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Quality of life among patients with Parkinson's disease: A cross-sectional study in Vietnam

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ABSTRACT

Background: Health-related quality of life (HRQoL) is an important indicator of treatment outcomes for patients with Parkinson's disease (PD). Accordingly, this study determined the HRQoL of PD patients in the context of Vietnam and explored whether disease duration and disease stage affect the HRQoL of the Vietnamese subjects.
Methods: The research assessed 268 PD patients whose conditions have had a mean duration of 8.46 years. Among them, 139 (51.87%) additionally suffered from motor fluctuations and/or dyskinesia. The evaluation was conducted using the 39-item Parkinson's Disease Questionnaire (PDQ-39), which consists of eight dimensions that can be scored from 0 to 100. The higher the score, the worse the QoL of a patient.
Results: The comparison of the groups with and without motor fluctuations showed that the former scored higher in terms of mobility (MOB), activities of daily living (ADL), emotional well-being (EMO), stigma (STI), social support (SOC), and cognition (COG). A trend observed in this work was that high Hoehn and Yahr scores resulted in equally high PDQ-39 scores, except for the EMO and STI dimensions. The patients suffering from the disease for more than 5 years had worse MOB, ADL, STI, SOC, and COG scores than those of the subjects grappling with PD for ≤5 years.
Conclusion: The PDQ-39 can determine a decrease in the QoL of PD patients, and such reduction is predicted by the occurrence of motor fluctuations.

Keywords: Dyskinesia, Fluctuation, HRQoL, Quality of life, QoL, Parkinson, Vietnam.

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INTRODUCTION

Quality of Life (QoL), as a leading measure through which a disease burden can be estimated, has in the recent past been increasingly applied in situations involving chronic diseases. Among such conditions, one of the most common degenerative diseases occurring globally is Parkinson's disease (PD) (Tamas *et al.*, 2014). Most of the results of studies on the incidence and prevalence of PD suggested that in every 100,000 individuals, about 31 to 201 will develop the illness (Akbar *et al.*, 2015; Lawrence *et al.*, 2014). Some symptoms associated with PD implicate the motor system, whereas others involve non-motor features. Examples of the latter include impaired mood and cognition, defective sebaceous gland activity, deteriorating gastric and bowel function, salivation, and impaired sleep, vision, and olfaction (Rosinczuk *et al.*, 2019). Motor symptoms take the form of tremors and postural instability, bradykinesia, and rigidity (Carod-Artal *et al.*, 2007). Investigations indicated that PD arises from various cardinal motor signs, with the degree to which the condition progresses reflected in the level of a patient's motor abilities. Correspondingly, the management of PD has been focused on motor symptom improvement (Carod-Artal *et al.*, 2007; Muslimovic *et al.*, 2008).

Aside from struggling with the above-mentioned symptoms, most PD patients are highly vulnerable to the deterioration of health-related quality of life (HRQoL). Perceived deterioration is attributed primarily to both compromised motor abilities and non-motor symptoms (Winter *et al.*, 2010; Gallagher *et al.*, 2010). The trends with respect to the decline in motor function highlight the criticality of ensuring that the HRQoL of PD patients is assessed. In particular, low HRQoL has been linked to different predictive factors, including (motor symptom-related determinants) gait disorder, postural instability, motor complications, and disease severity (Martinez-Martin *et al.*, 2011; Goetz *et al.*, 2008). Some of the predictive forces linked to non-motor symptoms are sleep problems, urinary disturbance, pain, fatigue, cognitive impairment, anxiety, and depression (Oguh *et al.*, 2014; Rodriguez-Blazquez et al., 2013). Researchers have also strived to unearth HRQoL determinants that are independent of clinical aspects, with studies identifying socio-demographic factors, namely, the number of individuals in each household among affected populations as well as the levels of education of patients and their families (Oguh *et al.*, 2014; Krikmann *et al.*, 2008).

