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Quality of Life of Caregivers of Individuals With Parkinson's Disease

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Abstract

Purpose: This study aimed to construct a structural equation model to predict the quality of life of caregivers of individuals with Parkinson's disease.

Design: A cross-sectional survey using a structured questionnaire in South Korea.

Methods: A total of 208 subjects participated in this study from August 31 to November 26, 2015. The questionnaire included caregiving appraisal, social support, educational program needs, and the Parkinson's Disease Questionnaire-Carer.

Findings: Participants were either spouses (46.2%) or adult children (45.2%) of individuals with Parkinson's disease. The mean score obtained on the caregiver's quality of life was 40.94 ± 25.30. Social support, caregiving appraisal, and educational program needs were the predictors, explaining 67.0% of the variance in caregivers' quality of life.

Conclusions: Predicting the quality of life is useful for the development of support resources for caregivers of individuals with Parkinson's disease. Further studies exploring the multidimensional aspects of caregivers' quality of life are needed.

Clinical Relevance: Rehabilitation nurses should identify caregivers at high risk in order to improve their quality of life. Nurses should assess education program needs and caregiving appraisal of caregivers of individuals with Parkinson's disease and develop a customized intervention program.

Keywords: Caregivers; Patient care; Parkinson's disease; Quality of life.

The number of individuals with Parkinson's disease (IWPD) in South Korea was estimated to be 96,466 in 2016 (National Health Insurance Service, 2017). According to a systematic review and meta-analysis, the prevalence of Parkinson's disease (PD) in individuals aged 70–79 years varied by geographic location. The prevalence of PD in individuals in North America, Europe, and Australia was higher than in individuals in Asia. However, the prevalence of PD among other Asian age groups did not show significant differences compared to that among Caucasians (Pringsheim, Jette, Frolkis, & Steeves, 2014). Comorbidities, such as delirium or diabetes, were similar by location or country (Santiago, Bottero, & Potashkin, 2017; Vardy, Teodorczuk, & Yarnall, 2015).

Individuals with Parkinson's disease experience functional decline that leads to the limitation of independent daily activities, subsequently leading to their dependence on family members or caregivers (Lee, Choi, Jung, Sohn, & Hong, 2015; Zhong, Peppard, Velakoulis, & Evans, 2016). A recent study found that the majority of IWPD who live in their homes experience comorbidities such as diabetes and cardiovascular diseases (Hassan et al., 2012).

Individuals with Parkinson's disease complain of disease-specific motor symptoms including resting tremors, bradykinesia, and rigidity, as well as nonmotor complications such as anxiety and depression (Lee, Choi, & Yoo, 2017; Lee, Park, & Choi, 2016). Comorbidities in IWPD increase strain and burden in caregivers. Complex symptoms of PD increase the care dependency of IWPD, such that caregivers' quality of life (QOL) changes across the continuum of care (Rodríguez-Violante, Camacho-Ordonez,

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Cervantes-Arriaga, Gonzalez-Latapi, & Velazquez-Osuna, 2015; Tanji et al., 2013; Zhong et al., 2016). Moreover, the management of these symptoms requires long-term care and poses a significant burden on caregivers (Hassan et al., 2012). Both IWPD and caregivers experience physical fatigue, changes in health condition, and psychosocial burden (Martinez-Martin et al., 2015; Theed, Eccles, & Simpson, 2017). These changes are closely related to Q-OL. Caregivers' QOL depends on emotional well-being, level of social support, and the quality of the relationship between IWPD and their caregivers (Martinez-Martin et al., 2015; Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2011). Caregivers' burden and the extent of family support that they receive affect the QOL of IWPD (Sohng, Lee, & Choi, 2005). In order to evaluate caregivers' QOL, rehabilitation nurses must explore the caregiving experience and burden. By providing physical and psychological support, rehabilitation nurses may improve caregivers' QOL and reduce the burden of their role.

Background

The majority of caregivers are family members with no formal training in caring for people with PD (Rodríguez-Violante et al., 2015). Untrained caregivers are more likely to experience caregiving burden (Razali, Ahmad, Rahman, Midin, & Sidi, 2011). To reduce their burden and improve their QOL, several training programs for caregivers, such as disease education and emotional support programs, have been developed (Deek et al., 2016; Savini et al., 2015). However, most of the programs focus on caregivers of people with Alzheimer's disease or stroke (Corry, While, Neenan, & Smith, 2015). There is a need for an independent program for caregivers of IWPD as PD has distinct clinical characteristics (Choi, Kim, Lee, & Park, 2014). It is worth noting that the caregiving experience can be positive if the caregiving burden is reduced (Razali et al., 2011).

