

Validation of the Polish version of the Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)

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ABSTRACT

Introduction. In 2008, the Movement Disorders Society (MDS) published a new Unified Parkinson's Disease Rating Scale (MDS--UPDRS) as the official benchmark scale for Parkinson's Disease (PD). We have translated and validated the Polish version of the MDS-UPDRS, explored its dimensionality, and compared it to the original English one.

Methods. The MDS-UPDRS was translated into Polish by a team of Polish investigators led by JS and GO. The back-translation was completed by colleagues fluent in both languages (Polish and English) who were not involved in the original translation, and was reviewed by members of the MDS Rating Scales Programme. Then the translated version of the MDS-UPDRS underwent cognitive pretesting, and the translation was modified based on the results. The final translation was approved as the Official Working Document of the MDS-UPDRS Polish version, and was tested on 355 Polish PD patients recruited at movement disorders centres all over Poland (at Katowice, Gdańsk, Łódź, Warsaw, Wrocław, and Kraków). Confirmatory and explanatory factor analyses were applied to determine whether the factor structure of the English version could be confirmed in the Polish version.

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Results. The Polish version of the MDS-UPDRS showed satisfactory clinimetric properties. The internal consistency of the Polish version was satisfactory. In the confirmatory factor analysis, all four parts had greater than 0.90 comparative fit index (CFI) compared to the original English MDS-UPDRS. Explanatory factor analysis suggested that the Polish version differed from the English version only within an acceptable range.

Conclusions and clinical implications: The Polish version of the MDS-UPDRS meets the requirements to be designated as the Official Polish Version of the MDS-UPDRS, and is available on the MDS web page. We strongly recommend using the MDS-UPDRS instead of the UPDRS for research purposes and in everyday clinical practice.

Key words: MDS-UPDRS, Parkinson's Disease, rating scale, validation, translation

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Introduction

Parkinson's Disease (PD) is a progressive, incurable, neurodegenerative disease presenting with motor and non--motor symptoms. There is no ideal biomarker to determine disease severity, and many different clinical, laboratory, and neuroimaging markers are used [1–3].

The 'gold standard' clinical rating scale for PD, and the one most commonly used, is the Unified Parkinson's Disease Rating Scale (UPDRS) introduced in the 1980s [4], with its revised version known as MDS-UPDRS available from 2008 [5].

The MDS-UPDRS is composed of four sections: Part I: Non-Motor Experiences of Daily Living, has six rater-based items and seven for patient self-assessment; Part II: Motor Experiences of Daily Living, with 13 patient-based items; Part III: Motor Examination, with 18 items (33 scores); and Part IV: Motor Complications, with six items covering dyskinesia and fluctuations assessment. Each item scores from 0 (normal) to 4 (severe) and total scores are obtained from the sum of the corresponding item scores for each part. Differing from the previous version, the MDS-UPDRS is completed by a mix of both clinician-rated sections (Part 1A, Part 3 and Part 4) and patient- and/or caregiver-completed sections (Part 1B and Part 2), without direct input from the rater.

The new version relies on more information coming directly from patient and caregiver, and so it is vital that they understand the questions, preferably in their mother tongue. For this reason, the MDS Rating Scales Programme sets a specific protocol to designate successful translation of non--English versions. We aimed to translate and validate a Polish version of the MDS-UPDRS scale, and to compare it to the original English language version. Herein, we present the scale translation and clinimetric testing results of the Polish version of the MDS-UPDRS.

Clinical rationale for the study

The MDS-UPDRS has become the 'gold standard' of clinical assessment of PD patients. Being an expanded patient/ /caregiver-reported questionnaire means that it relies more on subjective information from the patient and/or his or her caregiver. The presented validation of the Polish translation of the MDS-UPDRS that is consistent with the English language version, confirms its suitability for use, and guarantees obtaining results for research purposes and everyday clinical practice that are comparable across different languages.

Material

The participants were 355 PD patients recruited from the neurology departments in ten sites located in different parts of Poland (two in Katowice, two in Krakow, one in Wroclaw, three in Warsaw, one in Gdansk, and one in Lodz). At each site experienced Polish movement disorder specialists were recruited to examine Polish-speaking PD patients of all ages, and at all disease Hoehn & Yahr stages.

