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The Unified Dyskinesia Rating Scale: Presentation and Clinimetric Profile

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Abstract: We developed and tested a rating scale aimed to capture the essential features of dyskinesia in Parkinson's disease (PD). Although several scales assess selected attributes of PD-dyskinesias, no comprehensive rating tool exists. Available rating scales were evaluated by the investigators and patient focus groups. Modifications were finalized into the Unified Dyskinesia Rating Scale (UDysRS). The UDysRS has four parts: I: Historical Disability (patient perceptions) of On-Dyskinesia impact (maximum 44 points); II: Historical Disability (patient perceptions) of Off-Dystonia impact (maximum 16 points); III: Objective Impairment (dyskinesia severity, anatomical distribution over seven body regions, and type (choreic or dystonic) based on four activities observed or video-recorded (28 points); IV: Objective Disability based on Part III activities (maximum 16 points). For clinimetric testing, 70 PD patients with all severities of dyskinesia were interviewed and videotaped. Twenty movement disorder experts rated the videotapes with the UDysRS. Internal consistency was examined with Cronbach's alpha. Inter- and intra-rater reliability was evaluated with generalized weighted and nonweighted Kappa coefficients, and intraclass correlation coefficients. Both subjective (Sections I and II) and objective (Sections III and IV) demonstrated high internal consistency (alpha: 0.915, 0.971). Interrater reliability for the objective sections was acceptable for all items and likewise for intrarater reliability except for right leg. Reliable factor structures were found for both subjective (six factors) and objective sections (five factors). The UDysRS is a clinimetrically sound rating scale for dyskinesia in PD, demonstrating acceptable levels of internal consistency and inter- and intra-rater reliability. Testing scale responsivity to treatment interventions is planned. © 2008 Movement Disorder Society

Key words: Parkinson's disease; dyskinesia; rating scales

In Parkinson's disease (PD), one of the most troubling clinical and treatment issues is drug-induced dyskinesia.[1,2] Research efforts have focused on the anatomical basis and neuropharmacology of dyskinesias,[3,4] and, as a result, new treatments have been developed and are being tested.[5–7] These efforts have been limited by the paucity of a single, reliable, and valid clinical rating instrument for dyskinesia.

Several scales exist for rating dyskinesias, each focusing on one or multiple key attributes: anatomical distribution, phenomenology, duration, intensity, disability, and patient perceptions. Whereas all these features may influence a final assessment of dyskinesias, no single scale captures all these issues.[8] As examples, scales frequently incorporated into dyskinesia studies include: the Abnormal Involuntary Movement Scale (AIMS) that focuses on anatomical distribution and intensity of dyskinesia[9]; the Rush Dyskinesia Rating Scale (RDRS) that focuses on objective assessments of functional disability during prescribed tasks of daily living[10]; the Lang–Fahn Scale (LFS) that focuses on patient perceptions[11]; the Unified Parkinson's Disease Rating Scale (UPDRS) Part IV that assesses historical information on dyskinesia duration and an overall assessment of intensity.[12] Other scales less utilized include the Obeso Scale[13] and the dyskinesia rating protocol recommended in the Core Assessment

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

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Members of the "UDysRS Working Group" are listed as an Appendix.

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Program for Intracerebral Transplantation (CAPIT)[14] and its later modification (CAPSIT).[15] Home-based patient-completed diaries are also used in the context of motor fluctuations with designations of dyskinesia that vary from scale to scale (e.g., dyskinesia present vs. absent, dyskinesia divided into troublesome and nontroublesome).[16] More recently, and after the organization of this program, the Parkinson's Disease Dyskinesia Scale (PDYS-26) was developed as a patient self-assessment scale.[17]

In 1998, an international symposium on dyskinesias in PD occurred in Toulouse, France. The summary document[18] emphasized the need for a single scale for assessing dyskinesia, and by consensus, participants recommended a Unified Dyskinesia Rating Scale (UDysRS) to be composed of modified versions of existing scales. This report presents the UDysRS and its clinimetric testing program. An educational Teaching Tape will be presented in a separate manuscript.

