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PROFILE PD: Profile Of Function and Impairment Level Experience with Parkinson Disease -- Clinimetric Properties of a Rating Scale for Physical Therapist Practice

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Abstract

Background and Purpose—Individuals with Parkinson disease (PD) experience a range of deficits of body systems and activities. A clinical test is needed that is reliable, valid, applicable to physical therapist practice, and appropriate for use in early and mid-stages of the disease. PROFILE PD is one such scale, consisting of 24 items that would typically be assessed during the physical therapist's examination and evaluation of individuals with PD. The purpose of this paper is to report on clinimetric properties of the PROFILE PD and to make the test available for use.

Methods—Inter-rater reliability was determined using the intra-class correlation coefficient (ICC). Construct validity was determined by comparing scores on the PROFILE PD with the gold standard (UPDRS) as well as scales of physical activity and participation. Construct validity and structure of the PROFILE PD were further examined using exploratory factor analysis (EFA) using Principal Component Analysis (PCA) with Promax rotation which allows a correlated factor structure.

Results—Inter-rater reliability was estimated as 0.97. Construct validity was demonstrated with the UPDRS ($r = 0.86$, $p < 0.0001$), Schwab & England Activities of Daily Living Scale (S&E) ($r = -0.83$, $p < 0.0001$), and Continuous Scale Physical Functional Performance test (CS-PFP) ($r = -0.62$, $p < 0.0001$). PCA demonstrated a that the test comprises a single scale.

Conclusions—The PROFILE PD is a reliable and valid scale that can be used to quantify alterations in body systems and activity of individuals in early and mid-stages of PD. Use of the scale can provide an overall summary of the impact of PD on body systems and activities.

Keywords

Parkinson disease; clinical test

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INTRODUCTION

A number of measures specific to people with Parkinson disease (PD) have been developed and used since the 1980s to summarize the impact of PD on body systems and activities.[1,2,3,4] Because of the limitations of these early measures, the Unified Parkinson's Disease Rating Scale (UPDRS)[5] was developed by an international panel of neurologists and has been considered the gold standard for quantifying the signs, symptoms, and disease progression of PD since its inception. The UPDRS characterizes a number of deficits of body systems and activities based on a rating scale from 0-4. The UPDRS consists of three subscales: (a) mentation, behavior, and mood, (b) ADL, and (c) motor. The motor subscale includes a range of items describing body structure impairments such as tremor and rigidity, body movements such as foot taps, and functional movement such as rising from a chair.

Despite its usefulness the UPDRS scale has several problems that limit its applicability for physical therapist practice.[6] First, although the scale was developed for use across all Hoehn and Yahr stages (H & Y; an earlier scale used to classify signs and symptoms associated with stages of PD progression) of PD[7], the emphasis of responses is heavily weighted to those in the later stages of the disease. Thus, it does not adequately differentiate potentially meaningful changes in the earlier stages of the disease. A second and related problem, is that the UPDRS does not have uniform anchors associated with each question. Thus, a given numeric rating does not necessarily reflect a similar level of dysfunction on two different questions. Because of these two issues, the UPDRS may not be as sensitive to change as is desirable for individuals in the early and mid stages of the disease. In response to these and other limitations, a revised version of the UPDRS was made available for use in 2008.[8] However, several additional issues still limit applicability of the UPDRS for physical therapy practice. First, the UPDRS contains substantially more detail related to tremor, dyskinesia and dystonia than is needed for physical therapist practice. Specifically, these impairments are rated separately for each extremity. The consequence is that the scale is weighted to impairments that are not likely to respond to physical intervention. In addition, extensive training is required for reliable scoring on the UPDRS, in part because of the heavy weighting to tremor, dyskineia, and dystonia which require substantial judgment. Finally, the time required to administer the total UPDRS is long. For these reasons, the UPDRS is not easily applied by physical therapists in clinical settings.

The original PROFILE PD scale was developed in 1999 to overcome some of the limitations of the UPDRS and was reported as a letter to the editor (note that the original scale was referred to as the Duke University Parkinson's Disease Rating Scale in the initial publication).[9] Specifically, the scale was developed to meet four goals: 1) to include early and middle stages of PD in addition to later stages; 2) to organize the items into subscales that differentiate impairments of body structure and activity restrictions and thereby to improve responsiveness by redistributing the weighting to represent both body systems and activities more equally; 3) to be useful among people of different disciplines; and 4) to be administered easily and in a reasonable time frame. The scale included three subscales (referred to at the time as impairments, functional limitations, and cognitive /emotional). During the initial validation of the original scale, four of the items on the original scale did not perform as well as desired, and revisions were made accordingly. Several items were dropped from the scale (e.g., related to swallowing) and several were revised for better performance (e.g., body bradykinesia and motor planning items). Before the revised version could be made available for use, it was necessary to validate the completed scale.

The purpose of this paper is to report on the clinimetric properties of the final version of the PROFILE PD scale and to make this scale available for use. The scale was constructed to include the PD-specific information (e.g., rigidity, bradykinesia, specific functional

activities) that clinicians should obtain during the examinations of individuals with early and mid-stages of PD. Therefore, it can serve as a means of organizing the initial examination necessary to evaluate these individuals and provide a method for quantifying that information. A priori, we anticipated that the scale would be reliable and that it would have three distinct subscales in the initial iteration. We expected the PROFILE PD to correlate with the UPDRS total score and the Schwab and England Activities of Daily Living (S&E)[9], but not with a scale related to depression.

METHODS

Development of 'the PROFILE PD' Scale

PROFILE PD is a rating scale designed to quantify deficits in body systems and activities that typically are assessed during the examination of individuals with PD. The scale was developed in a series of steps, the first four of which were completed and reported previously.[9] To provide a context for the findings of this portion of the validation process, and because the present study represents the last step in the scale development, the following is a brief summary of the initial steps.

