



ORIGINAL ARTICLE

Patients and Their Caregivers' Burdens for Parkinson's Disease in Korea

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ABSTRACT

Objective Many patients with Parkinson's disease (PD) suffer from motor and non-motor symptoms. According to these variable symptoms of PD, patients or caregivers have a poorer quality of life than patients with other neurodegenerative diseases. Since the difficulties are varied for all patients, prioritizing their difficulties differs among all cases. The goal of this study was to investigate the burdens of PD among the caregivers as well as patients and to identify areas requiring aid from the government.

Methods We surveyed the awareness and perceptions of PD in patients and caregivers of PD by a face-to-face questionnaire. The questionnaire was divided into three sections: symptoms of PD (part A), desire for policies (part B), and difficulties faced by their caregivers (part C). Part A comprised 8 questions, Part B had 2 questions, and Part C had 3 questions.

Results In total, 853 subjects (702 patients and 151 caregivers) were enrolled in this study. The major difficulties experienced by PD patients were physical (67%), psychiatric (60%) and socio-economic (52%). Assessing the physical difficulties, more than half the patients experienced severe difficulties (29% very severe, 39% severe). Psychiatric difficulties were assessed as severe (35%) and very severe (21%) among the patients. Severe difficulties were also experienced socio-economically, at 52% in patients and 49% in caregivers, especially among patients in their fifties (58%) and those with their spouse (65%) as caregivers. The topmost need was the introduction of new technology for treatment of PD (62%), followed by relief of costs for treatment (38%) and a family support system (31%). The majority (91%) of the patients were diagnosed with PD within two years after onset of symptoms.

Conclusion We know that the difficulties of PD and the needs for government assistance are different between patients and caregivers. These results emphasize that perceiving the difficulties and needs of patients and caregivers early can help to prevent and ameliorate the burden of disease.

Key Words Awareness; perception; Parkinson's disease; survey.

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Parkinson's disease (PD) is a neurodegenerative disorder, with characteristic motor and non-motor symptoms. In the last ten years, Korea has seen a rapid increase in the number of PD patients. With increasing incidence of PD, there is an increased socio-economic burden on the caregiver, and more government support is required. According to the variable motor or non-motor symptoms of PD, patients or caregivers have a poorer quality of life than patients with other neurodegenerative diseases.

Previous survey studies about PD indicate gaps in disease awareness and its management among the patients, physicians, caregivers and the general population.¹⁻⁴ The awareness and knowledge of PD is different with respect to age, income and education levels,⁴ or cultural differences among the racially or ethnically diverse populations.⁵ Interestingly, over 80% of adults from senior citizen centers in the US had little or no knowledge of PD.⁵ These results suggest that there is a lack of awareness and knowledge of PD; in Korea, this could be due to a fast transition to an aging society.

Previously, a study undertaken in Korea researched public awareness and knowledge about PD.⁴ The authors of this study used telephone interviews with a structured 22-item questionnaire and concluded that awareness and knowledge of PD showed hierarchical gradients with respect to age, income and education level. However, a low response rate was a barrier in this survey, thereby influencing some bias in the study. Therefore, a face-to-face survey could increase the response rate and would be more useful for caregivers as well as patients with PD.

This study aimed to investigate the burdens of PD among the caregivers as well as patients and to identify areas requiring aid from the government.

MATERIALS & METHODS

Patients

We conducted a cross-sectional, questionnaire-based study in patients with PD. Twelve neurological centers from all over Korea, which were expert tertiary hospitals, collaborated to collect the data for one month. All PD patients were diagnosed with the United Kingdom Parkinson's disease Society Brain Bank criteria.⁶ Illiterate or demented patients or patients unwilling to participate in the study were excluded from this study. Willing caregivers of enrolled

patients were also involved in this study.

Questionnaire

A questionnaire was designed and developed to assess the symptoms of PD and the desire for a policy. It was divided into three sections: symptoms of PD-part A, desire for policies-part B, and difficulties faced by their caregivers-part C (Figure 1). Part A comprised 8 questions, Part B had 2 questions, and Part C had 3 questions. To assess the difficulties with symptoms of PD (part A), the severities were further categorized as none, mild, moderate, severe, and very severe.

