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Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale Presentation and Clinimetric Testing Results

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

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Abstract: We present a clinimetric assessment of the Movement Disorder Society (MDS)-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS). The MDS-UDPRS Task Force revised and expanded the UPDRS using recommendations from a published critique. The MDS-UPDRS has four parts, namely, I: Non-motor Experiences of Daily Living; II: Motor Experiences of Daily Living; III: Motor Examination; IV: Motor Complications. Twenty questions are completed by the patient/caregiver. Item-specific instructions and an appendix of complementary additional scales are provided. Movement disorder specialists and study coordinators administered the UPDRS (55 items) and MDS-UPDRS (65 items) to 877 English speaking (78% non-Latino Caucasian) patients with Parkinson's disease from 39 sites. We compared the two scales using correlative techniques and factor analysis. The MDS-UPDRS showed high internal consistency (Cronbach's alpha = 0.79–0.93 across parts) and correlated with the original UPDRS ($\rho = 0.96$). MDS-UPDRS across-part correlations ranged from 0.22 to 0.66. Reliable factor structures for each part were obtained (comparative fit index > 0.90 for each part), which support the use of sum scores for each part in preference to a total score of all parts. The combined clinimetric results of this study support the validity of the MDS-UPDRS for rating PD. © 2008 Movement Disorder Society

Key words: Parkinson's disease; rating scales; UPDRS; clinimetrics

The Unified Parkinson's Disease Rating Scale (UPDRS) was originally developed in the 1980s[1] and has become the most widely used clinical rating scale for Parkinson's disease (PD).[2] In 2001, the Movement Disorder Society (MDS) sponsored a critique of the UPDRS, and this document lauded the strengths of the scale but identified a number of ambiguities, weaknesses, and areas in need of inclusion to reflect current scientific developments.[3] The summary conclusions recommended the development of a new version of the UPDRS that would retain the strengths of the original scale, but resolve identified problems and especially incorporate a number of clinically pertinent PD-related problems poorly captured in the original version. Based on this critique, the MDS commissioned a revision of the scale, resulting in a new version, termed the MDS-sponsored UPDRS revision (MDS-UPDRS).[4] This scale successfully passed initial clinimetric testing[4] and was therefore submitted to a large-scale comparison with the original UPDRS. This report presents the MDS-UPDRS for the first time in published form and the clinimetric testing results of this large-scale program among native English speaking PD patients.

MDS-UPDRS (Table 1): The primary areas of revision were discussed in a prior publication.[4] First, whereas the original four component (Parts I–IV) design was retained, the focus of each part has been changed, and the data acquisition methodology has been both clarified and modified. Part I concerns "non-motor experiences of daily living," Part II concerns "motor experiences of daily living," Part III is retained as the "motor examination," and Part IV concerns "motor complications." Several questions from Part I and all questions from Part II have been designed to be amenable to a patient/caregiver questionnaire format and therefore can be completed without the investigator's input. For the remaining Part I questions that deal with complex behaviors and all questions in Part IV that deal with motor fluctuations and dyskinesias, the investigator is required to conduct the interview. Part III retains the objective assessments of parkinsonism, but all tasks now have specific instructions. Rater involvement time for administering the MDS-UPDRS is estimated to require less than 10 min for the interview items of Part I, 15 min for Part III, and 5 min for Part IV, resulting in an equivalent rater time investment to the original scale and meeting the 30-min goal. The remaining questionnaire items are answered by the patient or caregiver and, other than supervision, do not involve rater time. Whereas the detailed assessments still prioritize the motor aspects of PD, the screening questions on nonmotor elements are designed to capture both the presence and severity of clinically pertinent problems in this domain.

Each question is anchored with five responses that are linked to commonly accepted clinical terms: 0 = normal, 1 = slight, 2 = mild, 3 = moderate, and 4 = severe. After each clinical descriptor, a short text follows, which describes the criteria for each response. Whereas each response is tailored to the question, the progression of disability or impairment is based on a consistent infrastructure. "Slight" (1) refers to symptoms/signs with sufficiently low frequency or intensity to cause no impact on function; "mild" (2) refers to symptoms/signs of frequency or intensity sufficient to cause a modest impact on function; "moderate" (3) refers to symptoms/signs sufficiently frequent or intense to impact considerably, but not prevent, function; "severe" (4) refers to symptoms/signs that prevent function.

The full MDS-UPDRS contains questions/evaluations (Table 1), divided across Part I (13), Part II (13), Part III (33 scores based on 18 items, several with right, left or other body distribution scores), and Part IV (6). The MDS-UPDRS rates 65 items in comparison

TABLE 1. *Conceptual mapping of items and scores from the original UPDRS to the MDS-UPDRS*

MDS-UPDRS item	Original UPDRS item	General concepts for mapping ratings from the original UPDRS to MDS-UPDRS (UPDRS→MDS-UPDRS)
Part I		In the MDS-UPDRS, the conceptual construct focuses on the impact rather than the presence of symptoms, and whereas there is a general parallelism between UPDRS and MDS-UPDRS, this emphasis needs to be considered at all times by the rater and/or patient.
Cognitive impairment	Intellectual impairment	General conceptual comparison, although the emphasis is different in the two versions: 0→0; 1→2 (option 1 on MDS-UPDRS is new and not captured in original scale); 2→3; 3→4; 4→4
Hallucinations and psychosis	Though disorder	0→0; 1→0 (vivid dreams not part of this question in MDS-UPDRS); 2→1 or 2; 3→3; 4→4
Depressed mood	Depression	General conceptual comparison, although the emphasis is different in the two versions: 0→0; 1→1; 2→2; 3→3; 4→4
Anxious mood[a]		New item: No comparison
Apathy	Motivation/initiative	General conceptual comparison, although the emphasis is different in the two versions: 0→0; 1→1; 2→2; 3→3; 4→4
Features of dopamine dysregulation syndrome[a]		New item: No comparison
Nighttime sleep problems[a]	Sleep disturbances	0→0; 1 on UPDRS could be 0 (if the patient had only daytime sleepiness) or any of the available ratings on the MDS-UPDRS
Daytime sleepiness[a]	Sleep disturbances	0→0; 1 on UPDRS could be 0 (if the patient had only nighttime sleep problems) or any of the available ratings on the MDS-UPDRS
Pain and other sensations	Sensory complaints related to parkinsonism	General conceptual comparison, although the emphasis is different in the two versions: 0→0; 1→1; 2→2; 3→3; 4→4
Urinary problems[a]		New item: No comparison
Constipation problems[a]		New item: No comparison
Lightheadedness on standing[a]	Symptomatic orthostasis	0→0; 1→1,2,3,4 depending on severity
Fatigue[a]		New item: No comparison
Part II		As in Part I, for the MDS-UPDRS, the conceptual construct focuses on the impact rather than the presence of symptoms, and whereas there is a general parallel between UPDRS and MDS-UPDRS, this emphasis needs to be considered at all times by the rater and/or patient.
Speech	Speech	0→0; 1→1; 2→2, 3→3, 4→4
Salivation and drooling	Salivation	0→0; 1→2 (option 1 on MDS-UPDRS new and not captured in original scale; 2→3; 3→3; 4→4
Chewing and swallowing	Swallowing	General conceptual comparison, although the emphasis is different in the two versions: 0→0; 1→3 (options 1 and 2 on MDS-UPDRS are new and not captured well by the original scale); 2→3; 3→2; 4→4
Eating tasks	Cutting food and handling utensils	0→0; 1→1; 2→2; 3→3; 4→4
Dressing	Dressing	0→0; 1→1; 2→2; 3→3; 4→4
Hygiene	Hygiene	Although MDS-UPDRS focuses on all tasks and does not limit questions to tasks mentioned in UPDRS, general parallelism exists for the two: 0→0; 1→1; 2→2; 3→3; 4→4
Handwriting	Handwriting	The MDS-UPDRS emphasizes clarity of writing, not size, but a general parallelism exists for the two scales: 0→0; 1→1; 2→1; 3→2 or 3; 4→4
Doing hobbies and other activities[a]		New item: No comparison
Turning in bed	Turning in bed and adjusting bed clothes	The MDS-UPDRS emphasizes regularity of help needed, but a general parallelism exists for the two scales: 0→0; 1→1; 2→2 or 3; 3→3 or 4; 4→4
Tremor	Tremor	The MDS-UPDRS emphasizes interference from tremor, but a general parallelism exists for the two scales: 0→0; 1→1; 2→2; 3→3; 4→4
Getting out of bed, car, or deep chair[a]		New item: No comparison
Walking and balance	Walking	0→0; 1→1; 2→1 or 2; 3→3 or 4; 4→4
Freezing	Freezing when walking	Conceptually, the focus of the MDS-UPDRS is different from the UPDRS because the need for assistance is emphasized in the MDS-UPDRS rather than the consequence (falls) that will depend on availability of help. Only partial parallelism can be drawn on this question: 0→0; 1→1; 2→2,3,or 4; 2→2, 3, or 4; 4→2, 3, or 4
	Falls	This item is not part of the MDS-UPDRS because it is not a normal "experience of daily living." Falling is assessed in Part III

TABLE 1. (*Continued*)