Step 1: Five participants in different stages of PD were rated using the initial scale and the interviews were videotaped. The videotapes were rated by 16 raters from four professions (geriatricians, nurses, neurologists, and physical therapists). The variability in rating was accounted for almost exclusively by the differences in disease severity.[9]

Step 2: Inter-rater reliability was established for 19 participants rated by two different raters. Poorly performing items were deleted from the scale leaving a 24-item scale. An additional 21 participants were rated by a single rater and data from the 40 participants was compared to related instruments for characterizing PD (e.g., S&E).[9]

Step 3: The revised 24-item scale was administered to 38 subjects and rated by 2 raters. Factor analysis yielded three subscales. Tests of inter-rater reliability revealed 4 items with $k < 0.4$. [9]

Step 4: Using the 24 items remaining in the revised scale, construct validity was determined based on the ratings for the 40 participants rated in step 2.[9]

Step 5, the last step in the validation process, is presented in this manuscript. In this step, the four lowest-performing items were revised. Inter-rater reliability and determination of consistency, construct validity, and factor analysis all were established for the final version of the PROFILE PD.

Description of PROFILE PD

This final version of the PROFILE PD consists of 24 items (Appendix). The first eleven items relate to deficits in body systems associated with PD (e.g., tremor, rigidity, postural instability). The next ten items relate to difficulties with functional activities typically experienced by persons with PD (e.g., turning in bed, adjusting bed sheets, transfers, gait). The final three items relate to problems with memory, depression, and degree of involvement in home and community. Each item is scored from 0 to 4. In general, 0 = None (no problem with the item) and 4 = Severe or marked difficulty with the item. A total score for PROFILE PD is achieved by summing the 24 items for a minimum score of 0 and a maximum score of 96, with 0 indicating no dysfunction and 96 indicating the most extreme dysfunction.

Subjects

Subjects for this study were participants in a large randomized, controlled 16-month exercise study that was approved by the Institutional Review Board of Colorado University. Data were obtained for the parent study during screening, baseline testing, 4, 10 and 16 months. All participants gave informed consent. Volunteers were enrolled if they were in stages 1.5 to 3 according to the modified Hoehn and Yahr scale.[5] They were excluded if they had on-state freezing, uncontrolled hypertension, or limited exercise capacity based on musculoskeletal, neuromuscular (other than PD), or cardiovascular disorders. Participants who met screening criteria were scheduled for baseline data collection. Baseline data were used for validation of the PROFILE PD.

Procedures

To determine eligibility for the study, all potential participants underwent extensive testing. During the initial screening, diagnosis of PD was verified using the UK Brain Bank[10] criteria by a neurologist who was a movement disorders specialist. The UPDRS scale was administered. At baseline testing the participants completed a number of questionnaires and underwent a comprehensive assessment of disease symptoms and functional ability. The tests were administered by a physical therapist with over 30 years of clinical experience. To establish inter-rater reliability, the PROFILE PD was re-administered by a second physical therapist (with nearly 20 years of clinical experience) for 15 of the participants. This testing occurred during the same session (either 10 or 16 months) as the full test battery. Both testers were trained in use of the Continuous Scale Physical Functional Performance test (CS-PFP) by one of the authors (MS).

Tests and Measures

The UPDRS is considered the gold standard for quantifying signs, symptoms, and progression of PD with reports of test retest reliability.[11,12] We used the total score on the UPDRS in order to include measures of items related to both body systems and activities, analogous to the items that comprise the PROFILE PD. The modified H&Y, used to determine stage of PD, is part of the UPDRS and was used to identify the stage of PD.

Overall physical functional capacity was determined using the CS-PFP.[13,14] This test consists of 16 tasks, performed serially, as fast as is comfortably possible for the individual. A total and five subscores are obtained; each of the five subscores ranges from 0-100. Reliability and validity have been established for older adults without specific disorders[15,16] and for individuals with PD.[17]

Ability to complete activities of daily living was assessed using the S&E,1 a self-report of functional ability with well-established reliability and validity.18 This scale simply rates (from 0 to 100%) the degree to which an individual is independent with descriptive anchors in increments of 10 (e.g., 100, 90, 80, etc.).[19] The Center for Epidemiologic Studies Depression Scale (CES-D) was used to determine depression; this scale has high internal consistency and modest test-retest reliability .20

Analysis

Inter-rater reliability was determined for the PROFILE PD using the intraclass correlation coefficient (ICC) and consisted of a comparison of data obtained by the two physical therapists who administered that test at two separate times within a single test session. These analyses were performed using the SAS/STAT software, Version 9.2.* Methods are described in detail below for the determination of consistency, construct validity, and factor analysis. Internal consistency was established using Cronbach's alpha (α). Individual item contributions were examined by using the "α if item deleted" option. Construct validity was

established by correlating the UPDRS, the CS-PFP, and the S&E to the PROFILE PD total score. To establish discriminant validity, the correlation was estimated between the PROFILE PD and a common measure of depression (CES-D). Construct validity and structure of the PROFILE PD were further examined using exploratory factor analysis (EFA) using Principal Component Analysis (PCA) with Promax rotation which allows a correlated factor structure. These analyses were performed using SPSS Version 16.

RESULTS

Eighty-six individuals with PD (57 males, 29 females; mean age = 66 ± 10 years) were tested using the PROFILE PD. In this sample, the mean H&Y Stage of PD was 2.3 ± 0.4. The mean total score on the PROFILE PD was 18.5 ± 8.8 (range = 4.0 - 42.0) out of a maximum possible score of 96. The mean UPDRS score was 37.7 ± 13.9 (range 8.5 - 86.5) out of a maximum possible score of 156. Data are shown in Table 1 along with data from the CS-PFP, CES-D, and the S&E.

