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Validation of Slovak version of the Movement Disorder Society – Unified Parkinson’s Disease Rating Scale (MDS-UPDRS)

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Abstract

Recommendations for revision of the original version of Unified Parkinson’s Disease Rating Scale (UPDRS) were published based on its critique. Subsequently, a Movement Disorders Society (MDS)-sponsored revision designated as the Movement Disorder Society-Unified Parkinson’s Disease Rating Scale (MDS-UPDRS) was presented. After its successful clinimetric testing, a program for translation and validation of non-English versions of the MDS-UPDRS was initiated. The aim of this study was to validate and confirm the factor structure of the Slovak translation of the MDS-UPDRS.

We examined 354 patients with Parkinson’s disease in all Hoehn and Yahr stages with the Slovak version of MDS-UPDRS. The average age of our sample was 68 ± 9.5 years and average disease duration was 6.7 ± 5.1 years. Slovak data were compared using confirmatory factor analysis with the original English data. A pre-specified criterion for approving the Slovak translation as an official version of the MDS-UPDRS was a comparative fit index (CFI) ≥ 0.90 for all four parts of the Slovak MDS-UPDRS. Exploratory factor analysis was performed to explore the underlying factor structure without the constraint of a pre-specified factor structure.

For all four parts of the Slovak MDS-UPDRS, the CFI, in comparison with the English-language factor structure, was 0.91 or greater. Isolated differences in the factor structure of the Slovak MDS-UPDRS were identified by exploratory factor analysis compared with the English version.

The Slovak version of the MDS-UPDRS was designated as the sixth official non-English translation of MDS-UPDRS and can be downloaded from the website of the Movement Disorder Society (http://www.movementdisorders.org/publications/rating_scales/). In this paper we also present the major changes and advantages of the Slovak MDS-UPDRS compared with the original UPDRS.

Keywords: MDS-UPDRS, UPDRS, rating scales, validation, factor analysis

Introduction

The Unified Parkinson's Disease Rating Scale (UPDRS) (1) was compiled during the 1980s and since its origin has become the most used scale for clinimetric evaluation of Parkinson's Disease (PD). In 2001 the Movement Disorder Society (MDS) organised a work group whose goal was to evaluate the current state and to make recommendations for further use of the UPDRS (2). In addition to its strong sides, several shortages were identified in the scale. According the conclusions of the work group for evaluating the UPDRS, the scale does not cover the whole spectrum of non-motor manifestations of PD, some non-motor manifestations were evaluated as only a yes/no dichotomy, and the scale does not sufficiently cover and differentiate slight/mild symptoms of PD. Part IV of the UPDRS (Motor complications) was constructed differently from the other parts of the UPDRS. Furthermore, several ambiguities were identified in the text, and the instructions for the investigator were not clearly specified, which led to lower inter-rater agreement in several items of the original UPDRS. At the conclusion it was recommended that a new version of the UPDRS scale be developed which would preserve the strong sides of the original scale but which would address the identified shortages. On the basis of these recommendations the MDS sponsored the preparation of a new version of the UPDRS scale – designated as the Movement Disorder Society – Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (3). The MDS-UPDRS was clinimetrically tested and officially introduced in 2008 (4). Like the original UPDRS, the MDS-UPDRS consists of four parts which, however, were partially reorganized internally. Part I "Non-motor aspects of experiences of daily living" consists of 13 items, six of which are conceived in the form of a semi-structured interview, and seven items are conceived as a self-report questionnaire filled in by the patient or his caregiver. Part II, "Motor aspects of experiences of daily living" contains 13 items which are conceived as a self-report questionnaire filled in by the patient or his caregiver. Part III, "Motor examination", is an objective physical examination which contains 18 items, or 33 values, as in some items both sides of the body, or the limbs and neck or lips/chin are evaluated independently. Part IV "Motor complications" contains 6 items

