Guide to

Assessment Scales in Parkinson's Disease

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Dr Martinez-Martin's research interests are: clinical assessment and rating scales; patient-reported outcomes, particularly health-related quality of life; neurodegenerative diseases; Parkinson's disease; and Alzheimer's disease and dementia. He has received 14 awards for scientific activities in neurosciences and aging. Dr. Martínez-Martín has authored over 290 articles in peer-reviewed scientific journals and 87 book chapters, and is editor or co-editor of 17 books and monographs. He has participated in 348 platform or poster reports and 168 talks in scientific forums (congresses, symposia, expert workshops) and has given 159 lectures as invited professor in teaching institutions. At present, he is an active member of several study groups with the Spanish Society of Neurology and the Movement Disorder Society, as well as international steering committees for research and collaborative groups.

Carmen Rodríguez-Blázquez is a psychologist (National University of Distance Education, UNED) and research assistant at the National Centre of Epidemiology (Carlos III Institute of Health), where she participates in several national and international research projects on clinical and social aspects of neurological diseases (such as Parkinson's and Alzheimer's diseases), quality of life of older populations, and questionnaire adaptation and validation. She has also authored more than 30 papers in peer-reviewed scientific journals and book chapters on the field of disabilities, neurological diseases, quality of life, and psychometric properties of scales and questionnaires. She has participated in the translation and validation of the Spanish official version of the Movement Disorders Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS).

Maria João Forjaz is a scientific researcher at National School of Public Health, at the Spanish National School of Public Health; Carlos III Institute of Health. She graduated from the University of Lisbon and in 2000, as a Fulbright scholar, obtained her doctorate in clinical psychology from the University of North Texas, USA. Her main research interests are quality of life in Parkinson's disease and older adults, assessment of non-motor symptoms, and scale validation using classic psychometric and Rasch analysis techniques. She is the principal investigator of several research grants on the quality of life of older adults and she combines her research activity with teaching

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Kallol Ray Chaudhuri is a Professor of neurology and movement disorders and consultant neurologist at the King's College London Institute of Psychiatry and a principal investigator at the Medical Research Council Centre for Neurodegeneration Research at King's College London. He is also the medical director of the National Parkinson Foundation International Centre of Excellence at King's College, London. He sits on the Nervous Systems Committee of the UK Department of Health, National Institute of Health Research and also serves as co-chairman of the appointments/liaison committee of the Movement Disorders Society (MDS), where he is currently serving as the member of the scientific programme committee. He is the Chairman of the MDS non-motor study group and is on the scientific program committee for the MDS Congress (2013–2015). He serves on the American Academy of Neurology Practice Parameter task force for Parkinson's disease (PD), restless legs syndrome (RLS), and more recently, non-motor symptoms in PD. He is the European Editor of *Basal Ganglia* and is on the editorial board of *Parkinsonism and Related Disorders* and *Journal of Parkinson's Disease*. He is also the lead for London South Comprehensive Local Research Network neurosciences sub-speciality group. Professor Chaudhuri is the author of 227 papers, including reviews and book chapters, is co-editor of 4 books on PD and RLS, and has published over 200 peer-reviewed abstracts. He is the chief editor of the first comprehensive textbook on non motor aspects of PD, published by Oxford University Press, and is recipient of the British Medical Association book commendation prize. He has contributed extensively to educational radio and television interviews, including BBC and CNN, newspaper articles, and videos. He has also lectured extensively on PD and RLS at international meetings in USA, Japan, Europe, South America, South Africa, India, and Australia. His major research interests are continuous drug delivery treatment of PD and restless legs syndrome, Parkisnonism in minority ethnic groups, and sleep problems in PD. In 2005, he was awarded a DSc degree by the University of London.

1. Introduction

Importance of assessment scales in Parkinson's disease

To 'measure' entails the quantification of something by comparison with a fixed magnitude of the same species taken as the unit. This way, the attribute to be measured must be directly observable and a unit has to exist (eg, physical measures). However, many human attributes (eg, intelligence and emotions) are not observable and lack a unit of measurement. These conceptual or abstract objects are named 'constructs'.

The use of scales for assessment in neurology arises from the need to quantify disorders and states (such constructs as disability, symptoms, quality of life) for which genuine measures do not exist and to obtain pragmatic and comprehensive information that cannot be procured from available 'objective' methods (due to costs, need of equipment and expert personnel, conditions of application, etc.).

Initially, rating scales for Parkinson's disease (PD) were designed by an expert or group of experts and used with minimal or no previous testing of their quality as measurement instruments. This situation was characterized by a great variability in the design, content, and metric quality of available scales, resulting in a lack of comparability between studies using these tools. At present, however, systematic application of standardized methods for development, analysis, and formal testing of health status measures for PD is increasingly used.

This guide intends to summarize the characteristics of relevant rating scales and questionnaires for PD. Most of the included instruments, generic or specific for PD, have been qualified as 'recommended' by the ad hoc Movement Disorder Society Task Force (www.movementdisorders.org/publications/ebm_reviews/) and the template for presentation of data is based on the different models used by this task force. Data on the properties of each measure and recognized standard values for comparison are also shown. Recommended references for interested readers appear at the end of each section.

Classification

Scales used to assess PD may be classified into two categories: generic (ie, those scales usable in any health condition), and specific (ie, scales developed for exclusive use in PD). Also, they may be classified as single-item, multi-item or composite scale; unidimensional or multidimensional; and as disease or patient-centered measures. Disease-centered scales reflect aspects of interest to clinicians, such as severity and signs of the disease, disability, and motor complication, whereas patient-centered measures assess the impact of the disease from a patient's perspective and are linked to quality of life and psychosocial adjustment.

