



# Caregiver Burden and Quality of Life in Early and Late Stages of Idiopathic Parkinson's Disease

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**Objective** Idiopathic Parkinson's disease (IPD) is a chronic progressive neurodegenerative movement disorder characterized by motor and non-motor symptoms that affects patients' quality of life and caregiver burden. The aim of our study was to assess the caregiver burden (CB) in early and late stages of disease and to search if there was a relationship between quality of life and CB.

**Methods** A total of 74 patients who were diagnosed as having IPD by a movement disorder neurologist according to United Kingdom Brain Bank Criteria and their caregivers were randomly selected for participation the study. Staging of PD was performed by the neurologist based on the Hoehn and Yahr (H&Y) Scale. Disease severity was determined using the Unified Parkinson's Disease Rating Scale (UPDRS). CB was evaluated using the Zarit Caregiver Burden Inventory (ZCBI). The Hospital Anxiety and Depression Scale (HADS) and the Beck Depression Inventory (BDI) were used to assess anxiety and depressive symptoms in patients with IPD and their caregivers. The Short-Form Health Survey instrument (SF-36) was used to evaluate quality of life of the patients. The Mini-Mental State Examination (MMSE) was administered to patients to evaluate gross cognitive status.

**Results** Seventy-four patients (male, 58.1%) were included in the study. The mean age of patients was  $66.18 \pm 8.5$  and the mean duration of disease was  $67.23 \pm 41.8$  months. According to the H&Y scale, the patients were divided into two groups; stage I-II as early stage and stage III-V as late stage. Group 1 (H&Y I-II) consisted of 40 patients, and group 2 (H&Y III-V) comprised 34 patients. The mean duration of disease and UPDRS scores were significantly higher in group 2 ( $p=0.003$ ,  $p=0.001$ , respectively). Significant differences were found in group 2 according to BDI. There were significant differences between group 1 and 2 according to SF-36 subdomains such as general health, emotional role, social functioning, pain, and mental health ( $p=0.019$ ,  $p=0.038$ ,  $p=0.005$ ,  $p=0.004$ ,  $p=0.014$ , respectively). However, there were no significant differences between these two groups concerning CB.

**Conclusion** Although CB was found in 35 (47.3%) caregivers in our study, we found no significant differences between the caregivers of patients with early and late-stage IPD patients. We thought that this might be due to strong family relationships and cultural dynamics in Turkey. Burden was found to be higher in depressive patients' CGs and CGs who had depressive symptoms. It is important to recognize depressive symptoms earlier to protect the relationship between the CG and the patient because the main providers of care are family members.

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**Key Words** Parkinson's disease, Caregiver, Caregiver burden, Depression, Quality of life.

## INTRODUCTION

Idiopathic Parkinson's disease (IPD) is a chronic progressive neurodegenerative movement disorder characterized by motor and non-motor symptoms. Due to its progressive debilitating nature, it negatively affects caregivers rather than

patients.<sup>1-4</sup> In recent years, due to the extended human life span, an increased prevalence of IPD has been encountered and that seems to cause individual and social problems related to caregiving.<sup>2</sup> As disease progresses, the disability increases, then patients require more care and assistance for performing daily activities. Family members of patients usually assume primary responsibility for this burden.<sup>1,2</sup> Motor problems, mood disturbances, communication difficulties, impaired sexual and autonomic functioning also increase when the disease progresses and these problems may lead to economic consequences, the loss of employment, disruption in family roles, stigmatization, and coping with increasing difficulties in physical and mental disability.<sup>5</sup> Consequently, daily caregiving of patients with IPD can induce stress, frustration, tension, and

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a feeling of insecurity on caregivers.<sup>6</sup>

Caregiver burden (CB) can be defined as the strain or load borne by a person who cares for a chronically ill, disabled or elderly family member.<sup>7</sup> The duration and the stage of the disease, motor and non-motor symptoms, additional neuropsychiatric symptoms and adverse effects of medications can affect CB.<sup>1,6</sup> It has been described as all negative effects associated with the caregiving experience of chronic illnesses that cause physical, mental, and socioeconomic consequences.<sup>8</sup>

In Turkey, the caregivers of these patients are usually their family members, mostly their children or spouses. Their emotional and physical support prevents early admission in a nursing home and the disabling condition causes psychosocial and economic burden on their caregivers who were not trained formally in caregiving.<sup>9</sup>

Accordingly, the aim of this study was to assess the impact of early and advanced stage of IPD on caregivers' burden and to emphasize the importance of early prevention of caregivers' observable or subjective burden.

