0.75 in the Spanish study.[54] The test-retest reliability of the total score of the NS and DS was good (intraclass correlation coefficient [ICC] 0.94 [0.82–0.9] and 0.89 [0.49–0.82], respectively).[28]

The score on the NS scale of the SCOPA highly correlated with the PSQI and with the PDSS, whereas the score on the DS correlated with the ESS. A 6/7 score of the NS differentiated good sleepers from poor sleepers with good sensitivity and specificity, and a 4/5 score on the SCOPA DS was suggested to separate excessive daytime sleepiness from normal scores. The sensitivity of the SCOPA to change over time or to treatment has not been examined.

Overall Assessment

The SCOPA is a short, easy to use scale that has been used in two studies of PD patients. The scale is in the public domain. The original validation study

was conducted using a Dutch version, which was then officially translated into English for publication. A Spanish version is available in the aforementioned Spanish study.[54]

It is suitable for screening for sleepiness, sleep quality as well as the risk of sudden onset of sleep ("sleep attacks"). It is also useful for rating severity of nighttime sleep disturbance and daytime sleepiness. Based on the rating criteria the SCOPA fulfills criteria for a recommended scale in PD for rating overall sleep impairment and daytime sleepiness.

EPWORTH SLEEPINESS SCALE (ESS)

Constructs Being Measured

The ESS is a self-administered instrument designed to measure the general level of daytime sleepiness in adults. The ESS has been used in over 1,000 published studies to assess presence and severity of daytime sleepiness in both healthy subjects and those with primary sleep disorders, such as sleep apnea. The ESS has been used without modification since its first original publication in 1991.[29]

Completion of the ESS requires subjects to rate the likelihood that they will doze off in eight daily situations.[29] Each item of the scale is rated from 0 (would never doze), to 3 (high chance of dozing). The final score is the summation of the eight items, with a maximal total score of 24. If any of the situations mentioned in the scale have not been performed recently, then the subject is asked to "imagine their chances" of dozing in this situation. Hence, there is a low rate of noncompleted items.

For the ESS, cut-offs are available to detect pathological sleepiness: When used in healthy controls (n = 72), the distribution of total scores is Gaussian with a mean of 4.6 and a standard deviation (SD) of 2.8, giving a reference range of 0 to 10, coinciding with the 2.5 and 97.5 percentiles.[55] Another study in healthy controls (n = 188) reported a mean ESS of 4.5 ± 3.3, suggesting a reference range of 0 to 11 in this population.[56] ESS score severity is a continuum from normal to pathological sleepiness. A cut-off score > 10 has been used to distinguish (sensitivity, 93.5%; specificity 100%) healthy volunteers from patients with narcolepsy included in a large American study.[8] Usual values of ESS are available in most international classification of sleep disorders II (ICSD) categories. The time frame encompassed by the ESS varies from the last week to the last month. The ESS has been widely used in PD cohorts.

Clinimetric Properties (for More Extensive Details See Supporting Information 2)

The ESS has good clinimetric properties, with high test-retest correlation ($r = 0.82$), a high level of internal consistency as measured by Cronbach's alpha (0.88) and strong evidence for unidimensionnality.[57] In most studies the ESS score correlates significantly with the sleep-laboratory tests of somnolence (MSLT) in various sleep disorders, and it has shown sensitivity to change in several intervention studies.[58–60] Mean ESS scores in PD patients are usually higher than in controls.[16]

Overall Assessment

The ESS has been shown to be suitable for screening for sleepiness but unsuitable for screening for episodes of sudden sleep onset in PD patients. In patients with dementia, the ESS needs to be administered by a caregiver. The scale is in the public domain. It has been validated for use in PD and used in various translations.[61–63] It is useful to rate severity of daytime sleepiness and treatment effects. For pathological daytime sleepiness, a cut-off score of 10/11 has been proposed. Based on clinimetric testing and its manyfold use in PD, the ESS is recommended for use in PD for Daytime Sleepiness. However, a drawback to the ESS is the fact that sleep propensity measured by the ESS is self-assessed, which can be a limitation in some patients who may not be aware of short naps and are at higher risk of accidents. The ESS is influenced by numerous psychological factors, including anxiety, depression and somatisation.