Although several studies have focused on caregiving burden among caregivers of IWPD (Lageman, Mickens, & Cash, 2015; Martinez-Martin et al., 2015; Razali et al., 2011; Rodríguez-Violante et al., 2015; Tanji et al., 2013; Zhong et al., 2016), little is known about the caregivers' QOL. To understand QOL of caregivers of IWPD, structural equation modeling (SEM) technique was applied in this study. Structural equation modeling allows analyzing the interrelationships between independent variables and their indirect effect on other variables (Kline, 2016). To date, the SEM method has been used to determine the factors of QOL of IWPD. Comorbidity, functional mobility, self-reported history of falls, psychological well-being such as depression, and pain were found to be the significant determinants of health-related QOL of people with PD (Lee et al., 2015; Soh et al., 2013; Visser et al., 2008). Although various structural models for QOL of IWPD have been studied, there is limited research on the QOL of caregivers of IWPD.

Purpose of the Study

We aimed to evaluate the determinants of QOL of caregivers of IWPD.

Study Conceptual Model

We developed a model based on a literature review to test the following hypotheses: (1) social support is positively related to caregiver's QOL, (2) clinical features of IWPD such as comorbidities negatively influence caregiving appraisal by enhancing caring burden, (3) negative appraisal of the caregiving experience and high educational program needs (EPN) are negatively related to caregiver's QOL, and (4) social support influences caregiver's QOL through the mediation of both caregiving appraisal and EPN (Figure 1).

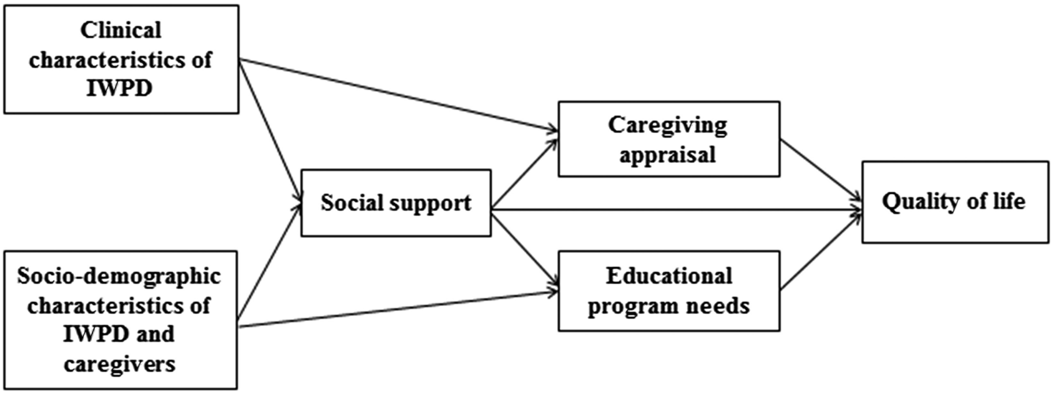

Figure 1. Conceptual model of this study.

Methods

Sample and Setting

A descriptive cross-sectional study design was used to explore the QOL of caregivers of IWPD. Data were collected from August 31 to November 26, 2015. A structured, self-reported questionnaire was used. Subjects were recruited from the outpatient neurology department of Yonsei University Hospital.

In this study, caregivers were represented by a family member, such as a spouse, daughter, or son, or any other member who cared for IWPD without pay. The following were the study's inclusion criteria: (1) primary caregivers of IWPD and (2) caring for clinically diagnosed IWPD for more than 3 months, to date.

In the SEM technique, a recommended ratio of sample size to parameters is 20:1, although there are no absolute standards about the relation between sample size and path model complexity (Kline, 2016). In this study, 10 identified parameters resulted in an ideal sample size of 200 to draw a valid conclusion. In considering a possible missing value rate of 10%, we determined to recruit 220 subjects. Of the 220 questionnaires returned, 12 were excluded due to incomplete data. The final sample size (n = 208) was statistically reasonable for the SEM approach.

Procedures and Ethical Considerations

The institutional review board at the College of Nursing, Yonsei University, South Korea, approved this study (IRB 2015-0019-2). The researchers explained the purpose and study procedures to participants. Participation in the research was voluntary. The survey took 20–30 minutes to complete. Face-to-face surveys were conducted. There were no identifying values that could link the information data to the participants; therefore, anonymity was ensured. In addition, we assigned a serial number to each participant and stored the data in a secure lock box to ensure confidentiality.