METHODS

Scale Development

At the original 1998 meeting, participants agreed that the key elements important to rate in dyskinesia were type (choreic vs. dystonic), anatomic distribution, relationship to ON or OFF states, objective impairment, functional disability, and patient perception. The authors reviewed available scales (see above) and considered several combinations and modifications based on feedback pilot programs involving movement disorder specialists. They also tested protocols for data acquisition, including tests of whether reliable data on dyskinesias could be obtained by raters in the midst of rating parkinsonism with the testing tasks from the UPDRS motor examination. This latter strategy, however, was rejected in favor of a specific dyskinesia rating protocol. For all materials to be completed by patient/caregivers, vocabulary and grammar were adapted to seventh grade reading levels and presented to patient focus groups for feedback and further adaptation. In anticipation that the scale would be utilized internationally and in multicenter studies involving large numbers of raters, the scale developers drafted a video-filming protocol for clarity and consistency of techniques, written instructions for all questions, and finally, a teaching tape with a certification exercise. Cognizant of a new version of the UPDRS (MDS-UPDRS), the developers designed items in parallel with the new version.[19] For uniformity of all items, each question had 0 to 4 rating options with written anchors for each response, based on the clinical concept that 0 = normal, 1 = slight, 2 = mild, 3 = moderate, and 4 = severe.

Clinimetric Testing Program

For the clinimetric testing program, we calculated a sample size estimate based on an effect size $r = 0.33$ with an alpha < 0.05 and a required power of 0.80. Based on these estimates, a sample size of 67 patients would be needed. Therefore, 70 PD subjects were recruited based on a global assessment by the authors to represent the gamut of dyskinesias from absent to severe. After providing informed consent approved by the local Institutional Review Board at Rush University Medical Center, each subject completed the historical disability questions for On-dyskinesia and Off-dystonia (Parts I and II of the UDysRS) and were filmed by the protocol described below. Videotapes were then distributed to the UDysRS Working Group members, 20 international movement disorder experts (see Appendix) who rated the tapes using the UDysRS. Raters received two DVDs, spaced 1 month apart. From the master videotape of 70 cases, raters received a first tape with 35 cases, followed by a second tape with 30 to 33 new cases, and the remaining cases (total: 35) were repeat films from the first tape. Interrater reliability was assessed for all 70 cases with a minimum of 10 and a maximum of 20 raters per examination. Intrarater reliability (test–retest) reliability was assessed on 10 videotape examinations by 15 raters with a 1-month test–retest interval. Stratification of rater assignment to master tapes ensured a random distribution of order of examination, severity of dyskinesia, and repeat rating. Agreement between investigator rated severity and patient subjective report of severity was assessed using the eta statistic which assesses the relationship between ordinal and interval levels of measurement.

We assessed interrater reliability for dichotomous items using generalized kappa statistic. For ordinal items, we used a generalized weighted kappa statistic. This statistical model allows for the comparison of rating values for multiple (more that two) raters per examination and applies a weighting for disparate values (e.g., a point difference of 2 is given a higher weighting than a point difference of 1). We used intraclass correlation coefficients to assess reliability for continuous item measures. To interpret both kappa and intraclass correlation coefficients values, we followed guidelines for acceptable levels of agreement, defined by the threshold of ≥ 0.2, with 0.2 to 0.39 = fair agreement, 0.4 to 0.59 = moderate agreement, 0.6 to 0.79

= good agreement, and ≥0.8 or greater = very good agreement.[20] Inter- and intra-rater reliability was assessed for the following scores: (1) the highest impairment ratings for seven body parts (face, neck, right arm/shoulder, left arm/shoulder, trunk, right leg/hip, and left leg/hip) during the four videotaped activities to assess communication, drinking, dressing and ambulation; (2) the sum score of the impairment ratings; (3) the disability ratings for the four activities; (4) the sum score for the disability ratings; (5) the presence of dyskinesia or dystonia (on dyskinesia, off dystonia, transition state and no dyskinesia or dystonia); (6) the type of movements identified (chorea, dystonia, other); (7) the predominant dyskinesia presented (chorea, dystonia, other); and (8) the total score of the objective ratings (sum of impairment scores and disability scores). Because we anticipate that the objective components may be used separately from the subjective components in pharmacological studies testing dyskinesia frequently over a fixed time period, we also examined the interrater and intrarater reliability of the impairment (AIMS) and disability (RDRS) components.

