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den Oudsten, B.L.; van Heck, G.L.; de Vries, J.

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The Suitability of Patient-Based Measures in the Field of Parkinson's Disease: A Systematic Review

Brenda L. Den Oudsten, MSc,[1]* Guus L. Van Heck, PhD,[1] and Jolanda De Vries, PhD[1,2]

[1]*Department of Psychology and Health, Medical Psychology, Tilburg University, Tilburg, The Netherlands*
[2]*Department of Medical Psychology, St. Elisabeth Hospital, Tilburg, The Netherlands*

Abstract: The aim of this study is to appraise the suitability of current quality of life (QOL) questionnaires for use in the field of Parkinson's disease (PD). Computerized bibliographic databases were screened for publications from 1960 to December 2006. Predefined selection criteria were used to identify QOL questionnaires in PD studies. Two investigators independently assessed and, subsequently, agreed on a set of multidimensional generic and PD-specific QOL questionnaires. Data were extracted concerning the internal structure, reliability, validity, and responsiveness of the included questionnaires. Sixteen-questionnaires were found, of which 14 questionnaires were included (six generic measures and eight PD-specific). In general, the psychometrics of all the questionnaires were adequately described. Sensitivity to change, however, has been reported for only a limited number of instruments. Almost all included questionnaires used QOL as a keyword, but only two questionnaires fitted the broad QOL definition used in this review. Considering the few "real" QOL questionnaires, we conclude that there is a strong need for such instruments. © 2007 Movement Disorder Society

Key words: QOL; assessment; Parkinson's disease; systematic review.

Parkinson's disease (PD) is a common, chronic neurodegenerative disorder that mainly affects persons of middle to old age. In addition to the motor functioning, PD also acts on emotional and cognitive functioning. Furthermore, sensorial and autonomic disorders are commonly reported by patients.[1] Prevalence rates range from 108 per 100,000 to 257 per 100,000 and annual incidence figures range from 11 per 100,000 to 19 per 100,000.[2] These differences in epidemiological data can be explained by environmental and/or genetic factors. Furthermore, they presumably reflect differences in methodologies, survey designs, case-finding strategies, and/or age distributions.[2]

It has been argued, particularly in the field of chronic disease, that more attention should be paid to the impact of illness and treatment on patient's physical, emotional, and social well-being.[3] The impact of PD is traditionally measured by determining symptom severity with rating scales, like the Unified Parkinson's Disease Rating Scale (UPDRS)[4] and the Hoehn and Yahr scale.[5] These scales, however, only reflect the physician's view on the disease and do not take the patient's perspective into account. However, during the past two decades, quality of life (QOL) and related concepts, such as health status (HS) and health-related quality of life (HRQOL), have become critical measures in health care.

The purpose of this review is to provide an overview of the QOL questionnaires that are currently used in the field of PD. Additionally, these questionnaires are reviewed with respect to their psychometric properties and suitability in PD research. In this effort, recommendations are provided for future development of QOL questionnaires and more adequate selection by researchers and practitioners of reliable and valid QOL questionnaires.

PATIENTS AND METHODS

Search Strategy

A computerized search of the literature was performed in Pubmed (110 hits), PsychINFO (20 hits), Cochrane

Library (no hits), and Web of Science (36 hits) for relevant publications published in the period 1960 to December 2006. The term "Parkinson's disease" was used in combination with the terms "quality of life" (or "health-related quality of life" and "health status" as equivalents) and "questionnaires". Reference lists of relevant retrieved studies were checked to identify additional published research not found in the computerized database searches. After applying the selection criteria (see below), 36 studies remained. The questionnaires used in these studies will be discussed in terms of their design and psychometric properties.

Selection Criteria

All questionnaires in the domain of QOL research were collated from the identified studies. Data on the questionnaires were derived from the identified studies and their references. From the identified studies, all questionnaires in the domain of QOL research were collated from the identified studies. Data on the questionnaires were derived from the identified studies and their references. An article was eligible if it met all of the following criteria: (1) the objective of the article was to describe (aspects) of QOL in Parkinson's disease, generated by means of QOL questionnaires and/or questionnaires measuring related concepts, that is health-related quality of life and HS; (2) the study population either exclusively concerned Parkinson's disease or included an identifiable and separately analyzed subgroup of patients with Parkinson's disease; (3) QOL and/or related concepts were measured with a standardized questionnaire; (4) questionnaires contained at least a physical, psychological, and social dimension reflecting the WHO definition of health[6]; (5) the article was a full report published in English, Dutch, or German; and (6) the studies had to be published in peer-reviewed journals.