Measures

Sociodemographic characteristics of caregivers included age, gender, marital status, employment, relationship with IWPD, and health-related expenditure. Sociodemographic characteristics of IWPD included age, gender, disease duration, comorbidities, and activities of daily living (ADL). The revised Schwab and England ADL Scale developed for IWPD was used to measure IWPD's ADL (Schwab & England, 1969). The instrument comprises 10 levels. A higher score indicates higher independence state with a 100% score indicates complete independence; whereas 0% score represents bedridden or a vegetative state.

Assessments of Social Support

The social support measurement tool consists of 24 items divided into two subscales, namely, family support (12 items) and physician support (12 items). Each item is rated on a scale from 1 = *do not agree at all* to 5 = *strongly agree*. A higher score indicates better social support (Kim, 1993). The original study reported a Cronbach's alpha of .93. In this study, Cronbach's alpha was .91.

Assessments of Caregiving Appraisal

Caregiving appraisal refers to the largest category that includes caregiving impact, burden, satisfaction, and mastery (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). This scale is useful for measuring multiple dimensions of caregiving appraisal; therefore, it has been widely used in English-speaking population (Lee, Friedmann, Picot, Thomas, & Kim, 2007). The Korean version of the Revised Caregiving Appraisal Scale was used to measure caregiving appraisal (Lee et al., 2007). The combined scale consists of five subscales, namely, burden (9 items), satisfaction (6 items), mastery (6 items), demand (3 items), and impact (3 items). Five of the scale's 27 items were evaluated on a 5-point scale ranging from 1 = *do not agree at all* to 5 = *strongly agree*. The remaining items were rated on a scale from 1 = *never* to 5 = *always*, indicating caregivers' agreement levels about caregiving experience. A higher score indicates a more negative appraisal of the caregiving experience. The original study reported a Cronbach's alpha of .85. In this study, Cronbach's alpha was .77.

Assessments of EPN

Educational program needs were measured with 28 items, which comprised part of the following subscales: knowledge and information (7 items), self-care (5 items), leisure activity and hobby (3 items), stress management (3 items), emotion control (2 items), social competency (2 items), and social support (6 items). Each item was answered on a 5-point scale ranging from 1 = *I do not want to know at all* to 5 = *I really want to know.* A higher score represents higher EPN for PD. This scale was developed by a Korean author (Yoon, 2011). The original study reported a Cronbach's alpha of .90. In the present study, Cronbach's alpha was .88.

Assessments of Caregiver's QOL

The Parkinson's Disease Questionnaire-Carer (PDQ-Carer; Jenkinson et al., 2012) was used to evaluate caregiver's QOL. The back translation method was used to develop the Korean version of the PDQ-Carer. An experienced nurse with a master's degree and a professor, both of whom who are fluent in Korean and English, participated in the translation process. The PDQ-Carer comprises

29 items making up four subscales, namely, personal and social activities (12 items), anxiety and depression (6 items), self-care (5 items), and strain (6 items). Items on each subscale were evaluated on a 5-point scale ranging from 0 = *never* to 4 = *always*. The score was converted to a standard score for analysis. A lower score indicates higher QOL with a score of 0 represents the best level of self-reported QOL. Whereas a score of 100 represents the poorest level of self-reported QOL. This scale suggests four dimensions of QOL, which specify salience and concern of caregivers of IWPD (Jenkinson et al., 2012). In the original study, the Cronbach's alphas were reported to be .94 for social and personal activities, .90 for anxiety and depression, .85 for self-care, and .85 for strain. In this study, Cronbach's alphas were reported to be .95 for social and personal activities, .90 for anxiety and depression, .83 for self-care, and .85 for strain.

Data Analysis

The data were analyzed using SPSS version 23.0 and AMOS version 21.0. The level of significance was set at $p < .05$. Descriptive statistics were used to analyze participants' demographic characteristics. Pearson's correlation coefficients were calculated to analyze the relationships between social support, caregiving appraisal, EPN, and caregivers' QOL. In order to determine differences in QOL, an independent *t* test and a one-way analysis of variance were performed.

SEM was performed to explore the determinants of QOL and the interrelationship among independent variables. Both maximum-likelihood classification and the bootstrapping method were used for analysis. For model fit verification, the goodness of fit index (GFI), adjusted goodness of fit index (AGFI), comparative fit index (CFI), Tucker–Lewis index (TLI), normed fit index (NFI), and chi-square (χ^2), root mean squared error of approximation (RMSEA), and normedχ^2 (χ^2/df) indices were used.