QoL standards are suitable measures for the outcomes of new treatments, such as rehabilitation (Gallagher *et al.*, 2010; Martinez-Martin *et al.*, 2011; Goetz *et al.*, 2008; Oguh *et al.*, 2014; Rodriguez-Blazquez *et al.*, 2013; Krikmann *et al.*, 2008). These standards can take the form of subjective measures, including perceptions regarding symptoms, level of fitness, self-image, satisfaction with family life and work, economic situation, interactions with other people, social support, and life in general. Another advantage of QoL measures is that they can be incorporated in questionnaires that may be completed by a patient in person or by telephone interview or by family members, individuals having close relationships with patients, and professional careers and other health professionals. However, the most desirable and reliable assessment is one conducted by a patient himself/herself, especially when the QoL items to be measured are of a subjective nature. The QoL scales for PD patients can be classified into universal (general–generic) and specific (disease-oriented) scales. The 39-item Parkinson's Disease Questionnaire (PDQ-39) was created in 1995 by a group of Oxford University colleagues led by Peto and Jenkinson (Peto *et al.*, 1995). Comparative studies on the PDQ-39 and the 36-item Short Form Health Survey (SF-36) showed the highest sensitivity in the evaluation of mobility, activities of daily life, emotions, and the stigma of PD (Peto *et al.*, 1995; Jenkinson *et al.*, 1995). These studies also reported that SF-36 is considerably sensitive in the assessment of physical conditions and pain (Peto *et al.*, 1995; Jenkinson *et al.*, 1995), indicating the substantial usefulness of the scale as a type of PDQ-39 that can be used to evaluate most dysfunctions in PD.

Notwithstanding the availability of accurate measures, however, the estimation of HRQoL among PD patients in Vietnam is limited. Local data and evidence on country-specific contexts are needed for health economic evaluations that have become increasingly important for PD with the spread of advanced device-aided therapies. With these issues in mind, we determined the HRQoL of PD patients in Vietnam using a PD-specific questionnaire and explored whether disease duration and disease stage affect the HRQoL of the subjects.

METHODOLOGY

Study design and study site

This research is a cross-sectional study conducted over a year and involving a sampling period of six months (January to June 2019). The study site was Lam Dong General Hospital, located in Lam Dong Province in the Central Highlands of Vietnam. Approval was granted by the Research Ethics Council of the hospital. The patients participated voluntarily, with written consent forms obtained from them.

Participants and sampling

Prospective participants were selected for participation via total population sampling. The patients were enrolled in the study upon satisfaction of the following criteria: a (1) confirmed diagnosis of PD, as indicated in medical records, (2) ages between 40 and 90 years, and (3) the absence of a diagnosis of depression before PD detection. The exclusion criteria were (1) secondary Parkinsonism caused by organic disease or brain damage, (2) the lack of a confirmed diagnosis of PD, and (3) the inability to fill out survey forms because of mental reasons (e.g., disorientation) or linguistic factors (e.g., foreigners).

Instrument

The instrument used in this research was the PDQ-39, whose original English version was translated by a non-healthcare professional into Vietnamese. Backtranslation was conducted by another translator to check for possible mistakes or cultural biases. The questionnaire was then reviewed by the researchers to ensure its easy accessibility and compatibility with the patients' reality. The instrument exhibited a Cronbach's alpha of 0.75 for reliability.

Each question in the PDQ-39 comes with five response options related to the frequency of disease manifestations. The answers essentially refer to the impact of the illness on a patient's life in a previous month, as explained to the respondents before interviews were initiated. The 39 questions are distributed across eight dimensions: mobility (10 questions), activities of daily living (6), emotional well-being (6), stigma (4), social support (3), cognition (4), communication (3), and bodily discomfort (3). Scoring for each question ranges from 0 to 4 (0 = "Never", 1 = Occasionally, 2 = "Sometimes", 3 = "Often", 4 = "Always"). The final score is calculated by taking the sum of the scores, dividing it by the result, multiplying this by 4 (the maximum score for each question), and dividing it by the total number of questions. The derived figure is then multiplied by 100. Correspondingly, for each dimension, patients can generate a score of 0 to 100 along a linear scale, with 0 denoting excellent QoL and 100 indicating poor QoL (Erola *et al.*, 2005).