Assessment of Quality

Two investigators (Den Oudsten and De Vries) assessed the internal structure and the methodological quality of each of the 14 selected questionnaires. In the present study, the internal structure, as well as internal consistency, test-retest reliability, content validity, construct validity, and responsiveness to change were evaluated.

Internal structure refers to the number of items, multiple-item scales, and response categories of the questionnaire. Additional information is included on the time required for completion. The selected questionnaires had to meet three methodological criteria in order to be considered a useful instrument: significant reliability, validity, and responsiveness to change.[7]

Two types of reliability are generally considered important: test-retest reliability and internal consistency reliability. Test-retest reliability reflects the level of stability of responses at different points in time. A questionnaire is considered to be stable across time when the association between scores derived at different measurement points, often represented by an intraclass coefficient (ICC), is sufficiently high. An ICC <0.40 is considered poor, 0.40 to 0.59 is fair, 0.60 to 0.74 is good, and >0.75 is excellent.[8] Depending on the number of questions in a (sub)scale, the internal consistency (Cronbach's alpha), reflecting the homogeneity of questions in the (sub)scale, should be at least 0.70.[9] Validity refers to the degree to which a test measures what it is supposed to measure and to the extent to which the instrument is free from systematic and random error.[10] Content validity is defined as the extent to which a particular theoretical construct is covered by the items or questions in the questionnaire.[11] Source of items can contribute to establishing content validity, for instance, using experts in a particular field will enhance this type of validity. Construct validity is the extent to which a particular theoretical construct is adequately measured.[11,12] It is psychometrically supported by investigating its relationship with other constructs; both related (convergent validity) and unrelated (divergent validity).[11,12] Correlations between related constructs should be relatively high (r ≥ 0.60), while correlations between unrelated constructs should be relatively low (r < 0.30). Definitions regarding responsiveness are numerous and diverse. Overall, definitions can be divided into three broad categories: (1) the ability to detect change in general, (2) the ability to detect clinically important change, or (3) the ability to detect real changes in the concept being measured.[13] As a consequence, various methods for calculating responsiveness are suggested. For instance, responsiveness to change can be expressed by an effect size coefficient[14] or a Receiver Operating Characteristic (ROC) Curve.[15] Effect sizes of 0.2, 0.5, and 0.8 are respectively considered as a small, a medium, and a large effect.[14] Terwee et al.[13] conclude that a judgment about what a good evaluative instrument is, will vary from study to study. Therefore, this review reports various measures of responsiveness.

Suitability for PD Research

Suitability for PD research is defined as the extent to which a questionnaire is reliable and valid in patients with PD. Nowadays, responsiveness or sensitivity to change has been proposed as a third requirement.[13,16] Therefore, in addition to reliability and validity, we will also discuss sensitivity to change. Data on the application and the psychometric testing of a questionnaire in pa-

TABLE 1. *List of the reviewed questionnaires*

Quality of life	Health status
Generic QOL instruments	Generic HS instruments
WHOQOL-BREF	Nottingham health profile (NHP)
	Sickness impact profile (SIP)
	Short form health survey—36 items
	EuroQoL (EQ-5D)
	15D questionnaire
Movement disorders-specific QOL instruments	Parkinson-specific HS instruments
QLS movement disorders and QLS DBS	Parkinson's disease questionnaire—39 items (PDQ-39)
	Parkinson's disease questionnaire—8 items (PDQ-8)
	Parkinson's disease questionnaire—quality of sexual life dimension
	Parkinson's disease quality of life questionnaire (PDQL)
	Parkinson impact scale (PIMS)
	Parkinson's disease quality of life instrument (PDQUALIF)
	Scales for outcomes in Parkinson's disease (SCOPA): SCOPA-PS, SCOPA-AUT, and SCOPA-SLEEP

tients with PD were extracted from the identified studies. In addition, the questionnaires should reflect the definition of QOL as formulated by the World Health Organization Quality of Life Group[17] (shown below).

Quality of Life and Related Concepts

There are several definitions of QOL, all of them emphasizing the subjective perception of the individual.[18-20] In this article, we use the definition formulated by the WHOQOL Group.[17,21] This definition conceives of QOL as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns " (p 1405). This definition implies that QOL is in the eye of the beholder and can only be judged by the individuals themselves.[22]

