RESEARCH ARTICLE

Health-Related Quality-of-Life Scales in Parkinson's Disease: Critique and Recommendations

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ABSTRACT: Health-related quality of life is an important patient-reported outcome used in intervention trials and for monitoring the consequences of health status on physical, mental, and social domains. Parkinson's disease is a complex disorder that strongly affects patients' quality of life. Several health-related quality of life tools have been used in Parkinson's disease. A Movement Disorder Society Task Force was commissioned to rate the psychometric quality of available health-related quality of life scales as applied to Parkinson's disease. Following the methodology adopted by previous work of the Movement Disorder Society Task Force, a review of generic and specific health-related quality of life scales applied in studies on Parkinson's disease was completed. Considering the scales from 3 perspectives—use in Parkinson's disease, use by multiple research groups, and clinimetric properties—a final classification as "recommended," "suggested," or "listed" was applied to each reviewed instrument. Four generic scales (EuroQoL, Nottingham Health Profile, 36-Item Short-Form Health Survey, and Sickness Impact Profile) and 5 specific scales (39-Item Parkinson's Disease Questionnaire, Parkinson's Disease Questionnaire Short Form, Parkinson's Disease Quality of Life Questionnaire, Parkinson's Impact Scale, and Scales for Outcomes in Parkinson's Disease–Psychosocial) reached the level of "recommended." The 39-item Parkinson's Disease Questionnaire is the most thoroughly tested and applied questionnaire. Three other generic measures (Quality of Life Questionnaire 15D, Schedule for the Evaluation of Individual Quality of Life-Direct Weighting, and World Health Organization Quality of Life Assessment Short Version) and the specific Parkinson's Disease Quality of Life Scale are "suggested." With a little additional effort in completing the stipulated requirements, they could reach the "recommended" level. At present there is a wide variety of health-related quality of life measures for application in the Parkinson's disease setting, and the task force does not recommend the development of a new scale. Selection of the most appropriate instrument for a particular objective requires consideration of the characteristics of each scale and the goals of the assessment.

Key Words: Parkinson's disease; health-related quality of life; measures; assessment; patient-reported outcomes

Additional Supporting Information may be found in the online version of this article.

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Parkinson's disease (PD) is a complex disorder with motor impairment and nonmotor manifestations that result in progressive disability and severe complications, factors that have a significant impact on patients' quality of life (QoL).

In recent years, clinical data have been increasingly supplemented with patient-reported outcomes that refer to a patient's report of a health condition and its treatment.[1] These include patient reports regarding symptoms, psychological well-being, health-related quality of life (HRQoL), satisfaction with care, and others.

In medical settings, the term *quality of life* is used to refer to 1 or more of a wide range of patient-reported outcomes. A lack of consistent terminology in this area has led to both misunderstanding and sometimes misuse of those measures. Confusion arises because there are no universally accepted definitions for many of the concepts, and the boundaries between these concepts are often not clear. In the Supporting Information to this article, we present some frequently used terminology and definitions, pointing out where there is agreement and where controversy remains (see Supporting Information 1).

In early articles, there was much philosophical debate about the definition of QoL and HRQoL.[2,3] Currently, however, there is general agreement about assessing the narrower domain of HRQoL in the clinical context and that the 3 broad domains of physical, psychological, and social well-being should be taken as the starting point of most approaches to HRQoL assessment. Health status refers to perceived health in descriptive terms, but is different from HRQoL in that it lacks judgments and reactions. Health status may influence and predict HRQoL but should not be considered equivalent to HRQoL.[4]

In practice, instruments measuring HRQoL assess the physical, emotional, and social well-being and satisfaction related to health, combining objective functioning and subjective perceptions and judgments.

Because of the impact of PD on patients' HRQoL, the profusion of studies including HRQoL measures, and the existence of a wide variety of HRQoL scales, the Movement Disorder Society (MDS) organized a task force to perform a systematic review of the psychometric properties of the scales used to measure HRQoL in PD along the lines of previous reviews of other scales.[5–11] The mission included a ranking of the scales according to prespecified criteria and a final judgment on the need for the MDS to advocate the development of a new scale because of serious insufficiencies in all existing tools.

