Tilburg University

Quality of life and related concepts in Parkinson's disease

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

Published in:
Movement Disorders

DOI:
[10.1002/mds.21567](https://doi.org/10.1002/mds.21567)

Publication date:
2007

Document Version
Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

Citation for published version (APA):
den Oudsten, B. L., van Heck, G. L., & de Vries, J. (2007). Quality of life and related concepts in Parkinson's disease: A systematic review. *Movement Disorders*, 22(11), 1528-1537. <https://doi.org/10.1002/mds.21567>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Review

Quality of Life and Related Concepts in Parkinson's Disease: A Systematic Review

Brenda L. Den Oudsten, MSc,^{1*} Guus L. Van Heck, PhD,^{1,2} and Jolanda De Vries, PhD^{1,3}

¹Medical Psychology, Department of Psychology and Health, Tilburg University, Tilburg, The Netherlands

²Tranzo, Tilburg University, Tilburg, The Netherlands

³Medical Psychology, St. Elisabeth Hospital, Tilburg, The Netherlands

Abstract: Several studies have investigated the quality of life (QOL) of patients with Parkinson's disease (PD). The purpose of this study was to review the conceptual and methodological quality of quality of life (QOL) studies among patients with PD and to identify factors associated with poor (HR)QOL. Computerized bibliographic databases were screened for publications from 1960 to January 2007. According to a list of pre-defined criteria, the methodological quality of the 61 studies, was moderate. The term 'QOL' was often used inappropriately. In fact, almost all studies in this review actually assessed health status (HS) instead of QOL. The functioning of patients with PD on physical, social, and emotional domains is affected by PD. Their HS seems to be lower when compared to healthy

persons or patients with other chronic diseases. HS studies augment the insight in self-perceived functioning. Therefore, HS is conceived as a valuable construct. However, QOL is also an important factor in health care. Attention towards QOL is needed in order to draw valid conclusions regarding a person's subjective experience of well-being in a broad sense. In order to accomplish this, future studies should apply the QOL concept with more rigor, should use an adequate operational definition, and should employ sound measures. © 2007 Movement Disorder Society

Key words: Parkinson's disease; quality of life; health-related quality of life; health status; systematic review.

INTRODUCTION

Nowadays, the physical consequences of PD are well described.¹ Therefore, the focus has shifted to the measurement of patient-based outcomes in order to assess (1) the impact of the disease and (2) the efficacy of inter-

ventions. The major patient-based outcomes are quality of life (QOL), health-related quality of life (HRQOL), and perceived health status (HS).

There exists considerable agreement that these concepts are multidimensional. Operational definitions, however, are diverse and the boundaries between these related, but not equivalent concepts, are far from clear.^{2,3}

In general, definitions of QOL emphasize that QOL is in the eye of the beholder, reflecting cognitive or affective reactions to the congruence or discrepancy between personal standards, goals, values on the one hand, and the actual situation and accomplishments on the other hand. QOL represents subjective evaluations of oneself and of one's social and material world and reflects the extent to which the individual is satisfied with them or is bothered by problems in those areas.⁴ The definition

This article is part of the journal's CME program. The CME form can be found on page 1680 and is available online at <http://www.movementdisorders.org/education/activities.html>

This article includes supplementary material, available online at <http://www.interscience.wiley.com/jpages/0885-3185/suppmat>

*Correspondence to: B.L. Den Oudsten, Tilburg University, Department Psychology and Health, Medical Psychology, P.O. Box 90153, 5000 LE Tilburg, The Netherlands. E-mail: b.l.denoudsten@uvt.nl

Received 8 February 2007; Revised 2 April 2007; Accepted 11 April 2007

Published online 21 May 2007 in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/mds.21567

formulated by the World Health Organization Quality of Life Group (WHOQOL Group) follows this principle by defining 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. It is a broad-ranging concept incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment” (p. 1405).⁵

Some researchers have proposed the concept of HRQOL in order to narrow the QOL concept. HRQOL focuses on QOL in relation to the impact of disease and treatment on patients,⁶ the physical, emotional and social well-being after diagnosis and treatment,⁷ but also on a combination of objective functioning and more subjective perceptions of health.⁸ Thus, HRQOL is QOL, but less broadly formulated.⁹ Full consensus on a single definition of HRQOL remains illusive.¹⁰ On the one hand, many researchers and clinicians see HRQOL as a concept containing both objective and subjective dimensions (e.g. Ref. ⁸). In doing so, however, HRQOL is actually predominantly referring to perceived HS, as can be learned from an inspection of the items of some well-known HRQOL instruments like the SF-36 or the Nottingham Health profile.¹¹ In contrast, others emphasize that HRQOL should reflect a purely subjective experience. For instance, Patrick and Erickson¹² formally define HRQOL in terms of the *value* assigned to opportunities, perceptions, functional status, impairment and death, associated with events or conditions as influenced by disease, injuries, treatments or policy. In spite of the fact that some authors use the term HS to include HRQOL (e.g. Ref. ¹³) or the term HRQOL to include HS (e.g. Ref. ¹⁴), there is a growing agreement that the two concepts should be clearly distinguished.¹² For instance, meta-analytic results indicate that, from the perspective of patients, HRQOL and HS are distinct constructs.² Therefore, we are strongly in favor of the position not to use HRQOL as an umbrella term for various desired medical outcomes.¹⁵ HS refers to perceived health in terms of physical and mental symptomatology, social conditions or functions, not to internal experiences. HS represents the impact of health on one’s ability to perform a variety of physical, emotional and social activities.¹⁶ In contrast, QOL represents reflections of the way that patients “perceive and react to their health status and to other, nonmedical aspects of their lives” (p. 619).¹⁷ Therefore, HS is at best a factor that may influence (HR)QOL and therefore should be conceived of as a predictor of (HR)QOL, not as part of it.