Results

Descriptive Statistics

A total of 208 subjects participated in this study (Table 1). The mean age was 56.20 ± 13.85 years. Female participants made up 59.1% of the sample. The majority of participants were married (86.1%). Almost half of the participants were unemployed. They reported their role of taking care of IWPD as the reason for their unemployment. Caregivers were either IWPD's spouses (46.2%) or adult children of IWPD (45.2%). The mean age of IWPD was 72.55 ± 7.89 years. More than half of the IWPD were female (52.4%). Three fourths of all IWPD had comorbidities. The mean score of IWPD's ADL was 63.51 ± 25.89, indicating a moderate level of independence.

Table 1 Descriptive Statistics of Variables (*N* = 208)

	Total Range	Mean	(*SD*)	Standard Score Range[a]	Mean	(*SD*)
Social support	24–120	86.50	(13.40)			
Family support (12 items)	12–60	46.28	(8.62)			
Physician support (12 items)	12–60	40.23	(7.95)			
Caregiving appraisal	27–135	82.71	(12.37)			
Burden (9 items)	9–45	24.74	(9.51)	1–5	2.75	(1.06)
Satisfaction (6 items)	6–30	20.16	(4.66)	1–5	3.36	(.78)
Mastery (6 items)	6–30	19.57	(3.39)	1–5	3.26	(.56)
Demand (3 items)	3–15	9.08	(1.79)	1–5	3.05	(.54)
Impact (3 items)	3–15	9.16	(1.63)	1–5	3.03	(.60)
Educational program needs	28–140	100.55	(15.13)			
Knowledge and information (7 items)	7–35	30.12	(5.21)	1–5	4.3	(.85)
Self-care (5 items)	5–25	21.45	(3.37)	1–5	4.3	(.85)
Leisure activity and hobby (5 items)	3–15	10.34	(2.67)	1–5	3.45	(1.18)
Stress management (3 items)	3–15	8.56	(3.09)	1–5	2.85	(1.3)
Emotion control (2 items)	2–10	5.62	(2.34)	1–5	2.82	(1.33)
Social competency (2 items)	2–10	6.30	(2.32)	1–5	3.16	(1.3)
Social support (6 items)	6–30	18.18	(4.40)	1–5	3.03	(1.31)
PDQ-Carer	0–100	40.94	(25.30)			
Personal and social activities (12 items)	0–100	38.43	(27.26)			
Anxiety and depression (6 items)	0–100	45.21	(27.84)			
Self-care (5 items)	0–100	34.30	(25.35)			
Strain (6 items)	0–100	47.22	(25.80)			

Note. PDQ-Carer = Parkinson's Disease Questionnaire-Carer; *SD* = standard deviation.

[a] Converting all subscale scores into scores ranging from 1 to 5 points.

The mean score of social support was 86.50 ± 13.40. The average score for caregiving appraisal was 82.71 ± 12.37. The factor with the highest score on caregiving appraisal was "burden" (24.74 ± 9.51). The mean score of EPN was 100.55 ± 15.13. The three highest EPN items were "knowledge and information" (30.12 ± 5.21), "self-care" (21.45 ± 3.37), and "social support" (18.18 ± 4.40). The mean score obtained on the PDQ-Carer was 40.94 ± 25.30. The two factors incurring the highest scores on the PDQ-Carer were "strain" (47.22 ± 25.20) and "anxiety and depression" (45.21 ± 27.84). The factor with the third highest score was "personal and social activities" (38.43 ± 27.26). "Self-care" was ranked fourth.

The average score of caregivers' QOL was 49.94 ± 25.30 (Table 2). Statistically significant differences in QOL were shown according to the following variables: participants' age and employment, relationship with IWPD, comorbidities, and IWPD's gender and ADL level. Caregivers younger than 60 years had lower QOL than those older than 60 years (F = 11.913, $p < .001$). Caregivers who were the spouse of IWPD reported a lower QOL than did those with different relations to IWPD (F = 21.729, $p < .001$). A lower ADL level among IWPD was found to be associated with worse QOL among caregivers (F = 21.782, $p < .001$).

There were significant positive correlations between caregivers' QOL and caregiving appraisal ($r = .78$, $p < .01$) and EPN ($r = .25$, $p < .01$). A significant negative correlation was apparent between caregivers' QOL and social support ($r = -.18$, $p < .01$).

Structural Equation Modeling

According to verification with a hypothetical model, the result did not fit the recommended level, with χ^2 = 238.907 ($p < .001$), GFI = .867, RMSEA = .094, NFI = .869, and TLI = .890. We revised the model by connecting the factors from the largest modification index in the following order: family support and social support, PD duration and IWPD's ADL, anxiety–depression and strain, PD duration, and comorbidities. The suitability indices of the final model were χ^2 = 173.069 ($p < .001$), χ^2/df = 2.137, GFI = .904, AGFI = .858, CFI = .947, RMSEA = .074, TLI = .931, and NFI = .905; all indices satisfied the recommended level (Table 3; Figure 2).