INAPPROPRIATE SLEEP COMPOSITE SCORE (ISCS)

Constructs Being Measured

The ISCS is a face-to-face questionnaire, administered by clinical staff, designed to identify patients at risk of sudden onset of sleep (SOS) while driving. The time period referred to by the questionnaire is unspecified. The ISCS combines two items from the ESS with four additional items regarding falling asleep in unusual situations (item 9, "while driving;" item 10, "while eating a meal;" item 11, "while attending work;" item 12, "while attending to routine housework activities").[58] These additional items capture the more vigorous activities in which falling asleep has been described in PD patients.[64–68] The ISCS measures the probability of dozing during six active tasks and is

scored from 0 (never) to 3 (high chance). In addition, subjects are asked whether the sleep onset was sudden (0, never to 3, always), and whether they had blank spells (0, never to 3, more than once a week) during each of these activities.[58] The ISCS score range is 0 to18; however, in nondemented, active PD patients (n = 638) the score range was 0 to 11, with a median of 0.[58]

Clinimetric Properties (for More Extensive Details See Supporting Information 2)

The clinimetric properties of the ISCS are unknown and it has not been used in a non-PD population. The reliability of the ISCS is unknown as internal consistency has not been tested, and test-retest reliability was not given.[27,32] The ISCS is complementary to the ESS although there is overlap with two items of the latter (6 and 8). The ISCS is heavily weighted towards detecting falling asleep in unusual situations and has not been used in non-PD populations. The scale has not been validated against objective measures of sleepiness such as the MSLT or MWT.

Overall Assessment

The ISCS is a useful addition to the ESS, but requires further study as its clinimetric properties have not been adequately evaluated. The ISCS is focused to capture severe daytime sleepiness appearing even in active situations. The suggested cut-off of 1 can be used to screen, whereas the range from 0 to 18 probably also allows to rate the severity of severe daytime sleepiness and inappropriate sleep propensity even in active situations. It has been used beyond the group who developed it, but based on lacking clinimetric testing, the ISCS fulfills criteria for a suggested scale for the use in PD, but is restricted to evaluating severe daytime sleepiness.

STANFORD SLEEPINESS SCALE (SSS)

Constructs Being Measured

The SSS is a one-item, self-rating, seven-point Likert-type scale designed to assess subjective sleepiness. A high score indicates a high level of sleepiness. The subject is instructed to choose the set of descriptors that best describe his or her current feeling of sleepiness. The scale has been used in almost all sleep disorders to measure daytime sleepiness and fatigue at the time of the examination, but does not provide information over a longer time period.

Clinimetric Properties (for More Extensive Details See Supporting Information 2)

The clinimetric properties of the SSS have not been adequately studied. One study has suggested that two components be added to the scale as sleepiness is not an unidimensional construct.[69]

Some correlation between the SSS and three sleepiness-related VAS has been shown, but there is no correlation with the ESS,[70] The SSS has been shown to be sensitive to change in healthy subjects.[71] Few studies have assessed the sensitivity to change in PD with mixed results.

Overall Assessment

The SSS is a simple, and quick to use scale that is widely used for measuring sleepiness at specific time points. In contrast to the ESS, the SSS rates actual sleepiness as assessed at the moment. Despite its worldwide use, it has never been properly validated. The scale is in the public domain and has been translated for use in other languages The SSS has only been used in two studies in PD patients and has also not been validated for use in this population. The SSS is classified as a suggested scale for use in PD.

DISCUSSION

Conclusions and Recommendations

The six critiqued scales are useful in assessing aspects of sleep or daytime sleepiness in PD, and have been used to varying degrees in the PD population. All scales are considered to be in the public domain, and all except the ISCS and the PSQI are self-assessment scales. Each has been shown to have specific advantages and limitations in PD. Some focus more on insomnia (e.g., PSQI), others more on daytime sleepiness (e.g., ESS, ISCS) while the PDSS screens for many, but not all of the sleep disorders encountered in PD. The PDSS, PSQI, SCOPA and the ESS have all been shown to be recommended scales for use in sPD. Each has been studied clinimetrically, validated for use in PD and used by multiple investigators besides those who originally developed the scale. The ISCS has been validated in PD but has not been studied clinimetrically, but may be a useful addition to the ESS. The SSS has not been validated in PD and has not been studied clinimetrically.

All six scales have in common that they are weighted towards severity more than the mere presence of a sleep disturbance or daytime sleepiness, and four

of the six (namely ESS, ISCS, PSQI, and SCOPA) have proposed cut-offs.

