

Validity and Reliability of the Korean Version of the Parkinson's Disease Questionnaire–Carer

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Background and Purpose The importance of the quality of life (QOL) of carers has been increasingly recognized as it has a wide range of effects on the psychological, emotional, and social outcomes of patients with Parkinson's disease (PD). Understanding their QOL is important as it reflects their unique characteristics; however, there have been few studies on this in Korea. This study aimed to translate and validate the Korean version of the Parkinson's Disease Questionnaire–Carer (PDQ–Carer).

Methods This was a methodological study that included a translation process and a cross-sectional investigation. The Korean version of the scale was developed using back translation, semantic adjustment, and pretests. The final version was self-administered by 125 Korean family carers. Cronbach's alpha values were used to assess the internal consistency of the PDQ–Carer. Exploratory and confirmatory factor analyses were used to validate the translated scale.

Results Exploratory factor analysis identified four factors that accounted for 64.51% of the variance. A modified model using modification indices was found to fit the data well in the confirmatory factor analysis. That factor analysis supported the structure of the original four factors with relocation of several items that reflected Korean culture. Cronbach's alpha values were 0.96 for the total scale, 0.93 for personal and social activities, 0.89 for strain, 0.85 for anxiety and depression, and 0.85 for self-care.

Conclusions This study verified that the Korean version of the PDQ–Carer can be used to acquire important information about the multidimensional aspects of the QOL of Korean carers for patients with PD.

Keywords Parkinson's disease; carers; translations; reliability; validity.

Received October 10, 2022

Revised January 12, 2023

Accepted April 3, 2023

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INTRODUCTION

Parkinson's disease (PD) is a common neurodegenerative disease in older adults.¹ Patients with PD gradually become dependent on carers due to reduced mobility and impaired ability to perform the activities of daily livings (ADLs).²⁻⁴ Family carers play a critical role in the disease progression and provide a wide spectrum of support to patients.^{4,5} The pattern of family caregiving may appear in various forms under the influence of regional differences including population demographics, family dynamics, and culture.⁵ Asian cultural values involve filial piety and familism.⁶ Family members in Korea mostly act as carers due to cultural characteristics and ethical values.⁷ The carers of patients with PD, who are mostly older adults, frequently have to take the responsibility of providing care alone, increasing the difficulty of the caring experience.^{8,9} As carers focus on providing care and its intensity increases, their social participation decreases and their psychological, economic, and physical burdens increase.¹⁰⁻¹² These consequences affect the quality of life (QOL) of carers

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for patients with PD, which is very important since it affects the health-related outcomes of those PD patients.^{4,13}

The QOL of carers is multidimensional and involves physical, psychological, and social aspects.⁴ Awareness of the importance of using disease-specific tools to measure QOL has recently been increasing, and the development of such tools has been increasingly regarded as a research priority.⁴ The World Health Organization Quality of Life Scale has limitations in assessing the QOL of carers because it does not reflect the specificity of PD.¹⁴ Reflecting this point, a scale was developed to measure the QOL of carers for patients with parkinsonism.¹⁵ However, that scale focuses on the carers of patients with parkinsonism, and only has one domain. Meanwhile, most of the studies on carers of patients with PD have used the terms “burden” and “pressure,” but these have narrow meanings compared with QOL, which is a broader concept associated with the overall well-being of the carer.¹⁶ Instruments should go beyond a narrow focus on the burden and pressure faced by carers for patients with PD to understand their QOL.¹⁶ Accordingly, Jenkinson et al.¹⁶ developed the Parkinson’s Disease Questionnaire–Carer (PDQ-Carer) to measure the QOL of carers for patients with PD. This tool is multidimensional, covering four domains of QOL: social and personal activities, anxiety and depression, self-care, and strain. The PDQ-Carer is currently used to assess the disease-specific QOL of carers across different cultures.¹⁷⁻¹⁹ In particular, a psychometric testing study of the PDQ-Carer found that the Cronbach’s alpha values of the Spanish version for the four domains were 0.80–0.95 and that it had good validity.¹⁷ However, the characteristics of caregiving and the applicability of the scale may differ between cultures, and the applicability of the PDQ-Carer to Korea has not been stud-

ied previously. This study aimed to translate the PDQ-Carer into Korean and determine its reliability and validity.

METHODS

This was a methodological study comprising two phases: 1) developing the Korean version of the PDQ-Carer using back-translation, expert panel evaluation, semantic adjustment, and pretests, and 2) conducting a cross-sectional study to examine the validity and reliability of the translated version of the PDQ-Carer.

Phase 1: translation process

This study followed the back-translation method (Fig. 1).²⁰ The translation process proposed by Brislin in 1970 is the most-commonly recommended method for cross-cultural studies.²¹ A pilot testing was subsequently conducted.