Assessment of scale reliability included testing of internal consistency (Cronbach's alpha) and factor structure. Internal consistency provides a measure of the average correlation between two halves of the scale over all possible ways of splitting the scale into two halves. Factor structure was assessed using a principle component extraction with promax rotation. This oblique rotation method was used because independence of factors could not be assumed. Scree plots resulting from the principal components analysis were examined to determine the number of salient factors. Data from this study were analyzed using SPSS (SPSS, Chicago, IL), and JMP (SAS Institute, Cary, NC).

RESULTS

UDyRS: Structure Description and Components (see Supp. Info. 1)

The UDysRS is a four-part scale that assesses: I: Historical Disability (patient perceptions) of On-Dyskinesia impact (11 items, 1 with involvement of the rater to assist in obtaining the portion of the day the subject has dyskinesia and 10 answered by the patient/caregiver in the form of a questionnaire. This section is based on the Lang–Fahn Scale, but with significant modification); II: Historical Disability (patient perceptions) of Off-Dystonia impact (4 items, 1 with involvement of the rater to determine the hours per day with Off-dystonia and 3 answered by the patient/caregiver in the form of a questionnaire. This section is based on the MDS-UPDRS); III: Objective Impairment (Dyskinesia severity and anatomical distribution based on four activities observed or video-recorded). Seven anatomical areas are rated for severity of dyskinesia or dystonia on each task with the highest score for the four tasks recorded as the final score for each body region. This section is based on the AIMS; IV: Objective Disability (four items with ratings based on the same four activities in Part III. This section is based on the RDRS); V: Total Objective Score (sum of impairment and disability scores). The scale extracted items and concepts from the following scales: Lang–Fahn questionnaire,[11] MDS-UPDRS,[19] AIMS,[9] and RDRS.[10] Score ranges are 0 to 44 for Part I, 0 to 16 for Part II, 0 to 28 for Part III, and 0 to 16 for Part IV, with a total score range of 0 to 104.

Clinimetric Testing Profile

Patient Profile

Seventy patients with a full range of dyskinesia were recruited and completed the UDyRS. Based on the organizing team's global assessment of the cohort, 15 patients had no dyskinesia, 20 had mild dyskinesia, 20 had moderate dyskinesia, and 15 had severe dyskinesia. There were 42 men and 28 women in the sample with a mean age of 65.2 (±8.9) years, a mean duration of PD of 13.3 (±8.5) years and a median HY stage 2 (range: 2–4). The score medians, interquartile ranges, and ranges of the subjective ratings in the cohort with dyskinesia were: Part I = 11.0 (5–20; 1–34); Part II = 1.5 (1–6; 1–15). Correlation between severity classification by the scale development team and patient self-report was high (eta = 0.81, $P < 0.0005$).

On the objective ratings of impairment (Part III), the highest rating occurred in neck, followed by trunk, right leg, right arm, left arm, left leg, and face. The highest disability ratings (Part IV) occurred in dressing, followed by ambulation, communication, and drinking. Importantly, however, the distribution of anatomical rankings was not consistent across all tasks, and, for example, neck ratings of impairment were highest during the communication task, whereas they were the lowest severity among all body parts during ambulation.

Inter- and Intra-rater Reliability (See Supp. Info. 2)

In the clinimetric program, there was 100% compliance by raters and all datasets were complete.