conceived in the form of a semi-structured interview. All items of the MDS-UPDRS are evaluated on a 5-point scale from 0 to 4. Unlike the original version of the UPDRS, all items contain clearly formulated instructions for both the patient and the investigator. The answer possibilities then follow which are specified for the individual items; however, their structure is uniform throughout the entire scale, as follows: The possibility slight (1) points out symptoms which are present, but which do not have an impact on the functioning of the patient. The possibility mild (2) points out difficulties which are present and which influence some function in the given area. The possibility moderate (3) refers to difficulties which limit the patient in most activities in the given area but do not make them fully impossible. The possibility severe (4) points to difficulties which render the patient completely incapable, or unable to perform the given activity. This structure of evaluation of items means a shift toward a more detailed assessment of the slight/mild manifestations of PD in comparison with the original version of the UPDRS. The MDS-UPDRS contains 9 new items in comparison with the original version of the UPDRS: Depressed mood, Features of dopamine dysregulation syndrome, Urinary problems, Constipation problems, Fatigue, Doing hobbies and other activities, Light-headedness on standing, Toe tapping and Freezing. Orthostatic problems, Sleep problems and Complexity of motor fluctuations were in the original version evaluated only dichotomically as yes/no. The item Action/postural tremor was divided into two items, and likewise the item Rest tremor was also divided into two items evaluating the amplitude and constancy of rest tremor. The list of MDS-UPDRS items and their comparison with items from the original UPDRS is shown in Table 3.1.

The English version of the MDS-UPDRS was clinimetrically tested and introduced in 2008 (4). On the basis of its successful testing an official program of validation of non-English translations of the MDS-UPDRS was initiated. The aim of this work was the clinimetric testing and validation of the Slovak version of the MDS-UPDRS.

Table 3.1 Comparison of the items of the MDS-UPDRS and original UPDRS scales

MDS-UPDRS	UPDRS
1.1 Cognitive	1. Intellectual impairment
1.2 Hallucinations and psychosis	2. Thought disorder
1.3 Depressed mood	3. Depression
1.4 Anxious mood ^a	-
1.5 Apathy	4. Motivation/initiative
1.6 Features of dopamine dysregulation syndrome ^a	-
1.7 Sleep problems ^b	41. Sleep disturbances
1.8 Daytime sleepiness ^b	41. Sleep disturbances
1.9 Pain and other sensations	17. Sensory complaints related to parkinsonism
1.10 Urinary problems ^a	-
1.11 Constipation problems ^a	-
1.12 Light headedness on standing ^b	42. Symptomatic orthostasis
1.13 Fatigue ^a	-
2.1 Speech	5. Speech
2.2 Salivation and drooling	6. Salivation
2.3 Chewing and swallowing	7. Swallowing
2.4 Eating tasks	9. Cutting food and handling utensils
2.5 Dressing	10. Dressing
2.6 Hygiene	11. Hygiene
2.7 Handwriting	8. Handwriting
2.8 Doing hobbies and other activities ^a	-
2.9 Turning in bed	12. Turning in bed and adjusting bed clothes
2.10 Tremor	16. Tremor
2.11 Getting out of bed, a car, or a deep chair ^a	-
2.12 Walking and balance	15. Walking
2.13 Freezing	14. Freezing when walking
-	13. Falls ^c
3.1 Speech	18. Speech
3.2 Facial expression	19. Facial expression
3.3 Rigidity	22. Rigidity
3.4 Finger tapping	23. Finger taps
3.5 Hand movements	24. Hand movements
3.6 Pronation-supination movements of hands	25. Pronation/supination
3.7 Toe tapping ^a	-
3.8 Leg agility	26. Leg agility
3.9 Arising from chair	27. Arising from chair
3.10 Gait	29. Gait
3.11 Freezing of gait ^a	-
3.12 Postural instability	30. Postural stability
3.13 Posture	28. Posture
3.14 Global spontaneity of movements	31. Body bradykinesia
3.15 Postural tremor of hands ^d	21. Action/postural tremor
3.16 Kinetic tremor of hands ^d	21. Action/postural tremor
3.17 Rest tremor amplitude ^d	20. Rest tremor
3.18 Constancy of rest tremor ^d	-
4.1 Time spent with dyskinesia	32. Dyskinesia duration
4.2 Functional impact of dyskinesias	-
4.3 Time spent in the off state	39. Off duration
4.4 Functional impact of fluctuations ^a	-
4.5 Complexity of motor fluctuations ^b	36., 37., 38. Offs: predictable, unpredictable, sudden
4.6 Painful OFF-state dystonia	34. Presence of early morning dystonia