Translation and back-translation of the original PDQ-Carer

We received approval from the original author to translate the PDQ-Carer into Korean. In the translation stage, two bilingual researchers with experience in clinical practice independently translated the original tool. In the back-translation stage, another translator who had not previously encountered the original tool translated the Korean version back into English. Back-translation works well in avoiding translation errors because a large part of the original language structure is retained.²¹

Final validation

The translated tool was finalized in the final stage (Supple-

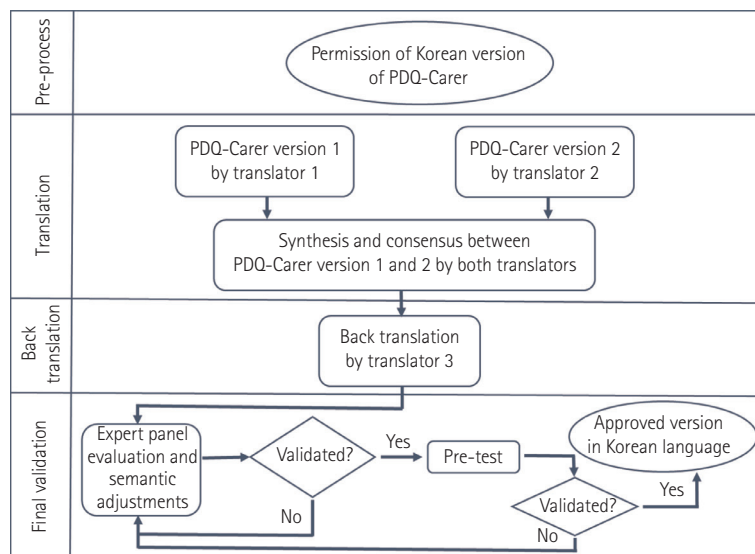


Fig. 1. Translation process of this study. PDQ, Parkinson’s Disease Questionnaire.

mentary Material in the online-only Data Supplement). This process requires comparing the two versions as a whole,²¹ and it confirmed that there were no meaningful differences between the original and translated versions. All differences were reviewed and corrected through discussions. The consensus process was repeated to complete the translation if corrections were needed due to the accuracy of translation or cultural differences.

Pretests for tool verification

Pretests have the advantage of verifying that future user can understand all of the questions and procedures in the translated version.²¹ The pretests of the Korean version of the PDQ-Carer was conducted on ten carers of patients with PD who were community-dwelling members of the Korean Parkinson's Disease Association (KPDA). The process identified any problems with the tool and assessed the feasibility through discussions about content clarity, ease of understanding, appropriateness of the form, and the time it takes to respond.

Phase 2: the cross-sectional study

Participants and setting

The concept of the carer is applied inconsistently across different disciplines.²² According to a recent evolutionary concept analysis, a family carer often refers to an individual who provides patients who need care involving a wide range of unpaid physical, psychological, and social assistance.^{22,23} A team renowned for caregiving research and headed by Lawton defined a carer as "the person who gives half or more of all the care needed."²⁴ The subjects of that study comprised primary family carers of community-dwelling patients with PD in Korea, who were defined as those who spent at least 1 day per week mostly caring for patients.²⁵ We tried to include adult child-carers who provide most of the care required by patients with PD and have primary responsibility for their care. The scope of care activities included disability-related, treatment, and health care activities. Disability-related activities referred to clinical skills for assistance with ADLs and instrumental ADLs of patients with PD who experienced difficulties performing activities such as bathing, toilet use, or transferring.^{23,26} Treatment-related activities included assistance in taking medication as prescribed and regular hospital visits. Healthcare activities included assistance in participating in peer-group activities, exercise, and seeking social resources.²⁶ The inclusion criteria were as follows: 1) caring for a patient diagnosed with PD by a neurologist, 2) being a family member of a patient with PD, and 3) being older than 20 years.

For the factor analysis, there are some criteria for the minimum sample size. The first suggestion was that the sample should be larger than 100.²⁷ The ratio of the number of cases to the number of factors was also considered. The number of cases should be larger than 20 times the number of factors in order to obtain stability in their effects.^{28,29} The present study included 125 participants for the 4 factors, so the case-factor ratio was considered to be acceptable.

Data collection

This study recruited subjects who attended regional events organized by the KPDA and visited regular follow-ups at the neurology outpatient clinic of a university hospital with patients with PD, between March 16 and August 16, 2019. In the case of data collection at the KPDA, the PD diagnoses were confirmed by checking the disability welfare card of the patients accompanied by their carer, because this verified that they were registered with a disability and were previously diagnosed with PD by a neurologist. Data were collected by trained researchers. Face-to-face surveys took 15 minutes to complete.

Instruments

The general characteristics included age, sex, education level, occupation status, relationship with patients with PD, cohabitation, caring period, and daily caring duration.