Standardized effect and square multiple correlations are summarized in Table 4. First, the factors affecting social support were IWPD's ADL ($\beta = -.48$, $p = .036$) and participants' characteristics, including caregivers' age, employment, and relationship with the IWPD, and IWPD's gender ($\beta = .88$, $p = .007$). Second, the factors influencing caregiving appraisal were IWPD's ADL levels ($\beta = -.44$, $p = .006$), social support ($\beta = .54$, $p = .009$), and participants' characteristics ($\beta = .48$, $p = .007$). In total, 42.5% of caregiving appraisal was explained by participants' characteristics, IWPD's ADL, and social support. Third, the factors affecting EPN were social support ($\beta = -.17$, $p = .011$), caregiving appraisal ($\beta = .42$, $p = .005$), and participant characteristics ($\beta = -.15$, $p = .007$). Social support, caregiving appraisal, and participants' characteristics explained 12.7% of the total variance in EPN.

Finally, our analysis showed that social support ($\beta = -.53$, $p = .011$), caregiving appraisal ($\beta = .71$, $p = .013$), and EPN ($\beta = .17$, $p = .009$) had a significant effect on the QOL of caregivers of IWPD. Thus, we concluded that higher social support and EPN are related to a caregiver's lower QOL, as well as more negative caregiving appraisal is related to the caregiver's lower QOL. These findings suggest that rehabilitation nurses should identify social support, caregiving appraisal, and EPN of caregivers to predict their QOL. Rehabilitation nurses should provide an educational program for people whose EPN is high in order to improve their QOL. Furthermore, nurses should provide caregivers with appropriate respite care and emotional stress management to lower the caregiving burden and improve QOL.

Discussion

This study was aimed at identifying the factors affecting the QOL of caregivers of IWPD. Based on the study results, the following factors related to QOL are discussed: sociodemographic factors of both IWPD and caregivers, social support, caregiving appraisal, and EPN.

In this study, ADL of IWPD were closely related to caregiving appraisal. Decreased ADL, which means impaired physical function, proved to be a major factor of caregiving appraisal, including caregiving burden (Sherwood et al., 2006; Tanji et al., 2013; Zhong et al., 2016). The clinical characteristics of PD, such as functional decline, lead to physical and emotional complaints among caregivers. An increase in the functional dependency of IWPD adversely affects caregivers' QOL (Goldsworthy & Knowles, 2008). When IWPD have physical disabilities, caregivers experience a higher caregiving burden, which leads to decreased QOL (Rodríguez-Violante et al., 2015; Tanji et al., 2013; Zhong et al., 2016). Comorbidities, such as cardiovascular disease and delirium, influence IWPD's cognitive functions, which makes caregiving more difficult (Pavon, Whitson, & Okun, 2010; Vardy et al., 2015). Our findings support those of the previous studies, which indicated that caregivers' QOL deteriorates when IWPD have comorbidities or physical disabilities, as a result of

Table 2 Caregivers' Quality of Life According to General Characteristics (*N* = 208)

Characteristics	Mean (*SD*)	Caregivers (*n*)	Quality of Life		*F* or *t*	*p*
			Mean	(*SD*)		
Total			49.94	(25.30)		
Age (years)	56.20 (13.85)					
≤40		28	29.43	(19.35)	11.913*	<.001*
41–60		91	33.38	(21.98)		c > a,b
61–70		43	52.08	(24.24)		d > a,b
≥71		45	51.86	(27.41)		
No answer		1				
Gender						
Male		85	37.17	(22.63)	−1.852	.066
Female		123	43.55	(26.77)		
Marital status						
Married		179	40.63	(25.85)	−.434	.665
Other (single, widowed)		29	42.84	(21.93)		
Employed						
Yes		96	34.39	(20.23)	−3.637	<.001
No		112	46.55	(27.83)		
Patient age (years)	72.55 (7.89)					
≤60		11	43.10	(23.62)	1.337	.264
61–70		68	41.75	(24.73)		
71–80		94	37.69	(25.71)		
≥81		35	47.41	(25.38)		
Patient gender						
Male		99	46.14	(27.29)	2.849	.005
Female		109	36.21	(22.44)		
Patient disease duration(years)						
<2		36	30.89	(18.73)	3.741*	.025*
2 to <10		105	42.04	(26.29)		b,c > a
≥10		67	44.61	(25.72)		
Relationship with the patient						
Spouse[a]		96	52.33	(25.98)	21.729*	<.001*
Daughter/son		94	31.37	(20.40)		a > b,c
Other family		18	30.13	(19.54)		
Caregiver's health expenditure (US$)						
0		16	29.15	(20.43)	1.765	.155
<100		50	40.09	(26.69)		
100 to <1,000		109	41.83	(26.38)		
≥1,000		27	47.06	(18.72)		
No answer		6				
Patient comorbidities						
No		57	32.67	(21.35)	−3.225†	.002†
Yes		151	44.06	(26.02)		
Patient ADL	63.51 (25.89)					
Good (100%–90%)		54	26.58	(22.13)	21.782†	<.001†
Moderate (80%–60%)		80	38.97	(22.26)		c > a,b
Poor (50%–0%)		74	53.55	(24.60)		b > a

