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Research Article

Validation of the Korean version of the 39-Item Parkinson's Disease Questionnaire (PDQ-39)

Hye-Ja Park, PhD,[1] Kyeong-Yae Sohng, PhD,[2] Sehyun Kim, PhD[3,*]

[1] College of Nursing, CHA University, South Korea
[2] College of Nursing, The Catholic University of Korea, South Korea
[3] Graduate School, Dankook University, South Korea

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SUMMARY

Purpose: To evaluate the reliability and validity of the Korean version of the 39-item Parkinson's disease questionnaire (PDQ-39).
Methods: Cross-cultural adaptation was performed according to the international guidelines: forward and backward translation, focus group meeting, and a field test. With Korean consensus translation produced, validation was assessed by evaluating reliability and validity. Ninety-three outpatients with Parkinson's disease (PD) and 89 healthy aged controls were recruited. Internal consistency reliability was assessed by Cronbach's alpha. Validity was assessed by Spearman correlation analysis, *t* test, factor analysis, and analysis of variance with Duncan's multiple range tests.
Results: In the PD group, mean age was 65.13 ± 9.84 years, and mean duration of PD was 42.41 ± 37.01 months. Ceiling and floor effects ranged 1.1%–2.2% and 1.1%–15.1%, respectively. Cronbach's alpha of eight dimensions ranged from .70 to .97. All dimensions were correlated with each other, except for the stigma dimension. PD patients had significantly lower quality of life than healthy aged controls did, except for the bodily discomfort dimension. Eight dimensions of Korean PDQ-39 loaded on one factor. PD patients with a Modified Hoehn and Yarh Staging score of 4 had the worst quality of life. The relationships among the eight dimensions of Koran PDQ-39 and the Modified Hoehn and Yarh Staging is fair to good, except for the stigma and social support dimension.
Conclusion: The Korean PDQ-39 was proved to be reliable and valid. Our results suggest that Korean PDQ-39 could be used in clinical research to assess and evaluate the disease process and its impacts on health-related quality of life in Korean PD patients.

Introduction

Parkinson's disease (PD) is a common neurodegenerative disorder affecting 0.37% among general population and 1.47% of the population over 60 years of age in Korea. These prevalence rates are similar to those of studies carried out in Western countries, and age is the main risk factor for Parkinson's disease in Korea (Seo et al., 2007). PD is a progressive, age-related, and degenerative disorder of the central nervous system, characterized clinically by tremor, bradykinesia, rigidity, and disturbed postural reflexes (Hankey & Wardlaw, 2008). As the disease progresses, nonmotor syndromes including disorders of sleep-wake cycle regulation, cognition, regulation of mood and hedonistic tone, autonomic nervous system function, sensory function and pain perception add significantly to overall disability and also are critical determinants of health-related quality of life of affected patients (Jankovic & Tolosa, 2007). Health-related quality of life (QoL for short) refers to the patient's own appraisal of the impact of the disease and include physical, psychological and social domains. Its measurement is of paramount importance to evaluating disease outcomes and in cost-benefit analyses. QoL assessment helps to identify problems and may be essential in chronic and disabling diseases such as in PD (Martinez-Martin, 1998). In addition, QoL assessment contributes to a better understanding of the disease's consequences and its treatment on the patient, and thus helps in decision making. QoL evaluations reflect the patients' point of view. Many relevant aspects related to the emotional and psychosocial well-being of patients cannot be evaluated appropriately by clinical methods (Martinez-Martin). Clinical scales of dysfunction assessment, which

* Correspondence to: Sehyun Kim, PhD, Graduate School of Dankook University, 152 Jukjeon-ro, Suji-gu, Yongin-si, Gyeonggi-do, South Korea.
E-mail address: kim.ssam@gmail.com

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are completed by clinicians, could not provide a complete picture of the illness on subjectively assessed function and well-being of patients (Longstreth, Nelson, Linde, & Munoz, 1992). QoL issues in nursing care should be considered throughout all stages of the disease including diagnosis, early disease, moderate disease, advanced disease, hospice and bereavement. Therefore, neuroscience nurses need to provide longitudinal care plans to promote QoL in the context of chronic disease by identifying key treatable symptoms and providing comfort measures based on the principles of palliative care for patients and families across the healthcare continuum (Bunting-Perry, 2006; Shin & Hendrix, 2013).

