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Original Article

Quality of life in people with Parkinson's disease: the relevance of social relationships and communication

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Abstract. [Purpose] Maintaining high quality of life is crucial for the rehabilitation of patients with Parkinson's disease. The quality of life scales currently in use do not assess all quality of life domains or their importance for each individual. Therefore, a new quality of life measure, the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting, was used to investigate quality of life in people with Parkinson's disease. [Subjects and Methods] Fifteen people with idiopathic Parkinson's disaese (average age = 80.0 years, standard deviation = 10.3 years, Hoehn & Yahr stages 1–4) were interviewed using the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting. Its quality of life constructs were tested by comparing them against disease-specific quality of life (39-items Parkinson's Disease Questionnaire), motor functioning (Unified Parkinson's Disease Rating Scale Part III), and activities of daily living (Barthel Index). [Results] Social connections such as "family" and "friends" were revealed as important constructs of life satisfaction. The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting was not significantly correlated with the 39-items Parkinson's Disease Questionnaire, Unified Parkinson's Disease Rating Scale Part III, or Barthel Index but was significantly correlated with the "communication" dimension of the 39-items Parkinson's Disease Questionnaire. [Conclusion] The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting detected various domains of quality of life, especially social relationships with family and friends. "Being heard" was also revealed as an essential component of life satisfaction, as it provides patients with a feeling of acceptance and assurance, possibly resulting in better quality of life.

Key words: Quality of life, Parkinson's disease, Social relationship

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INTRODUCTION

Parkinson's disease (PD) is a progressive neuromuscular disorder found most commonly among older adults; however, its progression is relatively slow[1)]. Thus, it is important to help maintain functional abilities related to independent living through rehabilitation[2–8)]. Quality of life (QOL) also plays an important role in independent living. For instance, happier people are more active in their daily lives and maintain better physical health[9)]. Therefore, maintaining high QOL could be a key factor during the rehabilitation of people with PD.

QOL is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns[10)]." It is a comprehensive state consisting of not only one's physical and mental status (or level of independence), which could easily be affected by PD symptoms, but also several other factors such as emotional and social functioning[11)]. Therefore, when treating patients with degenerative chronic conditions, dealing merely with physical function and independence is likely insufficient. Indeed, rehabilitation

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practitioners must approach various life domains, working from a broader perspective of QOL.

As a QOL outcome measure, a new measurement scale was developed to integrate various domains determining the QOL level[12–14]. Existing QOL measures, such as the 39-item Parkinson's Disease Questionnaire (PDQ-39)[15], the Medical Outcomes Study 36-item Short Form Survey (SF-36)[16], and the Sickness Impact Profile (SIP)[17], usually include concrete items addressing the patient's satisfaction level with reference to daily activities (e.g., eating and bathing). Thus, such scales might not include exact life domains or reflect the weight placed on each domain by a particular individual. A newly developed QOL measurement, the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) scale, is aimed at overcoming this limitation[18, 19]. In the SEIQoL-DW, each patient reflects on the meaningful areas of his/her life, and QOL is determined by multiplying the satisfaction and importance levels (weightings) of each area. For patients with chronic diseases, QOL might consist of many different factors. The SEIQoL-DW does not use preset items, which may make it better able to capture broader and more unique QOL aspects. Lee et al.[20] measured QOL among individuals with PD using the SEIQoL-DW in the United Kingdom. However, they did not examine the uniqueness of this measure, nor did they compare the SEIQoL-DW with other QOL measures. Furthermore, there is no evidence regarding similarities between QOL constructs across different countries and races.

In this study, we administered the SEIQoL-DW to investigate the QOL constructs in Japanese people with PD. We also compared the SEIQoL-DW with a more established QOL measure (PDQ-39) and other life domain variables, including motor function and independence in activities of daily living (ADL), to better understand the QOL constructs in Japanese people with PD.

SUBJECTS AND METHODS

Subjects were recruited via fliers posted on hospital bulletin boards. Additionally, staff neurologists informed their patients regarding the project. Individuals were eligible for inclusion in the study if they were (1) diagnosed with idiopathic PD, (2) currently at Hoehn and Yahr Stages 1–4, and (3) able to cognitively reflect upon and report about their current and past daily life (Mini-Mental State Examination [MMSE] > 24). We excluded individuals with a history or evidence of other medical conditions that could interfere with QOL. Sample size was calculated using the Hulley's matrix (1988), and 13 subjects was shown to be a sufficient sample size to achieve a significant correlation coefficient.

The present study analyzed data collected from 15 people with idiopathic PD (10 women, 5 men, mean age = 80.0 years, standard deviation [SD] = 10.3 years), equally distributed across disease severity. The subjects' demographic characteristics are shown in Table 1.