In conclusion, HS refers to function levels, while QOL and HRQOL reflect internal experiences.^{9,16} As a consequence, 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?”), HRQOL questionnaires focus on the subjective evaluation of health (e.g., “How satisfied are you with your abilities?”), while QOL questionnaires exceed the health domain by focusing on the subjective evaluation of life as a whole (e.g., “How would you rate your overall quality of life?”). Therefore, HS questionnaires are often emphasizing the frequency of certain behaviors, feelings, or social activities. In contrast, (HR)QOL questionnaires use scales assessing the level of satisfaction with activities and life conditions.⁴

Almost 20 years ago, Mor and Guadagnoli¹⁸ compared the conceptualization and measurement of QOL with the tower of Babel. Recently, Schrag¹⁹ still had to conclude that assessments are often called QOL while in fact a much narrower concept was measured. Taking this into account, the purpose of the current study was to appraise the conceptual rigor in published (HR)QOL studies in the field of PD.

METHODS

Search Strategy

A computerized search of the literature for the period 1960 to January 2007 was performed in Pubmed (692 hits), PsychINFO (172 hits), the Cochrane Library (37 hits), and Web of Science (415 hits). The term “Parkinson’s disease” was used in combination with the key term “quality of life” (including the related terms “health-related quality of life” and “health status”). Reference lists of relevant retrieved studies were checked in order to identify additional published research that was not found in the computerized database searches. After applying the selection criteria (see later) to these articles and their reference articles, 61 studies remained.

Selection Criteria

All studies were included that met the following criteria: (1) the objective was to describe QOL in PD with QOL questionnaires and/or questionnaires on related concepts; (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 or related concepts were measured with a standardized questionnaire; (4) studies contain at least a physical, psychological and social dimension, reflecting the WHO definition of health²⁰; (5) the article was a full report published in English, Dutch,

FIG. 1. Study selection process.

or German, and (6) studies were published in peer-reviewed journals. The primary objectives of the selected studies in this review, were to evaluate (HR)QOL in PD, to relate demographic and/or clinical factors to (HR)QOL (Supp. Table 1), and to assess the influence on (HR)QOL of neurosurgery (Supp. Table 2) and medication (Supp. Table 3).

The described inclusion criteria were applied to the initial 1316 hits (of which 83 were duplicates). Sixty-eight articles met the criteria, based on titles of articles and abstracts. Hard copies were obtained of almost all studies. Not-retrieved studies¹ could not be fairly judged and were excluded from this review. After inspection of the hard copies, 61 articles met our selection criteria and were included in this review.^{21–82} The selected studies were conducted between 1997 and 2007. The flow chart of study selection is shown in Figure 1.

Quality Assessment

The methodological quality of the studies was independently assessed by two reviewers (Den Oudsten and De Vries). A standardized checklist of 17 predefined criteria was used. The checklist was based on established criteria lists for systematic reviews.^{83–86} We included

¹Articles could not be ordered by Dutch libraries; authors involved were not reachable by e-mail.

also items based on a list of criteria, especially developed for reviewing QOL studies.^{17,87} The criteria are presented in Table 1.

Each item of a selected study, which met our criteria, was assigned one point. If an item did not meet a particular criterion or was described insufficiently or not at all, no point was assigned. The highest possible score was thus 17. Studies scoring 70% or more of the maximum attainable score (i.e. ≥ 12 points) were considered to be of “high quality.” Studies scoring between 50% and 70% were rated as “moderate quality.” Studies scoring lower than 50% were considered as “low quality” studies.

Findings were consistent if $\geq 75\%$ of the studies that investigated a particular factor showed the same direction of the association. We defined four levels of evidence^{85,86} (See Table 2).

RESULTS

Study Characteristics

The main findings are summarized in Supplemental Tables 1–3, available online at <http://www.interscience.wiley.com/jpages/0885-3185/suppmat>

In studies reporting the influence of neurosurgery on HS, the study size was often small. Overall, sample size ranged from five⁶⁰ to 1020 patients.⁶⁷

Almost all studies were cross-sectional, except for 22 studies. Eighteen of these 22 studies were studying the effects of medical treatment on HS.

Most studies described at least two demographic and clinical variables of interest. Age and sex were the most frequently included demographic variables, while the clinical variables were commonly represented by the age at onset, duration of symptoms, medication use, scores on the Hoehn and Yahr scale (H&Y),⁸⁸ the Unified Parkinson’s Disease scale (UPDRS),⁸⁹ and/or the Schwab and England scale.⁹⁰

Methodological Quality

The evaluation of the methodological quality of the 61 studies yielded the following results. There was disagreement (less than 5%) between the two reviewers when scoring the articles, mainly due to differences in applying the criteria B, F, and P. These disagreements were solved through discussion in a consensus meeting. The quality of studies is shown in the Supplemental Tables 1–4. The quality scores ranged from 6 (low quality) to 12 points (high quality). The mean quality score was 10. Methodological shortcomings mainly concerned the following items: the definition of (HR)QOL and/or HS (item A), reasons for choosing measurement instruments (item B), the distinction between (HR)QOL and HS (item C),

TABLE 1. List of criteria for assessing the methodological quality of studies on quality of life among patients with Parkinson's disease

