Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Process, Format, and Clinimetric Testing Plan

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Abstract: This article presents the revision process, major innovations, and clinimetric testing program for the Movement Disorder Society (MDS)–sponsored revision of the Unified Parkinson's Disease Rating Scale (UPDRS), known as the MDS-UPDRS. The UPDRS is the most widely used scale for the clinical study of Parkinson's disease (PD). The MDS pre-

strengths, but recommended revision of the scale to accommodate new advances and to resolve problematic areas. An MDS-UPDRS committee prepared the revision using the recommendations of the published critique of the scale. Subcommittees developed new material that was reviewed by the entire committee. A 1-day face-to-face committee meeting was organized to resolve areas of debate and to arrive at a working draft ready for clinimetric testing. The MDS-UPDRS retains the UPDRS structure of four parts with a total summed score, but the parts have been modified to provide a section that integrates nonmotor elements of PD: I, Nonmotor Experiences of Daily Living; II, Motor Experiences of Daily Living; III, Motor Examination; and IV, Motor Complications. All items have five response options with uniform anchors of 0 = normal, 1 = slight, 2 =

viously organized a critique of the UPDRS, which cited many

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mild, 3 = moderate, and 4 = severe. Several questions in Part I and all of Part II are written as a patient/caregiver questionnaire, so that the total rater time should remain approximately 30 minutes. Detailed instructions for testing and data acquisition accompany the MDS-UPDRS in order to increase uniform usage. Multiple language editions are planned. A three-part clinimetric program will provide testing of reliability, validity, and responsiveness to interventions. Although the MDS-UP- DRS will not be published until it has successfully passed clinimetric testing, explanation of the process, key changes, and clinimetric programs allow clinicians and researchers to understand and participate in the revision process. © 2006 Movement Disorder Society

Key words: Parkinson's disease; rating scales; Unified Parkinson's Disease Rating Scale; clinimetrics

The Unified Parkinson's Disease Rating Scale (UP-DRS) was originally developed in the 1980s1 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 core four-part structure 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. The effort resulted in a new version of the scale, termed the MDS-sponsored UPDRS revision (MDS-UPDRS). Although a draft is fully formulated, the new version requires clinimetric testing before it can be recommended for circulation, use, and replacement of the original scale. Only a final scale that meets clinimetric criteria will be published and this process will require approximately 2 years. The current report, however, details the structure and items being assessed, updates readers on the process to reach the final scale presentation, describes the clinimetric testing, welcoming readers to contact the authors for participation in the multiphase program.

REVISION PROCESS

The MDS International Executive Committee appointed the first-named author (C.G.G.) to organize the revision process. He recruited seven Steering Committee members, each in charge of a specific aspect of the revision process: Part I, Part II, Part IV, Scale Development Methods, Clinimetric Testing, and Appendix. The Steering Committee agreed to follow the overall recommendations of the MDS-sponsored critique³ in terms of retaining and modifying different aspect of the original scale. Each Steering Committee chair recruited two or three additional experts. These subcommittees assumed primary responsibility for an assigned section or task, but each member of the revision group reviewed all materials. The final committee consisted of 22 members (authors).

After an organizational teleconference, the Part I, II, III, and IV groups worked with the Scale Development Methods group to prepare a working revision draft of the four components of the MDS-UPDRS. In selecting items, committee members reviewed the neurological literature, systematically examined available scales, surveyed colleagues and patients, and utilized their own experience in rating PD-related disability and impairment. As they selected items, the groups communicated with the Appendix Committee to alert them to the items they were considering. The Appendix group's primary mission was to develop and evaluate a list of available scales to rate domains of PD-related impairment or disability in greater detail than would be possible within the MDS-UPDRS core document. Such in-depth scales covering areas such as depression, dementia, dysautonomia, and health-related quality of life would meet specified criteria, including established reliability and relevance to PD, thereby guiding clinicians and researchers on recommended measures to be used for better quantification.