In contrast, health status (HS) refers to perceived health in terms of physical, mental, and social conditions or functions.[23] HS is often used interchangeably with the terms "health-related quality of life" (HRQOL) and "QOL" (e.g., Ref. 24). Both HRQOL and HS are restricted to domains related to health, while QOL is a much broader concept also referring to, for instance, aspects of the environment that may or may not be affected by health or treatment. HS refers to function levels, while QOL and HRQOL reflect internal experiences.[25,26] While HS questionnaires contain items about actual patients' functioning (e.g., "Due to Parkinson's disease, how often did you have problems walking half a mile?"), QOL questionnaires focus on the subjective evaluation of life as a whole. HS questionnaires are often emphasizing the frequency of certain behaviors, feelings, or social activities. In contrast, QOL questionnaires use scales assessing the level of satisfaction with activities and life conditions.[27] Therefore, QOL should not be used as a generic label for an assortment of physical function-

ing and psychosocial variables. QOL clearly is a psychological construct and not a generic term for various desired medical outcomes.[28] From a patient's perspective, QOL and HS are two distinct constructs and, consequently, questionnaires designed to measure HS may not be appropriate for assessing QOL.[29] Because of the different meanings of these two patient-based measures, questionnaires of QOL and HS will be discussed separately in the results section.

RESULTS

A total of 170 publications were extracted from Pubmed, PsychINFO, and Web of Science. In these publications, 16 questionnaires in the domain of QOL and related concepts were identified. The following questionnaires were excluded from the study: the Belastungsfragebogen Parkinson Kurzversion (BELA-P-K).[30,31] This questionnaire was excluded because it is very domain-specific, solely containing items reflecting psychosocial functioning. The Parkinson's Disease Symptom Inventory (PDSI),[32] assessing PD symptoms and drug side-effects and subsequent distress of symptoms, was also excluded, due to its exclusive focus on the physical domain.

Six generic and eight PD-specific questionnaires met all of the inclusion criteria. In the following paragraphs these instruments will be discussed. An overview of all instruments in this review is presented in Table 1. A distinction will be made between generic and disease-specific instruments.[33] Generic instruments are broad measures, which are designed to measure across a variety of diseases and populations. Such instruments can also be used in healthy persons. In contrast, disease-specific instruments are developed to measure QOL in particular diagnostic groups or specific patient populations. They focus on problems that are specific for a particular dis-

TABLE 2. Scaling assumptions, floor and ceiling effects, acceptability, and missing items in the field of PD

Type	Instruments	Scaling assumptions	Floor and ceiling effects	Acceptability	Missing items
Generic QOL	WHOQOL-BREF	—[a]		—	—
MD-specific QOL	QLS-MD and QLS-DBS	PCA on QLS-MD led to 12 factors. PCA on QLS-DBS revealed 5 factors.	Floor and ceiling effects were small,[34] except for the quality and availability of doctor use, which showed a moderate ceiling effect (QLS-DBS; 17.3%).[35]	—	The frequency of missing items was relatively low (3.2% to 7.9%) for the QLS-MD, except for the item sexual excitability (14.4%). Missing items were somewhat higher for QLS-DBS (9.3% to 12%).[34]
Generic HS	NHP	—	Clear floor effects, ranging from 52.9% (SL) to 88.9% (SI) were evident in mildly perceived PD. Therefore, this instrument is not suitable in early stages of PD.[36] Only the EN scale showed substantial ceiling effects across all levels of severity and the total population.[36]	—	25.3% of the questionnaires contained missing items.[36]
	SIP	—	—	—	—
	SF-36	—	Floor effects were observed for the role physical (self-completed: 38.8%; telephone interview: 54.8%) and role emotional (self-completed 27.3%; telephone interview: 31.5%) domains. Ceiling effects were found for the same domains.[37]	—	8.2% missing responses.[38] See also Damiano et al.[37]
	EQ-5D	—		The median EQ-5D score was 0.62 (minimum −0.59 and maximum 1.0) with an interquartile range of 0.29.[38]	The response rate was 78% and the completion rate of the EQ-5D among responders was 96%.[38]
	15-D	—		—	The response rate to 15D was 99.2% and 84.9% of the patients fully completed the questionnaire.[39]