QOL was evaluated using two different measures: the SEIQoL-DW and PDQ-39. The SEIQoL-DW is a semi-structured interview tool with a specific manual[14, 17, 18]. First, the interviewer asks, "What are the five things that are important in your life?" In response to this, subjects pick five items that best determine their QOL. Next, the subjects rate their satisfaction level for each item using a Visual Analogue Scale. Subjects also use a disk to determine the significance of each item. Finally, the satisfaction level and significance ratio for each item are multiplied and summed to calculate a QOL index [Index =Σ (satisfaction level × significance ratio)]. Indices range from 0 to 100, and a higher index indicates higher QOL.

The PDQ-39 is a disease-specific QOL measure. This measure asks a patient how often she/he has experienced a certain event due to PD. Ratings are made on a five-point Likert scale from 0 "never" to 4 "always"[14]. The PDQ-39 consists of 39 items with 8 subscales: "mobility," 10 items; "activities of daily living," 6 items; "emotions," 6 items; "stigma," 4 items; "social support," 3 items; "cognitions," 4 items; "communication," 3 items; and "bodily discomfort," 3 items. The score is converted to a 0–100 scale, and higher scores indicate lower QOL. Adequate reliability and validity of the Japanese version of the PDQ-39 has been previously established[21].

The Unified Parkinson's Disease Rating Scale Part III (UPDRS-III) was used to measure motor function[22]. Twenty-seven items address motor function related to tremor, rigidity, posture, and bodily movements. Scores range from 0 to 108, and higher scores indicate lower motor functioning.

Level of independence in terms of ADL was measured using the Barthel Index (BI)[23]. The BI assesses independence with reference to each ADL: feeding, toileting, bathing, walking, dressing, and others. Scores range from 0 to 100, and higher scores indicate higher ADL independence.

The following demographics were collected in this study: gender, age, number of years since diagnosis, marital status, current living situation, caretaker, and disease severity (indicated by the Hoehn & Yahr stage).

Data were collected over a five-month period. After signing a consent form, each subject attended a single 60-minute interview. To ensure uniformity in the quality of the interviews, only one interviewer, who was trained in using the SEIQoL-DW, conducted all the interviews. During the interview, subjects completed the SEIQoL-DW and PDQ-39 and were then tested with the UPDRS-III and BI. General demographic information was collected from each subject's medical records (i.e., age and disease duration). The study protocol followed the guidelines of the Declaration of Helsinki and was approved by the Institutional Review Board of Kitasato University (09-526). A written consent form was obtained from all of the subjects.

In order to define the QOL constructs of interest, the SEIQoL-DW items reported by the 15 subjects were categorized into different domains: physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. To determine the unique constructs of QOL captured by the SEIQoL-DW, Spearman's correlation

Table 1. Demographic characteristics (N = 15)

Characteristic	
Gender, n (%)	
Male	5 (33.3%)
Female	10 (66.7%)
Age, M (SD)	69.8 (10.3)
Number of years since diagnosis, M (SD)	7.2 (4.3)
Marital status, n (%)	
Single or divorced	2 (13.3%)
Married	13 (86.7%)
Current living situation, n (%)	
Living alone in the community	1 (6.7%)
Living with family member	14 (93.3%)
Caretaker, n (%)	
None	3 (20%)
Spouse	9 (60%)
Children	2 (13.3%)
Spouse and children	1 (6.7%)
Hoehn & Yahr stage, n (%)	
Stage 1	1 (6.7%)
Stage 2	1 (6.7%)
Stage 3	6 (40%)
Stage 4	7 (46.7%)
Stage 5	0 (0%)
UPDRS III, M (SD)	24.3 (15.1)
Barthel Index, M (SD)	80.7 (17.8)
PDQ-39 total score, M (SD)	42.8 (19.9)
Mobility, M (SD)	61.6 (31.5)
Activities of daily living, M (SD)	46.4 (31.3)
Emotions, M (SD)	42.8 (23.1)
Stigma, M (SD)	27.2 (26.8)
Social support, M (SD)	15.6 (14.0)
Cognitions, M (SD)	40.0 (20.3)
Communication, M (SD)	27.2 (20.8)
Bodily discomfort, M (SD)	44.4 (24.1)
SEIQoL-DW index, M (SD)	74.6 (18.1)

coefficients were calculated to test the relationships between the SEIQoL-DW index, PDQ-39 total and subscale scores, and the UPDRS-III and BI scores. The statistical analyses were performed using SPSS for Windows, version 11.0 J (SPSS Japan Inc., Tokyo, Japan). The significance level was set at 5%.

RESULTS

Results related to each measure are shown in Table 1.

With reference to the QOL constructs drawn from the SEIQoL-DW, the most frequently reported item was “family” (13 patients, 87%), followed by “friends” (10 patients, 67%), “hobbies” (10 patients, 67%), “health” (9 patients, 60%), “financial situation” (6 patients, 40%), “neighbors” (4 patients, 27%), “relatives” (3 patients, 20%), and so on.