MDS-UPDRS item	Original UPDRS item	General concepts for mapping ratings from the original UPDRS to MDS-UPDRS (UPDRS→MDS-UPDRS)
Part III		
Speech	Speech	0→0; 1→1; 2→2; 3→3 or 4; 4→4
Facial expression	Facial expression	0→0; 1→1; 2→2; 3→3; 4→4
Rigidity of neck and four extremities[b]	Rigidity	Conceptually, the focus of the question has been changed to emphasize resistance to passive movement with greater clarity. Partial parallelism can be suggested: 0→0; 1→1; 2→2; 3→2; 4→3; 4 rating on the MDS-UPDRS is not captured by the original UPDRS
Finger taps[b]	Finger taps	The original UPDRS had descriptors (mild, moderate, severe), that fit better with the current designations of slight, mild and moderate, creating difficulties with a direct parallelism, but the task descriptions allow parallelism: 0→0; 1→1 or 2; 2→2 or 3; 3→3; 4→4
Hand movements[b]	Hand movements	See "finger taps" for explanation: 0→0; 1→1 or 2; 2→2 or 3; 3→3; 4→4
Pronation/supination[b]	Pronation/supination	See "finger taps" for explanation: 0→0; 1→1 or 2; 2→2 or 3; 3→3; 4→4
Toe tapping[b]		New item; no comparison
Leg agility[b]	Leg agility	See "finger taps" for explanation: 0→0; 1→1 or 2; 2→2 or 3; 3→3; 4→4
Arising from chair	Arising from chair	0→0; 1→1; 2→2; 3→3; 4→4
Gait	Gait	0→0; 1→1; 2→2; 3→3 or 4; 4→4
Freezing of gait[a]		New item: no comparison from original scale
Postural stability	Postural stability	0→0; 1→1 or 2; 2→3; 3→4; 4→4
Posture	Posture	0→0; 1→1; 2→2 or 3; 3→4; 4→4
Global spontaneity of movement	Body bradykinesia	0→0; 1→1; 2→2; 3→3; 4→4
Postural tremor of hands[a,b]	Action/postural tremor	The MDS-UPDRS separates these two forms of tremor and focuses only on amplitude, so there is no parallelism between the original and new versions Re-emergent tremor is rated as part of postural tremor (see Discussion)
Kinetic tremor of hands[a,b]	Action/postural tremor	
Rest tremor amplitude[b]		The MDS-UPDRS separates two features of rest tremor (amplitude and consistency), so there is no parallelism between the original and new versions
Constancy of rest tremor[a]		New item: no comparison. Tremor consistency was considered in original UPDRS but combined with amplitude, making the assessment ambiguous
Part IV		
Time spent with dyskinesia	Dyskinesia duration	0→0; 1→1; 2→2; 3→3; 4→4
Functional impact of dyskinesias		MDS-UPDRS provides written anchors whereas the UPDRS uses only "mild, moderate, severe, marked." 0→0; 1→2 (option 1 on MDS-UPDRS new and not captured in original scale); 2→3; 3→4; 4→4
Time spent in the OFF state	Off duration	0→0; 1→1; 2→2; 3→3; 4→4
Functional impact of fluctuations		New item: no comparison. Written to run in parallel with Function impact of dyskinesias
Complexity of motor fluctuations[a]	Offs predictable (yes/no) Offs unpredictable (yes/no) Offs sudden (yes/no)	MDS-UPDRS consolidates concepts covered by several yes/no questions on UPDRS. There is no simple mapping for this reason
Painful OFF-state dystonia	Presence of early morning dystonia (yes/no)	0→0; 1→1, 2, 3, or 4

Many items have shifted emphasis with the MDS-UPDRS, but this guide shows the general concept behind the two scoring systems and can be used as a reference. The mapping table is a guide and not recommended as an automatic transfer for scores from one scale to the other. Gray box marks items covered by patient/caregiver questionnaire without direct input from the investigator.

[a]Domains not previously assessed with 0 to 5 ratings.

[b]Items with right and left measurements.

to 55 on the original UPDRS, 48 that had 0 to 4 options and 7 with yes/no responses.

Nine new items in the MDS-UPDRS were not captured in any form on the original scale: anxious mood, dopamine dysregulation syndrome, urinary problems, constipation, fatigue, doing hobbies, getting in and out of bed, toe tapping, and freezing (objective rating). Lightheadedness was assessed in the original UPDRS as present or absent, but in the MDS-UPDRS, the symptom is assessed with the 0 to 4 rating system. Nighttime sleep problems and daytime sleepiness are assessed in the MDS-UPDRS and the yes/no sleep dis-

turbances option is replaced from the original UPDRS. The question on Complexity of Motor Fluctuations in the MDS-UPDRS merges the three yes/no questions related to predicable, unpredictable, and sudden OFF period from the UPDRS. In regards to tremor, the original Action/Postural Tremor question has been divided into two questions focusing on each component of tremor separately. For rest tremor, whereas the UPDRS combined amplitude and constancy of tremor into its descriptors, on the MDS-UPDRS the severity ratings for each body part concern only the amplitude and a separate question rates the constancy.

Direct item-to-item mapping from the original UPDRS to the MDS-UPDRS was not envisioned to be possible, because the two scales were not conceptually identical. Nonetheless, because the new version was directly based on the original scale, a number of parallels and guidelines were utilized in the construction of the MDS-UPDRS. For some questions, the insertion of slight/mild/moderate/severe was sufficient to realign the rating options. In some cases, however, because the original scale often used "mild/moderate/severe/marked" the former rating of 1 (mild) now could be separated into two choices (slight 1 or mild 2) in the MDS-UPDRS. In such cases, the former moderate scores (2) advanced to 3 in the MDS-UPDRS and the former severe (3) and marked (4) were collapsed into one option (severe 4) in the MDS-UPDRS. In other cases, adjustments in the mid-ranges (2 and 3) were felt to be necessary in order to maintain a consistent conceptual framework of slight/mild/moderate/severe in the MDS-UPDRS. This decision to shift from mild/moderate/severe/marked to slight/mild/moderate/severe as the scale's clinical construct was anchored in two concepts: first, that many clinical trials focus on early PD where change among scores of normal, slight, and mild problems are important to document; and, second, that at the high range of impairment or disability (formerly severe and marked), functional differences may not be clinically relevant. Another conceptual anchor of the MDS-UPDRS, especially apparent in Parts I, II, and IV was the progressing disability from none (0) to a perception of the problem without interference (slight 1), to interference with isolated activity (mild 2), to interference with normal activity (moderate 3), to preclusion of normal activity (severe 4). This process was not utilized consistently in the original UPDRS, although parallels could be constructed between the two versions in many cases. Yes/no questions from the original Part IV were reformatted and refined to fit the 0 to 4 rating format of the rest of the scale in the MDS-UPDRS, so that a partial parallelism between the two versions could be mapped. New items that assessed features not assessed in the original UPDRS could not have any mapping possibility from the original scale. With these caveats, general mapping patterns between the two scales were outlined to allow a guide to raters making the transition between the UPDRS and the MDS-UPDRS, but were not constructed with the aim of allowing automatic substitution (Table 1). As part of the clinimetric plan, however, a review of score ranges for each part of the MDS-UPDRS was planned to be tested against the original version (see below).

ON and OFF definitions are provided to ensure uniformity among raters and the score sheet documents the ON/OFF status associated with the Part III assessment. For Parts I and II, the official scale will not separate ON from OFF, but, for special studies, the same questions can be asked separately for ON or OFF periods. Throughout the MDS-UPDRS, specific instructions are provided to enhance a uniform application. Finally, questions have been written to be culturally sensitive and applicable to patients of different ethnic and social backgrounds.

As an ongoing process, at the end of the MDS-UPDRS, clinicians and researchers are directed to an Appendix of Additional Scales. This portion of the MDS-UPDRS is not considered a static document, but, instead, it will be updated as deemed appropriate by the MDS Task Force of Rating Scales for PD (see Supp. Info. Appendix 1 for listing of scales). This appendix is designed to direct clinicians and research investigators to scales that cover in greater detail the components of the MDS-UPDRS that are only assessed with single items. The Task Force has previously published assessments of scales for depression and psychosis, and others are planned.[5,6] These assessments use a standard set of criteria to establish Recommended and Suggested scales in an effort to encourage reporting in a consistent manner and to facilitate comparisons among different reports. For items that have not had official Task Force reports, the subcommittee of the MDS-UPDRS dedicated to the Appendix has reviewed scales using the same criteria (Cristina Sampaio, chairperson).

CLINIMETRIC TESTING PROGRAM

Methods

Based on successful preliminary testing,[4] the MDS-UPDRS validation program was designed to test the scale's intrinsic attributes, including internal consistency, factor structure, differential item functioning, and its comparability with the original UPDRS.

We recruited movement disorder specialists and experienced study coordinators to examine PD patients with both scales. Special attention was focused on recruitment of diverse race/ethnicity representations. Native English speakers (both raters and patients) participated. To complete separate clinimetric analyses within each racial/ethnic group, a minimal sample size of 650 per racial/ethnic group was desirable assuming that at least 10 observations per item were required.[7] After obtaining individual IRB approval, each participating site recruited patients to undergo both the UPDRS and MDS-UPDRS in a single setting. Participation was based on a commitment to rate between 10 and 20 subjects who covered the range of mild to severe PD, based on clinical judgment. Scores were sent to a central database electronically and verified for completeness. Queries were resolved between the statistical center and individual raters, and once completed, a given case was entered into the full data set and double-checked for accuracy.

Statistical Analyses

To describe patient demographics, we computed means, standard deviations, and ranges. To assess relationships between the new and original version, we computed Pearson's correlations between the MDS-UPDRS and the UPDRS for total score and for each part. Correlations were computed to assess the relationships among the parts of the MDS-UPDRS. As a measure of internal consistency (reliability), Cronbach's alpha was calculated for each part. Further, floor and ceiling effects were examined by calculating the percentage of lowest and highest possible scores for each part. *Mplus v. 4.21*[8] was used for the factor analysis using polychoric correlations because of the ordinal nature of the data.

The factor analysis was run in two parts. An exploratory factor analysis (EFA), informed by eigenvalues and Scree plots, was used to determine the number of factors that best represents the data. A factor loading cutoff of 0.40 was used to determine those items to retain in a factor. As a second step, a confirmatory factor analysis (CFA) was used in the assessment of dimensionality, with a comparative fit index (CFI) $\geq$ 0.90 defined as an acceptable fit. If the CFI was less than 0.90, each factor was examined to identify poorly behaved items, i.e., those with high loadings on more than one factor.[9] Based on the review of the items and the model fit statistics, additional EFAs and CFAs were run. The process was repeated until the most parsimonious model was found with a CFI $\geq$ 0.90. We assessed the entire scale as a single factor structure, each part as a separate set of factors, and all combinations of parts.

Results

Patient Sample

A total of 877 native English-speaking PD patients were examined with the UPDRS and MDS-UPDRS (560 men and 317 women). There were 682 non-Latino Caucasians and 195 (22%) of other race/ethnicity, specifically 49 African Americans, 87 Latinos, 1 native Hawaiian, 43 Asians, and 15 with other race/ethnicities. All Hoehn and Yahr stages were represented, with the majority of patients being stages II (stage I = 63, stage II = 467, stage III = 174, stage IV = 109, stage V = 53, missing 11). The mean age of the cohort was 68.2 years (SD: 10.8; range: 31–98), and the mean PD duration was 8.3 years (SD: 6.7; range: 0–40 years). Fifty-seven patients were not treated with antiparkinsonian medications. A total of 685 patients were treated with levodopa in combination with another symptomatic treatment for PD, 115 patients were on symptomatic therapy without levodopa, 5 patients were on levodopa alone, and 15 had missing treatment information. Motor fluctuations were observed in 483 patients and 304 patients had dyskinesia. A total of 723 were examined in the ON state and 99 in the OFF state, while ON/OFF information was not recorded for 55 patients.