Once the first drafts were prepared, they were circulated to the entire group for written comments. The program director integrated all comments and provided the group with suggestions for resolution of conflicting views. These suggestions were the focus of a 1-day face-to-face meeting of the entire group aimed at resolving concerns and arriving at a final working draft. This ratified draft was presented to the MDS membership during the Eighth International Congress on Parkinson's Disease and Movement Disorders in 2004. Preliminary testing among a series of English-speaking patients and reviews by the raters administrating the rating scale led to further modifications, including the revisions of questions into a patient/caregiver questionnaire for several Part I items and all Part II items.

MAJOR FEATURES OF MD-UPDRS

Retention of a Single Scale With Four Subscales

The revision committee agreed to follow the published critique of the UPDRS and to formulate a single scale for use in both research and clinical care settings. The scale MDS-UPDRS 43

should characterize the extent and burden of disease across different populations, define longitudinal disease course, and be a clinical endpoint in therapy trials. The MDS-UPDRS follows the original UPDRS format of four parts with scores that can be summed to render a total or be analyzed separately. A primary criticism of the original UPDRS focused on the irregular placement of nonmotor elements in PD throughout the subscales, with mental features captured in Part I, pain in Part II, and sleep disorders and dysautonomia in Part IV. Based on the identified need to place emphasis on nonmotor elements of PD and to compare their contribution to overall PD disability with the motor aspects of the disease, the group realigned the internal organization so that Part I of the MDS-UPDRS is now titled "Nonmotor Experiences of Daily Living." The items selected fall into complex behaviors that require medical expertise and probing to arrive at answers (cognitive impairment, hallucinations, depressed mood, anxious mood, apathy, and dopamine dysregulation) and simpler questions that were considered better suited for a patient/caregiver questionnaire (sleep, staying awake, pain and abnormal sensory sensations, urinary function, constipation, lightheadedness on standing, and fatigue). The new Part II has a similar focus to Part II of the original scale, but has been retitled "Motor Experiences of Daily Living" to establish a parallel conceptual construct with Part I. All these questions were considered amenable to the patient/ caregiver questionnaire format. Part III remains "Motor Examination," to be completed by the rater, and Part IV is restricted to "Motor Complications" (dyskinesias and motor fluctuations). The change in titles to "experiences" rather than "activities" addresses the criticism from the published critique that highlighted the irregular fusion within the original Part II of patient-based perception of disabilities in activities of daily living (e.g., dressing, walking) with perceptions of primary signs of parkinsonism (e.g., salivation). For all questions, disability or impairment are rated on a 0-4 scale discussed below.

Uniform Anchors

The original UPDRS was structurally inconsistent, having most items with 0-4 options but several questions in Part IV having yes/no responses. Further, even with 0-4 options, there was no consistent anchor across questions so that a given numeric option did not always reflect a similar level of dysfunction. To resolve these concerns, the MDS-UPDRS has only 0-4 ratings. 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 that de-

scribes 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" refers to symptoms/signs with sufficiently low frequency or intensity to cause no impact on function; "mild" refers to symptoms/signs of frequency or intensity sufficient to cause a modest impact on function; "moderate" refers to symptoms/signs sufficiently frequent or intense to impact considerably, but not prevent, function; "severe" refers to symptoms/signs that prevent function.

Included Items

The full revised version contains 50 questions (Table 1), divided across Part I (13), Part II (13), Part III (18; several with right, left, or other body distribution scores), and Part IV (6). This distribution contrasts with the original version (42 questions, distributed across the four parts sequentially as 4, 13, 14, and 11). In many cases, item titles have been altered but the overall domain under consideration is similar between the original and revised versions. In the current draft, new items not assessed with the original scale are marked in the Table 1 with a footnote. In Part III, tremor assessment divides postural tremor, assessed with the patient's arms outstretched from kinetic tremor, assessed during the finger-to-nose test. Further rest tremor is assessed for both amplitude and constancy. The clinimetric testing may identify phrasing that is unclear to the patient or subject and duplicative items, allowing future clarification and reductions for the final draft. The selection of the new items was based on the published critique of the UP-DRS,3 supplemented with each subcommittee's review of the medical literature on impairments and disabilities related to Parkinson's disease.