Inter-Rater Reliability

Inter-rater reliability was established by having the two raters independently rate the same 15 participants during a single test session. The order of testing varied, depending on who the primary rater was for that participant. The ICC for the total score was estimated as 0.97 using the Shrout-Fleiss estimator (for a single rating) with a random rater effect.[21]

Internal Consistency

Internal consistency of the PROFILE PD was high with coefficient $\alpha = 0.853$ (Table 2). Deleting 3 items with the lowest correlations: resting tremor, dyskinesia and depression, resulted in a maximum $\alpha = 0.872$; however, this gain in reliability was not sufficient to warrant deleting these items from the instrument. Item means, medians, and standard deviations are presented in Table 3. The median score for the majority of items was 1.

Construct validity

Construct validity was established by correlating the UPDRS, the CS-PFP, and the S&E to the PROFILE PD total score. To establish discriminant validity, the correlation was estimated between the PROFILE PD and a common measure of depression (CES-D). The total scores of the PROFILE PD were highly positively correlated with the total scores of the UPDRS, $r = 0.86$, $p < 0.0001$ (Figure 1) and highly negatively correlated with the S&E, $r = -0.83$, $p < 0.0001$ (Figure 2). As anticipated, the PROFILE PD was moderately negatively correlated with the CS-PFP, $r = -0.62$, $p < 0.0001$ (Figure 3). Also as anticipated, the PROFILE PD was not correlated with the CES-D, $r = 0.20$, $p = 0.0799$. Even after adjusting for age, sex, CS-PFP score and CES-D score, the PROFILE PD was still highly correlated to the UPDRS Total Score (UPDRS) in multiple regression analysis ($p < 0.0001$).

Exploratory Factor Analysis

Exploratory factor analysis (EFA) was performed on the PROFILE PD using Principal Component Analysis (PCA) with Promax rotation. Promax rotation was used because it was suspected that the items of the PROFILE PD would factor primarily on one component, yet still yield other small, but correlated components. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy = 0.732 and the Bartlett's Test of Sphericity was $\chi^2 = 760.9$, $p < 0.0001$ indicating that the data were factorable. A Scree plot (Figure 4) suggested the existence of

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one major component and two correlated components for a 3 factor solution which explained 43.8% of the variance. All but one item had a minimum loading of at least 0.30 on one or more factors (Table 4). The item that did not load was Dyskinesia which asks about abnormal movements that are fidgety, often slow, not smooth, and may be painful. The rater scores this item, based on individual report, as well as observation during the test (note that individuals with PD may deny dyskinesias yet be in constant motion during the interview). The highest loadings on component 1 described use of large muscle groups, while the highest loadings on component 2 represented activities of daily living (ADL). Items loading on component 3 appeared to be measures of more severe disease. The three components were correlated as follows: 1 and 2, r = 0.405, 1 and 3, r = 0.307, and 2 and 3, r = 0.247.

DISCUSSSION

The results of this study demonstrate that the PROFILE PD is a reliable and valid scale that can be used to quantify deficits in body systems and activities of individuals in early and mid-stages of PD. The internal consistency of the scale is high, with little improvement made by deleting questions. The high correlation between the PROFILE PD and UPDRS at baseline ($r=0.86$ $p < 0.0001$) demonstrates that the PROFILE PD examines the same components as the gold standard for measuring signs and symptoms of PD. Furthermore, the PROFILE PD was highly correlated with the S&E, another measure of the overall impact of PD. Approximately 50% of the items on the PROFILE PD relate to functional activities while the other 50% relate to deficits in body systems and cognitive /emotional factors. Many of these later items may affect physical performance; however, others are not expected to relate to physical performance, hence the moderate correlation between the two measures. As anticipated, the PROFILE PD did not correlate with the CES-D, a measure of depression.

The PROFILE PD was constructed with three subscales: body systems, activities, and cognitive/psychological domains. Although two of the three subscales of the original PROFILE PD were supported by an assessment of internal consistency (Cronbach's alpha of 0.82, 0.89, and 0.56 respectively), factor analysis of this final scale suggests that there is a single scale. Most likely this reflects the high level of interrelations between body systems and activities for those with PD. For this reason, only the total score is recommended for use in clinical practice and research.

It is noteworthy that the UPDRS recently was revised by a working group of the Movement Disorders Society because of many of the same concerns that prompted us to develop the PROFILE PD.6 Specifically, the MDS-UPDRS has an increased emphasis on rating mild impairments and disability of PD; uniform anchors are used with consistent meaning of numbers across questions.[6] The PROFILE PD was not compared to the MDS-UPDRS because the latter scale was not available until almost all of the data for this manuscript had been collected. Although the MDS-UPDRS is likely to be more responsive to physical interventions in individuals who are in early and mid-stages of PD, the scale may not meet all of the needs of the physical therapist for several reasons. The MDS-UPDRS continues to heavily emphasize items that are responsive to pharmacological intervention (e.g., many points are devoted to a detailed determination of tremor, hand bradykinesia, dyskinesia and dystonia). Thus the MDS-UPDRS is heavily weighted to problems in body systems that are not specifically responsive to physical intervention. Furthermore, because of the heavy emphasis on these items, which are difficult to score consistently, administration of the MDS-UPDRS requires substantial training for reliability of use. And finally, administration of the total MDS-UPDRS scale is anticipated to take upwards of 30 minutes (compared to about 15 minutes for the PROFILE PD). In contrast to the MDS-UPDRS, the PROFILE PD

is an attractive alternative for daily physical therapy practice, specifically tailored to the physical therapist's examination of the individual in early and mid-stages of PD.