Rater Sample

There were 69 raters from 39 English-speaking treatment centers (USA, 32; Canada, 2; UK, 5) who evaluated patients with the original and MDS-UPDRS instruments (see listing at end of manuscript). All raters were physicians or nurse coordinators regularly working with PD patients, regularly using the UPDRS for clinical care or research purposes, and all were recruited through the MDS. Raters were instructed to perform the UPDRS in their standard manner and to use the MDS-UPDRS following the instructions embedded in the new scale for each item. The choice of patients was left to the raters, but emphasis was placed by the Task Force team on recruitment of a maximal number of patients who were of a race/ethnicity other than non-Latino Caucasian with a full breadth of Hoehn and Yahr stages. The mean number of cases submitted by each rater was 11.4 (SD: 8.2; range: 1–29).

Clinimetric Profile of MDS-UPDRS

Internal consistency was computed for each of the MDS-UPDRS parts [Part I (13 items), alpha = 0.79;

TABLE 2. *Factor structures of the four parts of the MDS-UPDRS*

Factor	Item	Item factor loading
Part I: Nonmotor aspects of experiences of daily living (CFI = 0.94, RMSEA = 0.06)		
Factor 1	*Percent variance = 32.7*	
	Daytime sleepiness	0.57
	Sleep problems	0.40
	Cognitive impairment	0.48
	Pain and other sensations	0.48
	Hallucinations and psychosis	0.40
	Urinary problems	0.59
	Constipation problems	0.49
	Features of DDS	0.49
	Light headedness on standing	0.45
	Fatigue	0.54
Factor 2	*Percent variance = 9.8*	
	Depressed mood	0.83
	Anxious mood	0.66
	Apathy	0.53
Part II: Motor aspects of experiences of daily living (CFI = 0.95, RMSEA = 0.09)		
Factor 1	*Percent variance = 53.0*	
	Speech	0.79
	Saliva and drooling	0.45
	Chewing and swallowing	0.60
	Handwriting	0.45
	Doing hobbies and other activities	0.45
Factor 2	*Percent variance = 8.7*	
	Eating tasks	0.68
	Tremor	0.43
Factor 3	*Percent variance = 7.7*	
	Dressing	0.64
	Hygiene	0.64
	Turning in bed	0.65
	Getting out of bed	0.73
	Walking and balance	0.82
	Freezing	0.76
Part III: Motor examination (CFI 0.91, RMSEA = 0.10)		
Factor 1	*Percent variance = 36.8*	
	Speech	0.59
	Facial expression	0.53
	Arising from chair	0.77
	Gait	0.87
	Freezing of gait	0.83
	Postural stability	0.81
	Posture	0.70
	Global spontaneity of movement	0.64
Factor 2	*Percent variance = 15.1*	
	Rest tremor amplitude, RUE	0.72
	Rest tremor amplitude, LUE	0.71
	Rest tremor amplitude, RLE	0.73
	Rest tremor amplitude, LLE	0.71
	Rest tremor amplitude, lip/jaw	0.59
	Constancy of rest tremor	0.88
Factor 3	*Percent variance = 6.4*	
	Rigidity, neck	0.67
	Rigidity, RUE	0.73
	Rigidity, LUE	0.74
	Rigidity, RLE	0.80
	Rigidity, LLE	0.81
Factor 4	*Percent variance = 6.1*	
	Finger tapping, right hand	0.67
	Hand movements, right hand	0.66
	Pronation/supination, right	0.68
Factor 5	*Percent variance = 4.8*	
	Finger tapping, left hand	0.69
	Hand movements, left hand	0.72
	Pronation/supination movements, left	0.65
Factor 6	*Percent variance = 4.6*	
	Postural tremor, right hand	0.66
	Postural tremor, left hand	0.72
	Kinetic tremor, right hand	0.81
	Kinetic tremor, left hand	0.80
Factor 7	*Percent variance = 3.3*	
	Toe tapping, right foot	0.65
	Toe tapping, left foot	0.63
	Leg agility, right leg	0.64
	Leg agility, left leg	0.62
Part IV: Motor complications (CFI = 1.0, RMSEA = 0.05)		
Factor 1	*Percent variance = 63.6*	
	Time spent in the OFF state	0.87
	Functional impact of fluctuations	0.84
	Complexity of motor fluctuations	0.83
	Painful OFF state dystonia	0.49
Factor 2	*Percent variance = 15.6*	
	Time spent with dyskinesias	0.72
	Functional impact of dyskinesias	0.94

CFI, comparative fit index; RMSEA, root mean square error of approximation.

Part II (13 items), alpha = 0.90; Part III (33 items), alpha = 0.93; Part IV (6 items), alpha = 0.79]. Mean scores (SD) for each part were: Part I: 11.5 (7.0); Part II: 16.0 (10.0); Part III: 36.8 (18.4); Part IV: 4.0 (4.2). The distributions of the total scores in the MDS-UPDRS and original UPDRS were similar: UPDRS mean: 61.0 (SD: 30.3), covering 55 items; MDS-UPDRS mean: 68.4 (SD: 32.8), covering 65 items. The MDS-UPDRS showed strong concurrent validity based on high correlations between the two scales (total score r = 0.96), as well as between the individual parts of the two scales: [Part I, r = 0.76; Part II, r = 0.92; Part III, r = 0.96; Part IV (sum of items 32–39 covering dyskinesias and motor fluctuations on the UDPRS vs. total Part IV from the MDS-UPDRS), r = 0.89]. As a measure of internal validity, correlations among the MDS-UPDRS parts were examined. These analyses confirmed that each part assesses a different aspect of PD, with most parts, except Parts I and II, having relatively low correlations (Parts I and II, r = 0.67; Parts I and III, r = 0.43; Parts I and IV, r = 0.39; Parts II and IV, r = 0.44; Parts III and IV, r = 0.22). As anticipated, Parts II and III that covered patient perceptions of motor function and the objective examination were more highly correlated (r = 0.66). Our analysis for possible floor and ceiling effects demonstrated a low percentage of lowest and highest scores for Parts I

to III: Part I, lowest 0.1%/highest 0.8%; Part II, lowest 0.1%/highest 0.7%; Part III, lowest 0.1%/highest 0.2%. In the case of Part IV, covering the presence and severity of motor complications, there was an expected floor effect, but no ceiling effect: lowest 36.7%/highest 0.1%. (see Supp. Info. Appendix 2 for histograms of each part).

Factor Structure

Exploratory testing of the combined four parts of the MDS-UPDRS did not identify a single factor structure that could be confirmed (CFI = 0.74). A factor structure combining Parts II and III was explored, but could not be confirmed. Several items had salient loadings on more than one factor and some items did not load on any factor. A factor structure was also explored for the combination of Parts II to IV. A factor structure with 12 factors was identified by the EFA; however, the CFI was <0.90, too low to provide confirmation. As seen earlier, several items had salient loadings on more than one factor, and some items did not load on any factor. These combined results preclude using a total MDS-UPDRS score or scores based on combinations of parts.

We then analyzed the MDS-UPDRS parts individually (see Supp. Info. Appendix 3 for Scree plots). This analysis and the confirmatory analysis identified a factor structure that was statistically consistent (CFI for each part was >0.90) and clinically meaningful (Table 2) for all parts. For Part I (CFI = 0.94), two factors were identified, one covering depression, anxiety, and apathy and the other covering the other nonmotor functions (shared variance = 42.5%). For Part II (CFI = 0.95), three factors were identified, one covering several fine motor functions, one covering tremor and eating tasks, and one focusing on several large motor functions (shared variance = 69.4%). For Part III (CFI = 0.91), seven factors were identified: midline function, rest tremor, rigidity, bradykinesia right upper extremity, bradykinesia left upper extremity, postural and kinetic tremors, and lower limb bradykinesia (shared variance 77.1%). For Part IV (CFI = 1.0), two factors were identified, one focusing on fluctuations including off-state dystonia and the other on dyskinesias (shared variance = 79.2%). Intercorrelations among factors for each part ranged from 0.04 to 0.71, indicating both unique and shared information provided by the different factors.

DISCUSSION

The MDS-UPDRS was designed to be more comprehensive than the original UPDRS, with new items devoted to several nonmotor elements of PD.[3,4] The choice of the new items was based on input from the Task Force committee members, patient groups, and MDS members. Based on the published critique of the UPDRS,[3] the five-point range for each item was retained, and clinical anchors of normal (0), slight (1), mild (2), moderate (3), and severe (4) were added to provide a consistency across items. Importantly, the MDS-UPDRS places greater emphasis on distinguishing relatively mild impairments and disabilities, drawing distinctions between slight and mild, whereas former distinctions between severe and marked are now collapsed into the severe rating (4). This decision was anchored in the realities that clinical trials are focusing increasingly on early disease, and functional differences between severe and marked impairments from the original scale may not be clinically relevant. As a result of this decision, for several items in the MDS-UPDRS, moderate impairment and disability is now rated as 3 instead of 2.

An important addition to the MDS-UPDRS is a set of detailed instructions. Because the MDS-UDPRS is envisioned to be the primary international rating scale for PD clinical care and research, an emphasis was placed on clear and detailed descriptions of methods for data acquisition. These are officially part of the scale, so that international colleagues can perform ratings in a systematic manner within and across centers. The instructions are intended to standardize the method of application of the scale so that the MDS-UPDRS data are collected uniformly. The scale has not yet been translated into non-English editions, and this effort will start in 2008 through the MDS. A clinimetric program for each language edition is planned and the Task Force will offer statistical assistance.

The MDS-UPDRS involves participation by patients and caregivers for the assessment of several nonmotor and motor experiences of daily living. These questions were written at seventh grade level and extensively tested in patient focus groups. The question on fatigue was included based on patient responses that this symptom has a high impact on health-related quality of life and was not otherwise captured in the scale. Because cognitive impairments frequently occur in PD, the questionnaire was designed to be completed by the patient alone, with the input of caregivers, or by the caregiver alone, depending on patient/caregiver preference.

Given the number of items to be assessed in the MDS-UPDRS, the patient sample required for adequate statistical analysis was large. We were, however, successful in recruiting colleagues internationally from

English-speaking centers to help in this important effort. These colleagues were able to identify and examine PD patients across the spectrum of disabilities. Investigators were asked to select a gamut of severities among PD patients and to be attentive to obtaining diversity in gender and race/ethnicity. The distribution of this data set in terms of disease severity, drug treatment, gender, and ethnic balance should not be considered to be representative of the investigators' overall practice population, because the composition reflects an effort to have a clinically reasonable number of cases in different categories to test the clinimetric properties of the scale. Nonetheless, the majority of patients were Hoehn and Yahr stages II and III, a pattern seen in cross-sectional analyses in early, mid, and late disease.[10] Based on the wide range of severities sampled and the distribution of high and low scores within each part, we are confident that the MDS-UPDRS is not limited by floor or ceiling effects.