TABLE 2. *(Continued)*

Type	Instruments	Scaling assumptions	Floor and ceiling effects	Acceptability	Missing items
PD-specific HS	PDQ-39	The CFA produced an eight-factor solution,[40,41] with Eigen values greater than one, explaining 75.5% of variance. All of the items comprising mobility, stigma, and cognition clustered together; and the majority of the items in the ADL, communication, and bodily discomfort scales stayed together; while the items in the emotional well-being and social support scales tended to scatter.[41] The item-to-total correlations exceeded 0.40.[41] In the study of Ma et al.[42]four items had correlations less than 0.40 in the domains of social support (ranging from r = 0.25 to 0.37). In the study of Martinez-Martin et al. two-thirds of the item-dimension correlation coefficients attained values higher than the criterion.[43]	Substantial floor effects were evident in stigma, social support, and communication (all patients). The social support subscale showed substantial floor effect across all levels of PD severity. This finding on social support was also confirmed by Tan et al.[44] Ceiling effects were negligible.[36] See also Martinez-Martin et al.[43]	The distribution of the PDQ-39 covered the entire possible score range (0-100) in the PDQ-39 dimensions mobility, stigma, and bodily discomfort) and were very close to this range in the PDQ-39 dimensions ADL and emotional well being. Mean and median were very close, with the difference never reaching 10% of the possible maximum score. Skewness ranged from 0.04 (ADL) to 0.66 (emotional well-being).[43]	Completion rates were high, except for the social support dimension, especially the item on social support of the partner was not completed in 6.8% (Italy) to 14.8% (Canada) of the cases.[45] See also Hagell et al. and Jenkinson et al.[36,46]
	PDQL	—	—	—	—
	PIMS	The PIMS contains four distinct factors: physical, social, psychological and financial, with 63% of total variation accounted for by the psychological and social factors.[47]	—	—	—
	PDQUALIF	An exploratory PCA analysis, confirmed a 7-factor solution.[48] In general, item convergence and discrimination were satisfactory. Only eight correlations between an item and its own subscale failed to reach the 0.40 threshold. In five of these cases, the item–subscale correlation was above 0.30. The most problematic subscale in this regard was the physical function subscale.[48]	Subscales demonstrated reasonable score variability with exception of the Independence Subscale, which had a noticeable floor effect (78.9%). The Sleep subscale had a minor floor effect (9.7%).[48]	Distributions of scale scores were examined using mean scores, standard deviations, ranges and percentages of respondents having minimum (floor) and maximum (ceiling) scores.	

[a]Several aspects of scaling assumptions, floor and ceiling effect, acceptability, and missing items have not yet been investigated in the field of PD and are left blank. PCA, Principal Component Analysis; CFA, Confirmatory Factor Analysis.

ease or particular areas of function. Table 2 provides information on scaling assumptions, acceptability, floor and ceiling effects, and missing items in the field of PD. With regard to the scaling assumptions, Hobart et al.[49] suggest that (1) items in a questionnaire should be correctly grouped into scales, (2) items in the same scale should measure the same construct, and (3) that it should be possible to sum items of each scale without weights to produce scale scores. Floor and ceiling effects are part of the acceptability of item score distributions. Other criteria for acceptability of item score distributions refer to: (1) approximately equal endorsement frequencies, (2) maximum endorsement frequencies, and (3) a range of −1 to +1 for skewness statistics.[49] Information on these criteria in literature is rather scarce, except for the PDQ-39.

Generic QOL Instruments Used in PD

One generic QOL instrument that has been used to study QOL in Parkinson's disease is the World Health Organization Quality of Life assessment instrument-BREF.[50] The WHOQOL-BREF instrument is an abbreviated 26-item version of the World Health Organization Quality of Life assessment instrument-100 (WHOQOL-100).[51] Both instruments are fulfilling the aspects of the WHOQOL-definition and are therefore considered as QOL instruments. The WHOQOL-BREF contains 24 single items representing each of the 24 QOL-facets included in the WHOQOL-100, plus two additional items, assessing Overall QOL and General Health. The WHOQOL-BREF consists of four domains: Physical Health, Psychological Health, Social Relationships, and Environment. It has a five-point Likert scale. Test-retest reliability was good.[50,52] Internal consistency, as measured with Cronbach's alpha, was adequate to good ($\alpha >$ 0.70).[50,53] Construct validity was good ($r = 0.46–0.67$ between domains).[50,53] Construct validity was also established by comparing domain scores to general single-item QOL measures. The overall assessment of QOL was most strongly associated with the psychological and environmental domains.[53] Also sensitivity appears to be good. For instance, O'Carroll, Smith, Couston, Cossar, and Hayes,[54] examining the sensitivity to change in patients with a liver transplantation using the standardized response mean (SRM), found large effects on all four QOL-domains: Psychological Health (0.91), Physical Health (0.92), Social Relationships (0.43), and Environment (0.74).

Generic HS Instruments Used in PD

The generic measures of HS that are used in patients with PD include the Medical Outcome Study/Short Form-36 (SF-36),[55] the EuroQoL (EQ-5D),[56] the Nottingham Health Profile (NHP),[57] the Sickness Impact Profile (SIP),[58] and the 15D questionnaire.[39,59] Information on their internal structure, completion time, and suitability for PD research is presented in Table 3. The psychometric qualities, as far as they concern reliability and validity, are largely discussed in the field of PD. However, it is quite remarkable that there is virtually no information available regarding sensitivity to change.