The original PDQ-Carer consists of 29 items in 4 dimensions: personal and social activities, anxiety and depression, self-care, and strain.¹⁶ The items in each dimension are evaluated on a five-point scale, from 'never' to 'always'. The score was converted to a standard score for the present analysis. Lower scores indicate better QOL, with a score of 0 representing the best level of self-reported QOL and a score of 100 representing the worst level. The original study obtained Cronbach's alpha values of 0.94, 0.90, 0.85, and 0.85 for social and personal activities, anxiety and depression, self-care, and strain, respectively.

Validity refers to whether a tool measures what it is intended to.³⁰ Before conducting exploratory factor analysis (EFA), Kaiser-Meyer-Olkin (KMO) sample fit and Bartlett's test of sphericity were performed to verify that the collected data were suitable for the factor analysis. To evaluate the concept, convergence, and discrimination validities of the results, the standardized coefficient, the variance extraction index, and the r^2 value of the correlation coefficient were checked for each factor. Confirmatory factor analysis (CFA) was conducted to test the model of the Korean version of the PDQ-Carer based on a sample to determine the suitability of the factor model derived from the EFA. Reliability denotes the extent to which research results can be applied to a wider range of

samples than the actual sample.³⁰ Cronbach's alpha was calculated to confirm the reliability of the internal consistency.³¹

Data analysis

The statistical analysis was performed using IBM SPSS Statistics (version 23.0; IBM Corp., Armonk, NY, USA) and IBM SPSS Amos (version 22.0; IBM Corp.). Descriptive statistics were used for the general characteristics of the study subjects. Skewness and kurtosis were checked using the normality test. The reliability of the tool used Cronbach's alpha and the split-half coefficient to test its internal consistency. The validity of the tool was tested for construct validity and confirmed using the EFA and CFA. Data sets can be used for both the EFA and CFA since this is helpful for comparing similarities and differences between the results.³² EFA is often needed to compare construct differences in cross-cultural studies. The number of factors was determined based on an eigen value of ≥ 1 and a scree plot, and the factors were then extracted to determine that the total explained variance was at least 60%.²⁷ The EFA checks the KMO measures of sample fit and uses the principal-components analysis and varimax rotation methods. CFA was performed using Tucker-Lewis index (TLI), comparative fit index (CFI), and root-mean-square error of approximation (RMSEA). The model fit was evaluated using the criteria of CFI ≥ 0.90 , TLI ≥ 0.90 , and RMSEA < 0.08 . The research model was modified by reviewing the modification indices (MIs) of the model as results of the analysis.

Ethics approval

The Institutional Review Board of the hospital approved this study (IRB No. Y-2019-0013). The researchers explained the purpose and procedures of the study to its participants and conducted face-to-face surveys. All participants understood the purpose of the study and provided written informed consent.

RESULTS

Participant characteristics

Table 1 lists the characteristics of the participants. They were aged 57.24 ± 14.56 years (mean \pm SD) and approximately half of them were female (55.2%). Most participants had a college education or higher (52.8%), a spouse (66.9%), and lived with the patient that they were caring for (79.2%). The most frequent caring period was longer than 5 years (40.8%), and the most common daily caring duration was 1–6 hours (56.8%).

The differences in QOL according to general characteristics are listed in Table 2. QOL was better in the adult children of patients with PD than in the parents of those patients

Table 1. Participant characteristics

Characteristic	Mean \pm SD or n (%)
Age, years	57.24 \pm 14.56
Sex	
Male	56 (44.8)
Female	69 (55.2)
Education level	
Elementary school	2 (1.6)
Middle school	16 (12.8)
High school	41 (32.8)
College or above	66 (52.8)
Relationship with the patient	
Spouse	80 (64.0)
Parents	3 (2.4)
Sibling	6 (4.8)
Child	26 (20.8)
Other family member	10 (8.0)
Cohabitation	
Yes	99 (79.2)
No	26 (20.8)
Occupation status	
Employed	68 (54.4)
Unemployed	57 (45.6)
Unemployed because of caring	
Yes	12 (21.1)
No	45 (78.9)
Caring period, years	4.91 \pm 4.46
≤ 1	30 (24.0)
2	14 (11.2)
3	16 (12.8)
4	14 (11.2)
≥ 5	51 (40.8)
Daily caring duration, hours	7.94 \pm 8.22
1–6	80 (64.0)
7–12	22 (2.4)
13–18	3 (16.0)
≥ 19	20 (15.8)

($F=2.74$, $p=0.03$), and lower in participants who were unemployed due to the care than those who were not ($t=2.21$, $p=0.04$). Other characteristics were not associated with QOL.