Note. ADL = activities of daily living; *SD* = standard deviation.
*Post Hoc Test = Dunnett T3.
†Post Hoc Test = Scheffe.

the progression of PD (Goldsworthy & Knowles, 2008; Rodríguez-Violante et al., 2015; Tanji et al., 2013). When IWPD have physical disabilities and depression, caregivers experience a higher caregiving burden and decreased QOL (Rodríguez-Violante et al., 2015; Tanji et al., 2013; Zhong et al., 2016). As the disease progresses, limitations in physical function and chronic disease are lifelong symptoms, and rehabilitation nurses ought to support and manage IWPD and their caregivers across the continuum of care (Bunting-Perry, 2006; Savini et al., 2015). For example, a navigator service for caregivers can reduce caregiving burden (Feldman & Fertig, 2013; Palos & Hare, 2011).

Table 3 Model Fitness Indices of Quality of Life Among Caregivers of Individuals with Parkinson's Disease (*N* = 208)

Type	χ^2	*df*	χ^2/df	GFI	AGFI	RMSEA	NFI	TLI	CFI
Criteria	–	–	<3	≥.90	≥.80	≤.08	≥.90	≥.90	≥.90
Hypothetical model	238.907*	85	2.811	.867	.812	.094	.869	.890	.911
Modified model	173.069*	81	2.137	.904	.858	.074	.905	.931	.947

Note. AGFI = adjusted goodness of fit index; CFI = comparative fit index; *df* = degree of freedom; GFI = goodness of fit index; NFI = normed fit index; RMSEA = root mean squared error of approximation; TLI = Tucker–Lewis index; χ^2 = chi-square; χ^2/df = chi-square degree of freedom.
$^*p < .01$.

Also, rehabilitation nurses should provide IWPD with appropriate rehabilitation activities that can assist their limited physical function.

The duration of PD had a significant influence on caregivers' QOL. In line with previous studies, our study found that the longer the duration of PD, the lower the QOL of caregivers (Morley et al., 2012; Razali et al., 2011). This suggests that with ADL changes or functional decline, IWPD with long-term conditions require more supportive systems. However, it has been shown that disease duration does not affect caregiver burden, in contrast to the findings of Kim (1993) and Razali et al (2011). This suggests that there are many factors of rehabilitation that nurses should take into account, such as disease progression, disease duration, functional disability, and the psychological symptoms of IWPD and caregivers. Consideration of these factors by rehabilitation nurses would enable prediction of caregivers' QOL.

Spouses and elderly caregivers were seen to have poor QOL. Spouse caregivers were less likely to spend time outside of the house and seek healthcare services than nonspouse family caregivers, thereby reporting negative life experience (DiBartolo & Soeken, 2003; Tew, Naismith, Pereira, & Lewis, 2013). In addition, most older spousal caregivers encountered age-related challenges themselves (Tew et al., 2013). However, in a study by Razali et al. (2011), married caregivers of IWPD reported a lower caregiving burden compared to single or divorced caregivers. Although previous studies have reported inconsistent results, the present study result that caregiving burden affects caregivers' QOL is meaningful (Goldsworthy & Knowles, 2008). Studies have suggested that the caregiving burden is higher among younger caregivers of IWPD or people with dementia (Rodríguez-Violante et al., 2015; Vaingankar et al., 2016). There are still conflicting results in this regard, indicating a need for future studies.