Methods

Translation of the MDS-UPDRS

The MDS Rating Scales Programme has prepared a welldefined protocol, with objective criteria for translation and validation of non-English versions of the MDS-UPDRS in order to have an "official MDS translation" in a foreign language. The process of developing an officially approved translation of the MDS-UPDRS involves four steps: (1) translation and independent back-translation; (2) cognitive pretesting to establish that the translation is clear and comfortably administered by native-speaker raters and understood by native-speaker patients; (3) field testing in the native language using a large sample of PD patients; and (4) full clinimetric testing [6].

The Polish version validation was performed as follows: firstly, the MDS-UPDRS was translated into Polish by a team of Polish-speakers who were fluent in English, and who were physicians and specialists in movement disorders. This team was led by Dr. Joanna Siuda, and Prof. Grzegorz Opala. It was then back-translated into English by colleagues fluent in English and Polish and who had not been involved in the original translation. Finally, it was reviewed by a team of American experts, led by Profs. Christopher Goetz and Glenn Stebbins, who had been involved in the development of the original English language version [7].

Cognitive pretesting

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 [8]. Where differences were observed between the back-translated Polish 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: Cognitive Impairment, Anxious Mood, Handwriting, Freezing, Hand Movements, Arising from Chair, Time Spent with Dyskinesia, and Functional Impairment of Dyskinesia. Based on the results of the initial cognitive pretesting, other round(s) of translation, back-translation and cognitive pretesting could be required. Once cognitive pretesting was completed and no problems had been noted, the final translation was obtained.

Factor analysis

M-plus Version 7.4 was used to do the primary confirmatory and secondary exploratory factor analyses, as the variables are categorical [9]. We used an unweighted least squares (ULS) approach to factor estimation that minimises the sum of squared differences between observed and estimated correlation matrices, not counting diagonal elements. To assist in interpretation of the factors, we used an orthogonal CF-VARIMAX rotation that constrains the factors to be uncorrelated.

The sample size for the translation study was based on the need for five subjects per item of the questionnaire in order to perform the statistical analysis [10]. Because there are 65 items on the MDS-UPDRS, a sample of at least 350 was required. Any participants with missing values within a Part were deleted from analysis of that Part only. Thus, the sample size from Part to Part could vary.

Primary analysis

For the primary analysis of the Polish data, we conducted a confirmatory factor analysis (CFA) to determine whether the factor structure for the English language MDS-UPDRS could be confirmed in data collected using the Polish translation [11, 12]. This was the primary question of interest. The CFA was conducted separately for MDS-UPDRS Parts I to IV, with the Polish data constrained to fall into the factors defined in the English language data. 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, it is 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. Mean and variance-adjusted weighted least square (WLSMV) estimator is used to confirm model fit.

Secondary analysis

As a secondary analysis, we conducted an exploratory factor analysis for the Polish version of the 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 [13] uses a scatter plot of eigenvalues plotted against their ranks with respect to magnitude, to extract as many factors as there are eigenvalues that fall before the last large drop (i.e. an 'elbow' shape) in the plot. Once the factors were chosen, an item was retained in a factor if the factor loading for that item was 0.40 or greater. To assist interpretation of the factors, an orthogonal CF-VARIMAX rotation was used which sets the factors to be uncorrelated.

Ethics

All patients gave written consent to participate. The anonymised patient data was transferred to the US team for analysis via a secure website. The programme for validation of the MDS-UPDRS Polish version was approved for all sites by the Ethics Committee of the Medical University of Silesia in Katowice (KNW/0022/KB/110/14).

Results

Cognitive pretesting

Ten patients with Parkinson's Disease and their examiners were interviewed using the type of structured interview format typical for cognitive pretesting. No problems were identified for the raters. One of the 10 patients interviewed had difficulty comprehending the term "lightheadedness", and another patient reported difficulty in reading the material for the self-report sections of the scale because the font was too small. No other patient-identified difficulties were noted. Slight modifications of the scale were recommended from this round of testing. Five patients completed a second round of cognitive pre-testing, and no difficulties were identified. The modified version of the scale was approved as the Official Working Draft of the Polish MDS-UPDRS for testing in a larger group of patients with PD.