Taking into account the lack of agreement on the concepts inherent to HRQoL and the loose use of this term in some settings, the task force performed a comprehensive review, including all instruments typically recognized by clinicians as HRQoL scales that have been applied in studies on PD.

Materials and Methods

Administrative Organization and Critique Process

The process followed the same procedure as other reports (see Supporting Information).[5–11] The task force members selected the scales to be included in the review and identified unresolved issues and limitations of the critiqued scales. A pro forma assessment of each scale was developed and confirmed by 2 members and presented to the group. The assessment covered description, versions, availability, use, and clinimetric attributes in patients with and without PD (see Supporting Information).

In the final appraisal of a scale, the task force used the terminology developed for the Appendix of Ancillary Scales to complement the MDS-sponsored revision of the UPDRS (MDS-UPDRS).[12] This terminology was also used in recent reviews of scales to assess other aspects of PD.[5–11] The final assessment was based on consensus among the task force members and the Steering Committee of the Task Force on Rating Scales for PD. The official definitions for task force critiques are: "recommended," if it has been applied to PD populations, if there are data on its use in studies beyond the group that developed the scale, and if it has been studied psychometrically and found to be valid, reliable, and sensitive to change; "suggested," if it has been applied to PD populations, but only 1 of the other criteria applies; or "listed," if it has been applied in PD populations but does not meet either of the other 2 criteria defined for "recommended" scales (Table 1).

As an official MDS document, this report was submitted and approved by the Scientific Issues Committee of the MDS before submission to the *Movement* Disorders journal.

Literature Search Strategy

All specific instruments usually recognized by clinicians as "QoL scales" for PD, and the generic ones that have been applied in studies on PD more than anecdotally (ie, with published data about the instrument design, validation, and application in PD) were included in the review. These scales were identified by a systematic literature search (K.E.L.). Medline on PubMed was searched for relevant articles published until January 2010 with the terms "Parkinson's disease," "parkinsonism," or "Parkinson disease," and "quality of life," "QoL," "health-related quality of

TABLE 1. MDS criteria for classification of scales by the task force

Recommended	Suggested	Listed
1. Used in PD patients	1. Used in PD patients	1. Used in PD patients
	AND	BUT
2. Used by researchers beyond original developers	2. Used by researchers beyond original developers	2. Not used by researchers beyond original developers
	OR	AND
3. Successful clinimetric testing	3. Successful clinimetric testing	3. No successful clinimetric testing

life," and "HRQoL." For each scale, a search was conducted for the terms "Parkinson's disease," "parkinsonism," or "Parkinson disease" and the name of the scale. In addition, published articles known to the task force members were included in this review.

Results

For each scale commented below, a detailed review is available as Supporting Information (http://wileyonlinelibrary.com).

Generic Instruments

Sickness Impact Profile (SIP)

The SIP is a health status questionnaire consisting of 136 items in 12 categories and 2 dimensions: physical and psychosocial. Higher scores indicate worse health status.[13] The SIP is available in multiple languages and general population norms are available.

Validation studies showed satisfactory reliability, as well as convergent and discriminant validity of the scale.

It has been used in studies on PD and has been applied by authors different than the developers.[14,15] Numerous PD studies have reported associations of the SIP with constructs important in PD such as the UPDRS, Hoehn and Yahr, and SF-36. Validity and responsiveness have been tested and supported in PD populations.[14,15]

The SIP is "recommended" for use in PD.

Nottingham Health Profile (NHP)

The NHP[16] is a health status measure. It consists of 38 items (yes/no) covering 8 domains. The NHP is available in multiple languages and in the public domain. General population norms are available. The NHP has been validated in many patient populations[17,18] and has been tested in PD patients and used by multiple authors.

It shows acceptable face/content validity for PD, satisfactory internal consistency, and, usually, unidimensional factor structure.[19] The stability of the scale (test–retest) in PD has not been assessed. It has showed substantial floor effects relative to the PDQ-39.[20] There are studies showing NHP responsiveness to deep brain stimulation[21,22] and change over time.[23,24]

The NHP is "recommended" for use in PD.