## METHODS

### Study participants and design

A total of 74 patients who were diagnosed as having IPD by a movement disorder neurologist according to United Kingdom Brain Bank Criteria and their caregivers were randomly selected for participation in this study. Spouses (wife or husband), children (son or daughter), and paid CGs were the main categories inside the group of CGs. Demographic data were collected from both groups. History of severe systemic diseases (e.g. malignancy, severe arthrosis), severe stroke, dementia, epilepsy and other comorbid diseases (e.g. blindness, extremity amputation or psychiatric diseases) were excluded.

Staging of PD was performed by the neurologist based on the Hoehn and Yahr (H&Y) Scale; stage I and II were considered as early stage, and stage III, IV, and V as the late stage of the disease.<sup>10</sup> Disease severity was determined using the Unified Parkinson's Disease Rating Scale (UPDRS).

CB was evaluated using the Zarit Caregiver Burden Inventory (ZCBI), which contains 22 items that measure the impact of the disease on caregiver's physical, emotional, social, and financial status.<sup>11</sup> The responses range from 0 (never) to 4 (nearly always), the maximum score is 88, and higher scores indicate higher burden. The ZCBI total score was also categorized as follows: 0–20 (little or no burden), 21–40 (mild-to-moderate burden), 41–60 (moderate-to-severe burden), and 61–88 (severe burden). Scores were further aggregated into two categories: ZCBI total score from 0 to 20 (without burden) and from 21 to 88 (with burden).

The Hospital Anxiety and Depression Scale (HADS) and

the Beck Depression Inventory (BDI) were used to assess anxiety and depressive symptoms in patients with IPD and their caregivers. HADS consists of 7 items for the assessment of anxiety, and 7 items for the assessment of depression. A HADS-Anxiety and Depression scale score of  $\geq 10$  indicates risk of anxiety and scores  $\geq 7$  indicate risk of depression.<sup>12</sup> The BDI is a 21-item inventory and scores can range from 0 to 63. Scores  $\geq 17$  indicate risk for depression.<sup>13</sup>

The Short-Form Health Survey instrument (SF-36) was used to evaluate quality of life of the patients. The SF-36 includes 36 items covering 8 domains: physical function (PF, 10 items), role-physical (RP, 4 items), bodily pain (BP, 2 items), general health (GH, 5 items), vitality (VT, 4 items), social function (SF, 2 items), role-emotional (RE, 3 items), and mental health (MH, 5 items). Among them, physical functioning, physical role, pain, and general health belong to physical health, and emotional role, vitality, mental health, and social functioning belong to mental health. The scores range from 0 to 100, with higher scores indicating better quality of life.<sup>14</sup> The SF-36 Turkish standard version has been validated in our population.<sup>15</sup> The Mini-Mental State Examination (MMSE) was administered to patients to evaluate the gross cognitive status. MMSE scores  $>24$  were considered normal.<sup>16</sup>

### Ethical approval

The study was approved by the Ethics Committee of Antalya Education and Research Hospital (No: 169). All participants gave written informed consent.

### Statistical analysis

All statistical analyses were performed using the SPSS software package, version 21.0 for Windows (IBM Corp., Armonk, NY, USA). Demographic and baseline characteristics were summarized as mean $\pm$ standard deviation (SD) for continuous variables and as the percentage of the group for categorical variables. Non-normally distributed data are presented as medians (inter-quartile range). Normality analysis was performed using the Kolmogorov–Smirnov test. The independent samples t-test was used to assess the differences between the groups (sex and health status). The Fisher's exact or Chi-square tests were used to compare the proportions. For the results,  $p < 0.05$  was accepted as statistical significance.