This study also used the Hoehn and Yahr (HY) scale to assess the PD patients' level of disability and the clinical stage of the disease (Hoehn and Yahr, 1967). The scale was set in such a way that the conditions of individuals who were bedridden or bound to a wheelchair were assigned a rating of 5, whereas the conditions of those who presented with unilateral body involvement were provided a rating of 1. The patients were divided into two groups, namely, a group presenting with motor fluctuations and/or dyskinesia and a group comprising patients without these symptoms. The criteria used for group assignment were defined on the basis of the interviews and confirmed by the attending neurologist.

Data analysis

Data were entered into Microsoft Excel 2010 for management. The demographic and clinical characteristics of the patients were presented as descriptive statistics. Given normal data distribution, a t-test and analysis of variance (ANOVA) were carried out to ascertain differences between the groups of patients. A p-value lower than 0.05 was regarded as reflective of a statistically significant difference. Statistical tests were performed using the Statistical Package for the Social Sciences version 20.0.

RESULTS

This study involved 268 PD patients, among whom the majority were male, younger than 60 years, retired, run their households with help from an individual of a close relationship, and have suffered from PD for over 5 years. Half of them rated their health status as being of a moderate level and suffer from motor complications (fluctuations and/or dyskinesia) that have been

confirmed by a neurologist. The patient distribution according to the HY scale was as follows: 30 patients (11.19%) in stage 1 of the disease, 67 (25%) in stage 2, 68 patients (25.37%) at stage 3, 67 (25%) in stage 4, and 36 patients (13.43%) in stage 5. Table 1 shows the demographic and disease-related characteristics of the patients. Table 2 presents the scores of the patients with respect to the 39 items and eight dimensions of the PDQ-39. Most of the scores indicated intermediate-level conditions, consistent with the self-reports of the patients regarding their health status. The patients generated the highest mean score for bodily discomfort (51.52, standard deviation [SD]: 30.28), meaning that they felt worse as regards this dimension than the domains identified in the questionnaire.

Table 1. Characteristics of patients with PD (N = 268)

Characteristics	n (%)	Characteristics	n (%)
Gender		**Retired**	
Male	135 (50.37)	Yes	138 (51.49)
Female	133 (49.63)	No	130 (48.51)
Age		**Running a household**	
Mean (standard deviation)	64.61 (14.71)	Independently	57 (21.27)
40-60	115 (42.91)	With a close person	151 (56.34)
61-70	49 (18.28)	With family	60 (22.39)
71-90	104 (38.81)	**Hoehn and Yahr stage****	
Duration of Parkinson's disease (years)		I	30 (11.19)
Mean (standard deviation)	8.46 (3.97)	II	67 (25.00)
≤5	74 (27.61)	III	68 (25.37)
>5	194 (72.39)	IV	67 (25.00)
Severity*		V	36 (13.43)
Mild	68 (25.37)	**Fluctuation and/or dyskinesia*****	
Moderate	137 (51.12)	Yes	139 (51.87)
Severe	63 (23.51)	No	129 (48.13)

Notes: *Data presented as n (%) unless state otherwise. *Self-rated. **Treating physician confirmed, (I= unilateral disease, II= bilateral disease without impairment of balance, III= bilateral disease with impaired postural reflexes, IV= severely disabling disease, and V= confined to bed or wheelchair unless aided). ***Neurologist confirmed.*

