Tools and techniques

# Quality of life and Parkinson's disease: Philippine translation and validation of the Parkinson's disease questionnaire

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## ARTICLE INFO

## ABSTRACT

The 39-item Parkinson's Disease Quality of Life Questionnaire (PDQ-39) is the most widely used self-administered questionnaire assessing the quality of life of Parkinson's disease (PD) patients. We translated the PDQ-39 into the Filipino language as the Philippine-PDQ-39 (P-PDQ-39) and used it to assess the quality of life of Filipino patients with PD. The original PDQ-39 was translated into Filipino using forward and backward translation by independent bilingual translators and used among 100 consecutively sampled PD patients. Baseline demographic data, disease duration and levodopa equivalent dose were collected. Internal consistency was measured using Chronbach's α. The following rating scales and questionnaires were correlated with P-PDQ-39 through Pearson's correlation coefficient to assess construct validity: modified Hoehn & Yahr Stage, Hospital Anxiety and Depression Scale-Pilipino (HADS-P), Unified Parkinson's Disease Rating Scale (UPDRS) Parts I-III, and Non-motor symptom Assessment Scale for Parkinson's Disease (NMSS). The mobility and activities of daily living domains of the P-PDQ-39 were well correlated with the Hoehn & Yahr stage of the patients and the UPDRS II and III scores emphasizing the value of motor symptoms in quality of life. Non motor symptoms in PD were also important determinants of quality of life as demonstrated in the correlation of HADS-P and NMSS Total scores with the P-PDQ 39 domains. The P-PDQ-39 is a valid assessment tool for assessing the quality of life of Filipino-speaking PD patients.

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## 1. Introduction

Parkinson's disease (PD) is a multisystem disorder characterized by motor symptoms including rest tremors, bradykinesia, rigidity and instabilities in gait and posture and the occurrence of non-motor symptoms including autonomic dysfunctions which develop from chronic and progressive degeneration of pigmented nuclei in the midbrain and brainstem, the olfactory tubercle, the cerebral cortex and the enteric and peripheral nervous systems [1]. In its advanced stages, PD is often complicated by additional problems such as treatmen-related complications and non-motor symptoms such as depression and dementia, which may have much greater impact on the patients' quality of life than the cardinal motor features of PD [2].

Motor features have dominated clinical impact assessments in patients with PD, however non-motor symptoms are currently attracting more attention as determinants of health-related quality of life (HRQOL) in PD [3]. The Parkinson's Disease Quality of Life Questionnaire (PDQ-39) is the most widely used patient reported rating scale endpoint in clinical trials to assess effectiveness of treatment in PD and is considered the disease-specific tool for assessing HRQOL [3,5]. It is a self-administered questionnaire composed of 39 questions grouped into 8 domains that mainly evaluate HRQOL: mobility, activities of daily living (ADL), emotional well-being, stigma, social support, cognition, communication and bodily discomfort [3]. Each domain is calculated as a scale from 0 to 100, and a higher score translates to worse quality of life as perceived by the patient [6].

HRQOL is important in chronically ill patients [3]. It reflects the internal experiences of the patient in relation to the impact of

disease and its treatment, and also including the objective functioning and subjective perceptions of health [7]. HRQOL questionnaires focus on the subjective evaluation of health and use scales assessing the level of satisfaction of patients with activities and life conditions [7]. These subjective evaluations may vary according to cultural influence and linguistics, therefore translated and validated versions of HRQOL questionnaires tailored for different cultural contexts are required for research [3,4]. While there is no universal agreement about how these instruments must be translated and culturally adapted, back translation is thought to be the most appropriate mechanism [4].

The PDQ-39 was developed in the United Kingdom (UK) and has been translated and validated in more than 60 different languages and dialects. Although the original version was found to be reliable and valid in the UK, instruments created in one language must be translated and tested for use in other cultures [8]. Thus, a Filipino version of the PD quality of life questionnaire is necessary to assess the health-related quality of life of Filipino PD patients.

## 2. Methodology

### 2.1. Target population, subject sampling, sample size calculation

A consecutive sample composed of 100 idiopathic PD patients from the outpatient clinics of the authors who met the clinical diagnostic criteria of the UK PD Society Brain Bank were included in the study [9]. Baseline MOCA-P scores of the subjects were reviewed and ranged from 19 to 29. The cut-off for MOCA-P for Filipino patients is 21 with correction of 2 points for those with <7 years of education [10]. We excluded patients with PD Hoehn and Yahr (H&Y) stage V, those with symptoms of cognitive decline (as judged by the randomizing clinician from the history and examination), deep brain stimulation devices, younger than 40 years old at onset of PD, those with secondary causes of parkinsonism and those who are unable to participate in everyday activities due to comorbidities other than PD.