We placed special emphasis on the recruitment of subjects of diverse race/ethnicity. Although we did not achieve our goal of 650 per racial/ethnic group, we did succeed in involving a much higher percentage of subjects of race/ethnicity other than non-Latino Caucasian (N = 195, 22% of our total sample) than the usual 0% to 10% reported in clinical trials (personal communication, M. Schneider and C. Swearingen). Other than non-Latino Caucasians, we did not have enough participants in any one racial or ethnic group to conduct statistical analyses within any specific subgroup. Efforts to enhance diversity in clinical trials of PD is a focus of US government funding,[11] and this program demonstrates that PD investigators are able to exceed current performance in clinical trials. To continue to enhance this data set, the statistical center for the program (e-mail: tilleybc@musc.edu) will continue to accept additional ratings of the UPDRS vs. MDS-UPDRS for those patients other than non-Latino Caucasians.

The clinimetric analysis supports the reliability and validity of the MDS-UPDRS. It performs extremely well in comparison with the original version with high internal consistency for the entire scale as well as high internal consistency on each part. In addition, even though restructured, each part of the MDS-UPDRS correlates highly with the corresponding part of the original scale. The scaling modifications and item additions to the MDS-UPDRS provide new information while still capturing the features of PD from the original scale. On the other hand, because the item responses (0, 1, 2, 3, 4) have been substantially modified in terms of wording and concept, we cannot provide an algorithm with point-to-point or summary conversion numbers.

The technique of factor analysis is a particularly strong clinical/statistical method for scale evaluation, because it tests whether items cluster and allows clinicians to determine if these clusters fall into components that represent clinically relevant domains. Furthermore, it allows statistical assessment of whether the clusters correlate and thereby capture information about the overall entity being studied, in this case, PD. The MDS-UPDRS has excellent factor validity, and the factor analysis confirms that the items cluster in clinically pertinent domains. Because data are collected using three different methods, some based exclusively on patient or caregiver responses (questionnaire), some based solely on the investigator's assessments (motor examination), and some with a combination (complex behaviors and motor complications), we did not anticipate that the total score (combined Parts I–IV) would likely be a recommended outcome. Although the high correlation between the total scores on the original UPDRS and MDS-UPDRS demonstrates that the two scales are measuring the same overall entity of PD, the MDS-UPDRS factor analysis confirmed that neither the combined parts nor combinations based on different acquisition methods have a stable factor structure. However, when each part is considered separately, the factor structures are both clinimetrically sound and clinically pertinent. In this light, we recommend that each of the parts (I–IV) should be reported separately and not collapsed into a single "Total MDS-UPDRS" summary score.

Comparing the factor structure of Part III of the MDS-UPDRS to published factor analyses of the original UPDRS,[12] the MDS-UPDRS identifies lower limb bradykinesia as a new factor, likely because of the addition of toe tapping as a separate rating. Attention was directed to separating postural from kinetic tremor, and extensive discussion within the group focused on the placement of "reemergent rest tremor." Because reemergent tremor interferes with the holding of objects against gravity, this tremor was relegated to postural tremor.[13] Despite these deliberations, the factor structure identified postural and kinetic tremors as a single factor and the rest tremor was distinct from this factor.

The final step in the clinimetric analysis will involve an assessment of differential item function (DIF). Although this type of analysis was never performed on the original UPDRS, our large sample size and available statistical programs will allow this level of scrutiny for all items. DIF is defined as group differences in item response, conditional on the state or trait assessed. As an example, if in two groups defined by

gender, one rarely endorsed a high score for an item, while the other often endorsed a high score, but the two had similar scores on the overall part, this difference suggests that gender has an influence on the item interpretations or responses. DIF may be due to group differences in neurological burden, comprehension, adaptation, or bias. There are two types of DIF: uniform and nonuniform. Uniform DIF is present when item thresholds differ between the groups, but the slopes are parallel on the item characteristic curves. Nonuniform DIF is present when the two curves do not follow a linear progression across the rating options. The presence of either form of DIF would suggest that the item in question does not perform the same in different groups of the patient sample. We plan to examine three patient characteristics for the DIF analysis in our study sample: gender, race/ethnicity, and age. If DIF is identified, future modifications will be considered and tested in subsequent phases of our clinimetric program (see below). In this light, although we present the MDS-UPDRS for immediate application in clinical settings, we emphasize that the scale will continue to be evaluated and that further refinements may develop in the future based on additional and ongoing clinimetric analyses.

The Appendix of Additional Scales is officially part of the MDS-UPDRS and directs clinicians and researchers to scales that focus in more detail on areas of disability that are considered as single-item questions on the MDS-UPDRS. The MDS Task Force on Rating Scales in PD has initiated a number of critiques of available scales dealing with different areas of dysfunction, and rankings of Recommended and Suggested have been developed using predefined criteria.[5,6] The results of these reports have been supplemented by assessments by the MDS-UPDRS subcommittee dedicated to the Appendix and, as new clinimetric reports on scales are published and new scales are introduced, the Appendix will be updated. Because the nonmotor aspects of PD are an increasing focus of clinical decision-making and research, we recommend a uniform selection of scales so that different reports can be compared with similar measures.

The next steps in the MDS-UPDRS program include the non-English translations, testing the MDS-UDPRS for responsivity to change over time, and analysis of questions with DIF. The planned clinimetric program leaves several additional projects available for investigator-initiated research. Correlations between the MDS-UPDRS and other scales such as quality of life measures or global disease burden scales that are not specific for PD are encouraged by the authors, but are not part of this core program. Future clinical trials in PD will tend to be of longer duration (often 5 years or longer) as new therapies are tested to delay progression post-levodopa administration. The long duration makes it unlikely that the participant in a trial will have the same rater at every visit. Thus, it is important that temporal stability, sensitivity to change, and interrater reliability be established in the MDS-UPDRS. To facilitate interrater reliability, a Teaching Tape, modeled after the one developed for the motor section of the original UPDRS, is being developed.[14]

The MDS-UPDRS is available on the MDS web site (www.movementdisorders.org). Likewise, the Appendix of Additional Scales is also available electronically and will be updated through the MDS web site.

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Author Roles: All authors participated in MDS-UPDRS design, clinimetric analysis, interpretation of results, and manuscript writing. Dr. Goetz worked with the MDS to procure funding. Statistical analysis was conducted by Barbara Tilley, Stephanie Shaftman, and Glenn Stebbins with input from all other authors.

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MDS-UPDRS

The Movement Disorder Society (MDS)-sponsored new version of the UDPRS is founded on the critique that was formulated by the Task Force for Rating Scales in Parkinson's disease (*Mov Disord* 2003;18:738-750). Thereafter, the MDS recruited a Chairperson to organize a program to provide the Movement Disorder community with a new version of the UDPRS that would maintain the overall format of the original UPDRS, but address issues identified in the critique as weaknesses and ambiguities. The Chairperson identified subcommittees with chairs and members. Each part was written by the appropriate subcommittee members and then reviewed and ratified by the entire group. These members are listed below.

The MDS UPDRS has four parts: Part I (non-motor experiences of daily living), Part II (motor experiences of daily living, Part III (motor examination) and Part IV (motor complications). Part I has two components: IA concerning a number of behaviors that are assessed by the investigator with all pertinent information from patients and caregivers and IB that is completed by the patient with or without the aid of the caregiver, but independently of the investigator. It can, however, be reviewed by the rater to ensure that all questions are answered clearly and the rater can help explain any perceived ambiguities. Part II is designed to be a self-administered questionnaire like Part IB, but can be reviewed by the investigator to ensure completeness and clarity. Of note, the official versions of Part1A, Part1B and Part2 of the MDS-UPDRS do not have separate on or off ratings. However, for individual programs or protocols the same questions can be used separately for on and off. Part III has instructions for the rater to give or demonstrate to the patient; it is completed by the rater. Part IV has instructions for the rater and also instructions to be read to the patient. This part integrates patient-derived information with the rater's clinical observations and judgments and is completed by the rater.

The authors of this new version are:

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Part I: Werner Poewe (chair), Bruno Dubois, Anette Schrag
Part II: Matthew B. Stern (chair), Anthony E. Lang, Peter A. LeWitt
Part III: Stanley Fahn (chair), Joseph Jankovic, C. Warren Olanow
Part IV: Pablo Martinez-Martin (chair), Andrew Lees, Olivier Rascol, Bob van Hilten
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Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

Overview: This portion of the scale assesses the non-motor impact of Parkinson's disease (PD) on patients' experiences of daily living. There are 13 questions. Part 1A is administered by the rater (six questions) and focuses on complex behaviors. Part 1B is a component of the self-administered Patient Questionnaire that covers seven questions on non-motor experiences of daily living.

Part 1A:
In administering Part IA, the examiner should use the following guidelines:

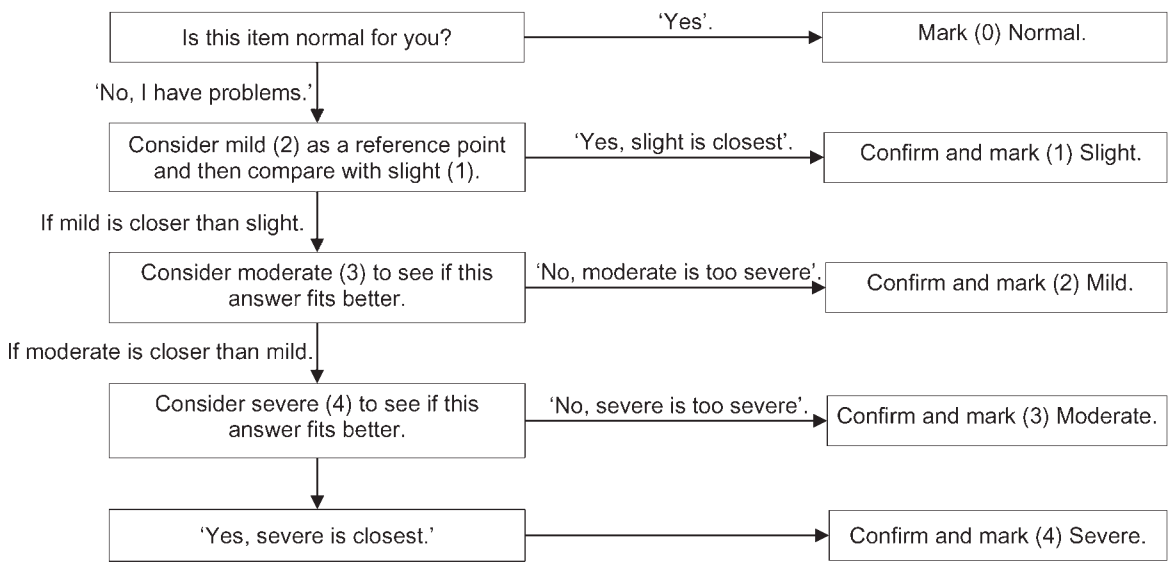
1. Mark at the top of the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.
3. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputee who cannot walk), the item is marked UR for Unable to Rate.
4. The answers should reflect the usual level of function and words such as "usually", "generally", "most of the time" can be used with patients.
5. Each question has a text for you to read (Instructions to patients/caregiver). After that statement, you can elaborate and probe based on the target symptoms outlined in the Instructions to examiner. You should NOT READ the RATING OPTIONS to the patient/caregiver, because these are written in medical terminology. From the interview and probing, you will use your medical judgment to arrive at the best response.
6. Patients may have co-morbidities and other medical conditions that can affect their function. You and the patient must rate the problem as it exists and do not attempt to separate elements due to Parkinson's disease from other conditions.