MDS-UPDRS – Movement Disorders Society - Unified Parkinson’s Disease Rating Scale; UPDRS - Unified Parkinson’s Disease Rating Scale

^a New item added to the MDS-UPDRS; ^b Responses in the corresponding UPDRS item only dichotomous (yes/no); ^c Item not included in the MDS-UPDRS; ^d Original UPDRS item divided into two separate MDS-UPDRS items

Materials and methods

The MDS-UPDRS was translated into Slovak by a team of investigators in Slovakia led by Dr. Matej Skorvanek. The translation was back-translated by colleagues fluent in English and Slovak and not involved in the original translation. The back-translation was reviewed by the MDS team (Stebbins, Goetz, LaPelle, Tilley).

Cognitive pre-testing

Cognitive pretesting is a qualitative approach to assessing instrument completion in terms of task difficulty for examiner and respondent, and respondent interest, attention span, discomfort and comprehension (5). Where differences were observed between the back-translated Slovak version and the English version, items were selected for cognitive pretesting along with questions that were identified in cognitive testing of the English version. Questions included in cognitive pretesting were: Items 1.2 Hallucinations and Psychosis; 1.6 Features Of Dopamine Dysregulation Syndrome; 1.10 Urinary Problems; Instructions to Patient – Part 2; 2.13 Freezing; 3.12 Postural Stability; 3.17 Rest Tremor Amplitude; 4.1 Time Spent With Dyskinesias; and 4.2 Functional Impact Of Dyskinesias. Based on the results of the initial cognitive pretesting, another round(s) of translation and back translation and cognitive pretesting could be required.

Factor analysis

M-plus, Version 6.11 was used to do the confirmatory and exploratory factor analyses. The sample size required for the translation study and statistical analyses was at least 325 (6). Any participants with missing values within a part were deleted from analysis of that part only. Thus the sample size could vary from part to part.

The investigators obtained approval from the human subjects to collect the data. The study was approved by the local Ethics Committees of the UPJS in Kosice and the UK in Bratislava. Data without patient names or medical record numbers were transferred to the analytic team via a secure website.

As the primary analysis of the Slovak data, we conducted a confirmatory factor analysis (CFA) to determine if the factor structure for the English language MDS-UPDRS (4) could be confirmed in data collected using the Slovak translation. This was the primary question of interest. The CFA was conducted separately for MDS-UPDRS Parts I to IV with the Slovak data constrained to fall into the factors defined in the English language data (3). We evaluated the CFA results based on the Comparative Fit Index (CFI). According to the protocol, to establish a

successful translation and to designate that translation as an official MDS translation of the MDS-UPDRS, we required that the CFI for each Part (I-IV) of the translated MDS-UPDRS be 0.90 or greater relative to the English language version.

As a secondary analysis we conducted an exploratory factor analysis for the Slovak version of MDS-UPDRS Parts I-IV to explore the underlying factor structure without the constraint of a pre-specified factor structure. We used a scree plot to choose the number of factors to retain for each MDS-UPDRS Part. The subjective scree test (7) is scatter plot of eigenvalues plotted against their ranks with respect to magnitude in order to extract as many factors as there are eigenvalues that fall before the last large drop (i.e., an “elbow” shape) in the plot.