A few limitations should be acknowledged. The UPDRS and PROFILE, used in determining construct validity of the PROFILE PD were administered as much as two months apart. This was because of the number of steps (and scheduling constraints) required to determine eligibility of participants for the randomized, controlled exercise study. One of the eligibility requirements for the study was being stable on dopamine replacement therapy. Despite the long delay between administrations of the two measures, the correlation was high. Perhaps it would have been even higher had the two measures been administered at the same time. Secondly, findings only can be generalized to individuals in Stages 2 and 2.5 of Hoehn and Yahr scale because of the small numbers of participants in the earlier and later stages of the disease. Third, responsiveness over time should be evaluated in a future study. Two issues should be examined: the natural history of change on the PROFILE PD and the effects of exercise interventions on performance on PROFILE PD. With these additional data, a judgment can be made regarding the use of this scale as an outcome measure for physical interventions for people in the early and mid-stages of PD. Finally, additional data, specifically examining individuals with PD whose disease is in H&Y Stages 3 and 4 will elucidate the benefits of this scale in later stages of the disease.

In summary, PROFILE PD consists of 24 items that would typically be assessed in examination and evaluation of individuals with PD. Using this scale to quantify the information obtained during the initial examination, the physical therapist has available a quantitative documentation of the individual's status in almost all areas that are important in a global assessment. These data are not intended to substitute for the quantitative performance data also required (e.g., measures of balance and gait). However, they provide the overall summary of the individual's difficulty with body systems and activities associated with PD. Additionally, the PROFILE PD may complement the UPDRS in investigative trials. Data obtained with the MDS-UPDRS (the gold standard for quantifying change in PD) are essential for comparison with any other studies. However, future investigations will determine whether PROFILE PD is more responsive to change than the UPDRS in participants with PD undergoing a physical intervention.

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APPENDIX: Profile of Function and Impairments Level Experience with PD (PROFILE PD)

Instructions to the examiner:

This rating scale is to be completed using a combination of questions to the patient and observations by the examiner. To develop an appreciation of the patient's usual condition, you may need to probe using simple examples. Avoid ‘yes / no’ questions as these questions will not always give a true picture of the patient's condition. Use any observation throughout the session, coupled with patient/caregiver report in rating the patient. If the patient denies having a particular impairment, but if you observe that impairment, rate the patient based on your observation. For example, a patient may deny having dyskinesia, yet be clearly dyskinetic during the interview. Always record the average/usual level of performance or

report for each question or task. For bilateral activities of the upper and lower extremity, record the 'worst' extremity. For all questions, responses are based on the past week unless specifically indicated otherwise.

A. BODY SYSTEMS

1. TREMOR WITH ACTIVITY

The patient is seated in a chair without armrests. Place a bottle of water and a cup on the desk. Ask the patient to fill the cup with water, bring cup to mouth and return it to the desk. Then ask the patient to repeat with the other hand. Ask the patient if his / her hands are steady when reaching or holding a newspaper in unsupported position. **If the answer is 'no'**, ask the patient to close eyes & raise arms forward to shoulder height with elbows extended/forearms pronated. Have the patient hold this position briefly. Observe for tremor. Rate tremor with activity based on the worst extremity. In addition, observe for tremor throughout the session and revise rating if necessary.

0 = None

1 = Slight; present with fine motor action, able to perform

2 = Moderate; clearly present with any action/intention, occasionally bothersome

3 = Marked; present with action and sustained position (may drop items, spill drink)

4 = Severe; marked in amplitude and present most of the time, cannot feed self, write

2. **RESTING TREMOR**

The patient is seated in a chair without armrests facing you. The patient has both feet flat on floor and forearms are resting on lap palms up. Ask the patient to close his or her eyes. With his or her **hands relaxed**, ask the patient to name presidents backward from present president (i.e., Obama, Bush, Bush, Clinton, Bush, Sr., Reagan, Carter, Nixon/Ford). **OR**, ask the patient to name months backwards. Rate resting tremor based on the 'worst' extremity. Observe the patient throughout the interview and revise the rating if necessary.

0 = None

1 = Slight; "pill rolling" (circular motion of approximated tip of thumb & forefinger) not bothersome

2 = Moderate; only occasionally bothersome, may increase with attention

3 = Marked; present at rest, increases with attention; noticeable and bothersome most of the time

4 = Severe; constant; very disturbing

3. RIGIDITY

The patient is seated in a relaxed position with arms at sides. Hold patient's hand and just above elbow. Move each upper extremity through full flexion and extension range of motion and determines resistance to passive range of motion, (PROM). Next ask the patient to scoot hips forward in chair. Move the lower extremity through flexion and full available ROM of the knee. Again determine resistance to PROM. Be careful to differentiate between tight hamstrings and rigidity. Finally, ask the patient to remove his or her eyeglasses; determine resistance to passive flexion, extension and lateral flexion of the neck.

0 = None

1= Slight or detectable only with reinforcement (contralateral fist)

2 = Mild; present with passive alternating movements; tenting of hands

3 = Moderate; present in joints associated with movement but full ROM

4= Marked; full range achieved with difficulty, or contractures are present.

4. **POSTURE**

With patient standing in a relaxed position, assess posture from the perspective of an RN or MD as opposed to the in depth postural assessment consistent with a physical therapist's usual practice. That is, use criteria that an MD or RN might use to judge abnormality.