EXAMPLE OF NAVIGATING THROUGH THE RESPONSE OPTIONS FOR PART 1A

Suggested strategies for obtaining the most accurate answer:
After reading the instructions to the patient, you will need to probe the entire domain under discussion to determine Normal vs. problematic: If your questions do not identify any problem in this domain, record 0 and move on to the next question.

If your questions identify a problem in this domain, you should work next with a reference anchor at the mid-range (option 2 or Mild) to find out if the patient functions at this level, better or worse. You will not be reading the choices of responses to the patient as the responses use clinical terminology. You will be asking enough probing questions to determine the response that should be coded.

Work up and down the options with the patient to identify the most accurate response, giving a final check by excluding the options above and below the selected response.



Patient Name or Subject ID	Site ID	Assessment Date (mm-dd-yyyy)	Investigator's Initials
____ ____ ____ ____ ____ ____ ____ ____	____ ____ ____	___ ___ - ___ ___ - ___ ___ ___ ___	____ ____ ____

MDS UPDRS
Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

Part 1A: Complex behaviors: [completed by rater]

Primary source of information:

☐ Patient ☐ Caregiver ☐ Patient and Caregiver in Equal Proportion

To be read to the patient: I am going to ask you six questions about behaviors that you may or may not experience. Some questions concern common problems and some concern uncommon ones. If you have a problem in one of the areas, please choose the best response that describes how you have felt MOST OF THE TIME during the PAST WEEK. If you are not bothered by a problem, you can simply respond NO. I am trying to be thorough, so I may ask questions that have nothing to do with you.

1.1 COGNITIVE IMPAIRMENT — **SCORE**

Instructions to examiner: Consider all types of altered level of cognitive function including cognitive slowing, impaired reasoning, memory loss, deficits in attention and orientation. Rate their impact on activities of daily living as perceived by the patient and/or caregiver.

Instructions to patients [and caregiver]: Over the past week have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town? [If yes, examiner asks patient or caregiver to elaborate and probes for information]

0: Normal:	No cognitive impairment.	
1: Slight:	Impairment appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions.	☐
2: Mild:	Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions.	
3: Moderate:	Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions.	
4: Severe:	Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.	

	SCORE
1.2 HALLUCINATIONS AND PSYCHOSIS Instructions to examiner: Consider both illusions (misinterpretations of real stimuli) and hallucinations (spontaneous false sensations). Consider all major sensory domains (visual, auditory, tactile, olfactory and gustatory). Determine presence of unformed (for example sense of presence or fleeting false impressions) as well as formed (fully developed and detailed) sensations. Rate the patients insight into hallucinations and identify delusions and psychotic thinking. *Instructions to patients [and caregiver]: Over the past week have you seen, heard, smelled or felt things that were not really there?* [If yes, examiner asks patient or caregiver to elaborate and probes for information] 0: Normal: No hallucinations or psychotic behaviour. 1: Slight: Illusions or non-formed hallucinations, but patient recognizes them without loss of insight. 2: Mild: Formed hallucinations independent of environmental stimuli. No loss of insight. 3: Moderate: Formed hallucinations with loss of insight. 4: Severe: Patient has delusions or paranoia.	☐
1.3 DEPRESSED MOOD Instructions to examiner: Consider low mood, sadness, hopelessness, feelings of emptiness or loss of enjoyment. Determine their presence and duration over the past week and rate their interference with the patient's ability to carry out daily routines and engage in social interactions. *Instruction to the patient (and caregiver): Over the past week have you felt low, sad, hopeless or unable to enjoy things? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you carry out your usual activities or to be with people?* If yes, examiner asks patient or caregiver to elaborate and probes for information] 0: Normal: No depressed mood. 1: Slight: Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions. 2: Mild: Depressed mood that is sustained over days, but without interference with normal activities and social interactions. 3: Moderate: Depressed mood that interferes with, but does not preclude, the patient's ability to carry out normal activities and social interactions. 4: Severe: Depressed mood precludes patient's ability to carry out normal activities and social interactions.	☐

	SCORE
1.4 ANXIOUS MOOD Instructions to examiner: Determine nervous, tense, worried or anxious feelings (including panic attacks) over the past week and rate their duration and interference with the patient's ability to carry out daily routines and engage in social interactions. *Instructions to patients [and caregiver]: Over the past week have you felt nervous, worried or tense? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you to follow your usual activities or to be with other people*? [If yes, examiner asks patient or caregiver to elaborate and probes for information.] 0: Normal: No anxious feelings. 1: Slight: Anxious feelings present but not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions. 2: Mild: Anxious feelings are sustained over more than one day at a time, but without interference with patient's ability to carry out normal activities and social interactions. 3: Moderate: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions. 4: Severe: Anxious feelings preclude patient's ability to carry out normal activities and social interactions.	☐
1.5 APATHY Instructions to examiner: Consider level of spontaneous activity, assertiveness, motivation and initiative and rate the impact of reduced levels on performance of daily routines and social interactions. Here the examiner should attempt to distinguish between apathy and similar symptoms that are best explained by depression. *Instructions to patients (and caregiver): Over the past week, have you felt indifferent to doing activities or being with people?* If yes, examiner asks patient or caregiver to elaborate and probes for information.] 0: Normal: No apathy. 1: Slight: Apathy appreciated by patient and/or caregiver, but no interference with daily activities and social interactions. 2: Mild: Apathy interferes with isolated activities and social interactions. 3: Moderate: Apathy interferes with most activities and social interactions. 4: Severe: Passive and withdrawn, complete loss of initiative.	☐

1.6 FEATURES OF DOPAMINE DYSREGULATION SYNDROME	SCORE
Instructions to examiner: Consider involvement in a variety of activities including atypical or excessive gambling (e.g. casinos or lottery tickets), atypical or excessive sexual drive or interests (e.g., unusual interest in pornography, masturbation, sexual demands on partner), other repetitive activities (e.g. hobbies, dismantling objects, sorting or organizing), or taking extra non-prescribed medication for non-physical reasons (i.e., addictive behavior). Rate the impact of such abnormal activities/behaviors on the patient's personal life and on his family and social relations (including need to borrow money or other financial difficulties like withdrawal of credit cards, major family conflicts, lost time from work, or missed meals or sleep because of the activity). *Instructions to patients [and caregiver]: Over the past week, have you had unusually strong urges that are hard to control? Do you feel driven to do or think about something and find it hard to stop?* [Give patient examples such as gambling, cleaning, using the computer, taking extra medicine, obsessing about food or sex, all depending on the patients. 0: Normal: No problems present. 1: Slight: Problems are present but usually do not cause any difficulties for the patient or family/caregiver. 2: Mild: Problems are present and usually cause a few difficulties in the patient's personal and family life. 3: Moderate: Problems are present and usually cause a lot of difficulties in the patient's personal and family life. 4: Severe: Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.	☐

The remaining questions in Part I (Non-motor Experiences of Daily Living) [Sleep, Daytime Sleepiness, Pain and Other Sensation, Urinary Problems, Constipation Problems, Lightheadedness on Standing, and Fatigue] are in the **Patient Questionnaire** along with all questions in Part II [Motor Experiences of Daily Living].

Patient Questionnaire:

Instructions:

This questionnaire will ask you about your experiences of daily living.

There are 20 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you.

We are interested in your average or usual function over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

You may have other medical conditions besides Parkinson's disease. Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Your doctor or nurse can review the questions with you, but this questionnaire is for patients to complete, either alone or with their caregivers.

Who is filling out this questionnaire (check the best answer):

☐ Patient ☐ Caregiver ☐ Patient and Caregiver in Equal Proportion

Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)	
1.7 SLEEP PROBLEMS Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning. 0: Normal: No problems. 1: Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep. 2: Mild: Sleep problems usually cause some difficulties getting a full night of sleep. 3: Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night. 4: Severe: I usually do not sleep for most of the night.	**SCORE** ☐
1.8 DAYTIME SLEEPINESS Over the past week, have you had trouble staying awake during the daytime? 0: Normal: No daytime sleepiness. 1: Slight: Daytime sleepiness occurs but I can resist and I stay awake. 2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV. 3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people. 4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.	☐

	SCORE
1.9 PAIN AND OTHER SENSATIONS Over the past week, have you had uncomfortable feelings in your body like pain, aches tingling or cramps? 0: Normal: No uncomfortable feelings. 1: Slight: I have these feelings. However, I can do things and be with other people without difficulty. 2: Mild: These feelings cause some problems when I do things or am with other people. 3: Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people. 4: Severe: These feelings stop me from doing things or being with other people.	☐
1.10 URINARY PROBLEMS Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents? 0: Normal: No urine control problems. 1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities. 2: Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents. 3: Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents. 4: Severe: I cannot control my urine and use a protective garment or have a bladder tube.	☐

	SCORE
1.11 CONSTIPATION PROBLEMS Over the past week have you had constipation troubles that cause you difficulty moving your bowels? 0: Normal: No constipation. 1: Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable. 2: Mild: Constipation causes me to have some troubles doing things or being comfortable. 3: Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything. 4: Severe: I usually need physical help from someone else to empty my bowels.	☐
1.12 LIGHT HEADEDNESS ON STANDING Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down? 0: Normal: No dizzy or foggy feelings. 1: Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things. 2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down. 3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling. 4: Severe: Dizzy or foggy feelings cause me to fall or faint.	☐