EuroQoL (EQ-5D)

The EQ-5D[25] is a measure of health status. It provides a descriptive profile and a single index value (from 0 to 1) for clinical and economic evaluation of health care. The EQ-5D has 5 items, each with 3 possible response levels. Higher scores represent worse perceived health. In addition, a visual analog scale assesses the global "health status today" (from 0 = the worst, to 100 = the best). It has been widely translated. General population norms are available.

The EQ-5D has been used in studies on PD by multiple authors.[26–30]

The face/content validity of the EQ-5D in PD is adequate. The EQ-5D correlates with the UPDRS and SF-36 scores in PD patients[27] and discriminates PD stages.[26,27] It has been responsive to therapeutic interventions in PD patients.[29,31,32]

The EQ-5D is "recommended" for use in PD.

Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)

The SF-36 is a measure of health status[33] consisting of 36 questions with scores in 8 domains. Summary scores for physical and mental function can be calculated, with higher scores representing better health status. There are several versions and many translations available.

The SF-36 has been used by multiple authors in studies to assess patients with PD.[34–38]

It showed some floor and ceiling effects in several subscales and good reliability and discriminative validity.[34,36–41] Evidence to support the 2 physical and mental health components in PD was not found.[40,42] The SF-36 was partially responsive to change over time[43] and intervention.[44] In 1 study, it was more responsive than PDQ-39 and PDQUALIF.[45] The minimal detectable change has been determined.[38]

The SF-36 is "recommended" for use in PD.

Schedule for the Evaluation of Individual Quality of Life–Direct Weighting (SEIQOL-DW)

The SEIQOL-DW was designed to assess QoL from the individual's perspective in the clinical setting.[46–48] The assessment has 3 stages: (1) identification of the 5 areas of life considered most important, (2) rating of

the current state of satisfaction for each domain, and (3) weighting the relative importance of each domain. The SEIQOL-DW has been occasionally used on PD patients.[49]

Acceptable psychometric properties for non-PD conditions have been found.[48,50–52]

Content validity is considered satisfactory, but acceptability, stability, and known-groups validity have not been tested in PD. It showed a moderate correlation with PDQ-39.[49] Motor and cognitive impairment make assessment of the SEIQOL-DW difficult.[49,53]

The SEIQOL-DW is "suggested" for use in PD.

Quality of Life Questionnaire 15D (15D)

The 15D was designed to measure HRQoL.[54] There are 15 questions representing the 15 dimensions. Each question has 5 scoring options, with higher scores reflecting a greater impact on HRQoL. A profile can be created, and an index score (from 0 to 1) can be calculated for econometric purposes.[54–56] The 15D is available in 25 languages and is copyrighted.

The 15D has shown good psychometric properties in a number of non-PD populations.[54–56] In PD, it has been partially validated by the instrument's developers, showing strong correlations with UPDRS parts II and III and with PDQ-39.[57]

The 15D is "suggested" for use in PD.

World Health Organization Quality of Life Assessment Short Version (WHOQOL-BREF)

The WHOQOL-BREF is designed to measure quality of life.[58,59] The scale has 26 questions in 4 domains, a general question about quality of life, and a general question about health. All questions have 5 options of response, with higher scores indicating better quality of life. It is available in multiple languages and is copyrighted.

In non-PD populations, the WHOQOL-BREF showed good psychometric properties,[58–60] but in the PD population it has been used rarely[61,62] and has not been formally validated.

The WHOQOL-BREF is "suggested" for use in PD.

Questions on Life Satisfaction–Movement Disorders (QLS-MD) Module and Questions on Life Satisfaction–Deep Brain Stimulation (QLS-DBS) Module

The QLS-MD and QLS-DBS were developed to measure HRQoL.[63,64] They have 12 and 5 items, respectively, each item scoring on a 5-point scale for both importance and level of satisfaction. Higher scores demonstrate greater importance of the item to the patient and greater level of satisfaction. It is available in German and English.

The modules were validated primarily and partially in PD patients[64] but have not been used by multiple authors.