RESULTS

Demographic data

In total, 853 subjects (702 patients and 151 caregivers) were enrolled in this study (Table 1). Of the 702 patients, 53% were women, with the majority being in their seventies (33%) and sixties (33%). Of the 151 caregivers, 55% were women, the offspring of the patients (55%), and aged in their forties (30%) and fifties (25%).

Difficulties with symptoms of PD

All patients and caregivers had difficulties with their PD symptoms (Figure 2). The major difficulties experienced by PD patients were physical (67%), psychiatric (60%) and socio-economic (52%). Assessing the physical difficulties, more than half the patients experienced severe difficulties (29% very severe, 39% severe). Caregivers experienced greater difficulty than patients, and among caregivers, the patient's partner (50%) experienced very severe physical difficulties. Psychiatric difficulties were assessed as severe (35%) and very severe (21%) among the patients. However, the severity evaluated by caregivers was greater than patient assessment (43% severe, 30% very severe). Severe difficulties were also experienced socio-economically, at 52% in patients and 49% in caregivers, especially among patients in their fifties (58%) and those who had their spouses (65%) as caregivers. They experienced limitations of physical activities such as bradykinesia, gait disturbance, and falling (77%), decreased physical abilities, including visual accuracy, sleep disturbance, urinary difficulty (38%), and associated musculoskeletal diseases, such as back and knee pain (34%). Limitations

Screening questions

SQ1. What is your gender? [Choose one]
 1) Male 2) Female

SQ2. What is your age?
 Year of Birth: _____ Age: _____

SQ3. Do you have PD? [Choose one]
 1) Yes → **Go to Part A**
 2) No

SQ4. What is your relationship with the patient? [Choose one]
 1) Spouse (Husband or Wife)
 2) Child
 3) Parent
 4) Sibling
 5) Others (Specifically: _____)
 6) Does not apply to the above → **Stop**

(You are chosen as a candidate for this survey)

Part A. Symptoms of PD (both patient and caregiver)

(If you are the caregiver, please answer based on your family member's PD symptoms.)

A1. When did you (or your family member's) PD symptoms first occur?
 Month _____ Year _____

A2. When did you (or your family member) first get diagnosed with PD?
 Month _____ Year _____

A3. Where did you (or your family member) first get diagnosed with PD?
 1) Department of Neurology
 2) Department other than Neurology (Department: _____)
 3) Oriental Medicine Clinic
 4) Others (_____)

A4. What is the most effective treatment for PD? [Choose one]
 1) Drug treatment
 2) Kinesitherapy
 3) Adjuvant therapy (herbal medicine, tonic, etc.)
 4) Patient support groups & PD family groups
 5) No effective treatment

A5. In daily life, how difficult does it feel for you (or your family member) in the categories of physical/psychiatric/socio-economic? Please choose one in each category. 1 is very severe, 5 is not severe at all. [Choose on the 5-point scale for each category]

	Very severe	Severe	Moderate	Mild	None
1) Physical	1	2	3	4	5
2) Psychiatric	1	2	3	4	5
3) Socio-economic	1	2	3	4	5
4) Others (_____)	1	2	3	4	5

4) The category of 'others' is not compulsory.

A5-1. What physical difficulties do you (or your family member) usually have? [Choose two]
 1) Limitation of physical activities (bradykinesia, gait disturbance, and falling)
 2) Degeneration of oral functions (speech disorder, swallowing disorder)
 3) Decreased physical abilities (amblyopia, sleep disturbance, urinary difficulty)
 4) Associated musculoskeletal diseases (back, hip joint and knee joint pain, etc.)
 5) Complications with other diseases (difficulties due to diseases other than PD)
 6) Others (_____)