## RESULTS

### Patients

Seventy-four patients (male, 58.1%) were included in the study. The mean age of the patients was  $66.18 \pm 8.5$ . The mean duration of disease was  $67.23 \pm 41.8$  months. The mean UPDRS score was  $25.84 \pm 15.5$ . According to the H&Y scale, the

patients were divided into two groups; stage I-II as early stage and stage III-V as late stage. Group 1 (H&Y I-II) consisted of 40 patients and group 2 (H&Y III-V) comprised 34 patients. The age and sex of these groups showed no significant differences. The mean duration of the disease and UPDRS scores were significantly higher in group 2 ( $p=0.003$ ,  $p=0.001$ , respectively). Ten (25%) patients in group 1 and 16 (47.1%) patients in group 2 had off periods. The number of patients who had MMSE <24 and who had hallucinations were significantly higher in group 2 ( $p=0.027$ ,  $p=0.002$ , respectively). In group 1, nine (22.5%) patients were receiving levodopa only, 10 (25%) were receiving dopamine agonists only, and 21 (52.5%) patients were receiving both. In group 2, nine (26.5%) patients were receiving levodopa only, and 25 (73.5%) were receiving both levodopa and dopamine agonists. No patients were receiving agonists only in group 2. The demographic data

of the patients are summarized in Table 1.

There were no significant differences between group 1 and group 2 according to the HADS-Anxiety and HADS-Depression scales ( $p=0.140$ ,  $p=0.641$ , respectively); however, significant differences were found in group 2 according to the BDI ( $p=0.023$ ) (Table 1).

The scores of SF-36 subdomains are shown in Table 2. There were significant differences between groups 1 and 2 according to the SF-36 subdomains such as general health, emotional role, social functioning, pain and mental health ( $p=0.019$ ,  $p=0.038$ ,  $p=0.005$ ,  $p=0.004$ ,  $p=0.014$ , respectively).

### Caregivers

The mean age of the CGs in group 1 and group 2 was  $46.65 \pm 15.75$  and  $49.41 \pm 14.32$  years, respectively. Both group 1 and group 2 were had a female predominance (62.5% vs. 76.5%,

**Table 1.** Demographic features of patients in group 1 and group 2

Demographics	Group 1 (N=40)	Group 2 (N=34)	p value
Age (mean $\pm$ SD), years	66 $\pm$ 8.6	66.38 $\pm$ 8.5	0.849
Male sex, N (%)	24 (60.0)	19 (55.9)	0.721
Mean duration of disease (mean $\pm$ SD), months	54.18 $\pm$ 37.2	82.59 $\pm$ 42.2	0.003
UPDRS (Mean $\pm$ SD)	20.3 $\pm$ 11.3	32.35 $\pm$ 17.3	0.001
Mini-Mental State Examination (<24), N (%)	3 (7.5)	9 (26.5)	0.027
Hallucination, N (%)			0.002
Insight (+)	4 (10.0)	7 (20.6)	
Insight (-)	1 (2.5)	8 (23.5)	
Medication, N (%)			0.063
Monotherapy	19 (47.5)	9 (26.5)	
Polytherapy	21 (52.5)	25 (73.5)	
BECK Depression Scale ( $\geq$ 17), N (%)	6 (15.0)	13 (38.2)	0.023
HADS-Depression Scale ( $\geq$ 7), N (%)	19 (47.5)	18 (52.9)	0.641
HADS-Anxiety Scale ( $\geq$ 10), N (%)	8 (20.0)	12 (35.3)	0.140

N: number, SD: standard deviation, UPDRS: Unified Parkinson's Disease Rating Scale, HADS: The Hospital Anxiety and Depression Scale

