



# Effect of Disability and Self-care Agency on Activities of Daily Living in Patients with Parkinson's Disease

## Parkinson Hastalarında Yeti Yitimi ve Öz Bakım Gücünün Günlük Yaşam Aktiviteleri Üzerine Etkisi

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### Abstract

**Objective:** This study aimed to determine the effects of disability and self-care agency of patients with Parkinson's disease (PD) on activities of daily living (ADL).

**Materials and Methods:** The study sample comprised 81 individuals with PD meeting the inclusion criteria. The data to evaluate ADL were collected using a Patient Information Form, the Brief Disability Questionnaire (BDQ), Self-care Agency Scale, and Unified Parkinson's Disease Rating Scale (UPDRS).

**Results:** Severe disability was determined in 48.1% of the patients. Patients who were in stages 3 and 4 of PD according to the Hoehn and Yahr Staging Scale and who also had another chronic disease-in particular, chronic obstructive pulmonary disease-were found to have significantly higher UPDRS scores than those who did not. It was determined that age, ability to meet personal care, and the presence of a carer caused a significant difference in disability, self-care agency, and the level of ADL ( $P < 0.05$ ). The study identified a negative and moderately significant correlation between patients' disability and self-care agency, a positive and highly significant correlation between disability and ADL, and a positive and moderately significant correlation between self-care agency and ADL ( $P < 0.00$ ).

**Conclusion:** The development of disabilities in individuals with PD negatively affects their ADL and self-care power.

**Keywords:** Activities of daily living, disability, Parkinson's disease, self-care agency

### Öz

**Amaç:** Bu araştırmanın amacı; Parkinson hastalığı (PH) olan hastalarda yetiyitimi ve öz bakım gücünün günlük yaşam aktiviteleri (GYA) üzerine etkilerini belirlemektir.

**Gereç ve Yöntem:** Araştırmanın örneklemini araştırma kriterlerine uyan 81 PH'li birey oluşturmuştur. Araştırmanın verilerinin toplanmasında "Hasta Tanıtım Formu", "Kısa Yeti Yitimi Anketi (KYA)", "Öz Bakım Gücü Ölçeği (ÖBGÖ)" ve GYA'yı değerlendirmede "Birleştirilmiş Parkinson Hastalığı Değerlendirme Ölçeği (BPHDÖ)" kullanılmıştır.

**Bulgular:** Hastaların %48,1'inde ağır yeti yitimi olduğu saptanmıştır. Hoehn ve Yahr Evresi'ne göre hastalığının III. ve IV. evresinde olan, PH'ye eşlik eden tanısı konulmuş başka bir kronik hastalığı bulunan, kronik hastalığı kronik obstrüktif akciğer hastalığının olan, ağır yeti yitimi yaşayan bireylerin de KYA ve BPHDÖ puan ortalamasının daha yüksek, ÖBGÖ puan ortalamasının anlamlı düzeyde daha düşük olduğu bulunmuştur. Yaşın, kişisel bakımı karşılayabilme durumunun, kişisel bakımı üstlenen birisinin varlığı ve kimlerin karşıladığının yeti yitimi, öz bakım gücü ve GYA düzeyi üzerinde anlamlı bir farklılık ( $P < 0,05$ ) oluşturduğu saptanmıştır. Hastaların yeti yitimi ve özbakım gücü arasında negatif yönlü orta düzeyde anlamlı, yeti yitimi ve GYA arasında pozitif yönlü yüksek düzeyde anlamlı, özbakım gücü ile GYA arasında pozitif yönlü orta düzeyde anlamlı bir ilişki olduğu belirlenmiştir ( $P < 0,00$ ).

**Sonuç:** Sonuç olarak PH'li bireylerde gelişen yeti yitiminin GYA ve öz bakım gücünü olumsuz etkilediği belirlenmiştir.

**Anahtar Kelimeler:** Günlük yaşam aktiviteleri, yeti yitimi, Parkinson, öz bakım gücü

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## Introduction

Parkinson's disease (PD) is a chronic disease that develops due to the insufficient production of dopamine, a chemical that allows the brain to control involuntary movements. The disease is accompanied by symptoms such as hand tremors, a slowdown in movements, and the deterioration of posture; these can cause a deterioration in the activities of daily living (ADL) of patients (1,2,3,4,5,6).

Motor symptoms seen in patients with PD, such as akinesia, bradykinesia, tremor, rigidity, postural instability, postural balance, and gait disorder, cause significant disability (7). Disability is defined as the limitation or loss of the ability to perform an activity within the limits or form accepted as normal for the person (8).

