

Turkish Version Study of “Parkinson’s Disease Quality of Life Questionnaire” (PDQL)

“Parkinson Hastalığı Yaşam Kalitesi Sorgulama Formu (PDQL-TR)”nun Türkçe Versiyon Çalışması

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ABSTRACT

Introduction: This study aimed to evaluate Turkish transcultural adaptation, reliability, and validity of “Parkinson’s Disease Quality of Life Questionnaire” (PDQL), which has been developed to assess the quality of life of patients with Parkinson’s disease.

Methods: Eighty-nine patients who were included in the study were diagnosed with Parkinson’s disease. They were presented to the outpatient clinic of the İstanbul Faculty of Medicine, Physical Medicine and Rehabilitation department between July 2005 and April 2008. The Turkish translated version of PDQL (PDQL-TR), “Unified Parkinson’s Disease Rating Scale” (UPDRS), and Hoehn & Yahr (HY) were used as the main outcome measures.

Results: The calculated Pearson correlation coefficient for PDQL, H&Y, and UPDRS ranged between -0.36 and -0.80. Cronbach’s alpha

coefficients of the PDQL-TR complete questionnaire and subdomains were higher than 0.80. The absolute value of item-total score correlation coefficients by Pearson fluctuated between 0.40 (question 4-total score) and 0.88 (question 26-total score), whereas the subdomain-total score correlation coefficients ranged between 0.81 and 0.96. PDQL-TR showed high stability according to the ICC results, ranging between 0.75 (Emotional Function) and 0.88 (Parkinsonian Symptoms).

Conclusion: The psychometric features of PDQL-TR are satisfactory, and our results are consistent with the previous literature findings. PDQL-TR is a valid and reliable tool to measure health-related quality of life in patients with Parkinson’s disease.

Keywords: Parkinson disease, quality of life, reliability, validity

ÖZET

Amaç: Bu çalışma Parkinson hastalığı olan hastaların yaşam kalitesini değerlendirmek için geliştirilen “Parkinson Hastalığı Yaşam Kalitesi Sorgulama Formu’nun (PDQL-TR)” Türkçe kültürel adaptasyonunu, geçerlilik ve güvenilirliğini araştırmayı amaçlamıştır.

Yöntem: İstanbul Üniversitesi İstanbul Tıp Fakültesi, Fiziksel Tıp ve Rehabilitasyon Anabilim Dalı’nın polikliniğine Haziran 2005-Nisan 2008 tarihleri arasında başvuran, Parkinson hastalığı tanısı almış 89 hasta çalışmaya dahil edilmiştir. PDQL’in Türkçe versiyonu (PDQL-TR), “Birleştirilmiş Parkinson Hastalığı Derecelendirme Ölçeği” (UPDRS), “Hoehn & Yahr (H & Y) skolası” temel sonuç ölçüm yöntemleri olarak kullanıldı.

Bulgular: PDQL-TR, H&Y ve UPDRS skalaları için hesaplanmış Pearson korelasyon katsayısı -0,36 ve -0,80 arasında değişmekteydi. PDQL-TR sor-

gulama formunun total ve alt grup skorlarının Cronbach alpha katsayısı 0,80’den yüksekti. Madde toplam puan değeri Pearson korelasyon kat sayısı 0,40 (4.soru-toplam skor) ve 0,88 (26. soru-toplam skor) arasında değişmekteydi, alt-grup toplam skorlarının korelasyon katsayıları ise 0,81 ile 0,96 arasındaydı. PDQL-TR’nin sınıf içi korelasyon sonuçları 0,75 (emosyonel fonksiyon) ve 0,88 (Parkinson semptomları) aralığında yer alarak, yüksek stabilite göstermiştir.

Sonuç: PDQL-TR’nin psikometrik özellikleri memnuniyet vericidir ve sonuçlarımız önceki literatür bulgularıyla uyum göstermektedir. PDQL-TR Parkinson hastalığı olan hastaların sağlıklı ilişkili yaşam kalitelerini ölçmede geçerli ve güvenilir bir sorgulama formudur.

Anahtar kelimeler: Parkinson hastalığı, yaşam kalitesi, güvenilirlik, geçerlilik

INTRODUCTION

Parkinson’s disease is a chronic, progressive, and increasingly disabling disease which is associated with complex movement disorder, including rigidity, bradykinesia, and tremor as well as gait disorders and imbalance over time. Gradually increasing disability and decreasing quality of life can cause problems derived from the progressive character of the disease (1). This chronic disease leads a progressive impairment in various fields of a patient’s health state and independence and functional ability, causing a clearly negative impact on health-related quality of life, which is broadly understood by the subject as the effect of the disease process and of its medical treatment on his/her life (2,3,4,5).