**Table 2.** SF-36 sub-domain scores of patients

SF-36 sub-domains	Group 1	Group 2	p value
General health (mean, SD)	52.57 $\pm$ 21.26	41.32 $\pm$ 18.8	0.019
Physical functioning (mean, SD)	57.72 $\pm$ 29.7	45.29 $\pm$ 30.02	0.078
Physical role (median, IQR)	75 (0-100)	0 (0-100)	0.077
Emotional role (median, IQR)	100 (0-100)	0 (0-100)	0.038*
Social functioning (median, IQR)	100 (50-100)	50 (25-100)	0.005*
Pain (median, IQR)	100 (72.5-100)	61 (32-100)	0.004*
Mental health (mean, SD)	69.85 $\pm$ 18.67	57.47 $\pm$ 23.71	0.014*
Vitality (mean, SD)	47.87 $\pm$ 23.11	43.97 $\pm$ 23.73	0.477
SF-36 (physical) (median, IQR)	67 (43.25-83.43)	42.12 (31.06-64.18)	0.005*
SF-36 (mental) (median, IQR)	64.37 (47.37-83.50)	39.50 (30.12-74.18)	0.009*

\*Mann-Whitney U test. SF-36: The Short -Form Health Survey instrument, SD: standard deviation, IQR: inter quartile range

respectively), but there were no significant differences between the two groups. The relations of the caregiver to the patient were as follows: in group 1, 22 (55%) were their children, 18 (45%) were spouses; in group 2, 17 (50%) were their children, 16 (47.1%) were spouses, and 1 (2.9%) was a paid CG. In group 1, 33 (82.5%) CGs were living in the city, 7 (17.5%) in a suburban area, and in group 2, 30 (88.2%) CGs were living in the city, and 4 (11.8%) in a suburban area. There were no significant differences between groups 1 and 2 according to places that the CGs lived ( $p=0.787$ ).

Only one (2.9%) caregiver wanted to institutionalize their patient in a nursing home because of advanced stage IPD.

Nine (22.5%) CGs had a BDI score of  $\geq 17$  in group 1, whereas 3 (8.8%) had a BDI score of  $\geq 17$  in group 2. HADS-Depression scale scores  $\geq 7$  were observed in 11 (27.5%) CGs in group 1, compared with 10 (29.4%) CGs in group 2. HADS-Anxiety scale scores  $\geq 10$  were observed in 11 (27.5%) CGs in group 1, whereas it was 4 (11.8%) CGs in group 2 (Table 3).

According to the ZCBI, in group 1, 21 (52.5%) CGs described no burden, 15 (37.5%) had mild burden, and 4 (10%) had severe burden. In group 2, 18 (52.9%) CGs described no burden, 12 (35.3%) had mild burden, and 4 (11.8%) had severe burden; however, there were no significant differences between the two groups concerning CB ( $p=0.970$ ) (Table 3).

When evaluating the CB according to another 2 groups such as total score of 0 to 20 (without burden) and from 21 to 88 (with burden), we found no burden in 39 (52.7%) CGs and burden in 35 (47.3%) CGs. There were no significant differences between these groups according to CGs' and patients' sex, relations between patients and CGs, employment status, dementia and hallucinations, duration of the disease, UPDRS scores, medications, and the time spent with their patients (Table 4). The number of patients who had BDI scores of  $\geq 17$  was significantly higher in CGs with burden ( $p=0.008$ ). Similarly, CGs who had BDI scores of  $\geq 17$  and HADS-Depression Scale scores of  $\geq 7$  were significantly higher among CGs with burden ( $p=0.036$ ). When evaluating the SF-36 as physical components and mental components, there were significant differences in quality of life according to the group with burden ( $p=0.008$ ,  $p<0.0001$ , respectively).

## DISCUSSION

Although CB was found in 35 (47.3%) caregivers in our study, we found no significant differences between the caregivers of patients with early and late-stage IPD. We thought that this might be due to the strong family relationships and cultural dynamics in Turkey.