Positive if with respect to	
QOL assessment	
A.	A description is given of (HR)QOL and/or health status by describing at least the domains and/or the importance of the subjective experience of the patient.
B.	A reason is given for choosing a certain questionnaire.
C.	A distinction is made between (HR)QOL and HS.
Study population	
D.	A description is included of at least two socio-demographic variables (e.g., age, sex, employment status, educational status, etc.).
E.	A description is present of at least two clinical variables (e.g., duration of symptoms, use of medication, UPDRS score, etc.).
F.	Inclusion and/or exclusion criteria are provided.
G.	The study describes potential prognostic factors by using multivariate analyses or structural equation modeling.
H.	Participation rates for patient groups are described and these rates are exceeding 75%.
I.	Information is given about the ratio non-responders versus responders.
Study design	
J.	The study size is consisting of at least 50 patients (arbitrarily chosen).
K.	The collection of data is prospectively gathered.
L.	The design is longitudinal (more than 1 year).
M.	The process of data collection is described (e.g., interview or self-report, etc.).
N.	The follow-up period is at least 6 months.
O.	The loss to follow-up is <20%.
Results	
P.	The results are compared between two groups or more (e.g., health population, groups with different severity of PD or age) and/or results are compared with at least two time points (e.g., longitudinally or pre- versus post-treatment).
Outcome measures	
Q.	A psychometrically sound (health-related) quality of life or health status questionnaire is used.

potential prognostic factors (item G), participation and response rates for patient groups (item H), information about nonresponders versus responders (item I), study size (item J), longitudinal design (item L), a follow-up period of at least 6 months (item N), and the loss to follow-up (item O). In the next paragraphs, an overview is provided of our findings.

Appraisal of the Conceptual Rigor of Published Studies

More than half of the studies included in this review did not describe any of the QOL-specific criteria (A-C). Twenty-five studies discussed (HR)QOL by giving a full definition or by describing the characteristics of (HR)QOL, i.e., the importance of the patient's view and/or the domains of QOL.

One study made a distinction between (HR)QOL and HS.⁸¹ However, all studies claimed to measure (HR)QOL. According to the definitions as outlined in the introduction, all studies actually assessed HS, except for two studies.^{77,78} QOL was assessed by means of the World Health Organization Quality of Life instrument-BREF (WHOQOL-BREF) and the Schedule for Evaluation of Individual Quality of Life (SEIQoL). HS was measured by means of four generic and three disease-specific questionnaires. One study discussed HS by using several questionnaires covering the physical, psychological, and social domain.⁶⁹

Fourteen studies included reasons for choosing a specific measurement by stating that the questionnaire was widely used in the field of PD and/or by describing its adequate psychometrics. In our opinion, the description of a selection procedure should include more. Numerous HS instruments are available nowadays, all of them have adequate psychometrics (e.g. Ref. ⁹¹). Therefore, stating that a questionnaire is widely used does not rule out other potential questionnaires.

Quality of Life Among Patients With Parkinson's Disease

Two studies^{77,78} examined the QOL in patients with PD by means of the WHOQOL-BREF and the SEIQoL. Schestatsky et al.⁷⁸ found that the duration of disease was negatively associated with psychological health, while

TABLE 2. Level of evidence

Strong	Consistent findings ($\geq 75\%$) in at least two high-quality studies <i>or</i> one high-quality study and at least three moderate studies
Moderate	Consistent findings ($\geq 75\%$) in one high-quality study and at least one low-quality study <i>or</i> at least three moderate studies
Weak	Findings of two moderate studies or consistent findings ($\geq 75\%$) in at least 3 <i>or</i> more low-quality studies
Inconclusive	Inconsistent findings irrespective of study quality, <i>or</i> less than 3 low-quality studies available

the severity of disease correlated negatively with perceived quality of social relationships. Lee et al.⁷⁷ compared the PDQ-39 with the SEIQoL. The only predictor of QOL in patients with PD was depressive symptoms, while HS was predicted by disease stage, the number of symptoms, and depression.

Health Status Among Patients With Parkinson's Disease

In the majority of studies, PD patients reported a diminished HS when compared with healthy controls^{56,63,65} and groups of patients with other diseases, like diabetes mellitus⁶⁵ or multiple sclerosis.⁷³ Gage et al.⁴⁵ concluded that the HS in PD veterans was lower compared to depressive veterans and veterans with spinal cord injury, congestive heart failure, stroke, chronic low back pain, arthritis, diabetes mellitus, angina/coronary heart disease, and depressive persons. Only veterans with spinal cord injury reported a slightly lower level of physical functioning and depressed veterans scored lower on mental functioning when compared to veterans with PD.

Specific symptoms can be related to the diminishing experience of HS. Herlofson and Larsen⁴⁴ studied the differences between PD patients by splitting the group in persons with and without fatigue. Patients with fatigue scored not only worse on physical functioning, but also on emotional and social functioning when compared with patients without fatigue. Sweating, another symptom reported by patients with PD, was studied by Swinn et al.⁴¹ They concluded—although no significant associations between sweating and HS were found—that excessive sweating can have a considerable impact on patients' lives. Most patients felt uncomfortable, and some felt embarrassed or reported that they were limited in their social activities.

Another study investigated potential differences between younger patients and older patients with PD.⁴² Younger patients were experiencing more problems with respect to stigmatization, availability of social support, and cognitive functioning⁴² compared with the older ones.

HS After Neurosurgery

All studies among PD patients reported HS improvements after neurosurgery. In general, these studies found that patients improved on physical functioning (e.g., mobility, activities of daily living, and bodily discomfort), emotional functioning, and social functioning (e.g., stigmatization).