A5-2. What psychological difficulties do you (or your family member) usually have? [Choose two]
 1) Memory impairment or hallucinations
 2) Stress due to limitation of physical activity
 3) Depression and distress from insecurity
 4) Emotional pressure due to economic burden

Figure 1. The survey form. PD: Parkinson's disease. (Continued to the next page)

- 5) Feeling guilty for family member who suffering from PD
- 6) Fear for the future
- 7) Feeling helpless and anxious
- 8) Others ()

A5-3. What socio-economic difficulties do you (or your family member) usually experience? [Choose two]

- 1) Social isolation (reduction in range of activities)
- 2) Other people's views (prejudice towards disease)
- 3) Lack or absence of supporting groups such as family
- 4) Economical burden for treatment
- 5) Maintenance of working life or economic activity
- 6) Difficulty of outpatient treatment
- 7) (Only for caregiver) Limitation of balancing nursing and daily activities
(For example, difficulty in taking time off at work for accompanying hospital visits)
- 8) Others ()

Part B. Needs for Policy for PD (both patient and caregiver)

B1. What do you think the government should politically take into consideration for treatment of PD? If you have any other suggestions, please feel free to comment. [Choose multiple answers]

- 1) Introduction of new technology for treatment of PD
- 2) Reinforcement of education for PD and PD treatment
- 3) Support training of specialized institutions and specialists
- 4) Relief of costs for treatment
- 5) Family support system
- 6) Domestic research activation for PD (researchers or physicians to enhance their studies for PD treatment and discovery of new drugs.)
- 7) Others ()

B2. Do you have any suggestions for medical professionals for treatment and management of PD? Please feel free to answer.

Part C. Questions for Caregivers (only for caregivers)

C1. Do you currently live with the patient?

- 1) Yes
- 2) No

C2. As a PD caregiver, what are some major difficulties you experience? [Choose multiple answers]

- 1) Medical expenses (economic burden due to indirect/direct treatments)
- 2) Burden of nursing (physical, psychiatric, time-consuming burden)
- 3) Relationship with patient (troubles with patient due to depression, stress, and dystrophy)
- 4) Conflict/Discord/Indifference of other family members
- 5) Difficulty in maintaining relationships & Distress from stigma related to PD
- 6) Feeling guilty that you cannot be of enough help to the patient
- 7) Lack of social support or government aid
- 8) Others ()

C3. Do you have income through economic activities with a permanent or temporary job?

- 1) Yes
- 2) No

Figure 1. (Continued from the previous page) The survey form. PD: Parkinson's disease.

of physical activities were more pronounced for the caregivers than patients. Decreased physical ability was maximum for men in their sixties, whereas musculoskeletal disease was associated more with women than men. With respect to psychiatric difficulties, most subjects complained of stress due to limitation of physical activity (56%), cognitive im-

pairment (28%), and fear for the future (26%). Although depression was higher among the caregivers, the fear of the future was higher in patients. Spouses as caregivers complained of maximum stress due to limitation of physical activity, whereas offspring and patients above eighty complained of maximum stress regarding cognitive decline. For socio-economic dif-

difficulties, the main factors were social isolation (38%), prejudice of disease (34%), and economical burden for treatment (25%). Since caregivers were economically poor, they had to additionally bear the financial burden of treatment. Social isolation was more pronounced among spouses than other caregivers, and the difficulty to maintain economic activity was greater in caregivers aged less than forty years. Sons and daughters had maximum complaints regarding difficulties for both care and daily activity. The major challenges faced by caregivers were the burden

of care (67%), the relationship with patients (42%), and guilt for patients (38%). Non-earning caregivers, especially spouses, felt the burden of care the most. Conversely, working caregivers, especially women or children, felt more guilt for their patients, compared to other caregivers.