Study population characteristics

The demographic characteristics of the sample are set out in Table 1. The sample included 355 Polish PD patients (mean age 64.0 ± 9.5 years, 56.9% males), with mean disease duration of 9.0 ± 5.9 years, who were examined using the MDS-UPDRS. They were all native Polish-speaking PD patients, white Caucasians, and the majority had at least secondary education. The English language and Polish language cohorts were similar in terms of age and duration of disease. All Hoehn & Yahr stages (H&Y) were represented, with the majority (299 subjects, 87.9%) being stages II and III. The distribution of H&Y was significantly different between the two cohorts (p-value < 0.0001).

Study cohort	Male*	Age** (years)	Disease duration *** (years)		Hoe	hn&Yahr staging N (%)	***		E	ducation****	e
Number of patients	N (%)	Mean + SD	Mean + SD	I	II	ш	IV	v	Vocational	Secondary	University degree
Polish	169	64.0 <u>+</u> 9.5	9.0 <u>+</u> 5.9	18	148	151	19	4	20	131	133
(N = 355)	(56.9)			(5.3)	(43.5)	(44.4)	(5.6)	(1.2)			
English	554	67.5 <u>+</u>	8.3 <u>+</u> 6.7	63	467	174	109	53	NA	NA	NA
(N = 876)	(63.2)	10.9		(7.3)	(53.9)	(20.1)	(12.6)	(6.1)			

Table 1. Demographic characteristics of study population

Data available for 297*, 257**, 197***, 340****, and 284***** subjects in Polish PD population; SD — standard deviation, NA — not available

Primary analysis: Confirmatory Factor Analysis (CFA)

Table 2 displays the CFA models for each MDS-UPDRS Part. For all four Parts of the Polish MDS-UPDRS, the CFI, compared to the English-language factor structure, was 0.90 or greater. This confirmed that the pre-specified English factor structure was confirmed in the Polish dataset.

Secondary analysis: Explanatory Factor Analysis (EFA)

EFA analysis for the Polish MDS-UPDRS dataset differed from the EFA of the English language dataset in some areas. From the SCREE plot we extracted: for Part I - two factors, for Part II - three components, for Part III - seven factors, and for Part IV - two factors. The SCREE plots are given in Figure 1. Table 3 shows the results of the Exploratory Factor Analysis for the English and Polish languages.

For Part I, in contrast to the English language version of the MDS-UPDRS, Cognitive impairment and Hallucinations and psychosis loaded on factor 2, instead of factor 1. For Part II, Speech loaded on factor 3 instead of factor 1, Handwriting and Doing hobbies and other activities loaded on factor 2, which originally loaded on factor 1 in the English language. Eating tasks loaded on factor 1 instead of factor 2. Dressing and Freezing loaded on both factor 1 and factor 2, Hygiene and Turning in bed loaded on factor 2, which originally loaded on factor 3 in the English language. In Part III, Rigidity, neck did not load on any of the factors. Nine of the 33 items loaded on different factors in the two scales, and eight items loaded on more than one factor. Most of the items that loaded on different factors in the two versions also had cross-loadings on multiple factors. In Part IV, Time spent with dyskinesia did not load on any of the factors. Time spent in the OFF state and Functional impact of dyskinesia loaded on both factor 1 and factor 2 in the Polish Scale, having originally loaded on factor 1 and factor 2 respectively in the English language.

Discussion

The widespread use of the MDS-UPDRS instead of its predecessor the UPDRS, which was, and in some non-English

Table 2. Confirmatory factor analysis, CFA model fit

Part I: Non-motor aspects of experiences of daily living (a 2-factor model)*				
Polish language	CFI = 0.90, RMSEA = 0.10 (355 patients)			
English language	CFI = 0.96, RMSEA = 0.06 (849 patients)			
Part II: Motor aspects of experience of daily living (a 3-factor model)				
Polish language	CFI = 0.97, RMSEA = 0.09 (355 patients)			
English language	CFI = 0.97, RMSEA = 0.09 (851 patients)			
Part III: Motor examination (a 7-factor model)				
Polish language	CFI = 0.95, RMSEA = 0.10 (355 patients)			
English language	CFI = 0.95, RMSEA = 0.07 (801 patients)			
Part IV: Motor complications (a 2-factor model)				
Polish language	CFI = 1.00, RMSEA = 0.16 (355 patients)			
English language	CFI = 1.00, RMSEA = 0.04 (848 patients)			