One study randomly assigned patients to either a transplant or a sham surgery.⁶⁹ The investigators showed that

there was a placebo effect, when persons thought that they had transplantation, but in fact had been assigned to the sham surgery. In all cases, those who thought that they had received the transplant reported better HS scores. They reported, for instance, more interaction in the social domain, compared to the “real” surgery group.⁶⁹

All studies used a prospective design. One study used a prospective as well as a retrospective design to describe the effects of neurosurgery on HS and reported inconsistent findings.⁸² In the prospective assessment, patients perceived a general improvement of their HS after surgery, while assessing retrospectively the same patients did not report significant HS improvements at all. In other words, they seem to overestimate their preoperative functioning.⁸²

HS and Use of Medication

Seven studies investigated HS in combination with specific medications. Different study designs were used. Two studies used a placebo group^{25,75} in order to determine the effect of tolcapone or rasagiline on HS. Both studies concluded that medication improved the HS of patients. The placebo-group showed no effects.²⁵ Three studies found no significant improvements after drug treatments.^{26,50,68}

Predictors of HS

The predictors of demographic variables as well as disease characteristics were determined. More specifically, demographic (age, sex, education), psychological (depression, feelings of optimism, psychological adjustment, satisfaction with PD diagnosis), and disease variables (clinical stage/disease severity, use of medication, number of reported symptoms, the presence of specific symptoms, medication/neurosurgery) were investigated. Strong evidence was found for the predictive value of depressive symptoms and the level of independence in the domain of activities of daily functioning as measured by the Schwab and England scale.⁹⁰ Fourteen studies investigated depression as predictor, all of them found evidence for its predictive value.^{29,37,47,55,57,59,61,63,66,67,72,79,92,93} The presence of depressive symptoms was negatively associated with HS. Four studies assessed the ability to perform activities of daily functioning as a predictor of HS.^{57,59,63,92,93} Moderate evidence was found for the predictive value of self-reported insomnia,^{55,57,63} levodopa use/medication,^{26,63,67,75,93} and surgery.^{24,36,52,54,58,71} For instance, Caap-Ahlgren and Dehlin⁵⁵ investigated the influence of insomnia on HS, because of its high prevalence rates. They found that patients who reported problems to fall

asleep, a disturbed sleep, or early in the morning awakening, also reported poorer physical and emotional functioning as well as poorer general health. Predictors with weak evidence were, postural instability^{59,76} and gait function.^{66,76} Inconclusive evidence, that is, too few studies investigated the following predictors or inconsistent findings were reported, was found for the demographic variables: sex,^{61,93} age,³⁷ and education.^{39,47} Disease related variables with a weak level of evidence were duration of disease,³⁷ morbidity,³⁹ motor complications/physical functioning,^{35,40,61} dyskinesia,^{27,37} bradykinesia,⁷⁶ clinical fluctuations,²⁹ pain,³⁹ clinical stage/disease severity (H&Y),^{61,63,66,67} tremor,⁶⁶ UPDRS,^{47,93} cognitive impairment,⁵⁹ and number of reported symptoms.⁶⁶ Other factors investigated for their prognostic value were expenses related to disease,³⁷ psychological adjustment,²³ satisfaction of the (explanation of the condition at) diagnosis of PD,^{39,67} mental health symptoms,⁴⁹ and current feelings of optimism.⁶⁷ A lot of variables provide inconclusive evidence for an association with HS. Therefore, more research is needed to draw more definite conclusions on these variables.

DISCUSSION

The purpose of the current study was to appraise the conceptual rigor in published QOL studies in the field of PD. Additionally, data was presented on factors associated with impaired outcome in PD.

In general, PD patients suffer from a wide range of symptoms, probably affecting QOL, but definitely influencing self-perceived HS as this review points out.

Most studies claimed the assessment of (HR)QOL. However, according to the definitions used in this review, almost all studies actually reported results on HS. As outlined before, in HS studies, patients are asked to indicate their level of physical, emotional, and social functioning. Patients are not questioned on their life satisfaction nor on how much they are bothered by their limitations. Preliminary QOL findings suggest that the duration and the severity of disease are negatively influencing the QOL-domains Psychological Health and Social Relationships, respectively.⁷⁸ Lee et al.⁷⁷ asked patients to indicate those life-areas that were of eminent importance to them. They found that the majority of patients nominated family as the most important life area. In this study, QOL seems to be more determined by psychosocial issues than by physical ones. This idea was supported when the PDQ-39 and the SEIQOL were compared. The PDQ-39 domains that were predictive of the SEIQOL-index were the social support, cognitive impairment, and emotional domains. QOL of PD patients was predicted by depressive symptoms, while HS in this

population was predicted by the stage of disease. With regard to HS, it can be concluded that PD patients experience a lower HS when compared to healthy controls or patients with other chronic diseases. Besides a declined functioning in the physical domain, patients also experience a diminished social and emotional functioning. Prudence is necessary when conclusions are drawn based on diminished functioning and its relation to QOL. Some studies found that QOL can be maintained or even improved when patients experience a life-threatening or progressive illness.^{94,95}

QOL is an important factor in health care, because it is thought to be influenced by the type of treatment the patient receives.⁹⁶ When professionals advise patients regarding the (dis)advantages of a certain treatment modality, it is important to have knowledge of the results of QOL studies in PD and to know which factors are prognostic for a patient's well-being. Several articles reported outcomes on potential predictors of HS. It seems that having depressive symptoms is a strong predictor for experiencing a lower HS. The same applies for being dependent on other persons. Overall, the level of evidence of potential predictors with regard to QOL was predominantly weak or even inconclusive.

There are several obvious shortcomings in the set of available studies. Demographic and clinical variables should be more extensively and uniformly described in future studies. Most frequently reported demographic variables were age and sex, while marital status, educational levels, and employment status, could also be possible predictors of HS, as well as QOL (e.g. Ref. ⁹⁷). Clinical variables are reported in various ways. In order to compare studies with each other, however, it will be necessary to have some form of uniformity. By the implementation of additional qualitatively good studies, more clarity with respect to the HS and QOL of patients with PD could be achieved.

