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. 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. 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. 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. Consequently, daily caregiving of patients with IPD can induce stress, frustration, tension, and

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±8.5 and the mean duration of disease was 67.23±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.

Key Words

Parkinson’s disease, Caregiver, Caregiver burden, Depression, Quality of life.
a feeling of insecurity on caregivers.\(^6\)

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.\(^7\) The duration and the stage of the disease, motor and non-motor symptoms, additional neuropsychiatric symptoms and adverse effects of medications can affect CB.\(^8\) It has been described as all negative effects associated with the caregiving experience of chronic illnesses that cause physical, mental, and socioeconomic consequences.\(^4\)

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.\(^7\)

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.\(^10\) 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.\(^11\) 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 ≥10 indicates risk of anxiety and scores ≥7 indicate risk of depression.\(^12\) The BDI is a 21-item inventory and scores can range from 0 to 63. Scores ≥17 indicate risk for depression.\(^13\)

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 functioning (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.\(^14\) The SF-36 Turkish standard version has been validated in our population.\(^15\) The Mini-Mental State Examination (MMSE) was administered to patients to evaluate the gross cognitive status. MMSE scores >24 were considered normal.\(^16\)

#### 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±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±8.5. The mean duration of disease was 67.23±41.8 months. The mean UPDRS score was 25.84±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±15.75 and 49.41±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±SD), years | 66±8.6 | 66.38±8.5 | 0.849 |
| Male sex, N (%) | 24 (60.0) | 19 (55.9) | 0.721 |
| Mean duration of disease (mean±SD), months | 54.18±37.2 | 82.59±42.2 | 0.003 |
| UPDRS (Mean±SD) | 20.3±11.3 | 32.35±17.3 | 0.001 |
| Mini-Mental State Examination (<24), N (%) | 3 (7.5) | 9 (26.5) | 0.027 |
| Hallucination, N (%) | | | |
| Insight (+) | 4 (10.0) | 7 (20.6) | |
| Insight (-) | 1 (2.5) | 8 (23.5) | |
| Medication, N (%) | | | |
| Monotherapy | 19 (47.5) | 9 (26.5) | |
| Polytherapy | 21 (52.5) | 25 (73.5) | |
| BECK Depression Scale (≥17), N (%) | 6 (15.0) | 13 (38.2) | 0.023 |
| HADS-Depression Scale (≥7), N (%) | 19 (47.5) | 18 (52.9) | 0.641 |
| HADS-Anxiety Scale (≥10), N (%) | 8 (20.0) | 12 (35.3) | 0.140 |

**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±21.26 | 41.32±18.8 | 0.019 |
| Physical functioning (mean, SD) | 57.72±29.7 | 45.29±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±18.67 | 57.47±23.71 | 0.014* |
| Vitality (mean, SD) | 47.87±23.11 | 43.97±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 ≥17 in group 1, whereas 3 (8.8%) had a BDI score of ≥17 in group 2. HADS-Depression scale scores ≥7 were observed in 11 (27.5%) CGs in group 1, compared with 10 (29.4%) CGs in group 2. HADS-Anxiety scale scores ≥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 ≥17 was significantly higher in CGs with burden (p=0.008). Similarly, CGs who had BDI scores of ≥17 and HADS-Depression Scale scores of ≥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 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. 17-20 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 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) | 0.609 |
| High school | 11 (27.5) | 5 (14.7) | 0.856 |
| University | 3 (7.5) | 9 (26.5) | 0.93 |
| Employment, N (%) | | | 0.350 |
| 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 (%) | | | 0.112 |
| Married | 33 (82.5) | 25 (73.5) | |
| Relationship status, N (%) | | | 0.112 |
| Children | 22 (55.0) | 17 (50.0) | |
| Spouse | 18 (45.0) | 16 (47.1) | |
| Paid caregiver | 1 (2.9) | | |
| Duration of caregiving, N (%) | | | 0.436 |
| >3 months | 39 (97.5) | 31 (91.2) | |
| Time spent caregiving, N (%) | | | 0.856 |
| 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 (≥17), N (%) | | | 0.008 |
| HADS-Depression Scale (≥7), N (%) | 11 (27.5) | 10 (29.4) | |
| HADS-Anxiety Scale (≥10), N (%) | 11 (27.5) | 4 (11.8) | |
| 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
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 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. 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%. 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.

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

| Zarit caregiver burden scale | Without burden | With burden | p value |
|-----------------------------|----------------|-------------|---------|
| 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.
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