

Subjective and Objective Caregiver Burden in Parkinson's Disease

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Purpose. Parkinson's disease (PD) is a common neurodegenerative disorder characterized by motor disabilities and increasing dependence on others for daily life activities with consequent impact on patients' and caregivers' quality of life. The aim of this study was to elucidate the burden on primary caregivers of patients with PD, and identify related factors.

Methods. A cross-sectional descriptive study. Seventy-six primary caregivers of PD patients in a neurology outpatient clinic, Seoul, Korea completed structured questionnaires, of which 68 were analyzed. The structured self-report questionnaire included (1) demographic information on the caregivers, (2) information regarding the disease characteristics of the patients, and (3) the subjective and objective caregiver burdens as assessed on Montgomery, Gonyea, & Hooyman's scale.

Results. The mean age of the caregivers was 54.56 years, and spouses represented the largest proportion (47.0%). Caregivers of PD patients experienced high levels of burden (mean scores on the subjective and objective burdens were 45.22 and 34.90, respectively), which were comparable to the caregiver burdens in stroke, and higher than the caregiver burdens in general chronic disease. Older caregivers and spousal caregivers experienced significantly higher burdens ($p=.004$ and $p=.019$, respectively). A greater motor disability and higher modified Hoehn and Yahr grade were related to higher caregiver burden ($p=.001$ and $p=.018$, respectively).

Conclusion. Caring for PD patients is associated with a high level of caregiver burden. Therefore, healthcare professionals should identify the burden of caregivers who look after PD patients and develop comprehensive management strategies both for patients and their caregivers.

Key Words : Burden, Caregiver, Parkinson's disease.

INTRODUCTION

Most chronically ill patients are cared for by an informal support system comprised of family members. Caring for patients with chronic and disabling disease is

associated with the caregivers experiencing physical and psychological distress, limitations to their personal and social activities, and financial burden (Choi & Eun, 2000). Parkinson's disease (PD), one of the common chronic diseases, is a progressive neurodegenerative disorder characterized by resting tremor, cogwheel rigidity,

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and bradykinesia, which result in a decreased functional status and increased physical and psychological distress (Greenberg, Aminoff, & Simon, 2005). The majority of the research into PD has focused on the PD patients themselves, the informal caregivers of PD patients, however, have been largely ignored in research.

Providing care to a family member with PD can have far-reaching effects on the caregiver's social activities, emotional health, and stress (Caap-Ahlgren & Dehlin, 2002; Edwards & Scheetz, 2002). Even though medication is initially effective at controlling patients and allowing them to function normally while making little, if any, physical demands, the caregiver may experience emotional stresses related to uncertainty about the prognosis. Moreover, as the disease progresses, dependency increases as the patients experience fluctuations in the control of their symptoms. This increases the physical care provided by caregivers, which increases their incidence of depression (as indicated by the use of tranquilizers) and episodes of chronic illness (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996).

Caregiver well-being has important implications for caregiving outcomes, particularly in the elderly, such as the use of institutional placement and the course of the disease (Dunkin & Anderson-Hanley, 1998). Caregiver burden has been shown to be correlated with patients' depression, quality of life, and incidence of falls, and also with caregivers' own satisfaction with their marital and sexual relationship (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). However, there have been very few studies into familial caregivers and the burden imposed on them by PD patients in Korea.

Therefore, this study aimed at elucidating both the subjective and objective burdens of Korean informal caregivers of PD patients, and identifying the related factors.

METHODS

Participants and procedure

The participants included married and cohabitating individuals who were the primary caregiver for an individual with clinical diagnosis of PD. Participants were recruited from patients who attended the neurology outpatient clinic of a medical center in Seoul. Primary caregivers of community-dwelling PD patients were informed about the study and invited to participate while visiting the clinic with the patients. Those who volun-

teered to participate completed the questionnaire at the outpatient clinic. A nurse in the clinic reviewed the patients' medical records and answered the questions regarding their medical condition. Sixty-two caregivers who could not complete the questionnaire during the visit were given a stamped addressed return envelope, and 15 of them returned the questionnaire. A total of 126 questionnaires were distributed and 76 caregivers returned it, of which 68 were completed and analyzed.

This study was approved by the Institutional Review Board of Asan Medical Center, Seoul, Korea, before the participants were approached and their written consent was obtained. Data collection was conducted from March to June, 2006.