Table 2. Description of PD questionnaire with item and dimension scores

Mobility (MOB)	**49.63 (30.27)**	**Stigma (STI)**	**49.23 (30.86)**
Leisure activities	1.87 (1.18)	Felt need to conceal PD	2.01 (1.25)
Looking after home	2.13 (1.23)	Avoid eating/drinking in public	2.08 (1.24)
Carrying shopping bags	1.99 (1.21)	Embarrassed due to PD	1.75 (1.19)
Problems walking half a mile	1.95 (1.14)	Worried people's reactions	2.03 (1.23)
Walking 100 yards	1.98 (1.23)	**Social support (SOC)**	**47.76 (30.40)**
Getting around the house	1.96 (1.22)	Close relationships	1.89 (1.19)
Getting around in public	1.96 (1.14)	Support from partner	1.85 (1.26)
Need company when going out	2.01 (1.26)	Support from family or friends	2.02 (1.19)
Worry falling in public	1.95 (1.21)	**Cognitions (COG)**	**49.53 (30.69)**
Confined to the house	2.07 (1.26)	Unexpectedly fallen asleep	2.04 (1.21)
Activities of daily living (ADL)	**48.85 (30.47)**	Concentration	2.03 (1.25)
Washing	1.98 (1.26)	Poor memory	1.99 (1.21)
Dressing	1.92 (1.23)	Dreams or hallucinations	1.90 (1.25)
Do buttons or shoelaces	1.97 (1.22)	**Communication (COM)**	**49.88 (30.97)**
Writing clearly	2.06 (1.21)	Speech	1.97 (1.23)
Cutting food	1.84 (1.22)	Unable communicate properly	2.13 (1.21)
Hold a drink without spilling	1.97 (1.17)	Felt ignored	1.88 (1.27)
Emotional well-being (EMO)	**51.12 (30.57)**	**Bodily discomfort (BOD)**	**51.52 (30.28)**

Depressed	2.04 (1.23)	Painful cramps or spasms	2.13 (1.17)
Isolated and lonely	2.10 (1.23)	Pain in joints or body	1.97 (1.24)
Weepy or tearful	2.11 (1.12)	Unpleasantly hot or cold	2.09 (1.22)
Angry or bitter	1.98 (1.27)		
Anxious	1.99 (1.20)		
Worried about the future	2.04 (1.28)		

Notes: *Data presented as mean (standard deviation). Item score range from 0 to 4. Dimension score range from 0 to 100.*

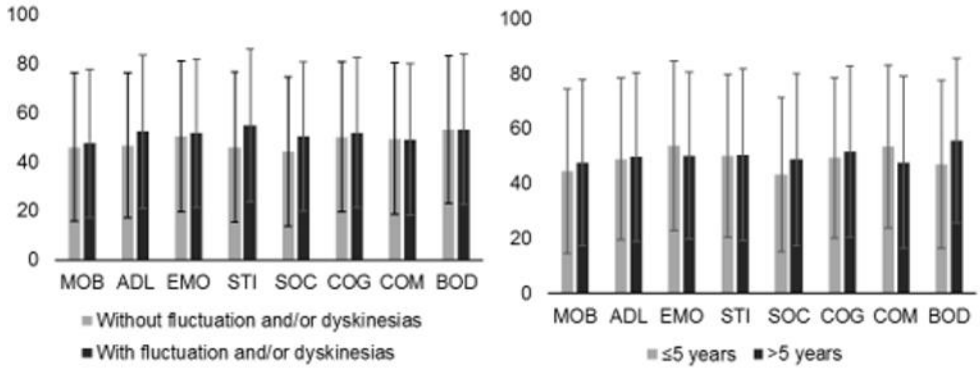
Table 3. PDQ-39 dimension scores of PD patients in HY stage groups