Based on the works of Gill and Feinstein, Moons et al., Van der Steeg et al.,^{17,87,96} we suggest implementation of the following recommendations when designing future studies. First, determine whether (HR)QOL or HS is the subject of interest. If the study objectives focuses on merely the functional consequences of PD, the use of HS instruments is sufficient to answer the research question at hand.⁹⁶ If the study aims to describe how much a patient with PD is bothered by these limitations in life, (HR)QOL instruments are needed. If both objectives are present, then both types of instruments should be represented in the test booklet. Second, provide an explicit definition of the concept of interest.^{17,87} Because a uniform definition of QOL does not exist and related concepts are often erroneously used interchangeably, it is

important to be very explicit about the employed concepts; not only for directing the study design, but also to give other scientists and clinicians insight in what is measured in the study. In addition, QOL measurements can only be evaluated if QOL is explicitly defined.¹⁷ Therefore, simply referring to the existence of a wide variety of definitions or describing relevant components of QOL is not enough to clarify the concept.⁸⁷ Third, the selection of instruments should be based on systematic reasoning and, therefore, will depend on the study aims and the way (HR)QOL and/or HS is conceptualized.⁹¹ According to the definition of QOL used in this review, QOL can, for instance, be measured using the generic instruments *World Health Organization Quality of Life-100 items* (WHOQOL-100)⁹⁸ and WHOQOL-BREF,⁹⁹ SEIQOL^{100,101} or with a movement disorder-specific instrument, like the *Questions of Life Satisfaction* scale.^{102,103} Regularly, the rationale for using a specific questionnaire is that it is widely used. Of course, widely used instruments make comparison between studies a lot easier, but there are other aspects of importance when selecting an instrument.⁹¹ The first aspect is whether to choose a generic or PD-specific instrument. Both types of instruments have advantages and disadvantages (see for a detailed overview Patrick and Deyo¹⁰⁴). Make sure, by inspecting several questionnaires that may be used, that the selected questionnaires measure the concept you are interested in. It should also be kept in mind that instruments which measure a certain concept, like HS, differ considerably from one another. For example, cognitive functioning is only a topic in the Parkinson's Disease questionnaire-39 items (PDQ-39)¹⁰⁵ and Parkinson's Disease Quality of Life (PDQL),¹⁰⁶ while the Parkinson's Impact scale (PIMS)¹⁰⁷ and the Parkinson's Disease Quality of Life scale (PDQUALIF)¹⁰⁸ both assess financial consequences of PD,⁹² a facet that is lacking in other instruments. The final aspect is to inspect the psychometric properties of questionnaires. For instance, when one is interested in studying changes over time in PD, the sensitivity to change of an instrument should be adequate. In the end, the actual selection of questionnaires should systematically rule out other potential questionnaires. Fourth, when patients are eventually assessed on HS and/or (HR)QOL, and it comes to describing the outcomes in an article, it is of eminent importance to present the outcomes in accordance with the initially described definition and the instruments used. As stated above, all studies included in this review made no distinction between (HR)QOL en HS. Too often, a HS instrument is used, while the title of the article points out that the focus is on QOL. Finally, we would like to point out that criteria lists developed for

reviewing articles and writing systematic review, such as used in this study, could provide guidelines to improve the quality of studies. Eventually, this makes that more definite conclusions can be drawn on variables of interest.

In conclusion, HS studies are well represented in the field of Parkinson's disease. Attention towards QOL, however, is needed in order to draw conclusions on a person's well-being.

REFERENCES

1. Samii A, Nutt JG, Ransom BR. Parkinson's disease. *Lancet* 2004;363:1783-1793.
2. Smith KW, Avis NE, Assmann SF. Distinguishing between quality of life and health status in quality of life research: a meta-analysis. *Qual Life Res* 1999;8:447-459.
3. Hunt SM. The problem of quality of life. *Qual Life Res* 1997;6:205-212.
4. Orley J, Saxena S, Herrman H. Quality of life and mental illness. Reflections from the perspective of the WHOQOL (editorial). *Br J Psychiatry* 1998;172:291-293.
5. WHOQOL group. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995;41:1403-1409.
6. Kaplan RM. Quality of life measurement. In: Karoly P, editor. *Measurement strategies in health psychology*. New York: Wiley; 1985. pp. 115-146.
7. Greer S. The psychological dimension in cancer treatment. *Soc Sci Med* 1984;18:345-349.
8. Testa MA, Simonson DC. Assessment of quality-of-life outcomes. *N Engl J Med* 1996;334:835-840.
9. Curtis JR, Patrick DL. The assessment of health status among patients with COPD. *Eur Respir J* 2003;41:36-45.
10. Wood-Dauphinee S. Assessing quality of life in clinical research: from where have we come and where are we going? *J Clin Epidemiol* 1999;52:355-363.
11. Moons P, Budts W, De Geest S. Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches. *Int J Nurs Stud* 2006;43:891-901.
12. Patrick DL, Erickson P. What constitutes quality of life? Concepts and dimensions. *Drug Ther Res* 1988;13:152-158.
13. Haave E, Hyland ME, Skumlien S. The relation between measures of health status and quality of life in COPD. *Chron Respir Dis* 2006;3:195-199.
14. Ware JE, Jr. Conceptualization and measurement of health-related quality of life: comments on an evolving field. *Arch Phys Med Rehabil* 2003;84:S43-S51.
15. Rejeski WJ, Mihalko SL. Physical activity and quality of life in older adults. *J Gerontol A Biol Sci Med Sci* 2001;56:23-35.
16. De Vries J. Quality of life assessment. In: Vingerhoets AJJN, editor. *Assessment in behavioural medicine*. Hove, UK: Brunner-Routledge; 2001. p 353-370.
17. Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994;272:619-626.
18. Mor V, Guadagnoli E. Quality of life measurement: a psychometric tower of Babel. *J Clin Epidemiol* 1988;41:1055-1058.
19. Schrag A. Quality of life and depression in Parkinson's disease. *J Neurol Sci* 2006;248:151-157.
20. WHO. The first ten years of the World Health Organization. Geneva: WHO; 1958.
21. Antonini A, Tesi S, Zecchinelli A, et al. Randomized study of sertraline and low-dose amitriptyline in patients with Parkinson's disease and depression: effect on quality of life. *Mov Disord* 2006;21:1119-1122.