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Recently, the concept of health-related quality of life gained more importance, and it became an important outcome measure of studies conducted on chronic diseases (6,7). It is now possible to measure quality of life because of the development of reliable, valid, and accurate instruments (8). Because it is well-known, disease-specific quality of life questionnaires better reflect the course of the disease for a particular subject, and they are generally more sensitive for changes in the health-related quality of life (9). General and disease-specific quality of life questionnaires are used to evaluate the quality of life of patients with Parkinson's disease. There are disease-specific questionnaires such as the 39-item Parkinson's Disease Questionnaire (PDQ-39) (10), the Parkinson's Disease Quality of Life Scale (PDQUALIF) (11), and the Parkinson's Disease Quality of Life Questionnaire (PDQL) (12), which are currently in use to evaluate disease-specific quality of life in Parkinson's disease. Those questionnaires were originally written in foreign languages and developed for relevant cultures; thus, there is no Turkish questionnaire, which is developed specifically for Parkinson's disease in our country (according to the search results performed between 2004 and 2012 by PubMed, OVID, SumSearch, CINAHL, EMBASE, MEDLINE, Cochrane, and Medscape). Research studies conducted using such questionnaires are used to evaluate the effects of the diseases on the quality of life, and they are also valuable with respect to determining the status of the patient and observing the effects of the treatment. Hence, it is important to examine these questionnaires to check whether they are reliable and valid for Turkish culture and language.

We aimed to evaluate Turkish transcultural adaptation, reliability, and validity of the PDQL, which has been developed to assess the quality of life of patients with Parkinson's disease.

METHODS

The current study used the Turkish translated version of PDQL (PDQL-TR), which is a quality of life questionnaire comprising 37 questions and four subdomains. Each item is rated on a 5-point scale (always, 1; mostly, 2; sometimes, 3; rarely, 4; never, 5). The four subdomains are comprised of Parkinsonian symptoms with 14 items, systemic symptoms with 7 items, social function with 7 items, and emotional function with 9 items. The subdomain scores are calculated by summing scores given to each question of the relevant subdomain (11). A higher score implies a better quality of life. There are various studies which were conducted using the questionnaire (8,13,14). The Turkish version of the questionnaire, which had been translated into many languages, was written by our study team in accordance with linguistic validation rules as requested by "MAPI Research Institute" (15) and the final questionnaire was acknowledged. Accordingly, at the first phase of the translation, the English version of the PDQL was independently translated into two Turkish versions by a translation group, including authors of the current study comprising one physical medicine and rehabilitation physician and three physiotherapists with good command in English (forward translation), and a final text was derived from those two translations following relevant discussions. The translators did not meet, and they translated separately. When the translations were completed in the forward translation phase, the two forward translations were examined. The translation of all the questions was equivalent to the original. Both forward translations of questions 1, 2, and 20 were synonyms referring to the same meaning. For question 1, "stiffness" was translated as "katılık" and "sertlik" in Turkish; "sertlik" was accepted as final. For question 2, "feeling generally unwell," was translated to "genel olarak rahatsız hissetme" and "genel olarak hasta hissetme;" "genel olarak hasta hissetme" seemed to be appropriate. For question 20, "on/off periods," was translated as "açılma-kapanma dönemleri" in both the forward translations; however, it did not seem to reflect the original meaning clearly and it needed to be explained. It was changed as a result of reconciliation to "hastalık

aktivite durumunuzda ani artma veya azalma" to avoid misunderstanding of question 20. The other questions were translated without conflict, and the final version of these two forward translations was completed. In the second phase of translation, the final text was translated into English by a native speaker who also has a good command in Turkish (back translation); he had no access to the original version of the questionnaire. The question 1, returned as "stiffness" which is the synonym for "rigidity" and they both refer to the same word "sertlik" in Turkish. Question 20 was returned as "Sudden increase or decrease in condition of illness activity," which reflects the original version of question 20 "on/off periods" in a detailed and clear way to understand. The translation of all the questions was equivalent to the original. Hence, we concluded that the Turkish translation of the questionnaire is appropriate and reflects the original English version of the questionnaire. The reconciliation was performed by comparing the translated text with the original version of the questionnaire in the third phase. This final text was applied to five patients, and it was re-evaluated for non-consistent items to ensure that all items are clear in the pilot testing phase. The mean completion time of the questionnaire was 16.8 min; no difficulty in understanding the questionnaire in Turkish was reported. Because the patients seemed to have no problem with answering the questions, we may infer that the questions were clear and simple to understand. The earliest result was obtained in the 14th min and the latest result in the 19th min. The patient who completed the questionnaire first had a higher educational and social degree than the others; therefore, we had idea that it can be reason to make her understand and answer quickly. Thus, the linguistic translation phase of the study was completed, and we carried on for the psychometric analysis of the questionnaire as the Turkish version of the questionnaire was obtained.