Correlations between the scales are shown in Table 2. The SEIQoL-DW index showed no significant correlations with the PDQ-39 total score or the UPDRS-III and BI scores ($rs = -0.06$, $p = 0.83$; $rs = -0.15$, $p = 0.59$; $rs = 0.27$, $p = 0.34$, respectively). However, when looking at each of the PDQ-39 dimensions, the SEIQoL-DW index was significantly correlated with “communication” ($rs = -0.52$, $p = 0.04$; Table 2), but not with any other dimension. In contrast, the PDQ-39 total score was strongly and significantly correlated with the UPDRS-III and BI scores ($rs = 0.79$, $p < 0.01$; $rs = -0.72$, $p < 0.01$, respectively).

Table 2. Correlations between the SEIQoL-DW score and other variables (N = 15)

Variables	rs
UPDRS-III	−0.15
Barthel index	0.27
PDQ-39 total score	−0.06
Mobility	0.24
Activities of daily living	−0.33
Emotions	0.1
Stigma	0.01
Social support	−0.26
Cognitions	−0.06
Communication	−0.52*
Bodily discomfort	−0.26

*Statistically significant ($p < 0.05$)

DISCUSSION

In the present study, the SEIQoL-DW revealed "social relationships" as the most significant domain of QOL in people with PD, including items related to family, friends, neighbors, and relatives. Lacking social relationships within the family and community may lower QOL in people with PD. Similarly, we observed a significant correlation between the SEIQoL-DW index and the "communication" dimension of the PDQ-39. Items related to the "communication" dimension in the PDQ-39 were "had difficulty with speech," "unable to communicate with people properly," and "felt ignored by people." This suggests that the feeling of being "able to communicate" is important in maintaining social relationships with one's family and relatives, and "feeling accepted by people" is also very important, as it can provide patients with a feeling of acceptance and assurance. Previous studies have shown that a communication deficit is a significant concern for PD patients because it limits their social relationships with those they trust the most: family and relatives[26, 27]. Again, social connection was shown to be a significant factor affecting QOL in people with PD.

According to the World Health Organization[10], QOL consists of six significant domains: physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. In our study, the PDQ-39 total score significantly correlated with the UPDRS-III and BI scores. These results resemble those of a previous study showing disease-specific QOL measures, such as the PDQ-39, to be strongly related to the "physical domain" and "level of independence" of QOL[24]. Lee et al.[20] used the SEIQoL-DW in people with PD and found "walking/mobility" and "going out" to be significant items; thus, the QOL as measured by the SEIQoL-DW in their study likely captured the motor function and independence level, which may have led to the significant correlation between the SEIQoL-DW and PDQ-39 revealed in their study.

On the other hand, the present study appeared to capture QOL in other unique areas, specifically those related to "social relationships" but not other domains (the "physical domain" assessed by the UPDRS-III or "level of independence" assessed by the BI). One explanation of the difference between Lee's study and our study is cultural values. Molzahn et al. have shown that culture explains 15.9% of variance in one's reported QOL domains[28]. Moreover, they found that ADL was the most important domain in many countries, but not in Japan. Lee's study may have reflected Western cultural values (United Kingdom), and, thus, their subjects primarily valued independence level. On the other hand, Japan and other Eastern countries are considered to value social connection over other domains. Likewise, Kato et al. reported that Japanese patients with neuromuscular diseases trust their families and relatives for advice should any deficits emerge[25]. Thus, the patients in our study reported "family" and "relatives" to be the most important QOL domains. Consequently, our findings suggested that QOL domains vary between different countries and races.

The sensitivity of the SEIQoL-DW was supported in our study. Compared with the disease-specific QOL measures, such as the PDQ-39, the SEIQoL-DW was able to capture more individualized domains of QOL. For instance, the PDQ-39 consists of items regarding difficulty due to PD, which could highly reflect disease severity. However, the SEIQoL-DW allows clients to select their own domains of QOL, enabling them to interpret cultural values regardless of disease severity. The SEIQoL-DW could be a useful tool to measure the level of QOL and could validly reflect the diverse values of individuals.

With reference to the clinical implications of these findings, therapists and other medical professionals should value social relationships and communication in aiding positive patient outcomes. Social support has been shown to be associated with depression in PD[29]. However, the social support network in the community is still in its infancy[30]. Introducing a social support group may be a good start to build a social support network for PD patients.

The present study was limited by its use of a small sample of 15 patients with moderately severe PD symptoms (Hoehn &

Yahr stages 3–4). Future work must include more subjects to better investigate the variables and diverse constructs of QOL. A longitudinal study would also be helpful to better capture changes in the QOL domains and related factors. Finally, when targeting communication skills and social support networks in interventions to enhance QOL, intervention efficacy should be addressed.

The SEIQoL-DW revealed that social relationships with family and friends, as well as communication ability, were reported as essential aspects of QOL by our sample of patients with PD. On the other hand, other QOL domains, such as the physical domain (motor functioning: UPDRS-III) and level of independence (ADL independence: BI), were not related to QOL as measured by the SEIQoL-DW. Building a social network/support and facilitating communication might be important for enhancing QOL among individuals with PD.

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