22. Rodrigues de Paula F, Teixeira-Salmela LF, Coelho de Moraes Faria CD, Rocha de Brito P, Cardoso F. Impact of an exercise program on physical, emotional, and social aspects of quality of life of individuals with Parkinson's disease. *Mov Disord* 2006; 21:1073–1077.
23. Suzukamo Y, Ohbu S, Kondo T, Kohmoto J, Fukuhara S. Psychological adjustment has a greater effect on health-related quality of life than on severity of disease in Parkinson's disease. *Mov Disord* 2006;21:761–766.
24. Siderowf A, Jaggi JL, Xie SX, et al. Long-term effects of bilateral subthalamic nucleus stimulation on health-related quality of life in advanced Parkinson's disease. *Mov Disord* 2006;21:746–753.
25. Biglan KM, Schwid S, Eberly S, et al. Rasagiline improves quality of life in patients with early Parkinson's disease. *Mov Disord* 2006;21:616–623.
26. Noyes K, Dick AW, Holloway RG. Pramipexole versus levodopa in patients with early Parkinson's disease: effect on generic and disease-specific quality of life. *Value Health* 2006;9:28–38.
27. Pechevis M, Clarke CE, Vieregge P, et al. Effects of dyskinesias in Parkinson's disease on quality of life and health-related costs: a prospective European study. *Eur J Neurol* 2005;12:956–963.
28. Lyons KE, Pahwa R. Long-term benefits in quality of life provided by bilateral subthalamic stimulation in patients with Parkinson disease. *J Neurosurg* 2005;103:252–255.
29. Slawek J, Derejko M, Lass P. Factors affecting the quality of life of patients with idiopathic Parkinson's disease—a cross-sectional study in an outpatient clinic attendees. *Parkinsonism Relat Disord* 2005;11:465–468.
30. Behari A, Srivastava AK, Pandey RM. Quality of life in patients with Parkinson's disease. *Parkinsonism Relat Disord* 2005;11: 221–226.
31. Drapier S, Raoul S, Drapier D, et al. Only physical aspects of quality of life are significantly improved by bilateral subthalamic stimulation in Parkinson's disease. *J Neurol* 2005;252: 583–588.
32. Erola T, Karinen P, Heikkinen E, et al. Bilateral subthalamic nucleus stimulation improves health-related quality of life in Parkinsonian patients. *Parkinsonism Relat Disord* 2005;11:89–94.
33. Grosset KA, Grosset DG. Patient-perceived involvement and satisfaction in Parkinson's disease: Effect on therapy decisions and quality of life. *Mov Disord* 2005;20:616–619.
34. Zimmerman GJ, D'Antonio LLD, Iacono RP. Health-related quality of life in patients with Parkinson's disease two years following posteroventral pallidotomy. *Acta Neurochir* 2004;146: 1293–1299.
35. Chapuis S, Ouchchane L, Metz O, Gerbaud L, Durif F. Impact of the motor complications of Parkinson's disease on the quality of life. *Mov Disord* 2005;20:224–230.
36. Lezcano E, Gomez-Esteban JC, Zarranz JJ, et al. Improvement in quality of life in patients with advanced Parkinson's disease following bilateral deep-brain stimulation in subthalamic nucleus. *Eur J Neurol* 2004;11:451–454.
37. Zach M, Friedman A, Slawek J, Derejko M. Quality of life in polish patients with long-lasting Parkinson's disease. *Mov Disord* 2004;19:667–672.
38. Shimbo T, Goto M, Morimoto T, et al. Association between patient education and health-related quality of life in patients with Parkinson's disease. *Qual Life Res* 2004;13:81–89.
39. Quittenbaum BH, Grahn B. Quality of life and pain in Parkinson's disease: a controlled cross-sectional study. *Parkinsonism Relat Disord* 2004;10:129–136.
40. Marras C, Lang A, Krahn M, Tomlinson G, Naglie G, Grp PS. Quality of life in early Parkinson's disease: impact of dyskinesias and motor fluctuations. *Mov Disord* 2004;19:22–28.
41. Swinn L, Schrag A, Viswanathan R, Bloem BR, Lees A, Quinn N. Sweating dysfunction in Parkinson's disease. *Mov Disord* 2003;18:1459–1463.
42. Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Young- versus older-onset Parkinson's disease: impact of disease and psychosocial consequences. *Mov Disord* 2003;18: 1250–1256.
43. Scaravilli T, Gasparoli E, Rinaldi F, Polesello G, Bracco F. Health-related quality of life and sleep disorders in Parkinson's disease. *Neurol Sci* 2003;24:209–210.
44. Herlofson K, Larsen JP. The influence of fatigue on health-related quality of life in patients with Parkinson's disease. *Acta Neurol Scand* 2003;107:1–6.
45. Gage H, Hendricks A, Zhang S, Kazis L. The relative health related quality of life of veterans with Parkinson's disease. *J Neurol Neurosurg Psychiatry* 2003;74:163–169.
46. Lagrange E, Krack P, Moro E, et al. Bilateral subthalamic nucleus stimulation improves health-related quality of life in PD. *Neurology* 2002;59:1976–1978.
47. Cubo E, Rojo A, Ramos S, et al. The importance of educational and psychological factors in Parkinson's disease quality of life. *Eur J Neurol* 2002;9:589–593.
48. Just H, Ostergaard K. Health-related quality of life in patients with advanced Parkinson's disease treated with deep brain stimulation of the subthalamic nuclei. *Mov Disord* 2002;17: 539–545.
49. Chrischilles EA, Rubenstein LM, Voelker MD, Wallace RB, Rodnitzky RL. Linking clinical variables to health-related quality of life in Parkinson's disease. *Parkinsonism Relat Disord* 2002; 8:199–209.
50. Happe S, Berger K. The association of dopamine agonists with daytime sleepiness, sleep problems and quality of life in patients with Parkinson's disease: a prospective study. *J Neurol* 2001;248: 1062–1067.
51. Martinez-Martin P, Valldeoriola F, Tolosa E, et al. Bilateral subthalamic nucleus stimulation and quality of life in advanced Parkinson's disease. *Mov Disord* 2002;17:372–377.
52. Gray A, McNamara I, Aziz T, et al. Quality of life outcomes following surgical treatment of Parkinson's disease. *Mov Disord* 2002;17:68–75.
53. Woods SP, Fields JA, Lyons KE, et al. Neuropsychological and quality of life changes following unilateral thalamic deep brain stimulation in Parkinson's disease: a one-year follow-up. *Acta Neurochir* 2001;143:1273–1277.
54. De Bie RM, Schuurman PR, Bosch DA, De Haan RJ, Schmand B, Speelman JD. Outcome of unilateral pallidotomy in advanced Parkinson's disease: cohort study of 32 patients. *J Neurol Neurosurg Psychiatry* 2001;71:375–382.
55. Caap-Ahlgren M, Dehlin O. Insomnia and depressive symptoms in patients with Parkinson's disease - Relationship to health-related quality of life. An interview study of patients living at home. *Arch Gerontol Geriatr* 2001;32:23–33.
56. Schrag A, Jahanshahi M, Quinn N. How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. *Mov Disord* 2000;15:1112–1118.
57. Karlsen KH, Tandberg E, Arslan D, Larsen JP. Health related quality of life in Parkinson's disease: a prospective longitudinal study. *J Neurol Neurosurg Psychiatry* 2000;69:584–589.
58. D'Antonio LL, Zimmerman GJ, Iacono RP. Changes in health related quality of life in patients with Parkinson's disease with and without posteroventral pallidotomy. *Acta Neurochir* 2000;142:759–767.
59. Schrag A, Jahanshahi M, Quinn N. What contributes to quality of life in patients with Parkinson's disease? *J Neurol Neurosurg Psychiatry* 2000;69:308–312.
60. Hagell P. Health-related quality of life following bilateral intrastriatal transplantation in Parkinson's disease. *Mov Disord* 2000; 15:1049–1049.