PD-Specific QOL Measures

An instrument, consisting of four modules, that fits the definition of QOL as described above,[21] is the Questions on Life Satisfaction (QLS).[63] The generic modules General Life Satisfaction and Satisfaction with Health were originally developed by Henrich and Herschbach. Kuehler et al.[34] developed two additional disease-specific modules: Movement Disorders (QLS-MD) and Deep Brain Stimulation (QLS-DBS) for patients with movement disorders (e.g., Parkinson's disease, dystonia, tremor, etc) and DBS. The developers recommend the use of all the modules in a total package of modules if possible, as only the combination of *all* subscales fully cover the aspects of QOL as proposed by the WHO Group.[34] The key feature of the QLS is that each item is weighted according to its relative importance to the individual. First, persons rate how important a specific area (e.g., the physical condition) is. Thereafter, they rate how satisfied they are with that particular element of life. The psychometric evaluation has shown that the QLS-modules are reliable and valid. Internal consistency was high (0.87 for Movement Disorders and 0.73 for Deep Brain Stimulation). Content validity was assumed by the developers; items were generated by interviewing patients on QOL. Convergent validity was examined by means of correlating the disease-specific modules with established outcome measures (SF-36 and EQ-5D), and the generic QLS modules General Satisfaction and Satisfaction with Health. Movement Disorder correlated between 0.60 and 0.70 with the SF-36/EQ-5D. Correlations between Deep Brain Stimulation and the SF-36 and EQ-5D were somewhat lower. The correlation coefficients between the two generic modules of life satisfaction and the two disease-specific modules were between 0.50 and 0.70.[34] No information is available regarding test–retest reliability, divergent validity, and sensitivity to change.

PD-Specific HS Questionnaires

The following PD-specific HS questionnaires were included: the *Parkinson's Disease Questionnaire* (PDQ-39,[40] the Parkinson's Disease Quality-of-Life questionnaire (PDQL),[3] the Parkinson's Impact Scale

TABLE 3. *Generic health status instruments in the field op PD*

Questionnaire	NHP	SIP	SF-36	EQ-5D	15D
Items	38	136	36	5	15
Score	Lower scores represent better health status	Lower scores represent better health status	Higher scores represent better health status	Lower scores represent better health status (ordinal scale) Higher scores on the VAS represent better imaginable health	Higher scores represent better health status (15D profile)
Response categories	Yes/no	Yes/no	Yes/no and 6-point Likert scale	3-point ordinal scale, in which 1 represents no problems, 2 represents moderate problems, and 3 represents severe problems. VAS indicates general HS	5-point ordinal levels on each dimension, in which 1 represents the best level and 5 the worst level of functioning
Completion time in minutes	Approximately 5 to 10 minutes	Approximately 20 to 30 minutes	Approximately 5 minutes	Approximately 5 minutes	Approximately 5 to 10 minutes
Subscales	Pain (PA); physical mobility (PM); emotional reactions (ER); energy (EN); social isolation (SI); sleep (SL).	Ambulation; body care; movement & mobility; eating; emotional behavior; social interaction; alertness behavior; communication; sleep and rest; home management; work, recreation, and pastimes.	Physical functioning (PF); social functioning (SF) role physical (RP); role emotional (RE); mental health (MH); vitality (V); bodily pain (BP); general health (GH)	Pain/discomfort (P/D); mobility (M); usual activities (U); self-care (S); anxiety/depression (A/D)	Mobility; vision; hearing; breathing; sleeping; eating; speech; elimination usual activities; mental function; discomfort and symptoms; depression; distress; vitality; sexual activity
Content validity	[a]	–	–	–	–
Internal consistency	0.83 to 0.90 except for SL, EN, and SI.	–	α's exceeding 0.70, except GH and SF when SF-36 is used as an telephone interview.[37] As a self-report measure all scales are exceeding 0.70.[37,60] For the total scale 0.95 is reported.[60]	–	–
Test-retest reliability					
Construct validity	All subscales were able to discriminate between patients according to their perceived PD severity, except SL. Correlations between the PDQ-39 and NHP scores and perceived overall QOL were moderate.[36]	–	Strong correlations between SF-36 (PF) and FSQ basic and ADL scores and UPDRS ADL. Also strong correlations for MH (SF-36) and FSQ-Mental Health and weaker links with ADL, interaction, and sexual scores.[60]	The EQ-5D summary index had good feasibility and validity in PD patients. It correlated moderately with H & Y (r = 0.68) and S & E (r= 0.63) It also correlated strongly with the PDQ-39-SI (r = 0.75) and its subscores (r −0.41; except SF) and, to a lesser degree, with the physical score of SF-36.[38]	Haapaniemi et al.[39] found correlations of −0.32 and −0.73 with the Parkinson's Disease Questionnaire (PDQ-39)[40] for corresponding aspects of QOL
Sensitivity to change	–	–	–	In the longitudinal study of Reuther et al. EQ-5D does not change over time during a 12-month observation period.[61]	Sensitivity to change is demonstrated in several diseases, for instance, chronic obstructive pulmonary disease (COPD; ρ = 0.86),[62] but is not yet assessed in PD[39]