The study was conducted in 89 patients diagnosed with Parkinson's disease who were admitted to the outpatient clinic of Istanbul Faculty of Medicine, Physical Medicine and Rehabilitation department.

The study excluded the subjects fulfilling the following criteria: illiterate, any disease other than cognitive condition that may lead to neurological impairment or disability, and Mini-Mental State Examination (16) score ≤ 23 . All participants were informed about the study. Informed consents were obtained from each patient, and ethical committee approval was obtained from the Istanbul University Faculty of Medicine. Patients filled the questionnaire on their own. The mean time to fill the questionnaire was 18.51 (SD 2.8) min. In addition to PDQL-TR, "Unified Parkinson's Disease Rating Scale" (UPDRS) was administered to the patients. The UPDRS is a scale that was developed to monitor PD-related disability and impairment. A higher score indicates a poor health status for the patient. The scale itself has four subscales, derived from pre-existing scales that were reviewed and modified by a consortium of movement disorder specialists (Part I, Mentation, Behavior and Mood; Part II, Activities of Daily Living; Part III, Motor; Part IV, Complications) (17). We used the first three parts of the scale. The UPDRS is used as a gold standard reference scale (18). The UPDRS is currently the most commonly used one among all the available clinical scales for the assessment of parkinsonian motor impairment and disability (19); there is a Turkish inter-rater reliability study of the scale (20). Hence, we chose this commonly used scale as a reference scale. The other scale that we used for comparisons was the Hoehn & Yahr (HY) disease rating scale, which is another commonly used system for describing how the symptoms of Parkinson's disease progress. The scale has five grading systems, which indicates that a higher score implies poor disease condition (21). Progressively higher stages correlate with neuroimaging studies of dopaminergic loss, and high correlations exist between the HY scale and some standardized scales of motor impairment, disability, and quality of life (22).

Table 1. Pearson correlation coefficients for PDQLQ-TR, HY, and UPDRS

PDQL-TR	HY	UPDRS			
		I	II	III	Total
Parkinsonian symptoms	-0.73**	-0.49**	-0.72**	-0.72**	-0.79**
Systemic symptoms	-0.45*	-0.55**	-0.53**	-0.56**	-0.63**
Emotional function	-0.46*	-0.56**	-0.44*	-0.42*	-0.51**
Social function	-0.55**	-0.63**	-0.56**	-0.56**	-0.65**
PDQL-total	-0.64**	-0.60**	-0.64**	-0.64**	-0.73**

*Significant at 0.05 level and **Significant at 0.01 level (two-tailed). PDQLQ-TR, the Turkish translated version of Parkinson's disease quality of life questionnaire; HY, Hoehn and Yahr; UPDRS, Unified Parkinson's disease rating scale; PDQL-TR, Turkish translated version of PDQL; PDQL, the Parkinson's Disease Quality of Life Questionnaire

Table 2. Cronbach's alpha coefficients of other versions of PDQL and PDQL-TR

	De Boer et al. (11)	Hobson et al. (27)	Serrano-Duenas et al. (28)	Campos et al. (29)	Current study
PDQL-total	0.96	0.95	0.96	0.93	0.97*
Parkinsonian symptoms	0.86	0.87	0.85	0.83	0.90*
Systemic symptoms	0.80	0.77	0.69	0.65	0.88*
Emotional function	0.82	0.85	0.81	0.80	0.89*
Social function	0.87	0.87	0.78	0.79	0.89*

*Significant at 0.01 level (two-tailed). PDQL, the Parkinson's Disease Quality of Life Questionnaire; PDQL-TR, the Turkish translated version of Parkinson's Disease Quality of Life questionnaire

Table 3. Pearson subdomain-total score correlation coefficients of PDQL-TR

	PDQL-total	Parkinsonian symptoms	Systemic symptoms	Emotional function	Social function
PDQL-total	1	0.92*	0.91*	0.91*	0.95*
Parkinsonian symptoms	0.92*	1	0.78*	0.71*	0.81*
Systemic symptoms	0.91*	0.78*	1	0.83*	0.82*
Emotional function	0.91*	0.71*	0.83*	1	0.93*
Social function	0.95*	0.81*	0.82*	0.93*	1