Measures

Data were collected via a structured questionnaire that consisted of three parts: (1) demographic information on the caregivers and features of the caregiving situation, (2) information regarding the disease characteristics of the patients, and 3) the subjective and objective caregiver burdens as assessed on Montgomery, Gonyea, and Hooymans' scale.

■ Demographic information on the caregivers and features of the caregiving situation

The gender, age, relationship with the patient, education level, occupational status, economic status, and family support were questioned, as were the caregivers' perception of the prognosis of the patient, the monthly medical cost, and the daily hours of caregiving.

■ Information regarding disease characteristics of the patients

The disease status was determined using both a structured interview with caregivers and the medical records of the patient, and included the disease duration, motor disability (using UPDRS part II, Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003), PD (using the grade on the modified Hoehn and Yahr scale), and the number of medications taken by the patient. UPDRS (Unified Parkinson's Disease Rating Scale) was developed as a compound scale to capture multiple aspects of PD. It has four components; Part I, Mentation, Behavior and Mood; Part II, Activities of Daily Living; Part III, Motor; Part IV, Complication. UPDRS Part II is self rating five point scale instrument comprised of 13 items including

speech, swallowing, writing, self-feeding, dressing, hygiene, going to bed, falling, tremor, walking (Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003). Among 400 early-stage PD patients examined on two occasions separated by approximately 2 weeks, the intraclass correlation coefficients of Part II were 0.85 (Siderowf, McDermott, Kieburtz, Blindaure, Plumb, & Shoulson, 2002). Hoehn and Yahr scale has been widely used to evaluate the severity of overall parkinsonian dysfunction relates to bilateral motor involvement and compromised balance and gait. It was originally designed as a five-point scale and "modified Hoehn and Yahr scale" includes 0.5 increments (Goetz et al., 2004).

- The subjective and objective caregiver burdens as assessed on Montgomery, Gonyea, and Hooyman's scale.

The burden measure developed by Montgomery, Gonyea, and Hooyman (1985) and translated and modified for Koreans by Lee (1993) was used to measure the subjective and objective burdens. This instrument comprises a list of 22 items: 13 on subjective burden and 9 on objective burden. This was originally designed as a 5-point scale, but was reconstructed as a 6-point scale to prevent centralization. The inventory asks respondents to select a number from 1 (strongly agree) to 6 (strongly disagree) to indicate whether the assessed aspect of their life or relationships has changed because of the caregiving activities. The internal consistency of the instrument was high in this study, with a Cronbach's α of .81. After standardized, a higher score indicated a greater level of burden.

Subjective burden refers to the affect and perception components of caregiver burden. Examples include "feeling that the patient manipulates me as he/she needs" and "I feel guilty about my relationship with the patient." The internal consistency was high, with a Cronbach's α of .74. Objective burden refers to the extent to which the demands of caregiving infringe on the caregiver's time for self and others. Examples include "time for yourself" and "time for friends and other relatives." The internal consistency of this measure was high, with a Cronbach's α of .87.

Data analysis

Data were analyzed using the SPSS program (ver. 12.0). Descriptive statistics were used to summarize the

demographic information of caregivers, features of the caregiving situation, and information regarding patients' disease status. The level of caregiver burden was described by the means of the subjective and objective caregiver burden. Differences between groups were analyzed using one-way ANOVA (Kruskal-Wallis test if not in condition of normal distribution). Scheffe test was used to find where the differences between means lie. Pearson correlation was computed to test the relationship between caregiver burden and demographic information, caregiving situation, and patients' disease status.

RESULTS

Demographic characteristics

The mean age of the primary caregivers was 54.56 years, and the majority was female (65.2%). The majority of primary caregivers were spouses (47.0%) followed by daughters/sons (31.8%), and the daughter-in-law being the primary caregiver in only 18.2% of cases. These relative percentages reflect Korean culture. A total of 62.1% of respondents were high school graduates or less, and 57.6% of respondents did not have an occupation besides managing the household. Most of the respondents (57.6%) reported their economic status as average, and one quarter of them reported it as poor (Table 1).

Features of the caregiving situation

The majority of respondents thought that the patient's disease might be controlled (54.5%), with 30.3% considering that it would become worse. The mean daily hours for caregiving was 3.25 hours, and the median monthly medical cost was 300,000 won (Table 2).