0 = Normal

1 = Not quite erect (slight truncal flexion)

2 = Definitely abnormal; may be leaning to one side; beginning arm flexion

3 = Moderately abnormal; kyphosis with leaning moderately to one side

4 = Severely abnormal, head extremely flexed forward, hands elevated above waist, flexion of knees

5. **POSTURAL STABILITY** (Response to sudden posterior displacement by the 'Pull Test').

Explain the test to the patient, reassuring the patient that he / she will not fall. Then ask the patient to stand erect, with eyes open and feet slightly parted. Now stand about 2 feet behind the patient. (You can position yourself a few feet in front of a wall, so that your will not fall should the patient fall backwards onto you.) Once positioned, gently pull the patient at the shoulders to give the patient an idea of the nature of the displacement and to provide you with an estimate of the patient's stability. Pull a second time with force sufficient to displace the patient in a posterior direction. To grade the patient as 'normal' the patient should be able to withstand the same force as a young, healthy individual.

0 = Normal; may bend at hips, take two or three steps backward w/o loss of balance

1 = Retropulsion (> 3 steps backward), but recovers unaided

2 = Absence of postural response; would fall is not caught by examiner

3 = Unstable; loses balance spontaneously

4 = Unable to stand unassisted

6. **DYSKINESIA.**

Ask the patient whether he or she experiences abnormal/involuntary movements that are fidgety, squirmy, antsy, often slow, not smooth, may be painful. Patients or caregivers/ others may report that the patient often has pursed lips, changes sitting position frequently (e.g., crossing/uncrossing of legs). Ask how many hours during waking day this movement is noted.

Note that patients may deny dyskinesias yet be in constant motion during the interview. Score dyskinesia, based on patient report s well as observation throughout the test. Note that dyskinesia often occurs at peak dose.

0 = None

1 = Mild, occasional or sporadic occurrences

2 = Moderate; 10-25 % time affected

3 = Marked: about 50% time have difficulties

4 = Severe; more than 75% time; debilitating

7. **DYSTONIA**

Ask the patient if he or she experiences abnormal tone, evidenced by involuntary clonic/cramping movements/"drawing" of arms, legs. Probe with questions such as: Do you experience any drawing, clawing, cramping of fingers, foot/toes, biceps/triceps, neck muscles? Does your foot turn in when you are walking? Do you have a tendency to walk on your toes? Do your neck muscles feel as though they are pulling to on side? Does this cramping interfere with activities? How many hours during the day are you aware of this tightness?

Note that patients may deny dystonia yet exhibit the symptom during the interview. Score dystonia, based on patient report as well as observation during the test.

0 = None

1 = Mild; occasional or sporadic abnormal movements

2 = Moderate; 10-25% time; infrequently interferes with some activities

3 = Marked; about 50% time; interferes or prohibits some activities

4 = Severe; more than 75% time; debilitating

8. **CLINICAL FLUCTUATIONS**

Ask the patient whether the symptoms of Parkinson's disease vary during the day, depending on when he/she takes medications or for any other reason. Probe with questions such as: Do fluctuations become noticeable or are you aware of any changes (e.g. handwriting, increased tremor or slowness) if you have forgotten to or are late taking PD meds? Do you experience a 'wearing off'? Are you any slower? Do you notice an increase in tremor or a change in your walking pattern or a decrease in legibility of your handwriting? **NOTE**: if the patient is not taking levadopa (sinemet) there will be NO 'off periods.'

0 = Are not noticeable

1 = Become noticeable if medications late/forgotten; not debilitating (1-25% time noticeable)

2 = Frequently interfere with daily activities between doses of medications (26-50% time noticeable)

3 = Interfere with daily activities a great deal. Activities and social interactions must be planned around time of medications. (50-75% time noticeable)

4 = Are debilitating; cannot perform simple activities or self care routines because of the symptoms regardless of medications (> 75% time noticeable).

9. **FALLING** (unrelated to freezing)

Ask the patient if he / she has experienced any falls (to the floor) in the past year that are not related to freezing. If the answer is 'yes', probe to determine how frequently falls occur.

0 = None (less than once per year)

1 = Rare falls (less than 4-6 times per year)

2 = Occasional falls (less than once per month)

3 = Frequent falls (less than once per week)

4 = Daily falls

10. **FREEZING WITH GAIT/START HESITATION**

Ask the patient if he / she has trouble getting started with 1st few steps or experiences falls if he / she freezes while walking. Probe with questions such as: Are you familiar with the term 'freezing' as it relates to PD? Have the patient try to define freezing before explaining it. Then explain freezing if necessary. Do your feet stick to the floor when you attempt to move forward when 1st standing from chair? Do you experience difficulty when approaching a chair/curb or when passing through narrow doorways or when navigating in crowded areas?

0 = None

1 = Rare freezing when walking; may have start hesitation

2 = Occasional falls due to freezing while walking

3 = Frequent freezing; may have frequent (less than monthly) falls

4 = Frequent falls from freezing (at least monthly)

11. **BODY BRADYKINESIA**

Ask the patient "Do you have trouble starting to move, or to keep moving? Do you feel you are slower in moving than you use to be or compared to those around you?" Ask the patient to open / close his hand repeatedly and as fast as possible. ('Raise your hand like you are being sworn in, then open and close your hand as fast as possible'). Also ask the patient to tap his or her foot and raise the heel about six inches from the ground repeatedly and as fast as possible. Also note whether the patient has a masked face, has limited postural adjustment during the session, moves slowly or through small amplitudes.

Rating of body bradykinesia is based on observation and self report related to slowness, hesitancy, decreased or lessened amplitude of movements. Score this test based on observations throughout the session as well as patient report. You should not rely on a single issue (e.g., hand opening/closing, masked face, but should score based on the total presentation. If you do not observe slowness and the patient denies being slow, but reported in previous questions that things take longer, base the rating on the patient's overall report.