61. Kuopio AM, Martilla RJ, Helenius H, Toivonen M, Rinne UK. The quality of life in Parkinson's disease. *Mov Disord* 2000;15: 216–223.
62. Martinez-Martin P, Valldeoriola F, Molinuevo JL, Nobbe FA, Rumia J, Tolosa E. Pallidotomy and quality of life in patients with Parkinson's disease: an early study. *Mov Disord* 2000;15:65–70.
63. Karlsen KH, Larsen JP, Tandberg E, Maeland JG. Influence of clinical and demographic variables on quality of life in patients with Parkinson's disease. *J Neurol Neurosurg Psychiatry* 1999; 66:431–435.
64. Grandas F, Martinez-Martin P, Linazasoro G. Quality of life in patients with Parkinson's disease who transfer from standard levodopa to Sinemet CR: the STAR Study. The STAR Multi-center Study Group. *J Neurol* 1998;245 (Suppl 1):S31–S33.
65. Karlsen KH, Larsen JP, Tandberg E, Maeland JG. Quality of life measurements in patients with Parkinson's disease: a community-based study. *Eur J Neurol* 1998;5:443–450.
66. Haas BM, Trew M, Castle PC. Effects of respiratory muscle weakness on daily living function, quality of life, activity levels, and exercise capacity in mild to moderate Parkinson's disease. *Am J Phys Med Rehabil* 2004;83:601–607.
67. Findley L, Eichhorn T, Janca A, et al. Factors impacting on quality of life in Parkinson's disease: results from an international survey. *Mov Disord* 2002;17:60–67.
68. Reichmann H, Boas J, Macmahon D, Myllyla V, Hakala A, Reinikainen K. Efficacy of combining levodopa with entacapone on quality of life and activities of daily living in patients experiencing wearing-off type fluctuations. *Acta Neurol Scand* 2005; 111:21–28.
69. McRae C, Cherin E, Yamazaki TG, et al. Effects of perceived treatment on quality of life and medical outcomes in a double-blind placebo surgery trial. *Arch Gen Psychiatry* 2004;61:412–420.
70. Vingerhoets G, Lannoo E, Van der Linden C, et al. Changes in quality of life following unilateral pallidal stimulation in Parkinson's disease. *J Psychosom Res* 1999;46:247–255.
71. Esselink RA, De Bie RM, De Haan RJ, et al. Unilateral pallidotomy versus bilateral subthalamic nucleus stimulation in PD: a randomized trial. *Neurology* 2004;62:201–207.
72. Croyle KL, Troster AI, Fields JA, Straits-Troster KA, Lyons KE, Pahwa R. Presurgical coping, depression, and quality of life in persons with Parkinson's disease. *J Clin Psychol Med S* 2003; 10:101–107.
73. Riazzi A, Hobart JC, Lamping DL, et al. Using the SF-36 measure to compare the health impact of multiple sclerosis and Parkinson's disease with normal population health profiles. *J Neurol Neurosurg Psychiatry* 2003;74:710–714.
74. Straits-Troster K, Fields JA, Wilkinson SB, et al. Health-related quality of life in Parkinson's disease after pallidotomy and deep brain stimulation. *Brain Cogn* 2000;42:399–416.
75. Welsh MD, Dorfinger E, Chernik D, Waters C. Illness impact and adjustment to Parkinson's disease: before and after treatment with tolcapone. *Mov Disord* 2000;15:497–502.
76. Lyons KE, Pahwa R, Troster AI, Koller WC. A comparison of Parkinson's disease symptoms and self-reported functioning and well-being. *Parkinsonism Relat Disord* 1997;3:207–209.
77. Lee MA, Walker RW, Hildreth AJ, Prentice WM. Individualized assessment of quality of life in idiopathic Parkinson's disease. *Mov Disord* 2006;21:1929–1934.
78. Schestatsky P, Zanatto VC, Margis R, et al. Quality of life in a Brazilian sample of patients with Parkinson's disease and their caregivers. *Revista Brasileira de Psiquiatria* 2006;28: 209–211.
79. Reuther M, Spottke EA, Klotsche J, et al. Assessing health-related quality of life in patients with Parkinson's disease in a prospective longitudinal study. *Parkinsonism Relat Disord* 2007; 13:108–114.
80. Gomez-Esteban JC, Zarranz JJ, Lezcano E, et al. Influence of motor symptoms upon the quality of life of patients with Parkinson's disease. *Eur Neurol* 2007;57:161–165.
81. Grossset D, Taurah L, Burn DJ, et al. A multicentre longitudinal observational study of changes in self reported health status in people with Parkinson's disease left untreated at diagnosis. *J Neurol Neurosurg Psychiatry* 2007;78:465–469.
82. Gronchi-Perrin A, Viollier S, Ghika J, et al. Does subthalamic nucleus deep brain stimulation really improve quality of life in Parkinson's disease? *Mov Disord* 2006;21:1465–1468.
83. Kuijpers T, Van der Windt DA, Van der Heijden GJ, Bouter LM. Systematic review of prognostic cohort studies on shoulder disorders. *Pain* 2004;109:420–431.
84. Borghouts JA, Koes BW, Bouter LM. The clinical course and prognostic factors of non-specific neck pain: a systematic review. *Pain* 1998;77:1–13.
85. Mols F, Vingerhoets AJ, Coebergh JW, Van de Poll-Franse LV. Quality of life among long-term breast cancer survivors: a systematic review. *Eur J Cancer* 2005;41:2613–2619.
86. Scholten-Peeters GG, Verhagen AP, Bekkering GE, et al. Prognostic factors of whiplash-associated disorders: a systematic review of prospective cohort studies. *Pain* 2003;104:303–322.
87. Moons P, Van Deyk K, Budts W, De Geest S. Caliber of quality-of-life assessments in congenital heart disease: a plea for more conceptual and methodological rigor. *Arch Pediatr Adolesc Med* 2004;158:1062–1069.
88. Hoehn MM, Yahr MD. Parkinsonism: onset, progression and mortality. *Neurology* 1967;17:427–442.
89. Fahn S, Elton RL. Unified Parkinson's disease rating scale. In: Fahn S, Marsden CD, Calne D, Goldstein M, editors. *Recent developments in Parkinson's disease*. Florham Park, NJ: Macmillan Health Care Information; 1987. P 153–164.
90. Schwab RS, England AC. Projection techniques for evaluating surgery in Parkinson's disease. In: Gillingham FJ, Donaldson IML, editors. *Third symposium on Parkinson's disease*. Edinburgh, UK: Livingstone; 1969. p 152–157.
91. Den Oudsten BL, De Vries J, Van Heck GL. The suitability of patient-based measures in the field of Parkinson's disease. *Mov Disord* (in press).
92. Marinus J, Ramaker C, Van Hilten JJ, Stiggelbout AM. Health related quality of life in Parkinson's disease: a systematic review of disease specific instruments. *J Neurol Neurosurg Psychiatry* 2002;72:241–248.
93. Behari M, Srivastava AK, Pandey R. Quality of life in Indian patients with Parkinson's disease. *Mov Disord* 2004;19:S253–S254.
94. Browne JP, O'Boyle CA, McGee HM, et al. Individual quality of life in the healthy elderly. *Qual Life Res* 1994;3:235–244.
95. Kreitler S, Chaitchik S, Rapoport Y, Kreitler H, Algor R. Life satisfaction and health in cancer patients, orthopedic patients and healthy individuals. *Soc Sci Med* 1993;36:547–556.
96. Van der Steeg AFW, De Vries J, Roukema JA. Quality of life and health status in breast carcinoma. *Eur J Surg Oncol* 2004;30: 1051–1057.
97. Parker PA, Baile WF, De Moor C, Cohen L. Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psychooncology* 2003;12:183–193.
98. WHOQOL group. The World Health Organization Quality of Life Assessment instrument (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998;46:1569–1585.
99. WHOQOL group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998;28:551–558.
100. Hickey AM, Bury G, O'Boyle CA, Bradley F, O'Kelly FD, Shannon W. A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ* 1996;313:29–33.