CFI — comparative fit index, RMSEA — root mean square error of approximation; *Dopamine Dysregulation Syndrome (DDS) was not included in this analysis as it did not load on any factor

speaking countries still is, the gold standard tool for the clinical assessment of PD patients, is to be recommended. The Movement Disorders Society Rating Scales Programme leads the global translation effort of different assessment scales including the MDS-UPDRS. Currently, this programme includes 19 non-English validated editions of the MDS-UPDRS.

The overall factor structure of the Polish language version of MDS-UPDRS was consistent with that of the English language version, confirming its suitability for use. A few isolated item differences in factor loadings were identified in the EFA of the Polish version. These small differences included some loading on more than one factor, while others loaded on a different factor, compared to the English MDS-UPDRS.

For Part I, in contrast to the English language version of the MDS-UPDRS, *Cognitive impairment* and *Hallucinations and psychosis* loaded on factor 2 instead of factor 1. This might be explained by the fact that cognitive impairment in Polish society is still not well recognised, especially among the elderly where it is treated as a normal component of the ageing process, and so goes underreported.



Figure 1. Scree plots for English and Polish exploratory factor analyses

Factor	ltem	ltem facto	Item factor loading			
		English*	Polish			
	Part I: Non-motor aspects	of experiences of daily living				
Factor 1	Percent variance	34.0	38.1			
	Davtime sleenings	0.53	0.64			
	Sleep problems	0.35	0.55			
		0.55	0.55			
	Dain and other consistions	0.33	0.67			
	Hallucinations and psychosic	0.45	0.07			
		0.50	XXXX			
	Crinary problems	0.61	0.45			
	Constipation problems	0.46	0.53			
	Lightheadedness on standing	0.46	0.70			
	Fatigue	0.47	0.76			
Factor 2	Percent variance	9.5	14.3			
	Depressed mood	0.81	0.84			
	Anxious mood	0.68	0.68			
	Apathy	0.55	0.83			
	Hallucinations and psychosis	XXXX	0.44			
	Cognitive impairment	xxxx	0.52			
	Part II: Motor aspects o	f experiences of daily living				
Factor 1	Percent variance	53.10	50.73			
	Speech	0.79	XXXX			
	Saliva and drooling	0.45	0.62			
	Chewing and swallowing	0.60	0.65			
	Eating tasks	XXXX	0.56			
	Dressing	XXXX	0.40			
	Handwriting	0.46	XXXX			
	Doing hobbies and other activities	0.46	XXXX			
	Walking and balance	xxxx	0.47***			
	Freezing	xxxx	0.41***			
Factor 2	Percent variance	8.70	8.90			
	Eating tasks	0.68	XXXX			
	Tremor	0.43	0.56			
	Handwriting	XXXX	0.94			
	Hygiene	XXXX	0.75			
	Doing hobbies and other activities	XXXX	0.48			
	Dressing	XXXX	0.49***			
	Turning in bed	XXXX	0.59			
	Walking and balance	XXXX	0.48***			
	Freezing	XXXX	0.46***			
Factor 3	Percent variance	7.70	7.33			
	Speech	XXXX	0.54			
	Dressing	0.64	XXXX			
	Hygiene	0.65	XXXX			
	Turning in bed	0.65	XXXX			
	Getting out of bed	0.73	0.49			
	Walking and balance	0.82	0.52			
	Freezing	0.76	XXXX			

Table 3. Comparison of English language and Polish Exploratory Factor structures for Parts I-IV of MDS-UPDRS