	SCORE
1.13 FATIGUE Over the past week, have you usually felt fatigued? This feeling is <u>not</u> part of being sleepy or sad 0: Normal: No fatigue. 1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people. 2: Mild: Fatigue causes me some troubles doing things or being with people. 3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything. 4: Severe: Fatigue stops me from doing things or being with people.	☐
Part II: Motor Aspects of Experiences of Daily Living (M-EDL)	
2.1 SPEECH Over the past week, have you had problems with your speech? 0: Normal: Not at all (no problems). 1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself. 2: Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday. 3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood. 4: Severe: Most or all of my speech cannot be understood.	☐

	SCORE
2.2 SALIVA & DROOLING Over the past week, have you usually had too much saliva during when you are awake or when you sleep? 0: Normal: Not at all (no problems). 1: Slight: I have too much saliva, but do not drool. 2: Mild: I have some drooling during sleep, but none when I am awake. 3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief. 4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.	☐
2.3 CHEWING AND SWALLOWING Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking? 0: Normal: No problems. 1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared. 2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week. 3: Moderate. I choked at least once in the past week. 4: Severe: Because of chewing and swallowing problems, I need a feeding tube.	☐

	SCORE
2.4 EATING TASKS Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knifes, spoons, chopsticks? 0: Normal: Not at all (No problems). 1: Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating. 2: Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat. 3: Moderate: I need help with many eating tasks but can manage some alone. 4: Severe: I need help for most or all eating tasks.	☐
2.5 DRESSING Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry? 0: Normal: Not at all (no problems). 1: Slight: I am slow but I do not need help. 2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets). 3: Moderate: I need help for many dressing tasks. 4: Severe: I need help for most or all dressing tasks.	☐

	SCORE
2.6 HYGIENE Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene? 0: Normal: Not at all (no problems). 1: Slight: I am slow but I do not need any help. 2: Mild: I need someone else to help me with some hygiene tasks. 3: Moderate: I need help for many hygiene tasks. 4: Severe: I need help for most or all of my hygiene tasks.	☐
2.7 HANDWRITING Over the past week, have people usually had trouble reading your handwriting? 0: Normal: Not at all (no problems). 1: Slight: My writing is slow, clumsy or uneven, but all words are clear. 2: Mild: Some words are unclear and difficult to read. 3: Moderate: Many words are unclear and difficult to read. 4: Severe: Most or all words cannot be read.	☐
2.8 DOING HOBBIES AND OTHER ACTIVITIES Over the past week, have you usually had trouble doing your hobbies or other things that you like to do? 0: Normal: Not at all (no problems). 1: Slight: I am a bit slow but do these activities easily. 2: Mild: I have some difficulty doing these activities. 3: Moderate: I have major problems doing these activities, but still do most. 4: Severe: I am unable to do most or all of these activities.	☐

	SCORE
2.9 TURNING IN BED Over the past week, do you usually have trouble turning over in bed? 0: Normal: Not at all (no problems). 1: Slight: I have a bit of trouble turning, but I do not need any help. 2: Mild I have a lot of trouble turning and need occasional help from someone else. 3: Moderate: To turn over I often need help from someone else. 4: Severe: I am unable to turn over without help from someone else.	☐
2.10 TREMOR Over the past week, have you usually had shaking or tremor? 0: Normal: Not at all. I have no shaking or tremor. 1: Slight: Shaking or tremor occurs but does not cause problems with any activities. 2: Mild: Shaking or tremor causes problems with only a few activities. 3: Moderate: Shaking or tremor causes problems with many of my daily activities. 4: Severe: Shaking or tremor causes problems with most or all activities.	☐
2.11 GETTING OUT OF BED, A CAR, OR A DEEP CHAIR Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair? 0: Normal: Not at all (no problems). 1: Slight: I am slow or awkward, but I usually can do it on my first try. 2: Mild: I need more than one try to get up or need occasional help. 3: Moderate: I sometimes need help to get up, but most times I can still do it on my own. 4: Severe: I need help most or all of the time.	☐

	SCORE
2.12 WALKING AND BALANCE Over the past week, have you usually had problems with balance and walking? 0: Normal: Not at all (no problems). 1: Slight: I am slightly slow or may drag a leg. I never use a walking aid. 2: Mild: I occasionally use a walking aid, but I do not need any help from another person. 3: Moderate: I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person. 4: Severe: I usually use the support of another persons to walk safely without falling.	☐
2.13 FREEZING Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor. 0: Normal: Not at all (no problems). 1: Slight: I briefly freeze but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing. 2: Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing. 3: Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help. 4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.	☐

This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this questionnaire.

Part III: Motor Examination

Overview: This portion of the scale assesses the motor signs of PD. In administering Part III of the MDS-UPDRS the examiner should comply with the following guidelines:

At the top of the form, mark whether the patient is on medication for treating the symptoms of Parkinson's disease and, if on levodopa, the time since the last dose.

Also, if the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the patient's clinical state using the following definitions:

ON is the typical functional state when patients are receiving medication and have a good response.
OFF is the typical functional state when patients have a poor response in spite of taking medications.

The investigator should "rate what you see". Admittedly, concurrent medical problems such as stroke, paralysis, arthritis, contracture, and orthopedic problems such as hip or knee replacement and scoliosis may interfere with individual items in the motor examination. In situations where it is absolutely impossible to test (e.g., amputations, plegia, limb in a cast), use the notation "**UR**" for Unable to Rate. Otherwise, rate the performance of each task as the patient performs in the context of co-morbidities.

All items must have an integer rating (no half points, no missing ratings).

Specific instructions are provided for the testing of each item. These should be followed in all instances. The investigator demonstrates while describing tasks the patient is to perform and rates function immediately thereafter. For Global Spontaneous Movement and Rest Tremor items (3.14 and 3.17), these items have been placed purposefully at the end of the scale because clinical information pertinent to the score will be obtained throughout the entire examination.

At the end of the rating, indicate if dyskinesia (chorea or dystonia) was present at the time of the examination, and if so, whether these movements interfered with the motor examination.

3a Is the patient on medication for treating the symptoms of Parkinson's Disease? ☐ No ☐ Yes

3b If the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the patient's clinical state using the following definitions:

☐ ON: On is the typical functional state when patients are receiving medication and have a good response.

☐ OFF: Off is the typical functional state when patients have a poor response in spite of taking medications.

3c Is the patient on Levodopa ? ☐ No ☐ Yes

3.C1 If yes, minutes since last levodopa dose: _____

	SCORE
3.1 SPEECH Instructions to examiner: Listen to the patient's free-flowing speech and engage in conversation if necessary. Suggested topics: ask about the patient's work, hobbies, exercise, or how he got to the doctor's office. Evaluate volume, modulation (prosody) and clarity, including slurring, palilalia (repetition of syllables) and tachyphemia (rapid speech, running syllables together). 0: Normal: No speech problems. 1: Slight: Loss of modulation, diction or volume, but still all words easy to understand. 2: Mild: Loss of modulation, diction, or volume, with a few words unclear, but the overall sentences easy to follow. 3: Moderate: Speech is difficult to understand to the point that some, but not most, sentences are poorly understood. 4: Severe: Most speech is difficult to understand or unintelligible.	☐
3.2 FACIAL EXPRESSION Instructions to examiner: Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, masked facies or loss of facial expression, spontaneous smiling and parting of lips. 0: Normal: Normal facial expression. 1: Slight: Minimal masked facies manifested only by decreased frequency of blinking. 2: Mild: In addition to decreased eye-blink frequency, Masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted. 3: Moderate: Masked facies with lips parted some of the time when the mouth is at rest. 4: Severe: Masked facies with lips parted most of the time when the mouth is at rest.	☐

	SCORE
3.3 RIGIDITY Instructions to examiner: Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. For arms, test the wrist and elbow joints simultaneously. For legs, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity. 0: Normal: No rigidity. 1: Slight: Rigidity only detected with activation maneuver. 2: Mild: Rigidity detected without the activation maneuver, but full range of motion is easily achieved. 3: Moderate: Rigidity detected without the activation maneuver; full range of motion is achieved with effort. 4: Severe: Rigidity detected without the activation maneuver and full range of motion not achieved.	☐ Neck ☐ RUE ☐ LUE ☐ RLE ☐ LLE
3.4 FINGER TAPPING Instructions to examiner: Each hand is tested separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to tap the index finger on the thumb 10 times as quickly AND as big as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude. 0: Normal: No problems. 1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) the amplitude decrements near the end of the 10 taps. 2: Mild: Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude decrements midway in the 10-tap sequence. 3: Moderate: Any of the following: a) more than 5 interruptions during tapping or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st tap. 4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.	☐ R ☐ L

	SCORE
3.5 HAND MOVEMENTS Instructions to examiner: Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to make a tight fist with the arm bent at the elbow so that the palm faces the examiner. Have the patient open the hand 10 times as fully AND as quickly as possible. If the patient fails to make a tight fist or to open the hand fully, remind him/her to do so. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude. 0: Normal: No problem. 1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) the amplitude decrements near the end of the task. 2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude decrements midway in the task. 3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st open-and-close sequence. 4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.	☐ R ☐ L
3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS Instructions to examiner: Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to extend the arm out in front of his/her body with the palms down; then to turn the palm up and down alternately 10 times as fast and as fully as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude. 0: Normal: No problems. 1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) the amplitude decrements near the end of the sequence. 2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude decrements midway in the sequence. 3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing c) the amplitude decrements starting after the 1st supination-pronation sequence. 4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.	☐ R ☐ L

	SCORE
3.7 TOE TAPPING Instructions to examiner: Have the patient sit in a straight-backed chair with arms, both feet on the floor. Test each foot separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the heel on the ground in a comfortable position and then tap the toes 10 times as big and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude. 0: Normal: No problem. 1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) amplitude decrements near the end of the ten taps. 2: Mild: Any of the following: a) 3 to 5 interruptions during the tapping movements; b) mild slowing; c) amplitude decrements midway in the task. 3: Moderate: Any of the following: a) more than 5 interruptions during the tapping movements or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) amplitude decrements after the first tap. 4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.	☐ R ☐ L
3.8 LEG AGILITY Instructions to examiner: Have the patient sit in a straight-backed chair with arms. The patient should have both feet comfortably on the floor. Test each leg separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the foot on the ground in a comfortable position and then raise and stomp the foot on the ground 10 times as high and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude. 0: Normal: No problems. 1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) amplitude decrements near the end of the task. 2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) amplitude decrements midway in the task. 3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing in speed; c) amplitude decrements after the first tap. 4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.	☐ R ☐ L