Table 1. Baseline characteristics of the patients and caregivers

	Patients (n = 702)	Caregivers (n = 151)
Gender		
Male	47	45
Female	53	55
Age group		
< 50	3.3	37.1
50–59	11.4	24.5
60–69	33.3	14.6
> 70	52.0	23.8
Relationship with the patients		
Spouse		26.5
Child		55.0
Parent		5.3
Sibling		1.3
Others		11.9
Live with the patients		
Yes		46.4
No		53.6
Economic activities		
Yes		47
No		53

Base for %

Needs for policy of PD

All patients and caregivers responded that better policies about PD are required from the government (Figure 3). The topmost need was the introduction of new technology for the treatment of PD (62%), followed by relief of costs for treatment (38%) and family support system (31%). The need among caregivers for more family support systems and activation of a PD study was higher than that in PD patients. They desired the researchers or physicians to enhance their studies for PD treatment and discovery of new drugs.

Visiting timing in PD clinics

Patients who participated in our survey had visited our PD clinic within the month that they noticed their symptoms (32%). The majority (91%) were diagnosed with PD within two years after onset of symptoms. Almost all (90%) were diagnosed with PD by neurologists, and 84% of them felt that the drugs administered relieved their PD symptoms, especially in women and those over eighty.

DISCUSSION

Our study demonstrated the physical, psychiatric, and socio-economic difficulties experienced by PD

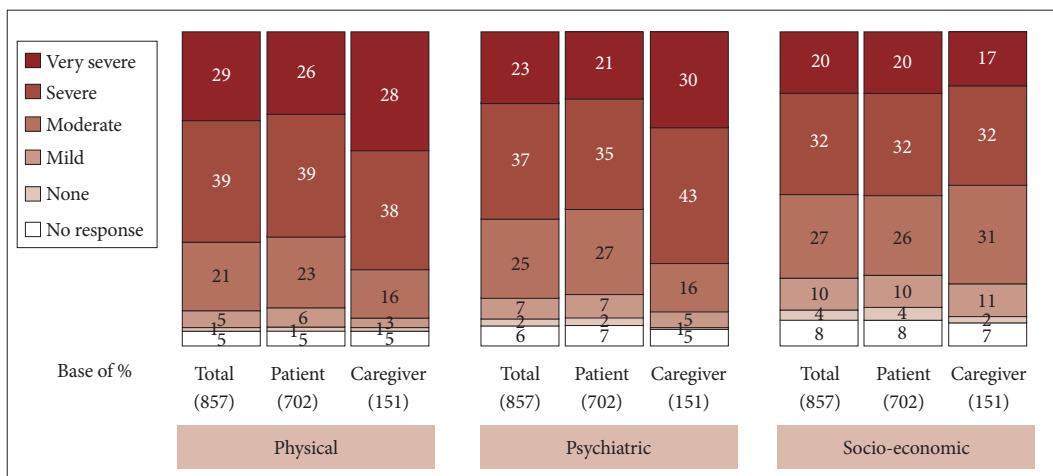


Figure 2. The physical, psychiatric and socio-economic difficulties of Parkinson's disease patients and caregivers.