Floor and ceiling effects as well as internal consistency are adequate as a whole. Convergent validity with the SF-36 and EQ-5D was moderate to high for the QLS-MD module and moderate for the QLS-DBS.[64]

The QLS-MD and QLS-DBS are "listed" for use in PD.

Specific Instruments for PD

Belastungsfragebogen Parkinson kurzversion (BELA-P-k)

The BELA-P-k[65,66] was designed to measure psychological and psychosocial problems as well as the individual need for help in PD. It contains 19 items, each item scoring from 0 to 4, grouped into 4 dimensions. Two subscale scores, "Bothered by" (Bb) and "Need for Help" (NfH), are obtained, ranging from 0 to 16 (fear/emotional symptoms) or from 0 to 20 (for the other subscales). A higher score indicates the patient is more bothered by and has a greater need for help. There are versions in German, Dutch, and English.[66]

A validation study in PD patients was performed by a group different than the developers,[66] but important psychometric properties have never been tested. The BELA-P-k showed excellent internal consistency, moderate to high convergent validity with other HRQoL instruments, and poor discriminative validity.[67]

The BELA-P-k is "suggested" for use in PD.

Parkinson's Disease Questionnaire (PDQ-39)

The PDQ-39 is composed of 39 items grouped in 8 subscales.[68] Each item scores from 0 (never) to 4 (always). Subscale scores and a summary index representing the global HRQoL can be calculated, with higher scores representing worse HRQoL.[69] The PDQ-39 has been translated and validated in many languages and cultural settings.

Used by multiple authors, the PDQ-39 SI lacks relevant floor and ceiling effects, and as a whole, it has shown satisfactory internal consistency and stability.[20,68–76] Content validity is satisfactory, although it lacks some relevant areas (sleep, sexual function).[74,77] Convergent validity is satisfactory,[20,68,70,72,73,76,78] and discriminative validity for PD severity levels has been established.[34,68,70,73,76] Interpretability parameters have been calculated for the PDQ-39 SI.[43,76,79,80]

The PDQ-39 is "recommended" for use in PD.

Parkinson's Disease Questionnaire Short Form (PDQ-8)

The PDQ-8,[81] the short version of the PDQ-39, includes 8 items, each representing a domain of the

PDQ-39. The summary index is obtained by summing the 8 items and standardizing on a scale of 0–100; higher scores reflect worse HRQoL.[81,82] It has been validated in a diversity of languages and used by multiple authors.

The PDQ-8 reaches lower reliability and validity than the PDQ-39. There is no evidence of floor or ceiling effects for the PDQ-8 SI. Internal consistency, item–total correlation, test–retest reliability, and convergent validity are satisfactory.[74,82–88] The PDQ-8 was shown to be responsive in interventions, and a MID for the PDQ-8 was calculated.[89]

The PDQ-8 is ''recommended'' for use in PD patients.

Parkinson's Impact Scale (PIMS)

The PIMS is a 10-item, 4-domain scale.[90] Items score from 0 (no change) to 4 (severe), and the total scale scores range from 0 to 40. Lower scores indicate less impact of PD.

The PIMS has been used by authors other than the developers and shows satisfactory internal consistency, test–retest reliability, and discriminative validity for the ''on–off'' state. Four factors were identified in the scale.[90,91] Close convergent validity with the PDQ-39 and PDQL has been demonstrated.[92] Responsiveness was found to be acceptable.[93] It is validated for use in caregivers[91] and in some cultural settings.[92]

The PIMS is ''recommended'' for use in PD.

Parkinson's Disease Quality of Life Questionnaire (PDQL)

The PDQL[94] is composed of 37 items grouped into 4 subscales. Item scores range from 1 to 5. The PDQL-Summary Index (SI) ranges from 37 to 185, with higher scores reflecting better HRQoL. Permission from the authors is required for use. The PDQL has been translated into a diversity of languages

As a whole, PDQL-SI score distributions, floor and ceiling effects, internal consistency, and test–retest reliability have been found to be satisfactory.[76,94,95] Strong correlations with other HRQoL scales have been found. Also, the internal and known-groups validity were adequate.[76,92,94–96] Data about responsiveness and MID are available.[43,97–100]

The PDQL is ''recommended'' for use in PD.