Time Required for Scale Completion

The revision effort prioritized reaching a time estimate of 30 minutes of rater involvement as a practical time frame for the final full MDS-UPDRS and 10 minutes for Part III (motor examination). On the other hand, because of scientific advances over the past 25 years, several new items were felt to be required in the revision and only a few items from the original scale could be comfortably dropped. To resolve this dilemma, 7 of 13 items from Part I and all of Parts II are designed to be self-administration instruments in the form of a questionnaire, written at seventh-grade reading level. The success of this plan will be assessed clinimetrically. Using this format, the MDS-UPDRS is estimated to require less than 10 minutes for the interview items of Part II, 15 minutes for Part III, and 5 minutes for Part IV, resulting in an

TABLE 1. MDS-UPDRS check

Part I: Nonmotor Aspects of Experiences of Daily Living

Cognitive impairment

Hallucinations and psychosis

Depressed mood

Anxious mooda

Apathy

Features of dopamine dysregulation syndrome

Sleep problems

Daytime sleepiness

Pain and other sensations

Urinary problems^a

Constipation problems^a

Lightheadedness on standing

Fatigue

Part II: Motor Experiences of Daily Living

Speech

Saliva and drooling

Chewing and swallowing

Eating tasks

Dressing

Hygiene

Handwriting

Doing hobbies and other activities^a

Turning in bed

Tremor impact on activities

Getting in and out of beda

Walking and balance

Freezing

Part III: Motor Examination

Speech

Facial expression

Rigidity

Finger tapping

Hand movements

Pronation-supination movements of hands

Toe tapping^a

Leg agility Arising from chair

Gait

Freezing of gait

Postural stability

Posture

Global spontaneity of movement (body bradykinesia)

Postural tremor of hands

Kinetic tremor of hands

Rest tremor amplitude

Constancy of rest tremor

Part IV: Motor Complications

Dyskinesias: time spent with dyskinesias Dyskinesias: functional impact of dyskinesias

Dyskinesias: painful *off* state dystonia Motor fluctuations: time spent in the *off* state Motor fluctuations: functional impact of fluctuations Motor fluctuations: complexity of motor fluctuations

equivalent rater time investment to the original scale and meeting the 30-minute goal. Though this goal is preset as part of the program, its success can only be tested in the context of practice and familiarity with the scale. The testing program is designed to track investigator time as a function of experience.

More Emphasis on Rating Mild Impairment/Disability

The original UPDRS placed considerable emphasis on marked and severe disabilities or impairments. The scientific advances since the original scale's development, along with the growing emphasis on neuroprotection and early therapies, prompted a strong recommendation in the published critique to adapt the scale so that it measured more mild deficits and allowed detection of small changes in early disease. This effort is reinforced by concerns of floor effects in the original scale.4 To this end, the scale revision has conceptually shifted away from differentiating the gradations of advanced disability to differentiating slight from mild deficits. In order to respect the limitation of five rating options for each item, this decision necessarily collapses impairments that separated severe vs. marked impairments in favor of allowing a wider range of differentiation among the lower ranges of disability. The question of whether the MDS-UPDRS will detect changes within the population of advanced patients was discussed by the writing team and will need to be tested in clinical trials; however, the revision effort focused on reducing anchors that represented extreme impairments and disabilities because they are rarely applicable even in advanced patients and would be considered unlikely to change even with substantive interventions. Further, the committee considered that many issues in advanced disease concern motor complications (dyskinesia and motor fluctuations), which are captured in detail in Part IV and nonmotor signs captured in Parts I and II.