In our country, the CGs of these patients are usually their family members, mostly their children or spouses. Except for

**Table 3.** Demographic features of caregivers of group 1 and group 2

CG demographics	Group 1 (N=40)	Group 2 (N=34)	p value
Age (mean±SD), years	46.65±15.75	49.41±14.32	0.436
Female sex, N (%)	25 (62.5)	26 (76.5)	0.196
Education degree, N (%)			0.585
Primary school	26 (65.0)	20 (58.8)	
High school	11 (27.5)	5 (14.7)	
University	3 (7.5)	9 (26.5)	
Employment, N (%)			0.609
Employed	14 (35.0)	10 (29.4)	
Unemployed	1 (2.5)	5 (14.7)	
Retired	6 (15.0)	6 (17.6)	
Housewife	19 (47.5)	13 (38.2)	
Marital status, N (%)			0.350
Married	33 (82.5)	25 (73.5)	
Relationship status, N (%)			0.859
Children	22 (55.0)	17 (50.0)	
Spouse	18 (45.0)	16 (47.1)	
Paid caregiver		1 (2.9)	
Duration of caregiving, N (%)			0.231
>3 months	39 (97.5)	31 (91.2)	
Time spent caregiving, N (%)			0.112
Multiple hours	13 (32.5)	8 (23.5)	
During daytime	6 (15.0)	2 (5.9)	
Night and day	21 (52.5)	24 (70.6)	
BECK Depression Scale ( $\geq 17$ ), N (%)	9 (22.5)	3 (8.8)	0.112
HADS-Depression Scale ( $\geq 7$ ), N (%)	11 (27.5)	10 (29.4)	0.856
HADS-Anxiety Scale ( $\geq 10$ ), N (%)	11 (27.5)	4 (11.8)	0.93
ZCBI			0.970
Little or no burden	21 (52.5)	18 (52.9)	
Mild to moderate burden	15 (37.5)	12 (35.3)	
Moderate to severe burden	2 (5.0)	3 (8.8)	
Severe burden	2 (5.0)	1 (2.9)	

CG: caregiver, N: number, SD: standard deviation, HADS: The Hospital Anxiety and Depression Scale, ZCBI: Zarit Caregiver Burden Inventory

one paid CG, all of the CGs in our study were family members including spouses or children. Similar to previous reports, CGs were mainly females (68.9%), especially wives and daughters.<sup>17-20</sup> The patriarchal system has been more prevalent in our country; therefore, according to Turkish social and cultural characteristics, females usually perform caregiving tasks. Traditionally, caregiving tasks were mostly nursing at home, caring

**Table 4.** Evaluation of characteristics related to disease according to Zarit Scale

	Zarit caregiver burden scale		p value
	Without burden	With burden	
	N=39 (52.7%)	N=35 (47.3%)	
Age (mean±SD), years	48.7±16.2	47.06±13.9	0.645
Female sex, patient, N (%)	17 (43.6)	14 (40.0)	0.755
Female sex, caregiver, N (%)	25 (64.1)	26 (74.3)	0.345
Wife, N (%)	18 (46.2)	16 (45.7)	0.970
Children, N (%)	21 (53.8)	18 (51.4)	0.835
Unemployed caregivers, N (%)	27 (69.2)	23 (65.7)	0.747
Patient with dementia, N (%)	5 (12.8)	7 (20.0)	0.403
Patient with hallucination, N (%)	9 (23.1)	11 (31.4)	0.419
Medication, polytherapy, N (%)	26 (66.7)	20 (57.1)	0.399
Mean duration of disease (mean±SD), months	62.54±30.7	72.46±51.39	0.311
UPDRS score (mean±SD)	22.56±15.24	29.49±15.26	0.055
Total duration of caregiving, N (%)			
>3 month	37 (94.9)	33 (94.3)	1
Hours for caregiving, N (%)			
Night and day	25 (64.1)	20 (57.1)	0.540
BDI Scale (≥17), patient, N (%)	5 (12.8)	14 (40.0)	0.008
BDI Scale (≥17), caregiver, N (%)	3 (7.7)	9 (25.7)	0.036
HADS-Depression Scale (≥7), N (%)	5 (12.8)	16 (45.7)	0.002
HADS-Anxiety Scale (≥10), N (%)	5 (12.8)	10 (28.6)	0.092
SF-36 (physical) (mean, SD)	62.57±22.6	47.41±24.8	0.008
SF-36 (mental) (median, IQR)	68.65 (50–87.50)	39.75 (28.62–58.50)	<0.001*