[a]Several aspects of psychometrics have not yet been investigated in the field of PD and are left blank

NHP, Nottingham Health Profile; SIP, Sickness Impact Profile; SF-36, Short Form Health Survey-36 items; EQ-5D, EUROQOL; HS, health status; H & Y, Hoehn and Yahr scale; S & E, Schwab and England scale; UPDRS, Unified Parkinson's Disease Rating Scale; PDQ-39-SI, Parkinson's Disease Questionnaire-39 items Summary Index; VAS, Visual Analogue Scale.

TABLE 4. *Parkinson-related health status instruments*

Questionnaire	PDQ-39	PDQL	PIMS	PDQUALIF
Items	39	37	10	33
Score	Lower scores represent better health status	Higher scores represent better health status	Lower scores represent better health status	Lower scores represent better health status
Response categories	5-point Likert scale Never, occasionally, sometimes, often, and always	5-point Likert scale All of the time, most of the time, some of the time, a little of the time, and never	5-point Likert scale No change, slight, moderate, moderately severe, and severe	5-point Likert scale Different response formats, see for a discussion Welsh et al.[48]
Completion time in minutes	Not formally evaluated, 30 minutes based on its length[80]	Approximately a few minutes	Approximately 10 minutes	Approximately 10 to 15 minutes
Subscales	Mobility; activities of daily living; emotional well-being; stigma; social support; cognitions; communication; bodily discomfort	Parkinson symptoms; systemic symptoms; emotional function; social function	Self (positive); self (negative); family relationships; community relationships; work; leisure; travel; safety; financial security; sexuality	Social/role function; self-image/sexuality; sleep; outlook; physical function; independence; urinary function. Additional item on current symptoms and symptoms experienced three months ago.
Content validity	Items were based on interviews with 20 patients	Items were based on interviews with patients on QOL. Other items were added based on the experience of neurologists, relatives, existing literature and other disease specific instruments	Items were developed by 10 nurses from 10 different centres.	Items were based on the experiences from patients, partners and professionals by answering the question 'how does PD change or affect one's life quality?'
Internal consistency	Tested in 359 patients Total scale[37,46,67]: $\alpha = 0.84$ to 0.94. Subscales[68]: $\alpha = 0.72$ (bodily discomfort) to $\alpha = 0.95$ (mobility)	Tested in 384 patients Total scale[3]: $\alpha = 0.94$ Subscales[3]: $\alpha = 0.80$ (systemic symptoms) to $\alpha = 0.87$ (emotional function).	Tested in 167 patients Total scale[64]: $\alpha = 0.90$	Tested in 233 patients Total scale[48]: $\alpha = 0.89$ Subscales: $\alpha = 0.55$ (physical function) to $\alpha = .85$ (social/role function). Note: three out of seven subscales exceeded 0.70.
Test-retest reliability	Adequate to good,[68] except for social support ($r = .68$).	–	Adequate: ICC $= 0.72$[64]	Acceptable: ICC $= 0.68$ (outlook) to $r = 0.86$ (social/ role function and $r = 0.88$ (overall scale score)[48]
Construct validity	*Construct validity*: 0.34 to 0.80 (SF-36) and 0.75 (EQ-5D)[37,46,67]	Divergent validity: Patients with higher disease severity had significantly lower PDQL scores on all subscales. Convergent validity: The correlations between PDQL scores and the generic MOS-24, and CES-D exceeded the 0.40 criterion for seven of the nine subscales. Higher correlations were found between the physical, parkinsonian and systemic symptoms, except for the correlations between physical pain. Highest correlations were found between the emotional function scale of the PDQL and both the mental health subscale of the MOS and CES-D. The social function subscale had high correlations with the social functioning scales of the MOS, but not with the social support survey.[3]	Construct validity: Significant correlations between the PIMS and subscales of the UPDRS.[64,65]	Construct validity: Moderate to strong support for construct validity was evident using generic health status scales (SIP and SF-36), disease-specific instruments (UPDRS), and stage of disease (H&Y stage).[48]
Sensitivity to change	Change in the PDQ-39 score was significantly correlated with self-reported change in the SF-36 The subscales mobility, ADL, stigma, and social support are responsive to deterioration in HS.[69]	–	Sensitivity to change: $\Delta = 0.37$ (effect size; small) ROC-curve (adequate): 80% sensitivity, 62.5% specificity[65]	Recent studies (e.g., Ref. 70) provide preliminary support for the sensitivity to change with regard to the PDQUALIF