Item analysis for the Korean version of the PDQ-Carer

Item analysis was conducted to evaluate the 29 items in the tool (Table 3). The mean score of the items ranged from 0.67 to 2.03 while the SDs ranged from 0.97 to 1.43 after analyzing all 29 items. Data are considered to confirm to the normal distribution when the absolute values of skewness and

Table 2. Differences in quality of life according to general characteristics

Variables	n	Mean±SD	t or F (p)
Age, years		<i>r</i> =0.12, <i>p</i> =0.19*	
Sex			0.15 (0.88)
Male	56	38.63	
Female	69	37.97	
Relationship with the patient			2.74 (0.03)
Spouse	80	40.71	
Parents	3	57.00	
Sibling	6	43.83	
Child	26	25.65	
Other family member	10	42.50	
Cohabitation			-0.26 (0.79)
Yes	99	38.22	
No	26	39.54	
Occupation status			1.20 (0.23)
Employed	68	40.60	
Unemployed	57	35.47	
Unemployed because of caring			2.21 (0.04)
Yes	12	47.83	
No	45	32.18	
Caring period, years			0.82 (0.52)
≤1	30	33.57	
2	14	41.29	
3	16	39.50	
4	14	48.13	
≥5	51	41.43	
Daily caring duration, hours			1.48 (0.22)
1–6	80	37.82	
7–12	22	43.85	
13–18	3	58.33	
≥19	20	46.42	

*Pearson's correlation coefficient.

kurtosis do not deviate from 2 and 7, respectively,³³ and every item in this study confirmed to this standard. The corrected item-total correlations were 0.492–0.822, with all items exceeding 0.4 indicating a significant degree of reliability.³⁴ All 29 items were therefore maintained for use in subsequent analyses.

Validity

Exploratory factor analysis

Four factors appeared to have eigen-values of ≥1 and an elbow point on the scree plot (Fig. 2). The explanatory powers of factor 1 to 4 were 47.90%, 6.77%, 5.00%, and 4.95%, respectively; these four factors explained 64.51% of the total variance, which satisfied the standard, and so four factors were used (Table 4). The KMO test was performed to deter-

mine whether the number of variables and cases in this study sample were suitable for factor analysis, and obtained a result of 0.92. Bartlett's sphericity test was performed to confirm whether the correlation coefficient matrix was suitable for factor analysis, which yielded a value of 2678.365 (*p*<0.001). Both results indicated suitability for the factor analysis. In the factor extraction method, principal-components analysis was used to extract factors that explain as many parts as possible, and EFA was performed using varimax rotation. This analysis yielded loadings for factors 1 to 4 of 0.546–0.761, 0.451–0.780, 0.467–0.786, and 0.541–0.812, respectively (Table 4).

Factor 1 comprised ten items: eight items (items 5, 18, 19, 20, 21, 25, 27, and 29) in the 'personal and social activities' domain and two (items 22 and 26) in the 'self-care' domain in the original tool. Factor 1 was named 'personal and social activities,' the same as in the original tool. Factor 2 comprised eight items: two (items 10 and 16) in the 'strain' domain, three (items 14, 24, and 28) in the 'personal and social activities,' and one each in the 'self-care' (item 13), 'anxiety and depression' (item 15), and 'strain' (item 9) domains in the original tool. Factor 2 was named 'strain,' the same as in the original tool. Factor 3 comprised six items: four (items 6, 11, 12, and 17) in the 'anxiety and depression' domain as in the original tool, and two (items 7 and 23) in the 'strain' domain. Factor 3 was named 'anxiety and depression,' the same as in the original tool. Factor 4 comprised five items: two (items 2 and 3) in the 'self-care' domain and one each in the 'strain' (item 1), 'anxiety and depression' (item 4), and 'personal and social activities' (item 8) domains in the original tool. Factor 4 was named 'self-care,' the same as in the original tool. These results indicated that the four factors were same as the those in the original tool: personal and social activities, strain, anxiety and depression, and self-care (Table 4).

Confirmatory factor analysis

The statistics for model fit are presented in Table 5. A 4-factor model with all 29 items was maintained for the final model (Fig. 3). Model 1, which comprised the original 4 factors with all 29 items, was found to not satisfy the model fit criteria [$\chi^2/df=1.986$, *df*=371, *p*<0.001, TLI=0.841, CFI=0.855, parsimony normed fit index (PNFI)=0.691, incremental fit index (IFI)=0.869, and RMSEA=0.089]. We carefully reviewed the pairing error variances of two items in the personal and social activities domains (factor 1) (item 22 'felt that your physical health has been affected by your caring role?' and item 27 'felt unable to go on holiday or take short breaks?' [MI=16.923]) and two items in the strain dimension (factor 2) (item 14 'felt more withdrawn because of your caring role?' and item 15 'felt depressed?' [MI=15.624]).