0 = None

1 = Minimal slowness, giving movement a deliberate character; could be normal **for** some persons

2 = Mild degree of slowness and poverty of movement which is definitely abnormal or reduced amplitude

3 = Moderate slowness, poverty of small amplitude movement

4 = Marked slowness, poverty of small amplitude movement

B. ACTIVITIES

12. SPEECH

Ask the patient whether he/she has noticed changes in voice especially related to volume/ ability to communicate over the past few years or since PD was diagnosed. Probe with

questions such as: Are you aware of difficulty when talking on telephone? Do people other than your spouse ask you to repeat yourself sometimes? Frequently?

Rate speech based on your observation as well as the patient's report.

0 = Normal, clear, good volume, easily understood

1 = Slight loss of inflection, resonance; good volume, easily understood

2 = Moderate loss of diction, low volume; usually understandable, may need to repeat

3 = Marked impairment with dysarthria, hesitancy, monotone; difficult to understand

4 = Unintelligible

13. DRESSING

Ask the patient whether he or she has difficulty with dressing. Probe with questions about donning jackets, dress, shirts, or socks. Ask the patient 'Do you need to modify your approach for getting on pants/slacks? Do you have any problems with buttons/zippers? Are you slower than you used to be?' Also observe certain tasks (e.g., opening/closing a button).

Note that if the patient accepts assistance for several activities (e.g., buttons, socks, sometimes getting on pants) but *typically* completes more than half the dressing alone, the score will be 2.

0 = Normal

1 = Dresses independently; slightly slower, more effort, or both

2 = Requires minimal assistance (another person) with buttons, sleeves, and/or ties/ collars

3 = Requires moderate assistance (another person) with half of dressing activities (lower body dressing, shoes and socks)

4 = Requires maximal assistance (another person); may be able to help with bodily movements

14. HYGIENE

Ask the patient: Do you have difficulty with personal hygiene activities such as shaving/ washing/brushing hair? Do you use a wall bar or shower bench because of PD? Do you use an electric shaver/toothbrush because of PD? Are you any slower with these acts than you used to be?

Note that if the patient accepts assistance for several activities ((e.g., shaving, combing hair) but *typically* completes more than half the hygiene alone, the score will be 2.

0 = Normal

1 = Independent with more time and/or effort

2 = Independent; may employ adaptive equipment (electric razor, showers over baths, electric toothbrush, water pik)

3 = Partial assistance by another person required for hygiene activities

4 = Dependent for hygiene activities; always needs help from another person

15. **MEALTIME ACTIVITIES**

Ask the patient: Do you have difficulty with handling utensils, cutting meat or buttering bread? Probe with questions such as: Do you spill/drop from utensils/glass? Are you clumsier or slower than you used to be?

0 = Normal

1 = Fully feeds self with few accidents; slower than normal

2 = Moderately slow, greater effort; requires assistance in specific situation (cutting meat in restaurant); accidents not uncommon (spills, dropping food)

3 = Requires assistance with feeding ≥ 50% of time

4 = Totally dependent; requires full assistance with feeding

16. **SIMPLE TRANSFERS** (e.g. to and from bed) Note – do not include difficulties with turning in bed when scoring this item.) Ask the patient: Do you have difficulty getting onto or off of a bed? Are you any slower than you used to be?

0 = Normal

1 = Minimal impairment; may take a little longer, but can accomplish independently

2 = Mild impairment; definitely slower and requires more effort

3 = Moderate impairment; can accomplish independently, but with adaptive equipment (e.g. grab bars)

4 = Severe impairment; requires assistance from another person

17. **BED MOBILITY** (mobility in the bed, turning, rolling, and bridging) Ask the patient: Do you have difficulty turning/rolling in bed or adjusting the bed covers? Do you need to sit up in order to turn; or, need to use headboard for assistance? Are you slower than you used to be?

0 = Normal

1 = Slow and clumsy, but no help needed with turning or adjusting sheets

2 = Can turn alone but with great difficulty; may need compensatory techniques (e.g. holding onto headboard of bed)

3 = Can initiate, but not turn or adjust sheets without help

4 = Cannot initiate nor complete independently

18. **CHAIR RISE**

Ask the patient: Do you have difficulty standing up from the seated position? Then ask the patient to stand up from the seated position with his or her arms crossed over the chest. Finally, ask the patient whether he/she has difficulty at home, in other environments, has modified seating (e.g., firm, high seat).

Score this question based on observation as well as patient report. Score 2 if uses arms for push up from chair >25% of the time; score 1 if uses arms to push up < 25% of the time.

0 = Never

1 = Slow; may need to “rock” in chair for momentum, but does not need to use the arms.

2 = Performs independently, but ***requires*** use of arms to push up

3 = Tends to fall back and may have to try more than one time using arm rests may need assistance, especially to arise from deep or soft seating

4 = Unable to arise without assistance

19. **GAIT**

Ask the patient: Do you notice changes in or difficulty with your walking? Probe with questions such as: Do you feel as though you are any slower than you used to be? Are you less confident, especially on rough terrain? Do you stutter step when turning?