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Factor	ltem	Item fa	Item factor loading		
		English*	Polish		
	Pa	art III: Motor examination			
Factor 1	Percent variance	36.7	43.0		
	Speech	0.60	хххх		
	Facial expression	0.54	XXXX		
	Arising from chair	0.80	0.76		
	Gait	0.87	0.81		
	Freezing of gait	0.83	0.75		
	Postural stability	0.80	0.65		
	Posture	0.70	0.73		
	Global spontaneity of movement	0.67	0.53		
	Leg agility, right leg	XXXX	0.45***		
Factor 2	Percent variance	15.3	14.7		
	Rest tremor amplitude, RUE	0.73	0.82		
	Rest tremor amplitude, LUE	0.71	0.79		
	Rest tremor amplitude, RLE	0.74	0.78		
	Rest tremor amplitude, LLE	0.70	0.78		
	Rest tremor amplitude, lip/jaw	0.60	0.48***		
	Constancy of rest tremor	0.88	0.78		
	Postural tremor, right hand	XXXX	0.77		
	Postural tremor, left hand	XXXX	0.76		
	Kinetic tremor, right hand	XXXX	0.75***		
	Kinetic tremor, left hand	XXXX	0.72***		
Factor 3	Percent variance	6.6	8.5		
	Rigidity, neck	0.68	хххх		
	Rigidity, RUE	0.73	0.58***		
	Rigidity, LUE	0.74	0.65***		
	Rigidity, RLE	0.80	0.65***		
	Rigidity, LLE	0.82	0.70***		
Factor 4	Percent variance	6.2	5.1		
	Finger tapping, right hand	0.67	0.83		
	Hand movements, right hand	0.67	0.83		
	Pronation/supination, right hand	0.70	0.75		
	Leg agility, right leg	XXXX	0.72***		
	Toe tapping, right foot	XXXX	0.72		
	Rigidity, RUE	XXXX	0.69***		
	Rigidity, RLE	XXXX	0.56***		
Factor 5	Percent variance	4.9	4.3		
	Finger tapping, left hand	0.67	0.81		
	Hand movements, left hand	0.70	0.85		
	Pronation/supination movements, left har	nd 0.65	0.73		
	Toe tapping, left foot	XXXX	0.82		
	Leg agility, left leg	XXXX	0.74		
	Rigidity, LUE	ХХХХ	0.59***		
			\rightarrow		

Factor	ltem	Item factor loading				
		English*	Polish			
Part III: Motor examination						
	Rigidity, LLE	XXXX	0.47***			
Factor 6	Percent variance	4.5	3.7			
	Postural tremor, right hand	0.66	XXXX			
	Postural tremor, left hand	0.71	хххх			
	Kinetic tremor, right hand	0.81	0.44***			
	Kinetic tremor, left hand	0.81	0.44***			
Factor 7	Percent variance	3.3	2.8			
	Toe tapping, right foot	0.65	хххх			
	Toe tapping, left foot	0.62	хххх			
	Leg agility, right leg	0.62	хххх			
	Leg agility, left leg	0.60	хххх			
	Rest tremor amplitude, lip/jaw	XXXX	0.47***			
	Speech	XXXX	0.67			
	Facial expression	XXXX	0.76			
Part IV: Motor complications						
Factor 1	Percent variance	63.9	67.4			
	Time spent in the OFF state	0.87	0.62***			
	Functional impact of fluctuations	0.84	0.91			
	Complexity of motor fluctuations	0.82	0.94			
	Painful OFF state dystonia	0.5	0.92			
	Functional impact of dyskinesias	XXXX	0.48***			
Factor 2	Percent variance	15.6	17.6			
	Time spent with dyskinesias	0.71	хххх			
	Functional impact of dyskinesias	0.95	0.86			
	Time spent in the OFF state	XXXX	0.68			

*Different version of M-Plus, and the factor loadings may vary slightly from published version; *** item load on more than one factor with factor loading > 0.40; xxxx implies that the listed item did not load on the factor indicated

Moreover, PD patients may not recognise memory problems as part of a wide range of PD symptomatology, and thus do not report them. Another argument, raised by the team of MDS experts, is that a cognition item, assessed by a single screening question, has a weak correlation with the corresponding cognitive scales i.e. Addenbrooke's Cognitive Examination, ACE, Scales for Outcome of Parkinson's Diseasecognitive scale, SCOPA-COG, and Frontal Assessment Battery, FAB [14]. In regards to Hallucination and psychosis, rarely reported in the studied population (301 subjects; 84.8% reported no psychotic problems), the information mainly came from PD patients, and only rarely was the interview conducted in the presence of the patient's caregiver. Caregivers can be very good sources of information, especially when we are looking for information about non-motor symptoms of Parkinson's Disease, which possibly go unnoticed by patients.