Resolved Ambiguities and Corrected Inconsistencies

The published critique of the UPDRS provided several examples of ambiguities in language concerning the items being rated and their accompanying instructions (e.g., postural/kinetic tremor, speech, facial expression). Some items were worded with multiple options that could fulfill a given rating, but guidelines were unclear on how raters should rate a patient who fulfilled one but not all of the listed options. Further, if one fulfilled one criterion for a given level but the other criteria fit another level, should the worse score or the score associated with the most endorsed options be entered? The revision committee concurred with these criticisms, and the rewriting process focused on avoiding similar problems in the adaptations of old items and the writing of new items. Further, because several questions in Parts I and II were designed to be a self-administrated questionnaire instrument for patients, these questions were reviewed by the Scale Development Methods committee and by nonphysicians, including patients and caregivers. This review

^aDomains not previously assessed. The unmarked items are newly written, but were covered in some capacity in the original UPDRS.

MDS-UPDRS 45

was designed to adapt vocabulary to a seventh-grade level and avoid all medical jargon. Finally, because the interview portions of the original scale did not clearly indicate who should respond (patient, caregiver, or both), the new version specifies that patients should rate their own disability and if the caregiver is needed to participate or replace the patient as the primary data source, this involvement is specifically documented.

Instructions

The original scale was first published in book format that was never widely available.1 As such, the overview discussion and instructions for scale utilization were never regularly produced with the scale itself. Further, the instructions were brief, and there were only a few specified guidelines, especially for the examination techniques for testing the Motor Examination (Part III). A UPDRS teaching tape for Part III and a tape on one method to acquire Part II data on activities of daily living were developed, though these programs were never specifically part of the UPDRS development plan and appeared several years after the scale's introduction.^{5,6} To resolve these issues, the new version's core document includes a set of instructions that guide raters on the overall scale, each section, and each item. These instructions provide definitions and specifically indicate the time frame being covered for the assessment. On and off definitions are provided to ensure uniformity among raters and will apply to assessments for Part III when indicated and for Part IV. For Part I and Part II, the official scale will not separate on and off function, but, for special studies, the same questions can be asked for on periods and off periods separately. A formal teaching tape and a certification program will be produced at the close of the clinimetric program and will accompany the final published scale.

Issues of Cultural Sensitivity, Individually Tailored Questions, and Official Language Editions

The published critique identified cultural biases in the original scale and considered some questions to be restrictive with the risk of overlooking the impact of PD on activities that are particularly important to an individual subject (hobbies, personal interests). The MDS-UPDRS addresses these issues first by focusing on the experiences (e.g., feeding) rather than tasks (e.g., handling utensils). Second, a new question addresses the impact of PD disability on the performance tasks related to areas of personal interest, without specifying a given activity. This open-question format still retains the strict 0–4 structure but allows patients to sculpt their response to consider areas of personal importance, remaining bias-

free, and applying to piano playing, Ping-Pong, or raising snakes with equal specificity. These activities will necessarily differ among patients, but will allow each subject to choose a key activity of interest for a focused response. The Task Force recognized that hobbies could change over time and that this question could potentially be confounded by these changes, but the desire to capture the functional capacity to perform activities of personal importance to patients overrode this concern. Finally though the first phases of testing use only an English version, official translations in multiple languages will be prepared and tested.

Appendix of Other Scales

Given the multiplicity of nonmotor aspects of PD and the prioritization of a reasonably short overall scale, the rewriting committee accepted the reality that in-depth assessments of any single nonmotor feature was impractical. The committee therefore elected to develop one question for each pertinent nonmotor domain and to develop an official list of recommended or suggested scales for raters in need of more detailed information on a given disability. Scales listed in the Appendix under the designation "recommended" fulfilled criteria of successful clinimetric testing, established validation, reliability, and sensitivity assessments, and prior application in PD. If a scale met some but not all of these criteria, the Appendix listed it as "suggested." All scales reviewed are listed to document that their absence from the two primary lists is not due to oversight. This Appendix is considered a core part of the MDS-UPDRS and will be periodically updated and stored on an electronic site. Through the Appendix, research groups will be encouraged to favor the use of the recommended scales for detailed assessments of items endorsed during usage of the MDS-UPDRS, and uniform selection of scales among researchers will permit more direct comparisons of studies.

CLINIMETRIC TESTING PROGRAM

The field testing of the new version is composed of three sequential phases, all to be coordinated through the MDS, but designed to involve many participants, both MDS members and nonmembers.