Physical disability associated with the disease negatively affects the individual's self-care agency. Self-care is defined as the process of performing one's own activities to maintain one's own life, health, and wellbeing; the ability to perform these activities is expressed as self-care agency. Individuals with PD need partial or complete assistance in maintaining their own care in certain periods of their lives, especially in the later stages of the disease, since their physical movement is reduced and their self-care becomes a priority issue. Individuals with sufficient self-care agency can meet their self-care requirements adequately and appropriately, take responsibility for their health, and perform their ADL without being dependent on others.

ADL, which are defined as the activities performed by healthy individuals to maintain their lives, are activities such as ensuring environmental safety, communicating, eating, drinking, discharging, managing personal hygiene, and moving (9,10). Since PD causes impairment in mobility and functional activities at different levels, individuals with PD need other people's help. This situation transforms people from independence to a largely dependent condition. Some studies have found that patients with PD have difficulty in performing ADL, such as dressing, eating, bathing, and writing, and this situation negatively affects their quality of life (11). The negative effect on ADL of motor symptoms, such as tremors, hypokinesia, and rigidity, the presence of non-motor symptoms, such as cognitive impairment and depression, and the side effects of the drugs used in the treatment of PD have a direct negative effect on the quality of life of the patients (12,13,14,15,16).

Notably, there is no data examining the effect of disability and self-care agency on ADL in patients with PD in Türkiye; such studies are important in the care planning and rehabilitation of patients with the condition. In addition, healthcare professionals working with patients with many complex problems need more data to maximize their patients' motor functions, thereby increasing independence in their ADL and ensuring psychosocial wellbeing and adaptation to the disease.

## Materials and Methods

### Design and Participants

The purpose of this study was to determine the effects of disability and self-care agency on the ADL of patients with PD.

The population of the study was composed of individuals who were  $\geq 30$  years, had applied to the Neurology Outpatient Clinic

of a Health Research and Application Center within the previous year, and were diagnosed with PD. The sample, determined from 200 patients with PD who applied to the Research and Application Center Neurology Outpatient Clinic within a year at prevalence of 50%, deviation of 5% and confidence interval of 95%, was calculated from  $n = \text{formula}$  as  $n = 80$ .

The study sample comprised 81 individuals with PD who applied to the outpatient clinic between May 1, 2017, and January 30, 2018, and met the study inclusion criteria.

The inclusion criteria for the patient selection were as follows: patients who were being followed up after an idiopathic PD diagnosis; patients aged  $\geq 30$  years; patients who agreed to participate in the study.

### Procedure and Data Collection

During the data collection, the ADL of patients was evaluated using a Patient Information Form, the Brief Disability Questionnaire (BDQ), Self-care Agency Scale (SCAS), and Unified Parkinson's Disease Rating Scale (UPDRS). The researchers collected data by conducting face-to-face interviews with patients included in the sample and from patient records after obtaining the necessary permissions for the study. It took an average of 20–25 minutes to complete the questionnaire.

### Patient Information Form

The 16-question form was developed by the researcher based on the literature (1-16) and comprised two sections: sociodemographic characteristics and information about the disease.

### Hoehn and Yahr Staging Scale

The disease staging of the characteristics related to the disease was performed by a researcher physician using the Hoehn and Yahr (H-Y) Staging scale (17). The stages are defined as follows:

**Stage 1:** Unilateral tremor, rigidity, akinesia, or postural imbalance. Mild symptoms.

**Stage 1.5:** Unilateral and axial involvement.

**Stage 2:** Postural abnormalities with or without axial symptoms, such as bilateral tremor, rigidity, akinesia or loss/lack of facial expressions, swallowing difficulties, axial rigidity (especially neck), forward lean posture, slow or shuffling gait, and general stiffness. Minimal disability may be present.

**Stage 2.5:** Mild bilateral disease with improvement in the tensile test.

**Stage 3:** Balance problems in addition to the results from stage 2, but the patient can perform all the activities independently. Moderate dysfunction.

**Stage 4:** The patient needs assistance with some or all of his/her daily activities. Severe symptoms and significant disability.