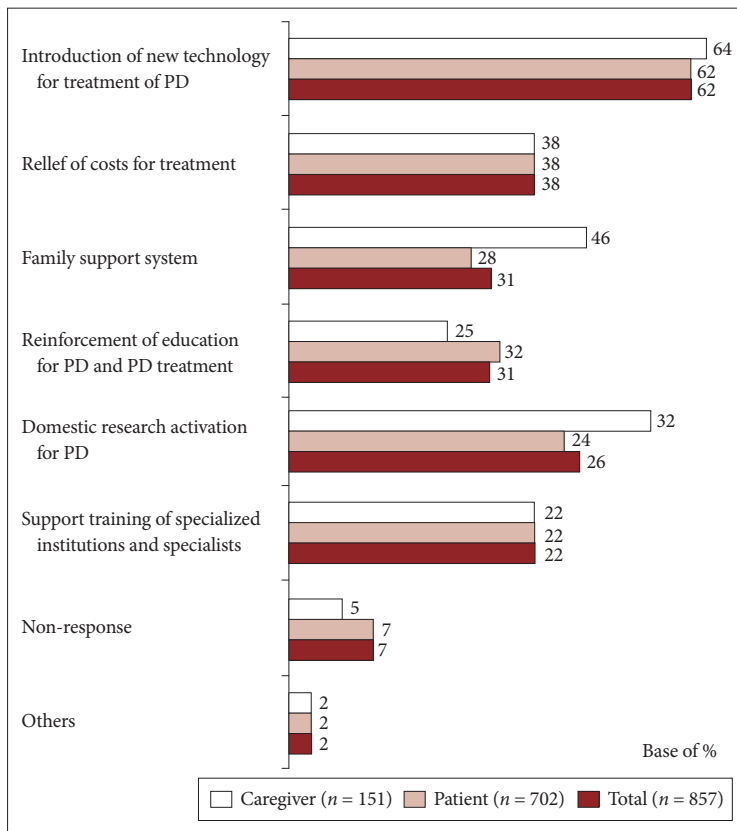


Figure 3. Needs for policy of Parkinson's disease (PD).

patients and their caregivers. Major motor symptoms in PD, such as tremors, rigidity and bradykinesia, help physicians to diagnose patients with PD; however, many patients also have PD associated non-motor problems. Since the difficulties are varied for all patients, prioritizing their difficulties differs among all cases. Furthermore, there are still some identifying gaps in the knowledge about PD among medical professionals.¹ All these elements prevent physicians from helping PD patients more precisely. Hence, it is imperative to gain maximum awareness and knowledge regarding PD patients. Additionally, understanding the precise needs required from the government will help formulate better policies for them.

Previously, few surveys have been conducted to assess the knowledge, attitudes and perceptions about PD.²⁻⁵ In Asian countries, patients have the misconception that PD is currently curable and usually familial.² The results of Jitkritsadakul et al.³ showed that recruitment of patients at a younger age (< 60 years old), female gender, and higher disease duration (> 4 years), were identified as predictors of a higher level of PD knowledge among patients. A similar study

undertaken in Korea by telephone survey was conducted for public awareness and knowledge regarding PD.⁴ It revealed that the awareness and knowledge of PD differed with age, income and education level.

PD is a long lasting neurodegenerative disease, requiring caregivers to attend to these patients all day long. As the disease progresses, the burden on caregivers increases. In Korea, Shin et al.⁷ studied caregiver burden in PD with dementia (PDD) compared to Alzheimer's disease (AD). They concluded that caregiver burden is higher in PDD than in AD and that neuropsychiatric problems are major contributors to caregiver burden in PDD patients.⁸ Recently, a similar paper concluded that cognitive impairment in patients was strictly correlated with lower quality of life scores in both patients and caregivers, which is a strong predictor of caregiver stress and burden.⁹

According to our results, the patients and caregivers of PD have severe psychological, socio-economical and physical difficulties. Physical difficulties due to PD symptoms become more severe as the patient ages. Psychiatric difficulties are also found in caregivers, especially in the spouse. According to previous reports,⁷⁻⁹ cognitive impairment is the most important factor for those difficulties, which is similar to the results in our study. Socio-economic difficulties are popular around the age of fifty in patients, who felt that social isolation was the most severe. Caregivers also have socio-economic difficulties, the foremost being the burden of caring for their patients. It is also true that the socio-economic burden increases due to PD. Schrag et al.¹⁰ concluded that the most adverse aspect of living with PD is its impact on the social interactions of those affected. We surveyed patients and caregivers regarding their needs for government policies. Patients need new treatment protocols for PD and a decrease in the burden of treatment costs. Interestingly, most cases require a support system for patients as well as caregivers. Based on these results, early diagnosis is important to minimize the many burdens faced by PD patients and their caregivers, since it helps to facilitate the suitable management of various PD symptoms.¹¹

In conclusion, our study had a better response rate using face-to-face interviews than the study that used a telephone survey. We know the difficulties of PD, and the needs for government assistance are

different between patients and caregivers. These results emphasize that perceiving the difficulties and needs of patients and caregivers early can help to prevent and ameliorate the burden of disease.

Conflicts of Interest

The authors have no financial conflicts of interest.

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