\*Mann-Whitney U test. N: number, SD: standard deviation, IQR: inter quartile range, UPDRS: Unified Parkinson's Disease Rating Scale, HADS: The Hospital Anxiety and Depression Scale, SF-36: The Short-Form Health Survey instrument

or cleaning. According to cultural psychosocial effects and our beliefs, they usually adapt to the diseases' state and accept this dependence. Therefore, the reason why there were no differences concerning burden between the early and late stages of the disease could be that the CGs perceived this condition as a task or obligation. Thus, under these circumstances, apart from the stage of the disease or progression, they had to continue caregiving. Again, according to our traditions, institutionalization is a non-preferred behavior. Thus, the proportion of caregivers who wanted to institutionalize their patients in a nursing home was very low, only one person wanted to institutionalize their patient and the patient was in advanced stage and had neuropsychiatric symptoms.

Previous studies showed significant differences between increased burden and disease duration, duration of caregiving, caregiving hours, H&Y stage, and hallucinations.<sup>8</sup> In contrast, we found a significant difference in depression scores between the groups with and without burden. Depression is known to have a major impact on the prognosis of PD. In one review, the prevalence of major depression in IPD was found

as 17%, minor depression was 22%, and dysthymia 13%.<sup>21</sup> Similar to these results, depressive symptoms were found as 15% in group 1, whereas it was 38% in group 2. Burden was found to be higher in depressive patients' CGs and CGs who had depressive symptoms.

IPD could negatively affect the patients' or CGs' quality of life by enhancing the stress and burden.<sup>22</sup> Compared with the general population, mostly physical and social functioning subdomains could be affected.<sup>23</sup> Our study showed significant differences between patients in groups 1 and 2 concerning general health, pain, emotional role, mental health, and social function. As expected, the scores were lower in group 2 (late-stage patients), so they had a lower quality of life. Additionally, the affected subdomains of SF-36 reflected that as well as the physical health, mental health could commonly be affected in the late stages of IPD. Our results showed a statistically significant difference between burden and SF-36 physical and mentally-related aspects. Depression could increase fatigue, decrease motivation, decrease independency, and decrease capacity of daily living activities. Thus, the need for a CG increas-

es and the positive effects of caregiving remains limited.<sup>24-26</sup> CGs' depression also affects burden. Furthermore, the prevalence of anxiety in IPD was found as 25–40% and mostly observed with depressive symptoms.<sup>27,28</sup> In some studies, depressive symptoms in CGs were reported as 40–50% and anxiety was 30%.<sup>18,19,23,29</sup> Some other studies showed a correlation between non-motor symptoms, especially depressive symptoms and anxiety, in patients and CGs with burden.<sup>6,25,26</sup> However, we found no significant differences concerning anxiety scores between patients in groups 1 and 2. Additionally, we found no correlation between anxiety and burden in CGs. These findings might be resulted as depressive symptoms might not be accompanied every time with anxiety. The duration of disease and disability could increase CGs depressive symptoms.<sup>17,23,30</sup> However, Lökk<sup>19</sup> reported an unexpected result as the general health condition of the CGs was regarded satisfactory independent of disease duration. This condition might be related to CGs' adaptation to strain and burden, and also might depend on learning to cope with these issues. In addition, they feel satisfaction by fulfilling the sense of mission by caring a patient. In concert with these findings, we found no significant differences between the duration of disease and burden. Additionally, we thought that our traditional characteristics might impacted on this situation. Some studies suggested that CB would differ according to their relationship to the patient because age and socioeconomic conditions could be different between spouses and children who are responsible for caring.<sup>2</sup> However, we found no significant differences between these two groups concerning burden. Similar to Lökk<sup>19</sup> study, there was no significant relationship between CGs' age and burden. Another study suggested that spousal CGs' sex had no impact on CGs' mental health.<sup>31</sup>

Depressive symptoms of patients with IPD are one of the main contributors that increase CB. Independent from the stage of the disease, the presence of depression is likely to be related to CGs' burden and depressive symptoms. When managing the treatment of patients, we also have to consider the CB and quality of life. It is important to recognize depressive symptoms earlier to protect the relationship between the CG and the patient because the main providers of care are family members. If necessary, we should recommend protective treatment earlier.

### Conflicts of Interest

The authors have no potential conflicts of interest to disclose.

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