P. Martinez-Martin et al., *Guide to Assessment Scales in Parkinson's Disease*,
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Design and validation of scales

The creation and validation of a rating scale is a complex task. Most areas relevant to the goal being pursued should be identified and included; the scale components must be specifically related to such areas and provide scores suitable for statistical analysis. Importantly, the scale should be as simple and as brief as possible. The first version of the measure is applied to a relatively small number of individuals from the target population in a pilot study aimed at identifying flaws and ambiguities. In addition, pilot studies provide preliminary data on acceptability and reliability, and allows shortening of the scale when necessary.

The definitive version of the scale is obtained through revision and refinement following these pilot studies. This version must be validated in a representative sample of the target population through a new study to determine the quality of the scale. Principles for rating scales validation come from the Classical Test Theory and Modern Test Theory, including Item Response Theory, and Rasch analysis [1–4].

Attributes and criteria of the rating scales

In the process of validation the following attributes should be tested to ascertain whether a scale is an effective instrument of measurement [1,5–7].

Conceptual model - rationale for and description of the concept and populations that the measure intends to assess.

Acceptability – refers to how acceptable an instrument is for respondents to complete and the extent to which the scores are well distributed in the sample.

Dimensionality – refers to the grouping of items in domains or latent variables.

Scaling assumptions – equivalence of the items in distribution of response options, and how correctly the items are grouped into scales**.**

Reliability – extent to which the scale is free of random error. Two aspects are distinguishable in this section: internal consistency (interrelation among scale components at a point in time) and reproducibility or stability of scores among different raters (inter-rater reliability) and at different moments of time (intra-rater or test-retest reliability).

Validity – ability of the scale to measure what it purports to measure. Content validity refers to the extent to which the construct of interest is adequately sampled by the scale components (items, questions). Criterion-related validity refers to the relationship between the scale and a gold standard (the 'criterion'), although there is no gold standard available for most of the constructs measured in neurology or movement disorders. Construct validity refers to the evidence that supports an interpretation of the scores based on the theoretical framework related to the construct being measured (hypotheses-testing). Within the construct validity, convergent validity refers to the relations of the scale with other measures for the same construct, while divergent validity refers to the absence of relations with measures for constructs different to the one being measured. Discriminative validity (known-groups or extreme-groups validity) represents the measure's ability to detect differences among specific groups in a single observation.

Precision (sensitivity) – refers to the ability of a scale to distinguish between small differences.
Responsiveness – related to precision, it refers to the ability of the scale to detect changes over time.
Interpretability – degree to which a comprehensible meaning can be assigned to the scale scores.
Other related aspects – respondent and administrative burden; alternative forms (different modes of administration: phone, interview, self-assessment); and cross-cultural adaptation (translation and adaptation to obtain an equivalent linguistic and conceptual version to be used in a different language or culture than the original).

Most of these measurement properties are analyzed using statistical methods and standard values or 'criteria' of quality have been proposed for the results (examples are shown in Table 1.1). Before using a scale in clinical practice or research, most of these criteria must be verified.

Table 1.1 Standard values for basic attributes of scales

Attribute	Value	Reference
Feasibility		
Missing data	<5%	[8]
Acceptability		
Floor and ceiling effects	<15%	[9]
Skewness	–1 to +1	[10]
Internal consistency		
Cronbach's alpha	α>0.70 (group); 0.90–0.95 (individual)	[6]
Inter-item correlation	r>0.20 and r<0.75	[8]
Item-total correlation	r>0.20 – r>0.40	[5,11]
Homogeneity coefficient	r>0.30	[12]
Reliability		
Inter-observer – nominal or ordinal	*Kappa* r>0.60 or r>0.70	[13]
Continuous data	Intraclass correlation coefficient r>0.70	[7]
Test-retest – nominal or ordinal	*Kappa* r>0.60 or r>0.70	
Continuous data	Intraclass correlation coefficient r>0.70	
Construct validity (Hypotheses-testing)		
Convergent validity	r>0.40 – r>0.60	[14,15]
Divergent validity	r<0.30	
Internal validity	r=0.30–0.70	[16]
Known-groups validity	Significant difference between groups	[17]

The guide: intention and organization

The review of scales presented in this Guide has been systematically adapted to these clinimetric attributes, following the proforma shown as Table 1.2. Our intention is to provide rapid and pragmatic information on the relevant aspects related to the characteristics and clinimetric properties of the most relevant scales used in PD.

Table 1.2 Guide to Assessment Scales in Parkingson's Disease

Scale Original reference	
Description of scale	Construct to be measured Content: number of items and subscales, answer options, type of scoring Time to complete the scale Time frame Rater: Patient /proxy, care professional… Generic/specific
Copyright?	Copyright or public domain?
How can the scale be obtained	How to access the scale
Clinimetric properties of the scale in patients with PD	
Feasibility	Appropriateness of questions for PD population Applicability across PD stages: mild, moderate, severe?
Dimensionality	The number of domains or dimensions that compose the scale
Acceptability	Floor and ceiling effects Score distribution
Reliability	Internal consistency Inter-rater reliability Test-retest reliability
Validity	Face/content validity Construct validity (convergent, known-groups, internal) Any other types of validity (eg, predictive) Scale validity tested for PD in different cultural settings?
Responsiveness & Interpretability	Sensitive to changes in the construct? Minimal clinically important change ? Scale valid for people with PD of both genders and at all ages?
Cross-cultural adaptations & Others	Translations & adaptations
Overall impression	
Advantages and disadvantages	List of advantages List of disadvantages

Selected scales are included in the guide. Owing to copyright restrictions of some of the instruments, this was not permitted for all of the rating scales. However, in all cases, a source from where the scale can be obtained is provided.