**Stage 5:** The patient is dependent on a wheelchair or bed (17).

### Brief Disability Questionnaire

The BDQ was developed by the World Health Organization and evaluates physical and social disability (18). The assessment of its validity and reliability and its Turkish adaptation were performed by Kaplan (19), who calculated the reliability coefficient of BDQ as 0.91. The questionnaire was based on the questions associated with the disability in the Short-Form General Health Survey. The BDQ contains 11 questions that investigate the patient's physical and social disability in the previous month. The initial questions query whether the person

can be considered disabled or not due to health problems in performing daily activities, such as engaging in sports, pulling a table, carrying bags, climbing stairs, walking uphill, bending down, standing up, heavy lifting, walking long distances, taking a bath, and going to the toilet. The later questions measure the effects of health problems on hobbies, daily work, desire to work, work efficiency, and interpersonal relationships. Disability in these fields is scored by the patient as 0 (never), 1 (sometimes or a little), or 2 (always or quite often). Due to the high number of patients who had difficulty understanding the tests in the study, the questions were read by the interviewer, and the patients' responses were marked. The disability total score of 49 is obtained by simply adding the scores. The total score ranges between 0 and 22 points. The questionnaire is evaluated as follows: 0–4 points = no disability; 5–7 = mild disability; 8–12 = moderate disability;  $\geq 13$  = severe disability (19).

#### Self-care Agency Scale

This scale, which is used to measure the self-care agency or self-care ability of an individual, was developed by Kearney and Fleischer (16) and consists of 43 items (20). The assessment of its validity and reliability for use in Turkish society was performed by Nahcivan (21) in 1993, and its Cronbach's alpha coefficient was determined to be 0.89. Each item on the scale is scored between 0 and 4 points, with the following meanings: 0 = "it does not describe me at all;" 1 = "it does not describe me much;" 2 = "I have no idea;" 3 = "it defines me a little;" 4 = "it defines me a lot." In the Turkish version of the scale, eight items (items 3, 6, 9, 13, 19, 22, 26, and 31) are evaluated as negative and the scoring is reversed. The maximum score on the scale is 140. A high score from the SCAS indicates that the individual is independent and sufficient in performing self-care. Receiving a score close to zero for an individual indicates that the SCAS has decreased, whereas receiving a score approaching 140 points indicates that the SCAS has increased (21).

#### V-unified Parkinson's Disease Rating Scale

This scale, developed by Fahn, Elton, and UPDRS Development Committee members in 1987 (21), determines patients' mental status, ADL, motor functions, and treatment complications as follows: UPDRS1: thought, behavior, affect; UPDRS2: ADL; UPDRS3: motor examination; UPDRS3 20: rest tremor; UPDRS3 21: action tremor or postural tremor in hands; UPDRS3 22: rigidity; UPDRS3 23: finger tapping; UPDRS3 24: hand gestures; UPDRS3 25: rapid hand movements. In the present study, the ADL section of UPDRS was used. The 42 items of the test are evaluated by scoring between 0 and 4; the higher the score is, the worse the situation for the patient. The validity and reliability of the scale were assessed by Akbostanci et al. (22) and found to be high.

In this study, Cronbach's alpha internal consistency coefficients were determined to be 0.89 for BDQ, 0.84 for SCAS, and 0.83 for UPDRS.

#### Ethical Considerations

Approval to conduct the study was obtained from the Erciyes University Faculty of Medicine Ethics Committee and written permission from the Erciyes University Health Research and Application Center Gevher Nesibe Hospital (2017/324, date: June

18, 2017). The purpose of the study was explained to the patients who participated in the study, and their informed consent was obtained in accordance with the Declaration of Helsinki.

#### Statistical Analysis

The data were evaluated using the IBM's Statistical Package for the Social Sciences Statistics 21 IBM Corp., Armonk, New York, USA) package program was used to evaluate the research data. software package. In the statistical evaluation, percentage calculations, the t-test, Kruskal–Wallis analysis of variance, the Mann–Whitney U test, Pearson correlation analysis, and Cronbach's alpha internal consistency test were used. The data showed an ordinal distribution.

#### Results

The mean age of the patients with PD ( $n = 81$ ) was  $64.00 \pm 10.87$  years; 56.8% of the patients were male, 34.6% were in the 50–59-year age group, 50.6% were primary school graduates, 80.2% were married, 53.1% were living with their spouses and children, 93.8% were unemployed, 69.2% had a moderate income status, and 88.9% were living in urban areas. A total of 43.2% of the patients stated that they could not care for themselves, 55.6% stated that they had someone caring for them, and 95.6% ( $n = 45$ ) stated that their family members took care of them (Table 1). According to the statistical analysis of the descriptive characteristics of the patients and their disability, self-care agency, and ADL scores, it was found that gender, education level, marital status, living with others, income level, and place of residence did not affect the BDQ, SCAS, or UPDRS scores (Table 1). Age, ability to perform personal care, presence of someone providing personal care, and relationship with the care provider caused a significant difference in levels of disability, self-care agency, and ADL ( $P < 0.05$ ). The BDQ and UPDRS mean score was higher and the SCAS mean score was significantly lower in the group aged  $\geq 70$  years compared with the other age groups (Table 1). It was also found that individuals whose personal care was provided by family members had higher BDQ and UPDRS mean scores and significantly lower SCAS mean scores (Table 1).