Disease characteristics of the patients

The disease duration was vary from 1 month to 19 years, and the mean was about 6 years, and 13.8% of the patients had suffered from PD for more than 10 years. The median grade on the modified Hoehn and Yahr scale was 2.0, and 64.7% of patients presented mild motor disability on UPDRS part II, with a mean score on this scale of 11.85. Patients were taking a mean of four or five classes of medications (Table 2).

Caregiver burden

The reported total caregiver burden ranged from 48 to 110 (80.12 ± 13.52 , mean \pm standard deviation), out of a

possible range of 22?132. The subjective burden ranged from 26 to 65 (45.22 ± 9.80) out of a possible range of 13?78, and the objective burden ranged from 15 to 54 (34.90 ± 6.95) out of a possible range of 9?54. The objective burden was 3.86 and the subjective burden was 3.45 after divided by the number of items.

Spouses (48.84) reported significantly higher subjective burden than daughters-in-law (41.91) and daughters/sons (41.52) ($p=.019$). The subjective burden was significantly lower in caregivers who were younger than 41 years (37.80) than in those who were 41?64 years old (47.00) and over 65 years old (47.84) ($p=.004$). The subjective burden was also lower in caregivers who had graduated from college or higher education (41.76) than in those with less education (46.93) ($p=.035$). The subjective burden did not differ with gender, occupation, or economic status, and the objective burden did not differ with demographic characteristics (Table 1).

The objective burden was higher in caregivers who spend more than 3 hours caregiving per day (49.00) than in those who spent less time caregiving ($p=.003$). The subjective burden was lower in those with disease durations of up to 1 year (37.91) and of at least 10 years

(42.89) ($p=.035$). The subjective burden was higher in caregivers whose monthly medical costs exceeded 200,000 won (47.62) ($p=.038$). The subjective burden did not differ with the number of medications (Table 2).

The score on UPDRS part II ($p=.045$) and the grade on the modified Hoehn and Yahr scale ($p=.018$) significantly affected the objective burden, and the subjective burden was significantly lower in those caring for patients with scores of up to 12 on UPDRS part II ($p=.001$) (Table 3).

DISCUSSION

O'Reilly et al. (1996) reported that ill health was better predicted by a subjective assessment of care demands than by objective measures, and suggested the significance of caregivers' perceptions. Therefore, factors affecting both the subjective and objective caregiver burdens should be used in assessments of care demands.

This study has demonstrated that caregivers of PD patients experience high levels of subjective and objective burden, comparable to that in stroke (Hong et al., 2000) and higher than that in general chronic disease (Choi &

Table 1. Correlation between Caregiver Burden and Caregiver Demographic Characteristics

Variables	Category	n (%)	Subjective burden (M \pm SD)	p	Objective burden (M \pm SD)	p
Gender	Male	23 (34.8)	46.70 \pm 10.70	.295	34.26 \pm 6.68	.667
	Female	43 (65.2)	44.05 \pm 9.16		35.05 \pm 7.22	
Age	\leq 40 years	15 (24.2)	37.80 \pm 6.61	.004** ^a	32.93 \pm 4.11	.358
	41–64 years	28 (45.2)	47.00 \pm 9.05		36.10 \pm 8.50	
	\geq 65 years	19 (30.6)	47.84 \pm 10.92		34.16 \pm 6.89	
Relationship	Spouse	31 (47.0)	48.84 \pm 9.15	.019*	35.03 \pm 7.99	.959
	Daughter/son	21 (31.8)	41.52 \pm 8.02		35.19 \pm 7.15	
	Daughter-in-law	12 (18.2)	41.91 \pm 10.81		33.41 \pm 4.42	
	Other (parents, relatives)	2 (3.0)	39.5		34.50	
Education	Up to high school	41 (62.1)	46.93 \pm 10.21	.035*	35.07 \pm 7.67	.659
	At least college graduate	25 (37.9)	41.76 \pm 8.07		34.28 \pm 5.83	
Employment	Employed	38 (57.6)	45.82 \pm 9.89	.415	35.03 \pm 7.60	.734
	Unemployed	28 (42.4)	43.82 \pm 9.55		34.43 \pm 6.20	
Family support responsibility	Total	24 (36.9)	47.96 \pm 11.19	.119	34.95 \pm 6.18	.466
	Partial	24 (36.9)	44.08 \pm 8.12		35.21 \pm 6.85	
	None	17 (26.2)	41.76 \pm 9.11		32.76 \pm 6.99	
Perceived economic status ^b	Very poor	6 (9.1)	50.17 \pm 11.23	.409	39.67 \pm 6.77	.138
	Poor	16 (24.2)	42.94 \pm 10.08		36.50 \pm 9.78	
	Average	38 (57.6)	44.58 \pm 9.57		33.37 \pm 5.56	
	Rich	6 (9.1)	47.67 \pm 8.04		34.17 \pm 4.62	

* $p \leq .05$, ** $p \leq .01$

^a significantly higher than at age 41–64 years, and over 65 years. There was no significant difference between ages of 41–64 years and over 65 years.