Parkinson's Disease Quality of Life Scale (PDQUALIF)

The PDQUALIF includes 32 items in 7 dimensions and 1 item of global HRQoL.[101,102] Total score ranges from 0 to 128, with higher scores indicating worse HRQoL. The scale has been translated into several languages, but has been tested and used only by the developing group.

The PDQUALIF internal consistency, test–retest reliability, convergent validity with other HRQoL scales, and discriminative validity have been acceptable, with some ceiling and floor effects.[102] It has been used in randomized clinical trials of PD.[103–105]

The PDQUALIF is ''suggested'' for use in PD.

Fragebogen Parkinson LebensQualität (PLQ)

This questionnaire consists of 44 items in 9 domains. Each item scores from 1 to 5. There are 3 types of scoring: intensity (24 items), applicability (14 items), and quality (6 items). Higher scores reflect worse HRQoL.[106] The scale is only available in German and has not been used by authors other than the developers.

PLQ face validity is adequate. Internal consistency is good, but test–retest reliability was not appropriately evaluated, and construct validity is uncertain. Responsiveness was tested in a very small sample.

The PLQ is ''listed'' for use in PD.

Parkinson's Problem Schedule (PPS)

The PPS[107] contains 39 items reflecting activities, behaviors, and emotions in a 3-factor structure: psychological, cognitive, and motoric. The presence of the problems is rated ''yes'' or ''no''; severity and stress are both rated from 0 to 4. Higher scores reflect more problems. It is available only in English.

It has been used only by the developers. Acceptability was not evaluated. Internal consistency for subscales was good. Face validity was adequate, and convergent validity was moderate.

The PPS is ''listed'' for use in PD.

Scales for Outcomes in Parkinson's Disease–Psychosocial (SCOPA-PS)

The SCOPA-PS consists of 11 items.[108] Each item scores from 0 to 3. Higher scores reflect worse psychosocial functioning. The scale is in the public domain and has been validated and translated into several languages by different authors.[70,109,110]

The scale has no floor or ceiling effects; face validity and internal consistency of the scale are good; test–retest reliability, convergent validity, and known-groups validity are satisfactory.[108,109] Factor analyses showed a single dimension[108] or 2 dimensions.[109,110] Responsiveness of the SCOPA-PS was determined using different methods.[111]

The SCOPA-PS is ''recommended'' for use in PD.

Discussion

Is There a Need for a PD-Specific Scale?

Four of the 8 reviewed generic measures (SIP, NHP, EQ-5D, and SF-36)[13,17,25,33] and 5 of the 9 specific

TABLE 2. Classification of the HRQoL measures applied in studies on PD

Acronym	Type	Criteria 1	Criteria 2	Criteria 3	Classification
EQ-5D	Generic	X	X	X	Recommended
NHP	Generic	X	X	X	Recommended
SF-36	Generic	X	X	X	Recommended
SIP	Generic	X	X	X	Recommended
PDQ-39	Specific	X	X	X	Recommended
PDQ-8	Specific	X	X	X	Recommended
PDQL	Specific	X	X	X	Recommended
PIMS	Specific	X	X	X	Recommended
SCOPA-PS	Specific	X	X	X	Recommended
15-D	Generic	X	X	—	Suggested
SEIQOL-DW	Generic	X	X	—	Suggested
WHOQOL-BREF	Generic	X	X	—	Suggested
PDQUALIF	Specific	X	—	X	Suggested
QLS -MD/-DBS	Other	X	—	—	Listed
BELA-p-k	Specific	X	—	—	Listed
Fragebogens PLQ	Specific	X	—	—	Listed
PPS	Specific	X	—	—	Listed

Criteria: 1. used in PD patients; 2. used by researchers beyond original developers; 3. successful clinimetric testing.

scales (PDQ-39, PDQ-8, PIMS, PDQL, and SCOPA-PS)[68,81,90,94,108] were classified as "recommended" (Table 2) according to MDS Task Force criteria (Table 1).