Results

Cognitive pre-testing

A total of 10 patients with Parkinson’s disease and their examiners were interviewed using the structured interview format typical for cognitive pretesting. One rater had difficulties with administering Part I of the Slovak MDS-UPDRS (question 1.2 “Hallucinations and psychosis”). One of the ten patients interviewed had difficulty comprehending question 1.2 “Hallucinations and psychosis”, and two patients had difficulty comprehending question 1.10 “Urinary Problems”. No other patient-identified difficulties were noted. Ten patients completed a second round of cognitive pre-testing after a slight modification of the Slovak version of MDS-UPDRS. No difficulties were identified in this second round of testing by either raters or patients. The modified version of the scale was approved as the Official Working Draft of the Slovak MDS-UPDRS for testing in a larger group of patients with PD.

Demographics

The Slovak dataset included 354 native Slovak-speaking patients with Parkinson’s disease. The demographic characteristics of the Slovak patients are shown in Table 3.2. The patients in Slovakia were of similar mean age as those in the English MDS-UPDRS study at the time of recruitment (68.0 vs 67.5) but have shorter average years of disease duration (6.7 vs. 8.3 yrs).

Table 3.2 Characteristics of the sample

	Košice	Bratislava	Slovakia overall	Original English data (Goetz 2008)
No of patients	252	102	354	877
Male No (%)	125 (49.6%)	44 (43.1%)	169 (47.7%)	560 (63.2%)
Age at examination (years)	69.1 ± 9.1	65.3 ± 9.8	68 ± 9.5	67.5 ± 10.9
Age at diagnosis (years)	62.5 ± 10.0	58.1 ± 10.6	61.2 ± 10.3	59.2 ± 11.9
Disease duration (years)	6.5 ± 4.8	7.2 ± 5.7	6.7 ± 5.1	8.3 ± 6.7
Education (years)	12.6 ± 3.4	13.6 ± 3.0	12.9 ± 3.3	

Factor analyses

Confirmatory factor analysis (CFA)

Table 3.3 displays the CFA models for each MDS-UPDRS part. For all four parts of the Slovak MDS-UPDRS, the CFI, in comparison with the English-language factor structure, was 0.91 or greater. Our pre-specified criterion was a CFI of 0.90 or greater. Hence, we conclude that the pre-specified English factor structure was confirmed in the Slovak translation.

Table 3.3 Confirmation factor analysis model fit for Slovak version of the MDS-UPDRS

Part I: Non-motor experiences of activities of daily living (2-factor model)	
Slovak version	CFI=0.91, RMSEA=0.08 (N=346)
English version	CFI=0.96, RMSEA=0.06 (N=849)
Part II: Motor experiences of activities of daily living (3-factor model)	
Slovak version	CFI=0.98, RMSEA=0.09 (N=346)
English version	CFI=0.97, RMSEA=0.09 (N=851)
Part III: Motor examination (7-factor model)	
Slovak version	CFI=0.95, RMSEA=0.08 (N=324)
English version	CFI=0.95, RMSEA=0.07 (N=801)
Part IV: Motor complications (2-factor model)	
Slovak version	CFI=1.00, RMSEA=0.04 (N=351)
English version	CFI=1.00, RMSEA=0.04 (N=848)

CFI – Confirmatory fit index; RMSEA – root mean square error of approximation

Exploratory factor analysis (EFA)

The EFA analysis for the Slovak dataset differs from the EFA of the English language dataset in some areas. The EFA for the English version has been the factor structure used as the basis for all confirmatory factor analyses. From the scree Plot for Part I: Non-motor aspects of experiences of daily living we extracted two factors. For Part II: Motor aspects of experiences

of daily living we extracted three components. For Part III: Motor examination we extracted seven factors. For Part IV: Motor complications we extracted two factors.

For Part I, in contrast to the English language version of the MDS-UPDRS, *Cognitive impairment* and *Hallucinations and psychosis* loaded on factor 2, not factor 1. Constipation problems did not load on any of the factors. In Part II, a very different factor structure was found in the Slovak version MDS-UPDRS, although the scree plot suggested the same number (three) of factors as for the English version. Eight of the 13 items loaded differently. *Saliva and drooling* and *Chewing and swallowing* loaded on factor 2; *Doing hobbies and other activities* loaded on factor 3; *Hygiene, Turning in bed, Tremor, Walking and balance*, and *Freezing* all loaded on factor 1. Most of these items also had cross-loading on multiple factors. In Part III, the factor structure of Slovak scale was consistent with the English version. Although items *Speech* and *Facial expression* loaded on factor 3, and *Toe tapping, left foot* loaded on factor 1. In Part IV, *Time spent with dyskinesias* had a loading of 0.39 (just below the cutoff of 0.4) on factor 2 and would load on the same factor with the other dyskinesia items. *Time spent in the OFF state* had a dual loading on both factors.