Table 3. Item analysis for the Parkinson's Disease Questionnaire–Carer

Item no.	Item	Mean±SD	Item–total correlation	Skewness	Kurtosis
1	Found you could not sleep through the night?	1.26±1.19	0.509	0.534	-0.731
2	Found it difficult to get out to do the shopping?	0.98±1.23	0.771	1.016	-0.172
3	Found the demands of caring physically difficult?	0.89±1.16	0.788	1.107	0.128
4	Felt anxious because of the responsibility of caring?	1.48±1.26	0.608	0.644	-0.540
5	Been prevented from pursuing hobbies and other interests?	1.27±1.21	0.663	0.725	-0.323
6	Felt worried about your own physical health?	1.68±1.21	0.723	0.334	-0.816
7	Thought that your caring role was taken for granted by others?	1.78±1.41	0.594	0.189	-1.275
8	Felt that relationships with friends have been affected?	1.13±1.23	0.658	0.796	-0.475
9	Felt impatient with the person you care for?	1.34±1.18	0.691	0.592	-0.615
10	Felt exhausted?	1.30±1.22	0.638	0.670	-0.517
11	Felt worried about the future?	1.92±1.22	0.718	0.182	-0.934
12	Felt you lacked the energy and motivation to do the things you enjoy?	1.46±1.14	0.704	0.492	-0.611
13	Taken less care with your diet?	1.22±1.26	0.549	0.806	-0.411
14	Felt more withdrawn because of your caring role?	1.18±1.20	0.747	0.711	-0.581
15	Felt depressed?	1.26±1.15	0.635	0.723	-0.308
16	Felt less in control of your temper than before you became a carer?	1.02±1.00	0.726	1.001	0.652
17	Felt worried about what would happen if you were unwell?	1.49±1.12	0.698	0.557	-0.297
18	Been limited in what you can do socially?	1.19±1.26	0.747	0.806	-0.487
19	Felt that your workload around the house has increased significantly?	1.39±1.28	0.483	0.653	-0.752
20	Found it difficult to see friends and family?	1.06±1.24	0.766	0.945	0.000
21	Found it difficult to leave the person you care for alone for more than one hour?	1.16±1.28	0.663	0.747	-0.610
22	Felt that your physical health has been affected by your caring role?	1.17±1.28	0.688	0.896	-0.226
23	Felt that you are responsible for everything at home?	2.06±1.34	0.775	-0.098	-1.175
24	Felt that you cannot do things on the spur of the moment?	0.78±1.03	0.739	1.285	0.803
25	Found it difficult to be involved in activities which require commitment (e.g. volunteering work or regularly meeting friends)?	1.23±1.22	0.802	0.711	-0.601
26	Paid less attention to your own health (e.g. put off visiting a doctor, ignored symptoms etc.)?	1.18±1.14	0.718	0.865	0.079
27	Felt unable to go on holiday or take short breaks?	1.23±1.21	0.679	0.692	-0.563
28	Felt responsible for Parkinson's disease medication being available and/or taken at appropriate times?	1.70±1.37	0.676	0.360	-1.128
29	Had to limit outings because you worry that the person you care for won't be able to cope?	1.46±1.25	0.724	0.531	-0.767

The modified model (Model 2) still did not meet the model fit criteria ($\chi^2/df=1.806$, $df=366$, $p<0.001$, $TLI=0.870$, $CFI=0.883$, $RMSEA=0.081$).

The MI strongly suggested that item 4 'felt anxious because of the responsibility of caring?' should be relocated to the self-care domain (factor 4) ($MI=13.623$). Item 4 was relocated into the factor 3 domain (Model 3) based on the conceptual intimacy. The model fit was good at $TLI=0.901$, $CFI=0.90$, and $RMSEA=0.079$ (Fig. 3). The CFA results supported the use of the Korean version of the PDQ-Carer to assess the QOL of carers for patients with PD.

Reliability

Cronbach's alpha, as an internal consistency reliability value, was 0.96 for the total scale (95% CI=0.95–0.97), 0.93 for personal and social activities, 0.89 for strain, 0.85 for anxiety and depression, and 0.85 for self-care (Table 4).

DISCUSSION

The QOL of carers is strongly dependent on regional and national differences, including in family dynamics, population characteristics, and healthcare resources.⁵ It is necessary to accurately assess the QOL of carers to reflect their unique