	Stage I (n=30)	Stage II (n=67)	Stage III (n=68)	Stage IV (n=67)	Stage V (n=36)	P-value*
MOB	36.67 (31.18)	48.13 (30.15)	49.26 (29.75)	47.39 (30.58)	46.53 (30.20)	0.006
ADL	55.98 (29.48)	52.24 (29.91)	45.96 (31.59)	45.52 (30.28)	53.47 (30.67)	0.005
EMO	52.50 (28.78)	48.88 (30.85)	52.21 (30.43)	50.01 (30.74)	54.17 (31.62)	0.065
STI	44.17 (32.07)	51.87 (30.69)	52.57 (30.01)	50.34 (31.12)	49.31 (31.39)	0.070
SOC	50.67 (31.42)	41.79 (29.71)	53.31 (29.36)	46.64 (30.61)	44.44 (32.41)	0.007
COG	49.17 (30.58)	55.97 (31.79)	51.10 (31.07)	45.90 (30.19)	52.78 (28.91)	0.041
COM	48.33 (30.21)	50.21 (31.88)	45.59 (30.64)	52.61 (30.72)	49.31 (31.31)	0.036
BOC	54.17 (28.34)	52.61 (31.94)	50.23 (31.41)	54.85 (29.72)	56.94 (27.87)	0.023

Note: *Data presented as mean (standard deviation). *ANOVA test.*

Abbreviation: *ADL, activities of daily living; BOD, bodily discomfort; COG, cognitions; COM, communication; DIF, differential item functioning; EMO, emotional well-being; HY, Hohen and Yahr; MOB, mobility; PD, Parkinson's disease; PDQ-39, 39 item Parkinson's disease questionnaire; SOC, social support; STI, stigma.*

As can be seen in Table 3, the mean score of the dimensions fluctuated depending on HY stage. However, the ANOVA confirmed significant differences among the scores in six out of the eight dimensions. Emotional well-being and stigma were the two dimensions for which no significant difference between disease stages was found.



Note: *Data presented as mean (standard deviation). T-test showed significant difference for ADL (p=.002), STU (p=.024), SOC (p=.039) **i**n left chart; for MOB (p=.023), SOC (p=.045), BOD (p=.018) in right chart.* ***Abbreviation:*** *ADL, activities of daily living; BOD, bodily discomfort; COG, cognitions; COM, communication; DIF, differential item functioning; EMO, emotional well-being; MOB, mobility; PD, Parkinson's disease; PDQ-39, 39 item Parkinson's disease questionnaire; SOC, social support; STI, stigma.*

Figure 1. PDQ-39-dimension scores of PD patients with and without motor complications (left chart) and patients grouped by disease duration (right chart)

Figure 1 illustrates the mean dimensional scores of the groups with and without motor complications and such scores arranged by disease duration. In general, the patients suffering from fluctuations and/or dyskinesia had a low QoL. Disease duration may have also affected the patients' QoL in respect of mobility, bodily discomfort, and social support.

DISCUSSION

The central purpose of this investigation was to examine some of the parameters that shape the HRQoL of PD patients in Vietnam. PD is a chronic disease that tremendously affects quality of life (Damiano *et al.*, 2007). Its impact on QoL is frequently measured using the PDQ-39 because this questionnaire is the most extensively adopted measure worldwide and encompasses a number of items designed to assess the effects of the disease. Other instruments, such as the SF-36, the Nottingham Health Profile, and the Sickness Impact Profile, are good but general scales and are not specific to PD (Jenkinson and Fitzpatrick, 2007).