Consistent with previous findings, caregivers with lower social support showed poorer QOL (Soh et al., 2013; Tanji et al., 2013; Yoon & Tak, 2014). Social support is a major factor of caregivers' QOL as it can reduce the caregiving burden and improve the caregiving experience. Moreover, provision of rest to caregivers through social support can relieve their burden and stress. In a study of caregivers of hemodialysis patients, significant correlations were found between caregiving burden, social support, and caregivers' QOL (Yoon & Tak, 2014). Caregivers' QOL can be improved through rest, assistance with health expenditure, and caring intervention programs (Goldsworthy & Knowles, 2008). Family support, which constitutes a part of social support, is a key

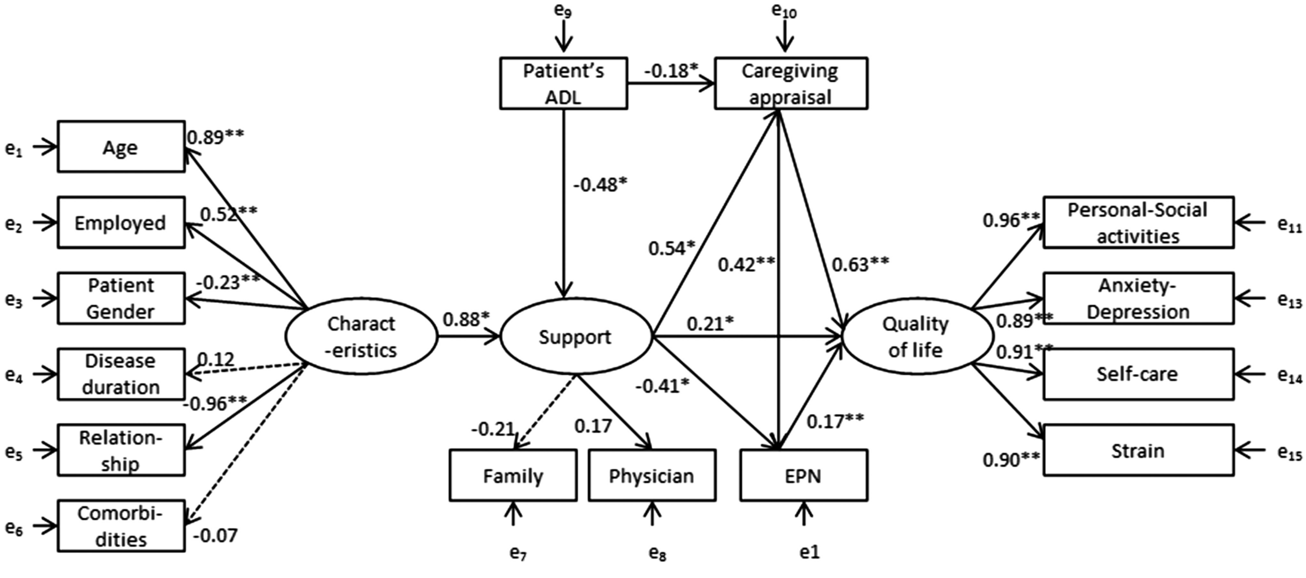

Figure 2. Modified structural model of the quality of life of caregivers of individuals with Parkinson's disease.

Table 4 Standardized Effect of Quality of Life Among Caregivers of Individuals with Parkinson's Disease (*N* = 208)

		Standardized Direct Effect		Standardized Indirect Effect		Standardized Total Effect		
Endogenous Variables	Predicting Variables	β	*p*	β	*p*	β	*p*	SMC
Social support	← ADL	−.479	.036*			−.479	.036*	.070
	← Characters	.878	.007**			.878	.007**	
Caregiving appraisal	← ADL	−.183	.150	−.261	.026*	−.444	.006**	.425
	← Support	.544	.009**			.544	.009**	
	← Characters			.477	.007**	.477	.007**	
EPN	← Support	−.405	.013*	.230	.004**	−.174	.011*	.127
	← Appraisal	.424	.005**			.424	.005**	
	← ADL			.006	.900	.006	.900	
	← Characters			−.153	.007**	−.153	.007**	
PDQ-Carer	← Support	.213	.013*	.313	.012*	.526	.011*	.670
	← Appraisal	.631	.012*	.074	.002**	.705	.013*	
	← EPN	.174	.009**			.174	.009**	
	← ADL			−.381	.013*	−.381	.013*	
	← Characters			.461	.011*	.461	.011*	

Note. ADL = activities of daily living; EPN = educational program needs; PDQ-Carer = Parkinson's Disease Questionnaire-Carer; SMC = squared multiple correlation.

*$p < .05$.