101. Browne JP, O'Boyle CA, McGee HM, McDonald NJ, Joyce CR. Development of a direct weighting procedure for quality of life domains. *Qual Life Res* 1997;6:301–309.
102. Kuehler A, Henrich G, Schroeder U, Conrad B, Herschbach P, Ceballos-Baumann A. A novel quality of life instrument for deep brain stimulation in movement disorders. *J Neurol Neurosurg Psychiatry* 2003;74:1023–1030.
103. Henrich G, Herschbach P. Questions on life satisfaction (FLZM)—a short questionnaire for assessing subjective quality of life. *Eur J Psychol Assess* 2000;16:150–159.
104. Patrick DL, Deyo RA. Generic and disease-specific measures in assessing health status and quality of life. *Med Care* 1989;27:217–232.
105. Peto V, Jenkinson C, Fitzpatrick R. PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures. *J Neurol* 1998;245:S10–S14.
106. De Boer AG, Wijker W, Speelman JD, De Haes JC. Quality of life in patients with Parkinson's disease: development of a questionnaire. *J Neurol Neurosurg Psychiatry* 1996;61:70–74.
107. Calne S, Schultzer M, Mak E, et al. Validating a quality of life rating scale for idiopathic Parkinsonism: Parkinson's Impact scale (PIMS). *Parkinsonism Relat Disord* 1996;2:55–61.
108. Welsh M, McDermott MP, Holloway RG, et al. Development and testing of the Parkinson's Disease Quality of Life scale. *Mov Disord* 2003;18:637–645.