	SCORE
3.9 ARISING FROM CHAIR Instructions to examiner: Have the patient sit in a straight-backed chair with arms, with both feet on the floor and sitting back in the chair (if the patient is not too short). Ask the patient to cross his/her arms across the chest and then to stand up. If the patient is not successful, repeat this attempt a maximum up to two more times. If still unsuccessful, allow the patient to move forward in the chair to arise with arms folded across the chest. Allow only one attempt in this situation. If unsuccessful, allow the patient to push off using his/her hands on the arms of the chair. Allow a maximum of three trials of pushing off. If still not successful, assist the patient to arise. After the patient stands up, observe the posture for item 3.13 0: Normal: No problems. Able to arise quickly without hesitation. 1: Slight: Arising is slower than normal; or may need more than one attempt; or may need to move forward in the chair to arise. No need to use the arms of the chair. 2: Mild: Pushes self up from arms of chair without difficulty. 3: Moderate: Needs to push off, but tends to fall back; or may have to try more than one time using arms of chair, but can get up without help. 4: Severe: Unable to arise without help.	☐
3.10 GAIT Instructions to examiner: Testing gait is best performed by having the patient walking away from and towards the examiner so that both right and left sides of the body can be easily observed simultaneously. The patient should walk at least 10 meters (30 feet), then turn around and return to the examiner. This item measures multiple behaviors: stride amplitude, stride speed, height of foot lift, heel strike during walking, turning, and arm swing, but not freezing. Assess also for "freezing of gait" (next item 3.11) while patient is walking. Observe posture for item 3.13 0: Normal: No problems. 1: Slight: Independent walking with minor gait impairment. 2: Mild: Independent walking but with substantial gait impairment. 3: Moderate: Requires an assistance device for safe walking (walking stick, walker) but not a person. 4: Severe: Cannot walk at all or only with another person's assistance.	☐

	SCORE
3.11 FREEZING OF GAIT Instructions to examiner: While assessing gait, also assess for the presence of any gait freezing episodes. Observe for start hesitation and stuttering movements especially when turning and reaching the end of the task. To the extent that safety permits, patients may NOT use sensory tricks during the assessment. 0: Normal: No freezing. 1: Slight: Freezes on starting, turning or walking through doorway with a single halt during any of these events, but then continues smoothly without freezing during straight walking. 2: Mild: Freezes on starting, turning or walking through doorway with more than one halt during any of these activities, but continues smoothly without freezing during straight walking. 3: Moderate: Freezes once during straight walking. 4: Severe: Freezes multiple times during straight walking.	☐
3.12 POSTURAL STABILITY Instructions to examiner: The test examines the response to sudden body displacement produced by a quick, forceful pull on the shoulders while the patient is standing erect with eyes open and feet comfortably apart and parallel to each other. Test retropulsion. Stand behind the patient and instruct the patient on what is about to happen. Explain that s/he is allowed to take a step backwards to avoid falling. There should be a solid wall behind the examiner, at least 1-2 meters away to allow for the observation of the number of retropulsive steps. The first pull is an instructional demonstration and is purposely milder and not rated. The second time the shoulders are pulled briskly and forcefully towards the examiner with enough force to displace the center of gravity so that patient MUST take a step backwards. The examiner needs to be ready to catch the patient, but must stand sufficiently back so as to allow enough room for the patient to take several steps to recover independently. Do not allow the patient to flex the body abnormally forward in anticipation of the pull. Observe for the number of steps backwards or falling. Up to and including two steps for recovery is considered normal, so abnormal ratings begin with three steps. If the patient fails to understand the test, the examiner can repeat the test so that the rating is based on an assessment that the examiner feels reflects the patient's limitations rather than misunderstanding or lack of preparedness. Observe standing posture for item 3.13 0: Normal: No problems: Recovers with one or two steps. 1: Slight: 3-5 steps, but subject recovers unaided. 2: Mild: More than 5 steps, but subject recovers unaided. 3: Moderate: Stands safely, but with absence of postural response; falls if not caught by examiner. 4: Severe: Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.	☐

	SCORE
3.13 POSTURE Instructions to examiner: Posture is assessed with the patient standing erect after arising from a chair, during walking , and while being tested for postural reflexes. If you notice poor posture, tell the patient to stand up straight and see if the posture improves (see option 2 below). Rate the worst posture seen in these three observation points. Observe for flexion and side-to-side leaning. 0: Normal: No problems. 1: Slight: Not quite erect, but posture could be normal for older person. 2: Mild: Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so. 3: Moderate: Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient. 4: Severe: Flexion, scoliosis or leaning with extreme abnormality of posture.	☐
3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA) Instructions to examiner: This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner's global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking. 0: Normal: No problems. 1: Slight: Slight global slowness and poverty of spontaneous movements. 2: Mild: Mild global slowness and poverty of spontaneous movements. 3: Moderate: Moderate global slowness and poverty of spontaneous movements. 4: Severe: Severe global slowness and poverty of spontaneous movements.	☐
3.15 POSTURAL TREMOR OF THE HANDS Instructions to examiner: All tremor, including re-emergent rest tremor, that is present in this posture is to be included in this rating. Rate each hand separately. Rate the highest amplitude seen. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds. 0: Normal: No tremor. 1: Slight: Tremor is present but less than 1 cm in amplitude. 2: Mild: Tremor is at least 1 but less than 3 cm in amplitude. 3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude. 4: Severe: Tremor is at least 10 cm in amplitude.	☐ R ☐ L

	SCORE
3.16 KINETIC TREMOR OF THE HANDS Instructions to examiner: This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position, have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner's finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements. Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen. 0: Normal: No tremor. 1: Slight: Tremor is present but less than 1 cm in amplitude. 2: Mild: Tremor is at least 1 but less than 3 cm in amplitude. 3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude. 4: Severe: Tremor is at least 10 cm in amplitude.	☐ R ☐ L
3.17 REST TREMOR AMPLITUDE Instructions to examiner: This and the next item have been placed purposefully at the end of the examination to allow the rater to gather observations on rest tremor that may appear at any time during the exam, including when quietly sitting, during walking and during activities when some body parts are moving but others are at rest. Score the maximum amplitude that is seen at any time as the final score. Rate only the amplitude and not the persistence or the intermittency of the tremor. As part of this rating, the patient should sit quietly in a chair with the hands placed on the arms of the chair (not in the lap) and the feet comfortably supported on the floor for 10 seconds with no other directives. Rest tremor is assessed separately for all four limbs and also for the lip/jaw. Rate only the maximum amplitude that is seen at any time as the final rating. Extremity ratings 0: Normal: No tremor. 1: Slight.: < 1 cm in maximal amplitude. 2: Mild: > 1 cm but < 3 cm in maximal amplitude. 3: Moderate: 3 - 10 cm in maximal amplitude. 4: Severe: > 10 cm in maximal amplitude. Lip/Jaw ratings 0: Normal: No tremor. 1: Slight: < 1 cm in maximal amplitude. 2: Mild: > 1 cm but < 2 cm in maximal amplitude. 3: Moderate: > 2 cm but < 3 cm in maximal amplitude. 4: Severe: > 3 cm in maximal amplitude.	☐ RUE ☐ LUE ☐ RLE ☐ LLE ☐ Lip/Jaw

	SCORE
3.18 CONSTANCY OF REST TREMOR Instructions to examiner: This item receives one rating for all rest tremor and focuses on the constancy of rest tremor during the examination period when different body parts are variously at rest. It is rated purposefully at the end of the examination so that several minutes of information can be coalesced into the rating. 0: Normal: No tremor. 1: Slight: Tremor at rest is present < 25% of the entire examination period. 2: Mild: Tremor at rest is present 26-50% of the entire examination period. 3: Moderate: Tremor at rest is present 51-75% of the entire examination period. 4: Severe: Tremor at rest is present > 75% of the entire examination period.	☐
DYSKINESIA IMPACT ON PART III RATINGS A. Were dyskinesias (chorea or dystonia) present during examination? ☐ No ☐ Yes B. If yes, did these movements interfere with your ratings? ☐ No ☐ Yes	
HOEHN AND YAHR STAGE 0: Asymptomatic. 1: Unilateral involvement only. 2: Bilateral involvement without impairment of balance. 3: Mile to moderate involvement; some postural instability but physically independent; needs assistance to recover from pull test. 4: Severe disability; still able to walk or stand unassisted. 5: Wheelchair bound or bedridden unless aided.	☐

Part IV: Motor Complications

Overview and Instructions: In this section, the rater uses historical and objective information to assess two motor complications, dyskinesias and motor fluctuations that include OFF-state dystonia. Use all information from patient, caregiver, and the examination to answer the six questions that summarize function over the past week including today. As in the other sections, rate using only integers (no half points allowed) and leave no missing ratings. If the item cannot be rated, place UR for Unable to Rate. You will need to choose some answers based on percentages, and therefore you will need to establish how many hours generally are awake hours and use this figure as the denominator for "OFF" time and Dyskinesias. For "OFF dystonia", the total "Off" time will be the denominator. Operational definitions for examiner's use.

Dyskinesias: Involuntary random movements
Words that patients often recognize for dyskinesias include "irregular jerking", "wiggling", "twitching". It is essential to stress to the patient the difference between dyskinesias and tremor, a common error when patients are assessing dyskinesias.

Dystonia: contorted posture, often with a twisting component:
Words that patients often recognize for dystonia include "spasms", "cramps", "posture".

Motor fluctuation: Variable response to medication:
Words that patients often recognize for motor fluctuation include "wearing out", "wearing off", "roller-coaster effect", "on-off", "uneven medication effects".

OFF: Typical functional state when patients have a poor response in spite of taking mediation or the typical functional response when patients are on NO treatment for parkinsonism. Words that patients often recognize include "low time", "bad time", "shaking time", "slow time", "time when my medications don't work."

ON: Typical functional state when patients are receiving medication and have a good response:
Words that patients often recognize include "good time", "walking time", "time when my medications work."

A . DYSKINESIAS [exclusive of OFF-state dystonia]

SCORE

4.1 TIME SPENT WITH DYSKINESIAS

Instructions to examiner: Determine the hours in the usual waking day and then the hours of dyskinesias. Calculate the percentage. If the patient has dyskinesias in the office, you can point them out as a reference to ensure that patients and caregivers understand what they are rating. You may also use your own acting skills to enact the dyskinetic movements you have seen in the patient before or show them dyskinetic movements typical of other patients. Exclude from this question early morning and nighttime painful dystonia.