**$p < .01$.

element in the daily life of IWPD and has the potential to improve the IWPD's QOL (Sohng et al., 2005). Caregivers and the rehabilitation teams should maintain a close relationship with IWPD and their caregivers. In previous studies, therapeutic relationships and support programs through a navigator service for caregivers seemed to enhance the caregiving experience across different caring circumstances (Feldman & Fertig, 2013; Palos & Hare, 2011). Therefore, rehabilitation nurses should provide caregivers with a rehabilitation plan to facilitate provision of a continuum of care and a supportive environment.

Caregiving appraisal is a broad concept encompassing caregiving burden, satisfaction, mastery, demand, and impact (Lawton et al., 1989). Rehabilitation nurses must determine the caregiving appraisal, which can be a significant predictor of QOL (Lee, Brennan, & Daly, 2001). Our results showed that caregivers' self-care and strain led to more problems of negative caregiving appraisal, consistent with the findings of previous studies (Lageman et al., 2015; Morley et al., 2012). Korean caregivers often regard caring as a duty or responsibility (Yoon & Tak, 2014). Based on this unique culture, family members who do not assume the caregiver role may experience feelings of discomfort, such as guilt, due to avoiding the responsibility of patient care (Yoon, 2011). When caregiving is regarded as a sense of duty, caregivers are at greater risk for poor health outcomes (Hodgins, Wuest, & Malcolm, 2011). Caregivers cannot afford their own self-care because they spend most of their time caring for patients. This might lead to unexpected psychological problems such as emotional strain, feelings of guilt, and a sense of defeat (Abendroth, Lutz, & Young, 2012). On the other hand, high satisfaction and low burden in caregivers had protective effects on psychological symptoms such as anxiety and depression, which consequently led to higher QOL (del-Pino-Casado, Palomino-Moral, & Frias-Osuna, 2015). These findings suggest that rehabilitation nurses should help caregivers lower their caregiving burden so that caregivers can appraise their caregiving experience positively.

In this study, EPN for knowledge and self-management were high, and those for social support were low. EPN mediated the effect of social support on QOL. Most caregivers engaged in caregiving without PD-specific training or education (Razali et al., 2011). In addition, seeking information or getting help is difficult for caregivers because they do not expect the family member to be ill (Theed et al., 2017). Previous studies have reported the positive effects of an educational program for caregivers including decreased caregiver burden, high satisfaction levels, and mastery (Deek et al., 2016). In order to improve both quality of care and caregivers' QOL, there is a need for nursing programs to provide customized information for PD (Choi et al., 2014; Deek et al., 2016; Stolley, Reed, & Buckwalter, 2002).

Regarding the effect of the sociodemographic characteristics of IWPD on QOL of caregivers, longer duration of PD and comorbidity led to lower QOL, whereas a lower level of ADL led to higher QOL of caregivers. A majority of caregivers' sociodemographic characteristics such as marital status and relationship with IWPD did not affect their QOL. Regarding age and gender of caregivers, there were inconsistent reports in the literature, which indicates the need for continuing research in this area.

Key Practice Points

- Social support, caregiving appraisal, and educational program needs are the predictors of caregivers' QOL.
- Decreased activities of daily living of individuals with Parkinson's disease can increase burden and strain of caregivers, thereby decreasing their QOL.
- The duration of the disease is another determinant of caregivers' QOL, whereas the longer the disease duration, the poorer the QOL and appraisal of the caregiving experience.
- Social support and educational programs should be provided to caregivers of individuals with Parkinson's disease to enable them to overcome caregiving difficulty.

Limitations

There are several limitations in this study. First, the participants were selected from a single hospital, resulting in limited generalizability. We suggest sampling from various medical institutions, such as day-care centers and nursing homes. Second, this study verified caregivers' QOL model through cross-sectional data, with a limited explanation of the meaningful relationships between the variables. Further longitudinal studies are necessary to enable identification of more meaningful relationships between variables. Third, a comparison between previous research and this study was limited due to a dearth of research on caregivers of IWPD.

Conclusions

Caregiving is valuable, however, difficult because it requires the ability to overcome the associated physical and psychological burden. Family caregivers are confronted with the psychological challenges that affect the disease outcomes of IWPD. Rehabilitation nurses should identify caregivers at high risk in order to improve their QOL. First, the provision of necessary educational programs for caregivers, which enhance the caregiving experience, is required. Second, the emotional approach deals with various rehabilitation services, including respite care, and emotional stress management can lower the caregiving burden. Third, we suggest nurse-led navigator program ensuring continuum of care to deal with behavioral approach. In conclusion, rehabilitation nurses should assess education program needs and caregiving appraisal of caregivers of IWPD and develop a customized intervention program using social support to improve the QOL of caregivers of IWPD.

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Conflict of Interest

The authors declare no conflicts of interest.

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