## 3. Translation of the PDQ-39 into Filipino

The authors were granted permission by Isis Innovation Limited to translate the original PDQ-39 into Filipino. Two independent bilingual translators from Sentro ng Wikang Filipino, University of the Philippines Diliman and Sentro ng Wikang Filipino, University of the Philippines Manila, translated the original British English version of the PDQ-39 into Filipino. The translated Filipino version was translated back into British English by two different bilingual translators. The back-translated version was then compared to the original version, which was reviewed by the authors and the draft version was modified until a consensus was reached. After pretesting to four patients the translated version of the PDQ-39, the Philippine-PDQ-39 (P-PDQ-39) was finalized and used in subsequent analyses.

## 4. Data collection method, instruments used

The authors collected the following data from the subjects: age, sex, educational attainment, disease duration and levodopa equivalent dose per day. The levodopa equivalent dose was computed based on published conversion factors [11].

The patients were examined using the Unified Parkinson's Disease Rating Scale (UPDRS) parts I, II and III and they were classified based on the modified H&Y stage. The patients were asked to answer the P-PDQ-39, the Hospital Anxiety and Depression Scale-Pilipino (HADS-P) and the Non-motor Symptom Assessment Scale for Parkinson's Disease (NMSS) during a single visit at the outpatient clinic of the authors.

Correlation of the domains and summary index of the P-PDQ-39 with specific scales and assessments of the patients' symptoms, namely HADS-P, NMSS, UPDRS and H&Y stage, were examined to determine the construct validity of the translated questionnaire.

### 4.1. Statistical analysis

Descriptive statistics such as means and standard deviations were computed for quantitative data while values of categorical data was expressed as frequency and percentages. Cronbach's $\alpha$ coefficient was calculated to check for internal consistency between the eight domains of the P-PDQ-39 with the P-PDQ-39 summary index. The criterion value for $\alpha$ was $\geq 0.70$ and this was used to assess the questionnaire's reliability [3]. Analysis between P-PDQ-39 domains and H&Y stage was done using analysis of variance (ANOVA). The relationships between subscales of the P-PDQ-39 and other variables were analyzed using Pearson's correlation coefficient. Similar to other studies, convergent validity was measured by comparing the P-PDQ-39 domains to logically related clinical scales (3, 6, 8, 12–15). All statistical analyses were performed using 5% level of significance and STATA® V12.0 software.

### 4.2. Ethical considerations

This study [(NEU)2014-410-002] was approved by the University of the Philippines Manila Research Ethics Board.

## 5. Results

### 5.1. Demographic data

A total of 100 participants (60 men and 40 women) were enrolled in the study. The mean age of the patients was 61 years old (see Table 1). Fifty-six patients reached college level, 30% reached high school, 11% up to elementary level, 1% up to post-graduate level and 2% were illiterate. Among the 100 participants, majority are at modified H&Y stages 2 and 3 (28%), 15% at stage 2.5, 12% at stage 1.5, 10% at stage 1 and 7% at stage 4. Only five out of the 100 subjects were not taking levodopa. Levodopa dose ranges from 100.0 mg/ day to 1437.5 mg/ day. The mean levodopa equivalent dose was 502.12 ± 265.02 mg/day (range 120 – 1687.5 mg/day). Other medications taken by the patients were dopamine agonists (ropinirole and pramipexole), monoamine oxidase-B inhibitors (rasagiline and selegiline) and amantadine.

**Table 1**
Demographic data of subjects.

| Variables (n = 100) | Mean (SD) |
|---|---|
| Age (years) | 60.7 ± 9.33 |
| Parkinson's disease duration (year) | 4.67 ± 4.38 |
| Levodopa equivalent dose (mg/day) | 502.12 ± 265.02 |
| Hoehn & Yahr Stage | 2.34 ± 0.79 |
| HADS-P Depression | 5.45 ± 3.63 |
| HADS-P Anxiety | 6.93 ± 4.24 |
| UPDRS Part I | 1.53 ± 1.11 |
| UPDRS Part II | 11.41 ± 7.41 |
| UPDRS Part III | 20.2 ± 12.26 |
| NMSS Total | 40.89 ± 35.03 |

HADS-P: Hospital Anxiety and Depression Scale-Pilipino version; UPDRS: Unified Parkinson's Disease Rating Scale; NMSS: Non-motor Symptom Assessment Scale for Parkinson's Disease.