For Part II, *Speech* loaded on factor 3 instead of factor 1, and the majority of patients (231 subjects; 65.1%) was assessed as either having no or minimal problems with speech. *Handwriting* and *Doing hobbies and other activities* loaded on factor 2, which originally loaded on factor 1 in the English language. Probably due to cultural differences, Polish PD patients tend to refer to hobbies and other activities done for pleasure in a more practical manner than do patients from English-speaking parts of the world. On the other hand, it has been demonstrated previously on a large multi-cultural and multi-language population that the MDS-UPDRS is effective in capturing parkinsonism, and is not highly influenced by gender, age, or race/ethnicity [15].

Nowadays, we tend to do less handwriting, and it is possible that patients do not pay much attention to this activity as long as they still have a legible signature. *Eating tasks* loaded on factor 1 instead of factor 2, *Dressing* loaded on both factor 1 and factor 2. *Hygiene* loaded on factor 2, which originally loaded on factor 3 in the English language. *Walking and balance* loaded on all three factors, unlike the English version that loaded only on factor 3. A possible explanation here is that independence is very important to our PD patients; they do not want anyone to help them unless it is absolutely necessary; and being able to dress, bathe, eat, or walk without assistance is for them a determinant of a good quality of everyday life.

In Part III, Rigidity, neck did not load on any of the factors, even though 219 (61.7%) patients reported it. Resting tremor of the upper limbs loaded in factor 2 in both the English and the Polish versions, but Postural and kinetic tremor of both upper limbs loaded in factor 2 in the Polish version while being only factor 6 in the English language version. This can be explained by cultural differences between English- and Polish-speaking societies, by the fact that tremor is an easily recognisable symptom, and because for many of our patients it is embarrassing, especially in social situations. In the Polish version, Toe tapping and leg agility on the right side loaded in factor 4, and Toe tapping and leg agility on the left side loaded on factor 5, unlike the English version in which these items loaded only in factor 7. Here again, bradykinesia in the lower limbs, probably causing gait problems, makes a patient less independent in their everyday life.

In Part IV, most items loaded on factor 1 in both language versions, underlining the importance of motor complications. There was one exception: in the Polish version *Time spent with dyskinesia* did not load on any of the factors, possibly because more than half (202 subjects, 56.9%) of PD patients reported having no dyskinesia. On the other hand, *Functional impact of dyskinesia* and *Time spent in the OFF state* loaded on both factor 1 and factor 2 in the Polish version. This confirms that levodopa-induced motor complications significantly impact upon patient well-being, and are related to an impaired health-related quality of life (HRQoL) [16].

We are aware that this study has some limitations related to potential sample selection bias. The data comes from high reference neurology clinics specialising in movement disorders, and it does not represent the general PD patient population in Poland. In addition, the distribution of patients showed a predominance of patients in early Hoehn & Yahr stages, with very few patients in advanced stages (only four subjects in H&Y stage V; 1.12%), and most patients (284 subjects, 80%) were examined in the ON state. Furthermore, the assessment was based mainly on patients' responses, although caregivers may have valuable input into clinical evaluation, especially with regard to non-motor symptoms [17].

Conclusions and clinical implications:

The overall factor structure of the Polish version was consistent with that of the English version based on the high CFIs for all four parts of the MDS-UPDRS in the confirmatory factor analysis (all CFI \geq 0.90). The Polish MDS-UPDRS was confirmed to share a common factor structure with the English version.

Therefore, the MDS-UPDRS Polish version was designated as the Official Polish version of the MDS-UPDRS and is available from the MDS website (https://www.movementdisorders. org/MDS-Files1/Education/Rating-Scales/MDS-UPDRS_Polish_Official_Translation_FINAL.pdf).

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