*Significant at the 0.01 level (two-tailed). PDQL-TR, the Turkish translated version of Parkinson's Disease Quality of Life questionnaire; PDQL, the Parkinson's Disease Quality of Life Questionnaire

Table 4. PDQL-TR intra-class correlation coefficients (test-retest analysis)

	Martinez et al. (30) (n=50)	Current Study (n=46)
PDQL-total	0.90	0.82*
Parkinsonian symptoms	0.91	0.88*
Systemic symptoms	0.85	0.85*
Emotional function	0.88	0.85*

*Significant at the 0.01 level (two-tailed). PDQL-TR, the Turkish translated version of Parkinson's Disease Quality of Life questionnaire; PDQL, the Parkinson's Disease Quality of Life Questionnaire

Statistical Analysis

Statistical analyses of the study were performed using the Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL, USA) v18.0 software pack. The Kolmogorov–Smirnov test was applied to determine the normality of the study data, and it was found to have a normal distribution. Therefore, we continued with the parametric analysis. For a reliability analysis, Cronbach alpha (23,24) coefficients of each subdomain of PDQL-TR were separately calculated to ensure internal consistency. In addition, item-total score reliability coefficients were reviewed and correlation coefficients between subdomains and relevant items were calculated. Because it was another reliability analysis, test-retest reliability, intra-class correlation coefficient (ICC), and Pearson correlation coefficient was calculated between baseline measurement, and the next measurement was performed 1 week later. Correlation coefficients resulting from all statistical analyses were regarded as follows: 0–0.25, no relationship or very weak relationship; 0.25–0.50, weak-to-moderate relationship; 0.50–0.75, good relationship; and 0.75–1.00, very good relationship (25).

RESULTS

Our study group consisted of 89 participants [50 males (56.2%) and 39 females (43.8%)], all of whom completed the PDQLQ-TR. The age of the participants varied from 40 to 82 years; the mean age was 64.83±11.81 years. The onset of the disease ranged between 2 and 18 years, and there were 11 patients (12.4%) in stage I, 25 patients (28.1%) in stage II, 46 patients (51.7%) in stage III, and 7 patients (7.9%) in stage IV, according to the HY scale. The educational level of the subjects was determined as follows: 46 elementary school (51.7%), 14 secondary school (15.7%), 18 high school (20.2%), and 11 academy graduates (12.4%). The mean scores of the questionnaire were found to be 125.28±25.47 for the total PDQL-TR, 47.72±9.51 for Parkinsonian symptoms, 23.85±5.14 for systemic symptoms, 22.92±5.99 for social function, and 30.80±6.29 for emotional function. UPDRS mean scores were as follows: 2.83±2.16 (UPDRS-I), 14.10±6.73 (UPDRS-II), 17.37±6.8 (UPDRS-III), and 34.3±13.73 (UPDRS total). The calculated Pearson correlation coefficient for PDQL, HY, and UPDRS ranged between -0.42 and -0.79; the comparison of these variables are given in Table 1. We wanted to perform a factor analysis for testing the construct validity of the questionnaire. Therefore, we performed the Kaiser–Meyer–Olkin test. The value we obtained was 0.461 (less than 0.5), which is considered inappropriate for a factor analysis. Therefore, we did not conduct further analysis.

The internal consistency evaluation of the questionnaire was performed by calculation of the Cronbach's alpha coefficient; the complete questionnaire (items 1–37) and PDQL-TR subdomains had higher values than 0.80. The estimated Cronbach's alpha values for the PDQLQ-TR were greater than the standard value 0.70 (26). Table 2 presents the values of Cronbach's alpha coefficient for PDQL-TR, estimated by the current study, in addition to the original and the different versions (11,27,28,29).

The absolute value of item-total score correlation coefficients calculated by Pearson correlation fluctuated between 0.42 (Q4-total score) and 0.91 (Q26-total score), whereas the subdomain-total score correlation coefficients ranged between 0.71 and 0.95 (Table 3). Only 51 of the subjects could attend the second testing performed 1 week after the initial testing; the patients did not receive any change in their treatment routine during this time range. PDQL-TR showed high stability according to the ICC results, ranging between 0.76 (Social function) and 0.88 (Parkinsonian symptoms). The results compared with previous literature are given in Table 4 (30).