Instructions to patient [and caregiver]. Over the past week, how many hours do you usually sleep on a daily basis, including nighttime sleep and daytime napping? Alright, if you sleep ___ hrs, you are awake ____ hrs. Out of those awake hours, how many hours in total do you have wiggling, twitching or jerking movements? Do not count the times when you have tremor, which is a regular back and forth shaking or times when you have painful foot cramps or spasms in the early morning or at nighttime. I will ask about those later. Concentrate only on these types of wiggling, jerking and irregular movements. Add up all the time during the waking day when these usually occur. How many hours ____ (use this number for your calculation).

0: Normal:	No dyskinesias.
1: Slight:	≤ 25% of waking day.
2: Mild:	26 - 50% of waking day.
3: Moderate:	51 - 75% of waking day.
4: Severe:	> 75% of waking day.

1. Total Hours Awake: _____
2. Total Hours with Dyskinesia: _____
3. % Dyskinesia = ((2/1)*100): _____

	SCORE
4.2 FUNCTIONAL IMPACT OF DYSKINESIAS Instructions to examiner: Determine the degree to which dyskinesias impact on the patient's daily function in terms of activities and social interactions. Use the patient's and caregiver's response to your question and your own observations during the office visit to arrive at the best answer. *Instructions to patient [and caregiver]: Over the past week, did you usually have trouble doing things or being with people when these jerking movements occurred? Did they stop you from doing things or from being with people?* 0: Normal: No dyskinesias or no impact by dyskinesias on activities or social interactions. 1: Slight: Dyskinesias impact on a few activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods. 2: Mild: Dyskinesias impact on many activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods. 3: Moderate: Dyskinesias impact on activities to the point that the patient usually does not perform some activities or does not usually participate in some social activities during dyskinetic episodes. 4: Severe: Dyskinesias impact on function to the point that the patient usually does not perform most activities or participate in most social interactions during dyskinetic episodes.	☐
B . MOTOR FLUCTUATIONS	
4.3 TIME SPENT IN THE OFF STATE Instructions to examiner: Use the number of waking hours derived from 4.1 and determine the hours spent in the "OFF" state. Calculate the percentage. If the patient has an OFF period in the office, you can point to this state as a reference. You may also use your knowledge of the patient to describe a typical OFF period. Additionally you may use your own acting skills to enact an OFF period you have seen in the patient before or show them OFF function typical of other patients. Mark down the typical number of OFF hours, because you will need this number for completing 4.6 *Instructions to patient [and caregiver]: Some patients with Parkinson's disease have a good effect from their medications throughout their awake hours and we call that "ON" time. Other patients take their medications but still have some hours of low time, bad time, slow time or shaking time. Doctors call these low periods "OFF" time. Over the past week, you told me before that you are generally awake ____ hrs each day. Out of these awake hours, how many hours in total do you usually have this type of low level or OFF function ____ (Use this number for your calculations).* 0: Normal: No OFF time. 1: Slight: ≤ 25% of waking day. 2: Mild: 26 - 50% of waking day. 3: Moderate: 51 - 75% of waking day. 4: Severe: > 75% of waking day. 1. Total Hours Awake: _____ 2. Total Hours OFF: _____ 3. % OFF = ((2/1)*100): _____	☐

	SCORE
4.4 FUNCTIONAL IMPACT OF FLUCTUATIONS Instructions to examiner: Determine the degree to which motor fluctuations impact on the patient's daily function in terms of activities and social interactions. This question concentrates on the difference between the ON state and the OFF state. If the patient has no OFF time, the rating must be 0, but if patients have very mild fluctuations, it is still possible to be rated 0 on this item if no impact on activities occurs. Use the patient's and caregiver's response to your question and your own observations during the office visit to arrive at the best answer. *Instructions to patient [and caregiver]: Think about when those low or "OFF" periods have occurred over the past week. Do you usually have more problems doing things or being with people than compared to the rest of the day when you feel your medications working? Are there some things you usually do during a good period that you have trouble with or stop doing during a low period?* 0: Normal: No fluctuations or No impact by fluctuations on performance of activities or social interactions. 1: Slight: Fluctuations impact on a few activities, but during OFF, the patient usually performs all activities and participates in all social interactions that typically occur during the ON state. 2: Mild: Fluctuations impact many activities, but during OFF, the patient still usually performs all activities and participates in all social interactions that typically occur during the ON state. 3: Moderate: Fluctuations impact on the performance of activities during OFF to the point that the patient usually does not perform some activities or participate in some social interactions that are performed during ON periods. 4: Severe: Fluctuations impact on function to the point that, during OFF, the patient usually does not perform most activities or participate in most social interactions that are performed during ON periods.	☐
4.5 COMPLEXITY OF MOTOR FLUCTUATIONS Instructions to examiner: Determine the usual predictability of OFF function whether due to dose, time of day, food intake or other factors. Use the information provided by the patients and caregiver and supplement with your own observations. You will ask if the patient can count on them always coming at a special time, mostly coming at a special time (in which case you will probe further to separate slight from mild), only sometimes coming at a special time or are they totally unpredictable? Narrowing down the percentage will allow you to find the correct answer. *Instructions to patient [and caregiver]: For some patients, the low or "OFF" periods happen at certain times during day or when they do activities like eating or exercising. Over the past week, do you usually know when your low periods will occur? In other words, do your low periods always come at a certain time? Do they mostly come at a certain time? Do they only sometimes come at a certain time? Are your low periods totally unpredictable?"* 0: Normal: No motor fluctuations. 1: Slight: OFF times are predictable all or almost all of the time (> 75%). 2: Mild: OFF times are predictable most of the time (51-75%). 3: Moderate: OFF times are predictable some of the time (26-50%). 4: Severe: OFF episodes are rarely predictable. (≤ 25%).	☐

C. "OFF" DYSTONIA

4.6 PAINFUL OFF-STATE DYSTONIA

Instructions to examiner: For patients who have motor fluctuations, determine what proportion of the OFF episodes usually includes painful dystonia? You have already determined the number of hours of "OFF" time (4.3). Of these hours, determine how many are associated with dystonia and calculate the percentage. If there is no OFF time, mark 0.

Instructions to patient [and caregiver]: In one of the questions I asked earlier, you said you generally have ___ hours of low or "OFF" time when your Parkinson's disease is under poor control. During these low or "OFF" periods, do you usually have painful cramps or spasms? Out of the total ____ hrs of this low time, if you add up all the time in a day when these painful cramps come, how many hours would this make?

0: Normal: No dystonia OR NO OFF TIME.

1: Slight: < 25% of time in OFF state.

2: Mild: 26-50% of time in OFF state.

3: Moderate: 51-75% of time in OFF state.

4: Severe: > 75% of time in OFF state.

1. Total Hours Off: _____
2. Total Off Hours w/Dystonia: _____
3. % Off Dystonia = ((2/1)*100): _____

Summary statement to patient: READ TO PATIENT

This completes my rating of your Parkinson's disease. I know the questions and tasks have taken several minutes, but I wanted to be complete and cover all possibilities. In doing so, I may have asked about problems you do not even have, and I may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this scale with me.

_____ Patient Name or Subject ID	___ ___ ___ Site ID	__ __ - __ __ - __ __ __ __ (mm-dd-yyyy) Assessment Date	___ ___ ___ Investigator's Initials

MDS UPDRS Score Sheet

1.A	Source of information	☐ Patient ☐ Caregiver ☐ Patient + Caregiver	3.3b	Rigidity– RUE	
			3.3c	Rigidity– LUE	
Part I			3.3d	Rigidity– RLE	
1.1	Cognitive impairment		3.3e	Rigidity– LLE	
1.2	Hallucinations and psychosis		3.4a	Finger tapping– Right hand	
1.3	Depressed mood		3.4b	Finger tapping– Left hand	
1.4	Anxious mood		3.5a	Hand movements– Right hand	
1.5	Apathy		3.5b	Hand movements– Left hand	
1.6	Features of DDS		3.6a	Pronation- supination movements– Right hand	
1.6a	Who is filling out questionnaire	☐ Patient ☐ Caregiver ☐ Patient + Caregiver	3.6b	Pronation- supination movements– Left hand	
			3.7a	Toe tapping–Right foot	
1.7	Sleep problems		3.7b	Toe tapping– Left foot	
1.8	Daytime sleepiness		3.8a	Leg agility– Right leg	
1.9	Pain and other sensations		3.8b	Leg agility– Left leg	
1.10	Urinary problems		3.9	Arising from chair	
1.11	Constipation problems		3.10	Gait	
1.12	Light headedness on standing		3.11	Freezing of gait	
1.13	Fatigue		3.12	Postural stability	
Part II			3.13	Posture	
2.1	Speech		3.14	Global spontaneity of movement	
2.2	Saliva and drooling		3.15a	Postural tremor– Right hand	
2.3	Chewing and swallowing		3.15b	Postural tremor– Left hand	
2.4	Eating tasks		3.16a	Kinetic tremor– Right hand	
2.5	Dressing		3.16b	Kinetic tremor– Left hand	
2.6	Hygiene		3.17a	Rest tremor amplitude– RUE	
2.7	Handwriting		3.17b	Rest tremor amplitude– LUE	
2.8	Doing hobbies and other activities		3.17c	Rest tremor amplitude– RLE	
2.9	Turning in bed		3.17d	Rest tremor amplitude– LLE	
2.10	Tremor		3.17e	Rest tremor amplitude– Lip/jaw	
2.11	Getting out of bed		3.18	Constancy of rest	
2.12	Walking and balance			Were dyskinesias presen	☐ No ☐ Yes
2.13	Freezing			Did these movements interfere with ratings?	☐ No ☐ Yes
3a	Is the patient on medication?	☐ No ☐ Yes		Hoehn and Yahr Stage	
3b	Patient's clinical state	☐ Off ☐ On	**Part IV**		
3c	Is the patient on Levodopa?	☐ No ☐ Yes	4.1	Time spent with dyskinesias	
3.C1	If yes, minutes since last dose:		4.2	Functional impact of dyskinesias	
Part III			4.3	Time spent in the OFF state	
3.1	Speech		4.4	Functional impact of fluctuations	
3.2	Facial expression		4.5	Complexity of motor fluctuations	
3.3a	Rigidity– Neck		4.6	Painful OFF-state dystonia	