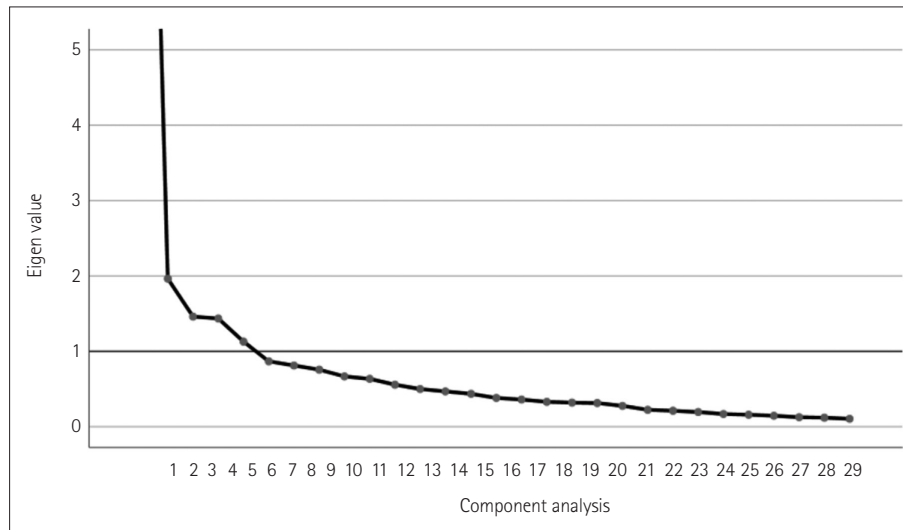


Fig. 2. Scree plot of the exploratory factor analysis.

beliefs and cultures to understand caregiving in different countries and cultures. The PDQ-Carer is a simple and convenient tool used worldwide to assess the multidimensional QOL of carers of patients with PD. The present study developed and tested a culturally adapted version of the PDQ-Carer, which was found to be reliable and valid for use in Korea. The Korean version of the PDQ-Carer included relocating some items from their domains in the original instrument. Item relocation was also performed in previous studies on cultural adaptation of the tool.^{35,36} Factor structure can be affected by the demographic or cultural characteristics of the sample,³⁷ and hence the model fit is sample-dependent.³⁸ The structural difference may be due to aspects of Korean culture and the characteristics of the subjects in the present study.³⁹

The two newly relocated items 22 and 26 were derived from the 'self-care' domain of the original scale and relocated to 'personal and social activities.' Asian cultures generally place more value on caregiving based on traditional practices than other cultures do.^{39,40} Korean carers often perceive caring for their physical health as being a matter of caring for the patient and their entire family, not just as a concept of self-care. Koreans traditionally prioritize the family over the individual, and the caregiving role includes considering social activities to apply to the whole family.⁶ Korean carers have a particularly strong sense of obligation to provide care to elderly people with disabilities.⁴⁰ The period of caring provided by the participants in this study was long, so they may have already adapted to this care in their daily lives. People who provided care for long periods tend to receive caregiving appraisal positively.³⁹

'Strain' was the domain with the most relocated items in the Korean version of the PDQ-Carer, and there may be con-

ceptual differences in its dimensions. Koreans often perceive the strain from caregiving to be their own responsibility.⁴¹ According to item 28, the carers may have accepted the responsibility of that strain. Family carers in Korea are expected to take responsibility for caring due to cultural beliefs. Carers take this caring for granted and as well as the responsibilities that come with it, but they are also under strain themselves.⁴⁰⁻⁴² The item-total correlation for item 13 in the self-care dimension yielded a value of 0.51 in the Spanish version of the PDQ-Carer.¹⁷ There may be several factors in reduced care with diet, which can be accepted with various meanings in relation to the strain of the carers. A previous concept analysis found that lack of time contributed to the caregiving burden.⁴³ It seems that carers are not able to meet their needs such as self-care (e.g., diet) due to difficulties in balancing their roles and responsibilities.⁴⁴ Carers may also feel depressed due to the strain. Item 15 was more suitable for the 'strain' factor in this population. A previous study that compared perceived burdens on Korean and American caregivers of stroke survivors found that caregivers with depression in Korea felt that strain was their burden.⁴⁵ In this context, the relocation of item 15 may be a result of traditional familism, independence of patient care, and lack of social support for Korean caregivers due to differences in culture or general ethical values between countries.⁴⁵ Items 14 and 24 may have been perceived as having similar contents regarding the psychological aspect rather than activities for carers. It is suggested that future studies should explore applying the scale in diverse cultures and countries.

Items 7 and 23 were perceived as 'anxiety and depression' by the Korean carer, which is originally included in the 'strain' domain. In the family-centered culture of Korea, there is a social perception that the families of patients should be the

ones providing care.³⁹ It is therefore often observed that Korean family carers become unemployed due to their caring activities. Our findings indicated that the QOL was low in unemployed than employed carers. Taking the caring role for granted can cause anxiety, depression, or distress beyond

the normal caregiving burden in the long run.^{41,42} This would be even worse if a female spouse had to take on everything at home while acting as a carer.^{6,41} The item-total correlation for item 7 of the strain domain obtained the lowest value of 0.33 in the Spanish study,¹⁷ and so further study is needed.