DISCUSSION

It is very important to investigate psychometric properties of a health-related quality of life questionnaire for its comprehensibility and answerabil-

ity by the target population. In particular, if the questionnaire is originally prepared in another language, there are some essential stages that need to be performed to provide a better understanding to the target population and adapt it to target sociocultural characteristics when performing a translation of a questionnaire to a second language. Therefore, we performed a translation process using the PDQL English version that was prepared following the guidelines of the MAPI Research Institute (15). After this linguistic validation process was completed, a copy of the PDQL-TR was sent back to the MAPI institute because many other versions took its place to be used in different studies. Therefore, it was another necessary step to evaluate the psychometric properties of PDQL-TR.

Our study group consisted of 89 participants with a large range of disease onset between 2 and 18 years; most of them were at stages 3 and 2 according to HY. We evaluated convergent validity, which determines the amount of association between two measures of the same construct, by using Pearson's correlation coefficient. PDQL-TR, HY, and UPDRS total and subdomain scores were found to be significantly correlated with each other. Many other studies showed similar results for the different versions of PDQL in the literature (28,29). PDQL-TR Parkinsonian symptoms subdomain was highly correlated with UPDRS II (activity of daily living) and III (motor symptoms), PDQL-TR ES subdomain showed the highest correlation with UPDRS I (mentation, behaviour, mood) as shown in the Table 1. A moderate-to-high correlation was observed between all PDQL measures with UPDRS subdomains (0.31–0.74) and HY (0.29–0.61) in a study comparing PDQL and PDQ-39 (28). In addition, our study sample size was small to perform a factor analysis for construct validity analysis. To the best of our knowledge, no study performed this type of analysis. Therefore, this issue can be the subject for a future study with a higher sample size.

To investigate the reliability of PDQL-TR, the coherence of the items were calculated by Cronbach's alpha and item-total correlation coefficient. In statistics, internal consistency or reliability of a psychometric test score is estimated by Cronbach's alpha and item-total correlation coefficients. Therefore, we used Cronbach's alpha coefficient to assess the internal reliability of the scoring system. Cronbach's alpha was calculated for each item of the PDQL-TR. It is known that 0.70 or higher values of Cronbach's alpha show a good correlation between the items (23). In our study, the estimated Cronbach's alpha value was 0.97 for PDQL-TR total, which addresses a high internal consistency of the questionnaire; this is a value that can be considered as highly consistent and shows internal coherence between the questions and the questions are complementing each other. In a similar way, the subdomains have showed coherent and consistent results with each other and also with the whole questionnaire. Our findings, presented in the Table 2, were similar and comparable to the original version of PDQL and the other versions of the questionnaire in the literature.

The absolute value of item-total score correlation coefficients calculated by Pearson fluctuated between 0.42 (Q4-total score) and 0.91 (Q26-total score), whereas the subdomain-total score correlation coefficients ranged between 0.71 and 0.95 (Table 3).

ICC values were found to be significantly high (0.76–0.88), which indicates that the results of the tests applied at different times were consistent with each other, as a test-retest reliability of the questionnaire. A systematic review in 2002 reported that the test-retest reliability of the questionnaire was not performed yet (7). Another study published in 2007 reported that test-retest analysis of PDQL remained unexplored till their study, and the authors concluded that their study results were satisfactory (30). We can report that our study would be the second to explore this

type of analysis for PDQL because we have not encountered any other study yet, and our results seem to be consistent with that study results.

It would be much better to compare PDQL with another disease-specific quality of life questionnaire in Parkinson's disease, such as PDQ-39; however, the lack of quality of life questionnaires specific to Parkinson's disease in Turkish was a limitation to perform this type of comparison. The sample size of our study may be considered rather small, but despite the small number of patients in this study, the results obtained for each subdomains and total questionnaire were similar to the results of previous studies.

We can thus conclude that the psychometric features of PDQL-TR are satisfactory, and our results are consistent with the previous literature findings, including different version studies of PDQL. We may infer that PDQL-TR is a valid and reliable tool to measure health-related quality of life in patients with Parkinson's disease, and it is easy to understand its use and administer it as a self-administered questionnaire.

It is an obvious need to perform version analysis of the questionnaires, which are originally developed in different cultures and languages. This type of study enables us to use these evaluation tools developed by different countries by removing the language and culture barriers. This may also be helpful to create new evaluation tools because it leads the way as well as it helps to evaluate patients. Although our reported findings in this study may not be definitive, the results with this number of subjects are still sufficient to conduct future studies.

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