The 39-item Parkinson's Disease Questionnaire (PDQ-39) will probably be the most appropriate instrument among QoL instruments for PD patients including the Parkinson's Quality of life questionnaire, and Parkinson Quality of life questionnaire (Marius, Ramaker, van Hilten, & Stiggelbout, 2002). The PDQ-39 includes eight disease dimensions: mobility, activities of daily living (ADL), emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort (Jenkinson, Peto, Fitzpatrick, Greenhall, & Hyman, 1995). It has been widely used in assessment of diverse signs and symptoms of PD or their impact on QoL (Jenkinson et al., 1995; Marius et al.). It was the first specific and consistent instrument for the QoL evaluation in PD patients (Zhang & Chan, 2012). Briefly, the PDQ-39 is identified as a patient-assessed instrument, which is feasible, reliable, valid, comprehensive, and sensitive to change. It reflects the entire spectrum of health-related QoL in PD (Damiano et al., 2000; Peto, Jenkinson, & Fitzpatrick, 1998; Zhang & Chan). Since a field study including clinical research using a QoL instrument will normally be conducted in a number of different countries, the instrument will need to be translated into other languages. The aims of the translation process should ensure that all language versions of the instrument are equally clear, precise, and equivalent in all aspect to the original language of the instrument (Fayers, & Machin, 2007). Even with its wide uses, translations, and validations into multiple languages (Auquier et al., 2002; Bushnell & Martin, 1999; Katsarou, Bostantjopoulou, Peto, Alevriadou, & Kiosseoglou, 2001; Luo, Tan, Li, Soh, & Thumboo, 2005; Martinez-Martin & Payo, 1998; Tan, Luo, Nazri, Li, & Thumboo, 2004; Zhang & Chan), the Korean translation of the PDQ-39 has not yet been developed, validated and reported.

We focused on the validation process to ensure that the Korean PDQ-39 will be equally clear, precise and equivalent to the original UK English PDQ-39 and have adequate validity and reliability. Therefore, the objective of this study was to develop the Korean version of PDQ-39 and to evaluate its reliability and validity for use in clinical research and application among Korean PD patients.

Methods

Study design

This was a psychometric validation study to evaluate reliability and validity of the Korean version of 39-Item Parkinson's Disease Questionnaire (PDQ-39).

Setting and sample

This study was conducted at a neurology outpatient center in a tertiary university hospital in Seoul, Korea. We consecutively recruited outpatients diagnosed with PD by a neurologist. A total of 102 outpatients with PD were registered at this center at the beginning of the study. Among these, 93 patients agreed to participate to this study.

To estimate the required sample size for convergent validity according to the point biserial correlation model by G*Power 3.1.7 program (Faul, Erdfelder, Lang, & Buchner, 2007), a two-sided test with a significance level of .05, a power $(1-\beta)$ of .80, and the anticipated difference (effect size) of 0.30 were specified. The sample size was calculated at 86 per group. For the criterion validity by Modified Hoehn and Yahr Staging (mH&Y) according to analysis of variance, a significance level of .05, a power of .90, an anticipated difference of 0.5, and the number of groups at 6 were specified. The required sample size was calculated as 270 in the PD group, so the limitation of a small sample size have emerged from a total population of 102 PD patients in this study. In addition, a total of 89 healthy aged controls without major comorbidities who were registered to the dance sports club at a community senior welfare center in Seoul were recruited for the purpose of assessing validity. To estimate the required sample size for known groups validity according to *t* test, a significance level of .05, a power of .90, and an effect size of 0.5 were specified. The required sample size was calculated as 86 per group.

Ethical consideration

Information about the research was given to these participants and informed consent was obtained. Study protocol and all of the study procedures were approved by the institutional review board of Bundang CHA University General Hospital (2007-18A).

Measurements

Demographics and clinical assessment

Demographics and clinical characteristics including age, sex, educational attainment (years), employment status, disease duration (months) since PD diagnosis and the disease status by mH&Y were assessed. The scale is designed to give an estimate of PD staging (Hoehn, 1992; Hoehn, & Yahr, 1967), and is the most widely used measure of clinical outcomes as a gold standard (Jenkinson, Fitzpatrick, & Peto, 1998). The scale ranged from 0 to 5 where 0 meant no evidence of disease, 1.0 meant unilateral disease only, 1.5 meant unilateral disease plus axial involvement, 2.0 meant bilateral mild disease without impairment of balance, 2.5 meant mild bilateral disease with recovery on pull test, 3.0 meant mild-to-moderate bilateral disease, with some postural instability but physically dependent; 4.0 meant severe disease, but still able to walk or stand unassisted, 5.0 meant wheelchair bound or bedridden unless aided (Hoehn). The assessment and diagnosis using mH&Y was performed by a neurologist at the university hospital.

PDQ-39 and PDQ-39 Single Index

We translated items and response choices in the original PDQ-39 consisting of eight dimensions: mobility (10 items), ADL (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognitions (4 items), communication (3 items), and bodily discomfort (3 items). Response choices of all questions were coded as: 0 = *never*; 1 = *occasionally*; 2 = *sometimes*; 3 = *often*; 4 = *always* (or *cannot do at all, if applicable*). Each dimension was calculated as a scale from 0 (*no problem at all*) to 100 (*maximum level of problem*). If the response to a question was missing, no scale score was calculated for that individual for that dimension. Finally, eight dimension scores of PDQ-39 were summed into PDQ-39 single index (PDQ-39SI) (Jenkinson et al., 1998). Summary score can prove helpful in providing a guide to the overall impact of ill health, as measured on questionnaires which provide a profile of scores (Ware, Kosinski, Bayliss, McHorney, Rogers & Raczek, 1995). Lower scores indicate better health-related QoL