Advantages of the generic instruments are that they cover aspects of general health not included in the specific instruments and that they allow for comparison between different disorders and with healthy populations. Importantly, normative values for the general population exist for the "recommended" SIP, NHP, SF-36, and EQ-5D, providing a benchmark for comparison of results. These 4 measures, different in content, number of items, and dimensions, cover a variety of aspects that may be affected by health problems. In addition, the EQ-5D provides utility values for econometric issues. These generic questionnaires have an impressive background of reference data, are widely utilized and available, and are frequently applied in PD studies. Therefore, the task force concluded that there is no need for the development of new generic scales from the perspective of PD.

In general, the following factors should be considered in making a selection of the most appropriate scale: objective of the study (eg, PDQ-39 and EQ-5D will be, a priori, not useful for a study focused on sleep disorders and fatigue); characteristics and availability of the instruments, including cross-cultural validation and legal issues (eg, for an international clinical trial, a responsive and widely cross-culturally available scale will be preferred); balance between required information and burden of respondent (eg, for a study with many assessments, short measures such as PDQ-8 and EQ-5D may be preferred); and capacity of the researchers for analyzing the data, as most of those scale scores need transformation. Therefore, in addition to knowing availability, detailed knowledge of the instruments and their attributes is needed to choose properly.[112] In the near future, such initiatives as the COSMIN study (COnsensus-based Standards for the selection of health Measurement INstruments) will help to select the most appropriate scale on the basis of their measurement properties.[113]

In relation to the specific measures, the PDQ-39 is the most thoroughly tested and used HRQoL questionnaire for PD. As a whole, it possesses adequate psychometric properties and adequately covers physical, mental, and social domains, though nocturnal sleep and sexuality are not included in this scale.[74,114] The PDQ-39 and its short form, the PDQ-8, are widely available and have been used in a variety of epidemiological studies and clinical trials.

The PDQL is the second most frequently used HRQoL instrument specific for PD. It has satisfactory psychometric attributes but does not adequately cover self-care, sleep, cognition, close relationships, and role functioning.[74,114] It is available in different languages and has been applied to a diversity of studies.

The PIMS has very few independent and cross-cultural validation studies[92] and has been used only occasionally in applied research. It has limitations in content, with no items on self-care, motor features, cognition and other mental aspects, and social stigma.[74]

Finally, the SCOPA-PS is really focused on psychosocial adjustment rather than in HRQoL and lacks physical and mental health domains. However, it has been tested psychometrically in several studies and showed satisfactory attributes. Available and validated in several languages, it has been applied only in epidemiological studies.

In conclusion, none of the "recommended" specific measures is completely free of limitations, but the task force considers they cover the needs for studies on HRQoL in PD. Refinement of the existent instruments, such as the addition of lacking dimensions, may improve the characteristics of these specific questionnaires.

Other Considerations

With regard to limitations of use, some comorbidities can impede patient self-assessment. For example, blindness or illiteracy may prevent the reading of questions, requiring help by another person who may influence the patient's response. Mental deterioration, particularly in the case of moderate and severe dementia, may make the assessment unreliable or impossible,[115–117] and evaluations by proxy may not be accurate.[87,117–119]

Interestingly, generic measures include assessment for nocturnal sleep, mental functioning, pain, depression, anxiety, sexual functioning, and fatigue. PD-specific HRQoL measures also address nonmotor symptoms in PD patients such as cognitive functioning, perceptual problems, paresthesias, and daytime somnolence.[120–124] In fact, some nonmotor symptoms are recognized determinant factors of HRQoL.[114,125]

HRQoL measurement represents an indispensable resource in clinical research. It furnishes information about the effects of treatment from the unique perspective of the patient in a more reliable way than the informal interview.[126] Therefore, performing clinical trials that include HRQoL end points (even as the main outcome), combining generic and specific measures, is needed.[31,32,127–131] Concerning clinical practice, HRQoL evaluation helps to prioritize interventions and to understand important aspects of the condition and treatment, impossible to assess through any other method.

New developments in design of measures and data capture systems (for example, computer-adaptive testing based on item response theory) will facilitate the use of HRQoL measures and their efficiency in application and interpretation. Currently, the task force does not consider necessary the development of another PD-specific QoL scale. ■

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