Eun, 2000). Patients with PD present diverse degrees of disability resulting from their physical and mental impairments. As a consequence, caregivers of PD patients are burdened by stress resulting from the presence of a long-standing and progressive disease. Carter et al. (1998) found a strong association between disease stage and caregiver stress. The caregiver stress was low in the early stages of PD (modified Hoehn and Yahr grade of 1–2), and this increased in the areas of worry, frustration, tension, direct care, role conflict, and global stress in middle-stage disease (modified Hoehn and Yahr grade of 2.5–3), and further still in the late stages (modified Hoehn and Yahr grade of 4–5). The results of this study are consistent with conclusions from previous studies

that the caregiver burden on those taking care of PD patients is strongly associated with the stage of PD and functional status, especially daily activities (Kim, Chung, Im, & Lee, 2005; Edwards & Scheetz, 2002).

In this study, the results indicate that the objective caregiver burden which reflects how caregivers perceive that their life has been disrupted by caregiving, was higher than the subjective caregiver burden. Hong et al. (2000) also reported higher objective caregiver burden than subjective caregiver burden in community dwelling stroke patients. The informal caregivers reported higher subjective than objective burden when looking after institutionalized patients, but they reported higher objective burden when taking care of patients at their home

Table 2. Difference between Caregiver Burden and Features of the Caregiving Situation

Item	Category	n (%)	Subjective burden (M ±SD)	p	Objective burden (M ±SD)	p
Perception of prognosis	Will be cured	6 (9.1)	41.33 ±13.65	.179	32.17 ±5.49	.158
	May be controlled	36 (54.5)	43.81 ±9.86		33.36 ±5.39	
	Will become worse	20 (30.3)	46.35 ±7.85		37.10 ±8.80	
	Close to death	2 (3.0)	49.00 ±5.66		40.50 ±7.78	
	Don't know	2 (3.0)	59.00 ±4.24		39.00 ±12.73	
Daily caregiving	< 1 hour	22 (46.8)	42.55 ±10.74	.224	32.14 ±4.53	.003*
	1–3 hours	15 (31.9)	44.07 ±9.74		36.20 ±5.90	
	> 3 hours	10 (21.3)	49.00 ±8.23		40.40 ±8.62	
Disease duration	< 1 year	11 (16.9)	37.91 ±9.60	.035*	31.18 ±6.49	.165
	1–5 years	28 (43.1)	47.50 ±9.41		36.39 ±7.17	
	5–10 years	17 (26.2)	45.53 ±8.31		35.35 ±6.75	
	> 10 years	9 (13.8)	42.89 ±9.39		32.89 ±6.97	
Number of medications	≤4	34 (53.1)	45.15 ±9.31	.763	35.62 ±6.54	.186
	≥5	30 (46.9)	44.40 ±10.40		33.33 ±7.13	
Monthly medical cost	< 100,000 won	21 (35.6)	40.33 ±9.36	.038*	32.57 ±8.38	.359
	100,000–200,000 won	17 (28.8)	45.71 ±8.01		35.18 ±6.94	
	> 200,000 won	21 (35.6)	47.62 ±10.03		35.42 ±5.34	

* $p \leq .05$

Table 3. Difference between Caregiver Burden and the Disease Characteristics

Item	Category	n (%)	Subjective burden (M ±SD)	p	Objective burden (M ±SD)	p
UPDRS II (motor disability)	0–12*	44 (64.7)	42.30 ±9.31	.001**	33.36 ±6.08	.045*
	13–25	21 (30.9)	49.76 ±8.60		37.81 ±8.10	
	26–52	3 (4.4)	56.33 ±4.93		37.00 ±4.35	
Modified Hoehn and Yahr grade	1.0 or 1.5	15 (22.7)	43.20 ±9.08	.178	33.27 ±3.71	.018*
	2.0 or 2.5	46 (69.7)	44.80 ±9.61		35.30 ±7.27	
	3.0	1 (1.5)	60.00		33.00	
	4.0	1 (1.5)	35.00		15.00	
	5.0	3 (4.5)	53.33 ±8.50		41.00 ±5.57	

* $p \leq .05$, ** $p \leq .01$

° significantly higher than scores on UPDRS part II of 13–25, and over 26. There was no significant difference between scores of 13?25 and over 26.