PDQ-39, Parkinson's Disease Questionnaire; PDQL, Parkinson's Disease Quality of Life Questionnaire; PIMS, Parkinson Impact Scale; PDQUALIF, Parkinson's Disease QUAality of Life instrument; SIP, Sickness Impact Profile; SF-36, Short Form Health Survey-36 items; ICC, intraclass correlation; EQ-5D, Euroqol; MOS-24; Medical Outcomes Study 36-item Health Survey; UPDRS, Unified Parkinson's Disease Rating Scale; H & Y, Hoehn and Yahr scale; CES-D, Center for Epidemiologic Studies Depression scale; ADL, Activities of Daily Living.

(PIMS),[64,65] and the Parkinson's Disease Quality of Life Instrument (PDQUALIF).[48] See Table 4 for information concerning the employed response categories, the subscales, and the psychometric properties of these questionnaires. Overall, psychometrics are good. However, not every questionnaire has been tested concerning test-retest reliability (i.e., PDQL) and sensitivity to change (i.e., PDUALIF and PDQL).

In addition to the development of the original PDQ-39, two other versions of this instrument were developed: a short version, the PDQ-8,[40,71] and an extended version[72]. The PDQ-8 is composed of eight items that are derived from the original scale using item-total correlations. Within each of the eight scales the item that most highly correlated with the domain scores of the PDQ-39 were selected. Scores on each item range from 0 (no problem) to 4 (continuous problem/unable to do it). The PDQ-8 is easy to administer, and can be conceived of as reliable and valid.[44,73] Its internal consistency was adequate (α = 0.72). Test–retest reliability was good (ICC = 0.72). In addition, the PDQ-8 correlated significantly with the SF-36, except for the SF-36 domain role physical.[44] The PDQ-8 had an excellent association with the PDQ-39 (ICC = 0.90). Moreover, the PDQ-8 is able to discriminate between different disease stages.[73] No information has been provided yet on sensitivity to change. In the extended version, four out of five items of the Quality of Sexual Life Questionnaire (QOSL-Q)[74] are added as an extra dimension to the PDQ-39. According to Moore et al.[72] (2002), sexual functioning is not thoroughly assessed by the PDQ-39, although many studies (e.g., Ref. 75) have indicated that intimacy and sexuality are important contributors to life satisfaction. For a more detailed discussion on the dimension "Quality of Sexual Life", see Moore et al.[72]

The SCales for Outcomes in PArkinson's disease (SCOPA) consist of several instruments assessing different areas that are important in Parkinson's disease. When used together, these scales encompass the physical, psychological, and social domain. The following scales have been developed: The SCales for Outcomes in PArkinson's disease PsychoSocial questionnaire (SCOPA-PS),[76] The SCales for Outcomes in Parkinson's disease Autonomic dysfunction (SCOPA-AUT),[77] and the SCales for Outcomes in PArkinson's disease Sleep (SCOPA-SLEEP).[78] The SCales for Outcomes in PArkinson's disease Cognition (SCOPA-COG)[79] and the Short Parkinson's Evaluation Scale SCales for Outcomes in PArkinson's disease (SPES/SCOPA)[80] will not be discussed here, because both instruments evaluate physical functioning judged by the clinician. When researchers would like to measure HS with an emphasis on physical functioning, the package, consisting of SCOPA-PS, SCOPA-AUT and SCOPA-SLEEP, is a suitable option. However, when researchers want to explore psychosocial functioning in depth, this package is less suitable. The SCOPA-PS consists of 11 items of which merely two items belong to the psychological domain: "During the past month, have you felt ashamed of your disease? " and "During the past month, have you been concerned about the future? " The other items reflect the social domain, except for the item 'During the past month, have you had difficulty with work, household, or other chores?', which is neither psychological nor social, but seems to belong at face value to the domain of physical functioning. With regard to the SCOPA-AUT, Visser et al. 2003 found few missing data, except for the subscale Sexual Functioning (i.e., 13%). Marinus et al. (2003) reported no missing data and no floor and ceiling effects in respect of the SCOPA-PS. Overall, the psychometrics of the three SCOPA-scales are good, with internal consistencies above 0.70, test-retest reliabilities exceeding 0.80, and high correlations with related questionnaires (>0.60). Information regarding sensitivity to change has not been reported yet.