Interrater reliability coefficients ranged from fair to very good agreement for impairment (AIMS-based) and disability (RDRS-based) ratings. Generalized weighted kappa coefficients for testing interrater reliability ranged from 0.38 (fair agreement) to 0.43 (moderate agreement) for highest rated impairments in the seven body parts across four activities. Lower agreements occurred on ratings of the upper extremities. The intraclass correlation coefficient for interrater reliability of the sum of the impairment ratings was 0.87 (very good agreement). Generalized weighted kappa coefficients for interrater reliability of disability ratings of the four activities ranged from 0.37 for dressing (fair agreement) to 0.52 for drinking (moderate agreement). The intraclass correlation coefficient for interrater reliability of the summary disability was 0.91 (very good agreement). Interrater reliabilities for the presence of dyskinesia or dystonia, type of movements observed, and predominant dyskinesia presented were assessed using a generalized kappa coefficient and ranged from 0.54 (moderate agreement) to 0.67 (good agreement). The intraclass correlation coefficient for interrater reliability of the total objective score was 0.89 (very good agreement).

Intrarater reliability coefficients ranged from fair to very good for impairment (AIMS-based) and disability (RDRS-based) ratings. Generalized weighted kappa coefficients for intrarater reliability of the highest impairment rating of the seven body parts ranged from 0.52 (moderate agreement) to 0.60 (good agreement). Consistent with the interrater reliability results, lower intrarater reliability coefficients were detected for the upper extremities scores. The intraclass correlation coefficient for intrarater reliability of the sum impairment score was 0.91 (very good agreement). Generalized weighted kappa coefficients for intrarater reliability of disability ratings for the four activities ranged from 0.54 (moderate agreement) to 0.79 (good agreement). The intraclass correlation coefficient for intrarater reliability of the sum disability score was 0.84 (very good agreement). Generalized kappa coefficients for intrarater reliability of the presence of dyskinesia or dystonia, type of movements observed, and predominant dyskinesia presented ranged from 0.34 (fair agreement) to 0.99 (very good agreement). There was perfect agreement for ratings of off dystonia, no dyskinesia or dystonia, and other predominant dyskinesia. The intraclass correlation coefficient for intrarater reliability of the total objective score was 0.90 (very good agreement).

Scale Internal Consistency and Factor Structure (see Supp. Info. 3)

The UDysRS demonstrated acceptable internal consistency and interpretable factor structure for both the subjective (I and II) and objective (III and IV) sections. The subjective rating sections (I and II combined) demonstrated high internal consistency (Cronbach's alpha = 0.92). Factor structure was interpretable with six factors identified, accounting for 69% of the variance. Factor loading for all items in the subjective rating sections exceeded 0.63. The six factors included: (1), the assessment of on-dyskinesia, (2) the effects of dyskinesia on speech, (3) the effects of dyskinesia on eating activities, (4) the effects of dyskinesia on activities of daily living, (5) the effects of dyskinesia on emotional function, and (6) the impact of off-dystonia.

For the objective rating sections (Parts III and IV combined), high internal consistency was also found (Cronbach's alpha = 0.97). Factor structure was interpretable with five factors identified accounting for 69% of the variance. Factor loadings for all items exceeded 0.42. The five factors included: (1) assessments of impairment and disability, (2) assessments of on-dyskinesia and chorea, (3) assessment of off-dystonia, (4) assessment of dyskinetic movements other than dystonia or chorea, and (5) occurrence of a transitional state between ON and OFF.

DISCUSSION

The UDysRS appears to provide a reliable and valid assessment of dyskinesia in PD. We developed the new scale to address problems inherent to the available scales which captured some, but not all, elements of importance.[8,18] The UDysRS includes modified portions of the Lang–Fahn patient interview[11] and has adapted questions to a questionnaire format for efficiency. In testing the new questionnaire in patient focus groups and modifying it further based on patient and caregiver feedback, we feel we have addressed the issues clinically pertinent to subjects who experience dyskinesia. In testing the objective components with colleagues in preliminary drafts of the scale, we feel we have also addressed the issues clinically pertinent to physicians regularly dealing with dyskinesia in clinical and research settings. The objective portions are anchored in the AIMS[9] and RDRS,[10] which are widely used in practice and clinical trials. Further, because we were aware of the revision of the UPDRS underway (MDS-UPDRS), we included core questions from this

new version. In this way, we have provided a single scale that captures patient perceptions, time factors of dyskinesia, anatomical distribution, objective impairment severity, and disability.