Table 4. Factor analysis and reliability coefficients of the 29-item Parkinson's Disease Questionnaire-Carer

Item no.	Items	Factor 1	Factor 2	Factor 3	Factor 4
Personal and Social Activities (ten items)					
20	Found it difficult to see friends and family?	0.761	0.131	0.359	0.257
25	Found it difficult to be involved in activities which require commitment (e.g. volunteering work or regularly meeting friends)?	0.748	0.237	0.362	0.140
18	Been limited in what you can do socially?	0.737	0.265	0.041	0.363
27	Felt unable to go on holiday or take short breaks?	0.733	0.302	0.080	0.209
29	Had to limit outings because you worry that the person you care for won't be able to cope?	0.693	0.366	0.156	0.231
26	Paid less attention to your own health (e.g. put off visiting a doctor, ignored symptoms etc.)?	0.657	0.312	0.264	0.223
21	Found it difficult to leave the person you care for alone for more than one hour?	0.655	0.328	0.110	0.283
22	Felt that your physical health has been affected by your caring role?	0.621	0.273	0.428	0.176
5	Been prevented from pursuing hobbies and other interests?	0.571	-0.113	0.386	0.402
19	Felt that your workload around the house has increased significantly?	0.546	0.104	0.290	0.182
Strain (eight items)					
24	Felt that you cannot do things on the spur of the moment?	0.258	0.780	0.213	0.118
16	Felt less in control of your temper than before you became a carer?	0.343	0.751	0.193	0.017
14	Felt more withdrawn because of your caring role?	0.150	0.726	0.353	0.263
9	Felt impatient with the person you care for?	0.333	0.664	0.272	0.256
15	Felt depressed?	0.087	0.635	0.406	0.238
10	Felt exhausted?	0.416	0.544	0.204	0.347
28	Felt responsible for Parkinson's disease medication being available and/or taken at appropriate times?	0.469	0.487	0.054	0.207
13	Taken less care with your diet?	0.226	0.451	0.321	0.284
Anxiety and Depression (six items)					
11	Felt worried about the future?	0.047	0.289	0.786	0.091
6	Felt worried about your own physical health?	0.277	0.226	0.710	0.266
17	Felt worried about what would happen if you were unwell?	0.448	0.298	0.630	0.037
12	Felt you lacked the energy and motivation to do the things you enjoy?	0.341	0.314	0.622	0.240
23	Felt that you are responsible for everything at home?	0.398	0.243	0.512	-0.143
7	Thought that your caring role was taken for granted by others?	0.104	0.242	0.467	0.330
Self-care (five items)					
2	Found it difficult to get out to do the shopping?	0.263	0.157	0.135	0.812
3	Found the demands of caring physically difficult?	0.324	0.259	0.081	0.767
8	Felt that relationships with friends have been affected?	0.500	0.235	0.051	0.592
1	Found you could not sleep through the night?	0.193	0.258	0.219	0.587
4	Felt anxious because of the responsibility of caring?	0.231	0.077	0.506	0.541
Eigen value		6.65	4.99	3.97	3.74
Percentage of variance explained, %		47.90	6.77	5.00	4.95
Cumulative percentage of total variance explained, %		47.90	54.67	59.56	64.51
Cronbach's alpha		0.93	0.89	0.85	0.85
Total alpha		0.96 (95% CI=0.95-0.97)			

Table 5. Fit indices of the Parkinson's Disease Questionnaire-Carer confirmatory factor analysis models

Criterion	χ^2 (p)	df	CMIN/df	TLI	CFI	RMSEA
Model 1: Original four factors	736.627 (<0.001)	371	1.986	0.841	0.855	0.089
Model 2: Model 1 with covariance allowed between e6 and e9, and between e14 and e15	660.999 (<0.001)	366	1.806	0.870	0.883	0.081
Model 3: Model 2 with item 4 relocated to factor 3	656.465 (<0.001)	366	1.794	0.901	0.900	0.079

CFI, comparative fit index; CMIN/df, chi-square divided by degrees of freedom; RMSEA, root mean square error of approximation; TLI, Tucker-Lewis index.