Phase 1: Qualitative (Cognitive) Pretesting

This first phase of scale testing has been carried out in a small sample (approximately 80 patients) and tested the scale in two versions. The testing used raters familiar with the scale (members of the rewriting committee) and raters unfamiliar with the scale (colleagues in the same PD service, but without prior exposure to the scale).

Patients were examined using the scale and after each item, they were asked about the clarity of the question and response options, about any difficult language or concepts, and about the item's relevance to PD. The rater likewise responded to these inquiries. Content analysis and descriptive summaries of patient and rater responses identified several problems. Of the 49 items, 15 were identified by raters as having substantive problems with clarity or conceptual scaling and 2 were identified by patients. Based on these data, the working draft was modified to enhance clarity of wording and focus. All instructions and items involving patient response were assessed for reading grade level requirements and, in the revised version, none exceeded the seventh grade. Seven of the Part I items and all of Part II were converted into a patient questionnaire to be administered independently of the rater.

Testing of this second version involved seven sites with 14 examiners and 32 patients. After each question, patients and examiners were asked to rate each item for ease of comprehension for instructions and response options using a six-point Likert scale with 0 representing "very difficult" and 6 representing "very easy." The overall modal response for examiner and patient ratings for all items was 6 ("very easy"). For items with modal ratings below 6, three authors (C.G.G., B.C.T., G.T.S.) reviewed and modified the wording slightly to address concerns when deemed necessary.

Phase 2: Intrinsic Attributes of MDS-UPDRS, Its Comparability With Original UPDRS, and Its Assessment in Different Ethnic Groups and Medical Environments

This phase will assess acceptability, scaling assumptions, construct validity, measurement equivalence, and other clinimetric attributes of the MDS-UPDRS in a large cross-sectional population of PD subjects. In addition, a core focus of this phase will be determining how each item, each section, and the total score from the MDS-UPDRS relates to the original UPDRS. Item-toitem relationship will vary because many items are minor revisions of the earlier scale items, but some items are new. Further, the new scale places emphasis on mild disability and impairment (1 = slight, 2 = mild) in contrast to the original scale, where ratings of 1 usually indicated mild problems and ratings of 2 related to moderate difficulties. To effect this comparability analysis, a large number of patients will be examined with both the MDS-UPDRS and the UPDRS. The plan will include 500 English-speaking Caucasian subjects and 250 English-speaking subjects from each of several major minority populations, African American, Asian, and Hispanic/Latino included. Factor analyses to identify duplicative items will be conducted on data from phase 2, with the intent to eliminate items that take time to assess and do not provide essential information. As a part of the analysis, we will perform confirmatory factor analysis and differential item functioning will be assessed. The large number of subjects studied in this phase will permit analyses of patients from different referral bases (clinical practices vs. research centers, rural vs. urban) as well as from different race, ethnic, and age groups. Afterward, a training tape will be prepared. Consortia such as the Parkinson Study Group in North America and comparable groups in Europe and other continents have and will be contacted for participation, in which case, the primary data will reside with the consortia, which will be encouraged to publish these data separately as long as they contribute the UPDRS and MDS-UPDRS ratings to our larger program. Consortia of trialists involved in new protocols and groups of investigators who wish to conduct the UPDRS and the MDS-UPDRS in the same patients and share these data are welcome to join the effort and can contact the Task Force (C.G.G.). Phase 2 data collection can potentially be included into clinical trials with acquisition of UPDRS scores along side MDS-UPDRS scores. Because the new scale was prepared in English and the original UPDRS had no official translations, this phase of testing will be conducted only in sites of English-speaking patients/ physicians and will be cross-sectional. Any longitudinal data collected by those participating will be included as part of phase 3. Because future clinical trials may focus on all or only some aspect of PD, the clinimetric analysis will focus on the total score as well as the scores on each of the four parts.