The objective sections were designed to rate the most severe level of impairment and disability observed during four tasks. Because each activity is part of daily life, we chose to accept the highest values for each body part as reflective of the impact of dyskinesia on function. This decision respected the operational conventions of the original AIMS and RDRS. Although not a primary goal of our study, our results provide, to our knowledge for the first time, inter- and intra-rater reliability assessments for these two scales in the same cohort. Both the AIMS and the RDRS have acceptable inter- and intra-rater reliability, ranging from fair to very good agreement estimates. Although we envision that the UDysRS will be used in its entirety in most instances, some dyskinesia treatment protocols call for frequent objective ratings. In these cases, the objective components of the scale, based on the RDRS and AIMS, are robust, even when used alone.

The clinimetric program demonstrated acceptable scale reliability, factor structure, and inter- and intra-rater reliability. We acknowledge the limitations of the analysis due to the absence of responsiveness testing to an intervention. Furthermore, although the clinimetric properties of the scale demonstrated good internal consistency and a statistically stable and clinically rational factor structure, we did not examine other key components of scale validity (concurrent validity, discriminative validity, and content validity). The results of the factor analysis must be viewed as preliminary, because our sample size was relatively small, and we did not perform a confirmatory factor analysis. As a result, we cannot specifically determine the factor association for the item focused on the impact of emotional settings on dyskinesia (Part I). This item had a primary loading on one factor, but was substantially associated with a second factor. Additional observations from a larger sample and a confirmatory analysis are needed to establish a definitive factor association for this item. Interrater reliability was established with acceptable levels of agreement among raters on all scale items, but not all items had high agreements. This finding suggests that further refinements may be beneficial. These issues can be assessed in the next phase of study that will include an assessment of the scale responsivity to change.

Patient-based home diaries to assess dyskinesia were not included in the UDysRS. Diaries have primarily been applied to the study of motor fluctuations, and dyskinesias are variably captured on these scales. Some scales distinguish between dyskinesia presence and absence, whereas others subdivide dyskinesia into troublesome and nontroublesome.[16,21] Diaries cannot be completed in an office setting and require specific educational efforts and training.[22] Furthermore, there is substantial literature on the poor compliance of diary completion.[23] For these reasons, we elected to focus the UDysRS on the scales specifically developed for dyskinesia and the ones that could be completed fully within the office visit.

Besides scale development and the clinimetric analysis of the UDysRS, the third part of the program includes the creation of a training tape. This tape and a certification exercise will permit tools to ensure that a common rating standard is used and will be anchored with the ratings provided by the experts who participated in the clinimetric program. Modeled after the teaching tape program developed for the original UPDRS,[24] this tape will provide introductory material on the background and conceptual framework of the UDysRS, show examples of interview techniques for data acquisition by the interviewer for Parts I and II, and demonstrate a rater giving the questionnaire to patients or patient/caregiver. For the objective sections, video segments for all levels of severity across all body areas will be selected based on examples of highest agreement among the expert panel during the clinimetric testing phase. At the conclusion of the teaching tape, four complete video examinations covering Parts III and IV will be provided along with expert ratings and 95th confidence intervals so that the examinees may assess their level of agreement with the experts. Upon completion, we plan to publish this material as a separate manuscript and DVD and to give these materials to the Movement Disorder Society.

APPENDIX

UDsyRS Working Group

Kailash Bhatia (London, UK), Kathy Chung (Portland, OR), Carlo Colosimo (Rome, Italy), Philippe Damier (Nantes, France), Shu-Leong Ho (Hong Kong, Peoples Republic of China), Mark Lew (Los Angeles, CA), Peter LeWitt (Detroit, MI), Irene Litvan (Louisville, KY), Marcelo Merello (Buenos Aires, Argentina), José Obeso (Pamplona, Spain), Paul Krack (Grenoble, France), Ronald Pfeiffer (Memphis, TN), Werner Poewe (Innsbruck, Austria), Olivier Rascol (Toulouse, France), Kapil Sethi (Augusta, GA), Fabrizo Stocchi (Rome, Italy), Philip Thompson (Adelaide, Australia), Ergun Uc (Iowa City, IA), J.J. Van Hilten (Leiden, Netherlands), Marie Vidailhet (Paris, France).

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