Discussion

The aim of the revised version of the MDS-UPDRS was to better cover the non-motor manifestations of PD, to evaluate the individual items in a uniform way and to provide clear instructions for the patient and the investigator, which should lead to higher inter-rater agreement (4). Evaluation of the individual items is done on a 5-degree scale which better distinguishes slight and mild symptoms of PD (possibilities 1 and 2), which is a shift versus the original version of the UPDRS, where greater emphasis was placed on the evaluation of more severe manifestations of the disease (possibilities 3 and 4), which were merged in the MDS-UPDRS into one possibility – severe (4). This shift is a result of the fact that PD research now focuses increasingly more on diagnostics and treatment of early stages of the disease. From this point of view, differentiating severe expressions of the disease is not clinically relevant. A component of the scale is likewise the appendix, which summarizes the recommended scales for individual non-motor manifestations of Parkinson's disease.

Clinimetric testing of the original English version was successfully carried out and presented in 2008 (4). A program for validation of the non-English versions of the MDS-UPDRS was subsequently initiated.

On the basis of confirmatory factor analysis as the primary analysis, the CFI for all four parts of the MDS-UPDRS (all CFI > 0.90), the agreement factor structure of the Slovak version of the scale with the original English version was confirmed. The Slovak version of the scale was therefore

confirmed as the sixth official non-English translation of the MDS-UPDRS. In the exploratory factor analysis where a certain variability between the different samples of patients was anticipated, isolated differences of the factor structure between the original English version and the Slovak translation of the scale were found, and differences were present particularly in Part II (Motor aspects of the experience of daily living). The Slovak version of the MDS-UPDRS is freely available for download on the website of the Movement Disorders Society (8). Satisfactory clinimetric characteristics of the MDS-UPDRS (reliability and validity) were also recently confirmed during an expanded and independent validation of the Spanish version of the MDS-UPDRS (9).

For the purpose of a more uniform evaluation of the MDS-UPDRS the MDS prepared certified teaching program available on DVD or online (10). A component of this program is a teaching module and test in which Part III (Motor examination) is evaluated in four patients with Parkinson's disease. The acceptable range of evaluation for each patient should fall within the 95th percentile of the confidence interval for evaluation of the given patient by an expert panel (11). This program is also available online and in the Slovak language.

Formulas for converting a UPDRS score to an MDS-UPDRS score have likewise been published (12). Conversion formulas which resulted in a difference between the two scales smaller than one point were identified for Part II (Motor aspects of experiences of daily living) and Part III (Motor examination). When selecting a conversion formula the assigning of a patient to one of three groups (1/2, 3, 4/5) according to Hoehn and Yahr staging is necessary (13). In view of the more significant changes in Part I (Non-motor aspects of experiences of daily living) and Part IV (Motor complications) and likewise with the total score, no conversion formula was identified which would allow a score to be converted between the individual scales with sufficient precision.

Conclusion

The satisfactory clinimetric characteristics of the MDS-UPDRS have been confirmed in several independent studies. On the basis of the congruent factor structures, the Slovak translation of the MDS-UPDRS was acknowledged as an official non-English version of the scale. The MDS-UPDRS better covers non-motor and motor manifestations of Parkinson's disease, better covers and distinguishes slight/mild manifestations of Parkinson's disease and with regard to clear instructions for the investigator and the patient and the available teaching modules has higher conformity during evaluations of the scales by different investigators. Therefore, we recommend using the MDS-UPDRS as a standard evaluation instrument in patients with PD both in common clinical practice and in the research environment.

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