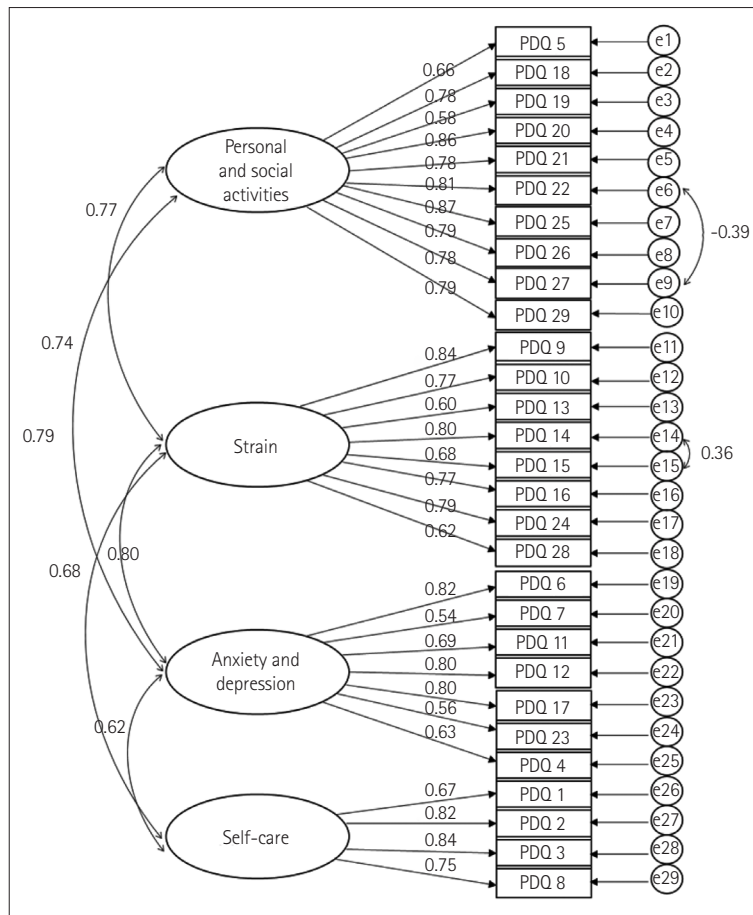


Fig. 3. Final measurement model of the PDQ-Carer. PDQ, Parkinson's Disease Questionnaire.

The 'self-care' dimension was culturally adapted in this study. The age and relationship with the patients of the participants were comparable with those of previous studies.^{16,17} The mean age of carers in the original and Spanish studies were 68.216 and 63.3 years,¹⁷ respectively, and the subjects included in the present study were younger, with a mean age of 58.4 years. The mean age of participants in this study may have been lower due to cases of the carer being a child of the patient accounting for 20% of the total sample. This was also a reflection of Korean culture, because adult children often take care of their parents due to the strong cultural emphasis on the value of filial piety.^{6,40} A previous study on carers for the elderly in Korean nursing homes found that more of

the carers were adult children than spouses of the elderly.⁴⁶ Since the carers were relatively young, they were physically better, so they did not report significant difficulties with sleep or relationships with friends. Stronger filial piety can result in a more-positive caring experience.^{6,39} Our analysis indicated that QOL was better when adult children were carers of patients with PD to support that context. This situation would have been considered to be part of the daily self-care of young Korean carers.

Limitations

This study had a few limitations. First, the use of convenience sampling and the small sample size limits the generalizabil-

ity of the results to all Korean carers of patients with PD. A long-term cohort construction project for patients with PD should be promoted by the Korea National Institute of Health. Future studies should assess larger samples of the Korean population in combination with these cohorts while performing EFA and CFA using different subjects. Second, we tried to include adult child carers who have the primary responsibility for providing most of the care to meet the needs of the patients with PD, although this type of caring had a relatively short duration. This aspect may be a limitation because participants in this study had daily caring durations of 1–24 hours, with an average of about 8 hours. Follow-up studies need to include participants who have a wide range of caring characteristics, such as cohabiting carers who provide care to patients throughout the day and carers who do not live with patients but frequently provide primary care. Third, the clinical characteristics of the patients with PD were not investigated. The main purpose of this study was to develop a Korean version of the PDQ-Carer, rather than to investigate the QOL of carers. The Korean version of the PDQ-Carer, which was translated and verified in this study, is expected to be used in future studies on carers of patients with PD with unique clinical characteristics such as disease severity. The relationship between the severity of PD in patients and the QOL of their carer, or the QOL of both patients and carers would provide more clinical information and insights. Fourth, relatively few previous studies have validated this scale in other languages, which restricts the ability to compare our results with those of other studies. However, this was the first study to examine the validity and reliability of the PDQ-Carer in the Korean context, and it has provided preliminary findings. It is suggested that future studies conduct psychometric testing to verify convergent and discriminant validity using the Korean version of the PDQ-Carer developed in the present study.

In conclusions, this study performed a cross-cultural adaptation of the Korean version of the PDQ-Carer. The preliminary evidence can be used to acquire important information about the multidimensional aspects of the QOL of carers for patients with PD. Future research is expected to establish a healthcare strategy that can address the unmet needs in a multidimensional manner using the Korean version of the scale.

Supplementary Materials

The online-only Data Supplement is available with this article at <https://doi.org/10.3988/jcn.2022.0390>.

Availability of Data and Material

The datasets generated or analyzed during the study are available from the corresponding author on reasonable request.

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Conflicts of Interest

The authors have no potential conflicts of interest to disclose.

Funding Statement

This study was funded by the Basic Science Research Program through the National Research Foundation of Korea (NRF) from the Ministry of Education (2018R1D1A1A02085559 and 2020R1A6A1A03041989). The funding body had no role in the design of the study; the collection, analysis or interpretation of the data; or the writing of the manuscript.

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