(Choi & Eun, 2000). These results imply the significance of practical social support, such as providing respite care, to lower the caregiver burden for those who taking care of community dwelling patients.

The convenience sample in this study included twice as many female caregivers as male caregivers. This demonstrates that the majority of patients are male and thus the majority of caregivers are female and also reflecting the Korean cultural context in which most caregivers are women. Results indicate that the degree of caregiver burden did not differ between being employed or unemployed, or between being male or female. However, the age of a caregiver was significantly correlated with the caregiver burden. Those younger than 41 years who has more likely to access social support reported the significantly lower subjective caregiver burden.

Caregivers who had more hopeful perceptions of the disease appeared to have a lower burden, but this result was not statistically significant. Caregivers exhibit the highest subjective and objective burdens at 1–5 years after the diagnosis, related to symptoms of PD being aggravated even when medications are taken during this period, and also it is considered that caregivers have not adjusted to or accepted their caregiving role. A monthly medical cost of more than 200,000 won was significantly associated with a higher subjective burden but not with a higher objective burden. Caring for PD patients requires substantial financial resources for medication, hospital visits, and other medical costs, since most patients and caregivers are not able to work (Jost, 2000). This study did not demonstrate the financial burden in caregivers of PD patients since there was no association between the monthly medical cost and the objective burden, or between economic status and caregiver burden. However, medical costs and subjective caregiver burden were related.

In the present study, the level of disability was the most significant factor associated with caregiver burden. This is in agreement with Kim et al. (2005) and Caap-Ahlgren and Dehlin (2002), who found the functional status of patients to be a determinant of the psychosocial burden on caregivers. Berry and Murphy (1995) also reported that the stage of PD was related to the caregivers' physical, social, and psychological well-being, and that caregivers of PD patients in more advanced stages of the illness self-reported that their own health status had declined. The results of this study suggest that

the subjective and objective burdens were strongly associated with the disability score, and that the grade on the modified Hoehn and Yahr scale was associated with the objective burden. However, the modified Hoehn and Yahr grade was not associated with the subjective burden. The small number of caregivers who were caring for severe PD patients (with grades on the modified Hoehn and Yahr scale of 3 and over) reduced the ability of this study to demonstrate statistical differences among groups of each stage.

Caring for a patient who has a progressive chronic disease that ultimately results in physical disability, such as PD, affects not only the caregiver's physical and psychosocial health but also patient outcomes (Davey, Wiles, & Ashburn, 2004). Study results confirm the findings from previous studies that the caregiver burden increases significantly with the disease severity. The limitations of this study are in the use of a convenience sample, low sample size and only a 60% return rate for the questionnaire, which means that results cannot be generalized and that the study participants were not representative of the entire population of caregivers of PD patients.

CONCLUSIONS

As the elderly population in Korea grows, PD will continue to be a challenge to Nursing. The management of PD requires an ongoing commitment not only from the patient but also from the family when ongoing lifestyle adjustments become necessary as the disease progresses. Considering lack of long-term care facilities in Korea and cultural belief which highly valuing filial piety, most of PD patients will stay at home with informal caregivers. Hereby, it is vital for nurses to support patients and their informal caregiver to make adjustment especially at home setting.

The result of this study suggested that the objective and subjective burden was strongly associated with the motor disability of the patients and their level of ADL performance. And the objective burden was higher than the subjective burden in home setting. Therefore, nurses should assess the knowledge base of the individual with PD and caregiver both with specific emphasis on maintaining and/or improving ADL and assisting caregiving, such as providing respite care.

Because we included few severely disabled cases, as defined by a score of over 30 points on UPDRS part II

and/or over grade 3 on the modified Hoehn and Yahr scale, our findings might represent underestimates of the true effects. Therefore, future studies focused on caregivers of severely disabled patients are recommended. Moreover, the actual health status of PD caregivers should also be investigated.

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