DISCUSSION

The popularity of the QOL concept is still growing and consequently the number of QOL instruments is increasing. Therefore, the purpose of this review was to present a critical overview of the most relevant QOL questionnaires that are currently used in the field of PD, emphasizing, their psychometric properties and suitability.

Despite the increasing interest in QOL, consensus is lacking with regard to its conceptualization. Concepts, like HS, HRQOL, and QOL, are often used interchangeably (e.g., Ref. 24). This has been criticized by many researchers (e.g., Refs. 81,82), who have stressed the fundamental distinction between the subjective, highly personal concept of (HR)QOL and the more objective scoring of physical, psychological, and social functioning in measures of HS. Critics of the appropriateness of employing HS measures as markers of (HR)QOL have pointed at the rather poor correlations between HS and (HR)QOL assessment instruments. Defenders of the position that HS measures can adequately capture patient's QOL admit that substantial minorities of patients have high-scores on HS and low-scores on (HR)QOL or vice versa. Notwithstanding these discrepancies, the latter conclude that, due to the fact that HS scales are at least moderately associated with (HR)QOL, HS scales can be conceived of as useful markers of (HR)QOL when comparing groups (e.g., Ref. 83). According to Covinsky et al. (1999),[83] caution should be exercised in basing con-

clusions about an individual patient's (HR)QOL. This position is taken in the present review. For clarity reasons, however, the questionnaires in this review have been split up, according to the different conceptualizations.

Almost all of the available questionnaires which used QOL as a key term, did actually not meet the definition of QOL used in this review. With the exception of one generic and one disease-specific instrument, they all actually evaluated HS. When researchers are planning to study QOL or related concepts within a particular population, then, it is important to think through which concept one wants to measure. When one aims to assess functioning, a HS measure will be needed. However, when the objective is to describe the patient's own evaluation of life aspects, a QOL measure or a HRQOL instrument will be needed, depending on the width of the scope. Use of a HS scale for measuring QOL or HRQOL will provide at best a satisfactory approximation of QOL of HRQOL, but will not assess these constructs directly. Therefore, it is important to check on keywords for QOL and HS to determine in which category test constructors place their questionnaire. This does not guarantee, however, that a proper distinction between the concepts is made.[22] This is also demonstrated by the fact that half of the PD-specific HS questionnaires are named "quality of life" instruments. As shown in this review, only one of them really is a QOL instrument. When HS is the objective, researchers have a plethora of questionnaires to choose from. When QOL is the option, this is not the case. As a consequence, there is a strong need for "real" QOL and HRQOL questionnaires.

After deciding which concept to choose, the next step is to decide whether to use a generic and/or disease-specific instrument. Both types of instruments have pros and cons.[33] Depending on the aim(s) of the study at hand, a choice has to be made. However, some researchers suggest the use of both types of questionnaires. In order to decide which questionnaire is most suited for a particular study, it is important to inspect the content of the questionnaire and the study objectives. In fact, HS questionnaires differ considerably in terms of content. For instance, almost half of the items in the PDQ-39, the PDQL, and the PDQUALIF concentrate on physical features, while the PIMS contains only two physical items. Cognitive functioning is only a topic in the PDQ-39 and the PDQL. The PDQ-39 is the only questionnaire containing a couple of items on social support. This instrument, however, does not discuss sexual activity, whereas the other three do. Moreover, the PIMS and the PDQUALIF both have an item on financial consequences (see also Ref. 84).

Finally, the selection of instruments will depend on psychometric properties: reliability, validity, and sensitivity to change (see Tables 3 and 4). In general, the psychometrics of the instruments discussed in this review were adequate. A few remarks, however, have to be made. First, when a generic instrument is used in a specific population, like persons with PD, it is very important that the psychometrics are well established in that particular population. For instance, no information was found on the reliability of the EQ-5D and the SIP and the validity of the SIP in patients with PD. Secondly, information on the sensitivity to change is often lacking. Sensitivity to change in the field of PD was only demonstrated with respect to the PDQ-39 and the PIMS.

In conclusion, many of the questionnaires claiming to assess QOL in fact predominantly measure HS. In addition, whether questionnaires are sensitive to change over time, is usually unknown. Therefore, there is a strong need for psychometrically sound instruments that really assess QOL. Furthermore, in addition to generic (sub)-scales, there is a need for instruments that are disease-specific or contain disease-specific facets. Finally, these assessment instruments should be tested longitudinally.

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