The phase 2 testing will involve healthcare professionals directly involved with PD patients, but will track prior experience with the original UPDRS and the raters' prior experience in dealing with PD. A key issue being examined in the clinimetric process is the utility of the patient/caregiver questionnaire. A subset of raters will be recruited to administer the items as an interview to assess if patients and caregivers respond similarly whether they provide information by questionnaire or by interview. High correlation of these two techniques will allow the patient-questionnaire methodology to be officially incorporated into the MDS-UPDRS. Demographic information on each patient who participates in this aspect of the program may identify subject profiles that will predict the need to gather the questionnaire data through a rater-based interview. The added rater time will be calculated and incorporated into the clinimetric analysis of feasibility.

MDS-UPDRS 47

Because of the concern that the MDS-UPDRS be practical for clinical care as well as research efforts, the time required for the investigator to complete the scale will be tracked. It is anticipated that familiarity with the scale will reduce the time needed; the time will be charted along with the rater's prior experience in using the scale.

Phase 3: Translation and Back-Translation to Non-English Languages and Responsivity Testing

Although the UPDRS is used internationally, the original version had no formally tested and validated translations. Part of the clinimetric program for the revised MDS-UPDRS will be the development of forms in multiple languages. The new scale will be translated, backtranslated, and be tested with qualitative cognitive assessments in a small number of patients for each language under consideration. In this phase as well, teaching tapes in core languages may be developed. Whereas the UPDRS has a teaching tape for the Motor Examination (Part III), the MDS-UPDRS teaching tape will include all items from the four parts with an appropriate example of patients at each rating level on each item to provide a more comprehensive didactic tool. 5.6 Internet-based certification programs are envisioned.

To test interrater reliability, multiple ratings of the same patient by different examiners will be conducted. To assess the ability of the new scale to detect change over time, the MDS-UPDRS will be tested against the original UPDRS in clinical trials using longitudinal data. In the context of a trial, responsiveness to interventions, including placebo treatment, can be assessed. Whereas the total score is envisioned as the primary outcome of such trials, the clinimetric analysis will assess responsiveness for each of the components (Parts I–IV).

Integration of Phases and Final MDS Document

At the completion of each phase, the need for revisions in the MDS-UPDRS will be assessed. The committee acknowledges that the scale may in fact evolve over the clinimetric testing program, and for this reason, the authors are not publishing any draft prior the final scale. At the end of phase 3, the document that has met sufficient reliability, validity, and responsiveness criteria and accommodates maximal information without duplication will become the MDS-UPDRS in its final form.

Investigator-Initiated Programs

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 Parkinson's disease are encouraged by the authors, but are not part of this core program. Testing of such scales against the MDS-UPDRS will be important to later efforts to establish both construct and convergent validity.

CONTACT INFORMATION AND PARTICIPATION

As an MDS-sponsored effort, the development and testing of the MDS-UPDRS has and will rely on membership participation. Clinicians interested in using the scale and providing data for the clinimetric program can contact the first-named author (cgoetz@rush.edu) or the MDS secretariat, Caley Kleczka (ckleczka@movementdisorders.org). Drafts of the scale in its current version will be available to members who wish to examine it, but the only published version will appear after the final scale has met the criteria of the clinimetric program. An estimated publication date will be 2007, and until that publication, the MDS-UPDRS revision committee recommends that the original UPDRS continue to be the standard for rating PD. Comments on the scale draft are welcome and can be addressed to the senior author.

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APPENDIX

MDS-UPDRS program director: Christopher G. Goetz; Steering Committee members: Stanley Fahn, Pablo Martinez-Martin, Werner Poewe, Cristina Sampaio, Glenn T. Stebbins, Matthew B. Stern, Barbara C. Tilley; members: Richard Dodel, Bruno Dubois, Robert Holloway, Joseph Jankovic, Jaime Kulisevsky, Anthony E. Lang, Andrew Lees, Sue Leurgans, Peter A. LeWitt, David Nyenhuis, C. Warren Olanow, Olivier Rascol, Anette Schrag, Jeanne A. Teresi, Jacobus J. van Hilten; consultant: Nancy LaPelle.

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