This study showed that disease severity as assessed on the basis of HY stages was harmful to the QoL of the patients, especially in terms of activities that involve motor skills (Slawek *et al.*, 2005) (Figure 1). The more serious the disease stage, the worse the QoL in relation to aspects concerning physical independence (Reuther *et al.*, 2007; Schrag *et al.*, 2000). The results on emotional well-being and stigma aspects contrasted with expectations; that is, the less severe the disease stage, the stronger the effects on QoL. This discrepancy may be explained by the patients' initial reaction in acknowledging that they have an incurable, progressive disease and that they may become physically, emotionally, and economically dependent, thus causing emotional problems. PD-associated depression sometimes precedes motor disabilities (Slawek *et al.*, 2005; de Lau *et al.*, 2006). The presence of motor fluctuations accelerates the decline in QoL compared with the situation of patients without fluctuations (Garrett *et al.*, 1998). As corroborated by the findings, the patients suffering from motor fluctuations scored higher under dimensions requiring greater bodily and motor independence, demonstrating that motor deficits are an important factor in worsening QoL. Another factor that negatively affected the QoL of the PD patients was disease duration, as depicted in Figure 1. However, this effect was evident only in five items. The longer the disease lasts, the worse the performance of afflicted individuals in all motor or cognitive activities. In our sample, however, we could not demonstrate statistically significant differences in most of the dimensions on the grounds of disease duration.

In healthcare, one of the key priorities is patient safety, driving the majority of current healthcare providers to embrace the use of systems designed to monitor and prevent harm and thereby ensuring that quality improvements are directed by investments in various approaches (Reuther *et al.*, 2007). Although these efforts are intended to enable the organizations to keep abreast with patient needs and industry demands, especially in terms of enhancing adverse event detection, one of the significant challenges confronting institutions is the efficient resolution of problems related to patient safety. In nursing practice, which involves serving in an intensive care unit (ICU), areas requiring quality improvement are palliative care and supporting the end-of-life stage of patients. A specific problem is the need for advance care planning for patients. On these bases, this research proposes the implementation of quality improvement initiatives in nursing departments, with particular emphasis on the need for ICU nurses to support PD patients undergoing end-of-life care.

For advance care plans and care planning discussions, the main problem is the lack of timely implementation, with the process taking months or weeks rather than days. Advance care plans have also been proven difficult to access by palliative care facilitators—a situation compounded by the lack of a common database for customized and community-wide reporting. Finally, advance care planning in ICU sections is problematic, wherein the integration of data into electronic health records has been difficult. Some studies (Slaughter *et al.*, 2001) suggested that advance care planning ensures the prevention of unwanted care. A similar investigation asserted that such endeavor empowers patients (Hinderer *et al.*, 2015), establishing further that patients who are aware of the documentation of their care goals and whose desires have been shared with their families and physicians are likely to gain confidence in the care that they receive (i.e., that it conforms to their wishes). Researchers have also observed that advance care planning guarantees the individualization of care, which increases the use of palliative care via a transition from a curative to a palliative orientation. On the basis of these outcomes, advance care planning improves patient QoL and enables concerned parties to focus on symptom management (Hinderer *et al.*, 2015; Laryionava *et al.*, 2015). Yet other explorations uncovered that allowing individuals to express their views about care reduces the length and number of hospital admissions (Kristian and Eleanor, 2015), especially when care providers are given leeway in arranging end-of-life requirements or life-sustaining treatment for the purpose of enabling patients to spend more time in home settings, hospices, or care homes. This initiative has also been associated with improved family bereavement experience and, hence, reduced depression, anxiety, and stress as it effectively prepares members in making appropriate financial and legal arrangements before the death of an afflicted loved one (Tokito *et al.*, 2015).

The current study's findings were insightful, but certain limitations are worth noting. For instance, clinical data collection occurred at a single point, which implied that the patterns of PD progression and how it shapes the HRQoL of other cohorts are unlikely to be determined or predicted. In addition, the results were derived from only one hospital, thus rendering the data unrepresentative of the national population.

CONCLUSION

The data demonstrated that the PDQ-39 is a multi-dimensional instrument that provides physical, emotional, and environmental insights that are useful in medical practice. It is easily understood and handled by patients, thereby allowing an enhanced assessment of disease progression and drug therapy. It is therefore an important tool in making therapeutic decisions that minimize the effects of PD and improve the QoL of afflicted patients.

CONFLICTS OF INTERESTS

The authors have no conflicts of interests to declare.

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