None of the reviewed scales is appropriate and/or sufficient to diagnose a specific sleep disorder in PD (e.g., specific types of insomnia, RBD, RLS, sleep-related breathing disorders). They are not substitutes for a clinical interview on sleep disorders and nocturnal problems in PD, but those instruments can rate its severity and making it comparable within different patient groups. Some of the scales can be used as screening instruments for several sleep disturbances in PD (e.g., the PDSS). A structured sleep history (obtained in a direct semistructured interview) may especially require the presence of a bed partner or caregiver whenever possible, and in some cases a PSG or an apnea screening. Table 2 gives information about whether a scale is more focused on screening for the presence of sleep disturbance or on assessing its severity.

When assessing sleep or daytime sleepiness in PD the input of a bed partner or caregiver should be sought because of the well-known discrepancies between perception of sleep and sleep insomnia, perception of daytime sleepiness and involuntary dozing in excessive daytime sleepiness and the major impossibility for an individual to be aware of snoring and nocturnal behavior (unless informed by another). This is particularly the case in patients with PD and dementia where it is difficult to evaluate sleep quality. It is for this reason that the task force would recommend that further studies assess whether the PSQI, the ESS, and the SCOPA, all self-administered questionnaires, can be completed by caregivers or bed partners based on their perception of the patients sleep. It has been shown in the non-PD population, that patients usually self-rate their sleepiness lower than their partners.[72] The PDSS could be completed by caregivers by proxy, but this has not been validated. The SSS is also self-administered, but as it only assesses sleepiness at a specific moment in time and is therefore less dependent on memory.

The length of time for which sleep is evaluated varies among the scales. The ESS and ISCS are vague on this issue, the former refers to "recent times", while the latter uses the term "since disease onset", which in one of the cases was 11 years. The PSQI and the SCOPA refer to the last month, and the PDSS refers to the last week. None of these scales can therefore be used to assess sPD with oscillating motor states as "on" "off"" phenomena are transient lasting minutes to hours. The only scale that could possibly be used for this purpose is the SSS as is an "instantaneous" scale that evaluates sleep at the current time.

Because all scales are brief, the question arose if a combination of certain scales makes sense. This is definitely the case in the ISCS which has been designed to complement the ESS and should be used in tandem, and the PSQI and the ESS have been used together, but beyond this an added value of combination has not been demonstrated and might be diminished by overlap and different approaches. In the future, the task force would like to see scales that better reflect PD-specific problems and responsiveness to the effect of treatments on sleep disturbances. Moreover, the importance of optimum treatment of motor disturbances (both drugs and deep brain stimulation) in PD has been emphasized and should be evaluated.[73,74]

Areas Still not Adequately Addressed

Several unresolved issues remain. Concerning the effect of medication on sleep, the best scale to assess the different treatment effects has yet to be identified. In many sleep related aspects, such as RBD and daytime sleepiness, there is a need for combined scales to be used by both patients and caregivers, but which can be used by patients alone when bed partners or caregivers are not present. In addition, the many faces of sleep disorders in PD beyond insomnia or daytime sleepiness, such as sleep apnea, RBD, RLS, and circadian disorders, and the interference with nocturnal disabilities, motor and nonmotor symptoms, cannot be disentangled using a scale. A scale cannot replace a full sleep history with the patient and or caregiver, and in selected cases a overnight sleep study PSG. The task force recommends that some basic aspects of sleep training should be integral part of each movement disorder training, e.g., how to take a comprehensive sleep history, and how to interpret a written report of a sleep study (polysomnography).

Final Statement of the Task Force

The six scales presented can be used to assess night sleep (insomnia, sleep disturbance) and daytime sleepiness in patients with PD and to rate their severity. Scales focusing on specific other sleep disturbances occurring frequently in PD (such as RLS, RBD, sleep apnea syndrome) were not reviewed. The development of additional new scales for night sleep and daytime sleepiness is not a priority at the current time as the existing scales fulfil their purpose. Additional new scales, while potentially covering additional aspects, could contribute to further disperse the field making comparisons in the future even more difficult.

Addendum

Recently, the PDSS has been revised and the new version, PDSS-2, has been validated: Trenkwalder C, Kohnen R, Högl B, Metta V, Sixel-Döring F, Frauscher B, Hülsmann J, Martinez-Martin P, Chaudhuri KR: Parkinson's disease sleep scale – Validation of the revised version PDSS-2. Mov Disord 2010 (in press).

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