Score this question, based on observation as well as patient report. Note, if patient uses an assistive device, the score automatically will be 3 *unless the device is for a reason other than PD.*

0 = None

1 = Can walk easily, no restrictions but may have decreased arm swing, less trunk rotation, slow to turn

2 = Can walk independently, but less sure with definite decreased arm swing, less trunk rotation; may have propulsion; abnormal posture; small base of support

3 = May walk with assistive walking device (cane/walker) or person (standby or minimal assistance); gait slower; may have propulsion or festination; multiple steps on turns; requires assistance outdoors

4 = Cannot walk at all or requires maximal assistance

20. **FINE MOTOR MOVEMENT PERFORMANCE**

Ask the patient: Have you had or do you have problems with any fine motor performance such as:

closing/opening buttons, clasps, zippers; putting on earrings

fastening or unfastening safety pins; opening twist tops

using tools (screwdriver, scissors, paintbrush)

turning pages of a book or magazine (do you turn more than 1 page at a time)

Use other probes as necessary, based on the activities that are normal daily activities for this patient.

0 = Normal; no difficulty, or rarely has a problem

1 = Sometimes; notices only occasionally with one or more activities or with only one specific act.

2 = Frequently; notices a problem at least weekly with one or more activities

3 = Always, common problem, interferes with daily routines

4 = Severe; cannot perform the movement required

21. GROSS MOTOR PERFORMANCE

This question is designed to identify problems with dual task performance and motor planning.

Ask the patient: Aside from freezing, have you had or do you have problems with any of the following activities or actions:

walking to a closed door, opening by turning the handles, and entering (smoothly)

walking toward a table, picking up an object, turn; carry with you (smoothly)

walking in crowds/narrow hallways

moving an object out of the way when your are walking

Use other probes as necessary based on the activities that are normal daily activities for this patient.

0 = Normal; not difficulty, or rarely has a problem

1 = Sometimes; notices only occasionally or with one or more activities

2 = Frequently; notices a problem at least weekly with one or more of the activities

3 = always; common problem, interferes with daily routines

4= Severe; cannot perform the movement required

C. COGNITION / AFFECT

22. **DEPRESSION** (This item is scored based on the last six months)

Ask the patient: Over the past 6 months, have you experienced episodes of sadness lasting greater than a day or 2? If the answer is yes, use each statement below to probe regarding the extent of the depression. Also, ask whether there are special circumstances that occurred during this period (e.g., death in the family). Note that this does not change the scoring.

0 = None

1 = Periods of greater than normal sadness lasting only a few days

2 = Sustained depression lasting greater than one week

3 = Sustained depression with vegetative signs (insomnia, anorexia, anhedonia)

4 = Depression with suicidal thoughts or intent

If responses to #'s 3 or 4 are yes, then ask the patient if his or her MD is aware of the depression? If the MD is not aware of the depression, advise the patient that you should notify the MD of his or her response.

23. **MEMORY**

Ask the patient: Do you have problems with memory, following a conversation, abstract thinking or problem solving (e.g., balancing checkbook)? Have you been aware of these only since you have had PD?

0 = Normal

1 = Mild impairment; forgets occasional event (name, place)

2 = Moderate impairment; above and disorientation (time, place); may defer decisions to spouse or caregiver

3 = Severe impairment; episodes of confusion and disorientation; misinterprets cues simple decision making problematic, needs some supervision (safety)

4 = Dementia; unable to make judgments or problem solve, requires 24 hour supervision

24. **INVOLVEMENT**

Ask the patient: Have you changed your routine re: daily/leisure/social activities because of decreased physical ability or PD symptoms that interfere (tremor/dyskinesia) or because of embarrassment assoc. with PD? Are you as interested in/involved with day-to-day activities and social functions as you used to be?

This question probes changes in involvement in typical daily activities, leisure activities, and social events. The score is based on changes in involvement due to one or more of the following: overall motivation, depression, change in priorities related to decreased physical ability or social embarrassment. Attempt to determine if the change is related to issues outside of PD (e.g., recent retirement; loss of a spouse).

0 = Normal

1 = Less assertive than usual; more passive

2 = Loss if initiative or interest in elective activities (clubs, organizations, parties, restaurants)

3 = Loss of initiative or interest in routine activities (shopping, reading, household activities)

4 = Withdrawn, complete loss of motivation

Comments: (Make any additional anecdotal comments here for future reference).

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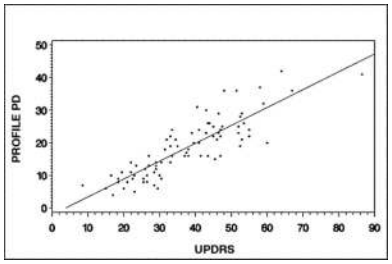

Figure 1.
Correlation between the UPDRS obtained during the medical screening process and the PROFILE PD obtained at baseline testing.

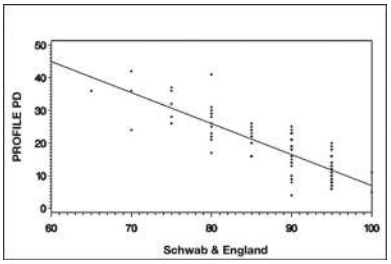

Figure 2.
Correlation between the PROFILE PD and the S&E (both obtained during baseline testing).

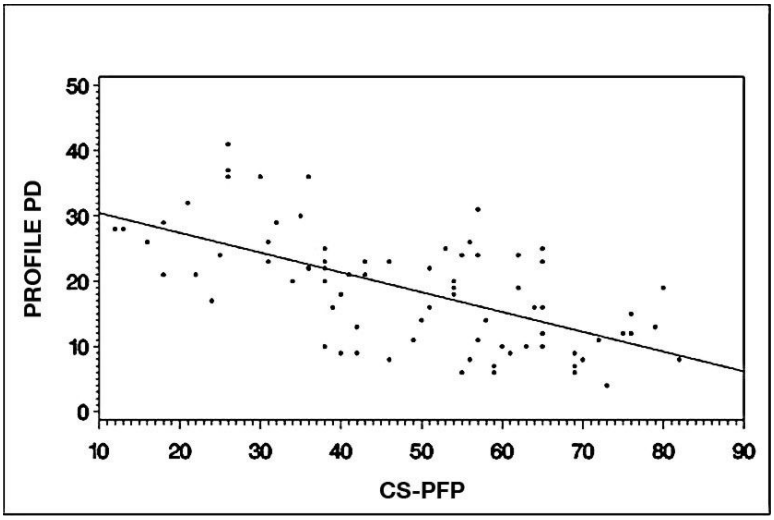

Figure 3.
Correlation between the PROFILE PD and the CS-PFP (both obtained during baseline testing).

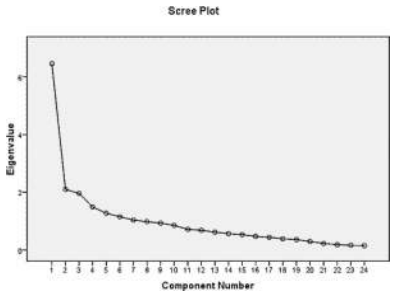

Figure 4.
Scree plot indicating 1 major and component and 2 minor components before the scree begins.

Table 1

Characteristics of individuals with PD who completed the PROFILE PD (n=86)

		Mean	Minimum	Maximum
Age		66 ± 10	49	92
Time since Diagnosis		4.7 ± 4.0	1.0	23.0
Hoehn & Yahr Staging of Parkinson's Disease		2.3 ± 0.4	1.0	3.0
Stage	n			
1	1			
1.5	2			
2	42			
2.5	32			
3	9			
PROFILE Total		18.5 ± 8.8	4.0	42.0
UPDRS		37.7 ± 13.9	8.5	86.5
Continuous Scale of Physical Performance (CS-PFP)		48.5 ± 17.8	12.0	82.0
CESDT		11.8 ± 8.2	1.0	43.0
Schwab & England Activities of Daily Living (S&E)		87.8 ± 7.7	65.0	100

Table 2

Reliability of the 24-item PROFILE PD total scale (n = 86)

Item	r[a]	α[b]
Tremor with Activity	0.406	0.848
Resting Tremor	0.069	0.862
Rigidity	0.306	0.851
Posture	0.453	0.846
Postural Stability	0.450	0.847
Dyskinesia	0.141	0.858
Dystonia	0.172	0.855
Clinical Fluctuations	0.144	0.855
Falling (unrelated to freezing)	0.521	0.845
Freezing with Gait/Start Hesitation	0.457	0.848
Body Bradykinesia	0.653	0.837
Speech	0.576	0.842
Dressing	0.419	0.848
Hygiene	0.558	0.842
Mealtime Activities	0.526	0.844
Simple Transfers	0.667	0.837
Bed Mobility	0.645	0.839
Chair Rise	0.594	0.843
Gait	0.628	0.840
Fine Motor Movement Performance	0.474	0.845
Gross Motor Performance	0.349	0.850
Depression	0.094	0.859
Memory	0.156	0.855
Involvement	0.465	0.846

Note: Overall coefficient α = 0.853

[a]Corrected item-total correlation

[b]Value of coefficient α if that item was deleted

Table 3

Item Statistics for the PROFILE total scale (n = 86)

Item	Mean	Std	Median
Tremor with Activity	.86	0.763	1.0
Resting Tremor	1.15	0.925	1.0
Rigidity	1.90	0.770	2.0
Posture	0.93	1.003	1.0
Postural Stability	0.40	0.642	0
Dyskinesia	0.65	0.857	0
Dystonia	0.61	0.640	1.0
Clinical Fluctuations	0.58	0.605	1.0
Falling (unrelated to freezing)	0.29	0.593	0
Freezing with Gait/Start Hesitation	0.29	0.454	0
Body Bradykinesia	1.39	1.030	1.0
Speech	1.15	0.814	1.0
Dressing	0.79	0.582	1.0
Hygiene	0.90	0.830	1.0
Mealtime Activities	0.67	0.717	1.0
Simple Transfers	0.73	0.883	0
Bed Mobility	0.83	0.819	1.0
Chair Rise	0.51	0.611	0
Gait	1.18	0.763	1.0
Fine Motor Movement Performance	0.95	0.981	1.0
Gross Motor Performance	0.38	0.790	0
Depression	0.26	0.823	0
Memory	0.44	0.567	0
Involvement	0.68	0.747	1.0

Table 4

Component loadings for a three factor solution with correlated components

	Component		
	1	**2**	**3**
Body Bradykinesia	**0.838**	0.333	0.172
Chair Rise	**0.772**	0.216	0.326
Simple Transfers	**0.761**	0.295	0.423
Gait	**0.739**	0.315	0.327
Bed Mobility	**0.707**	0.371	0.383
Postural stability	**0.683**	0.135	
Posture	**0.653**	0.258	
Speech	**0.585**	0.340	0.505
Falling	**0.531**	0.429	0.257
Rigidity	**0.438**	0.250	-0.107
Mealtime activities	**0.477**	**0.697**	0.152
Hygiene	**0.449**	**0.631**	0.394
Fine motor movement performance	**0.382**	**0.630**	0.282
Dressing	**0.388**	**0.597**	
Dystonia	-0.105	**0.581**	0.253
Tremor with activity	**0.318**	**0.549**	
Resting Tremor		**0.460**	-0.293
Memory		**0.376**	0.107
Involvement	**0.411**	0.234	**0.762**
Depression			**0.652**
Clinical fluctuations			**0.603**
Freezing with Gait/Start Hesitation	**0.391**	0.401	**0.499**
Gross Motor Performance	**0.324**	0.277	**0.378**
Dyskinesia	0.185		0.265