The average disease duration of the patients was  $4.84 \pm 1.79$  years, and 25.9% of them were in stage 3 of the H–Y scale. A total of 51.9% of the patients had a chronic disease, of whom 33.3% ( $n = 42$ ) had hypertension. Severe disability was determined in 48.1% of the patients (Table 2). Patients who were in stages 3 and 4 of PD according to the H–Y scale and who also had another chronic disease-in particular, chronic obstructive pulmonary disease (COPD)-were found to have significantly higher UPDRS scores than those who did not (Table 2).

The BDQ mean score of patients with PD was  $12 \pm 6.25$  (min: 0, max: 22), the SCAS mean score was  $104 \pm 23.63$  (min: 0, max: 140), and the UPDRS mean score was  $15.0 \pm 9.00$  (min: 0, max: 51) (Table 3).

There was a negative and moderate significant correlation between the patients' disability and self-care agency, a positive and highly significant correlation between disability and ADL, and a positive and moderate significant correlation between self-care agency and ADL ( $P < 0.00$ ) (Table 4).

Table 1. Comparison of individuals' disability, self-care agency, and activities of daily living total mean scores in terms of their descriptive characteristics

Descriptive characteristics	n (%)	BDQ $\bar{X} \pm SD$	Test and P value	SCAS $\bar{X} \pm SD$	Test and P value	UPDRS $\bar{X} \pm SD$	Test and P value
<b>Gender</b>							
Female	35 (43.2)	12.48 ± 5.59	0.107	98.42 ± 24.92	0.872	15.00 ± 8.36	0.251
Male	46 (56.8)	11.91 ± 6.76		105.02 ± 22.46		16.78 ± 9.48	
<b>Age groups</b>							
30-39 years	3 (3.7)	11.66 ± 8.50 <sup>a</sup>	0.022	112.33 ± 22.81 <sup>a</sup>	0.044	12.00 ± 7.93 <sup>a</sup>	0.012
40-49 years	13 (16.0)	8.30 ± 5.64 <sup>b</sup>		112.53 ± 21.28 <sup>a</sup>		12.84 ± 7.06 <sup>a</sup>	
50-59 years	13 (16.0)	13.61 ± 4.27 <sup>c</sup>		110.07 ± 15.16 <sup>a</sup>		14.92 ± 7.63 <sup>a</sup>	
60-69 years	28 (34.6)	10.92 ± 6.61 <sup>a</sup>		99.21 ± 26.05 <sup>b</sup>		13.28 ± 7.62 <sup>a</sup>	
≥70 years	24 (29.7)	14.95 ± 5.72 <sup>c</sup>		94.45 ± 23.71 <sup>b</sup>		22.00 ± 9.85 <sup>b</sup>	
<b>Education level</b>							
Illiterate	8 (9.9)	14.75 ± 4.89	0.524	84.87 ± 38.56	0.512	21.50 ± 9.10	0.192
Literate	7 (8.6)	13.85 ± 6.51		95.28 ± 29.06		19.85 ± 13.08	
Primary school	41 (50.6)	11.97 ± 6.20		106.39 ± 17.72		106.39 ± 17.72	
Secondary school and above	25 (30.9)	11.16 ± 6.67		102.72 ± 23.44		102.717 ± 14.52	
<b>Marital status</b>							
Married	65 (80.2)	13.62 ± 5.42	0.321	102.25 ± 23.96	0.972	15.12 ± 9.50	0.484
Single	16 (19.8)	11.80 ± 6.43		102.15 ± 23.74		16.23 ± 8.94	
<b>People with whom the patient lives</b>							
Living alone	4 (4.9)	14.00 ± 5.47	0.310	103.75 ± 14.12	0.239	11.00 ± 1.82	0.439
With spouse	23 (28.4)	11.78 ± 7.21		97.21 ± 26.43		17.26 ± 10.49	
With spouse and children	43 (53.1)	11.48 ± 6.07		105.86 ± 22.02		14.95 ± 7.89	
Only with children	10 (12.3)	15.70 ± 4.21		94.40 ± 25.54		20.10 ± 10.90	
With parents	1 (1.3)	7.00 ± 0.00		129.00 ± 0.00		12.00 ± 0.00	
<b>Working status</b>							
Employed	5 (6.2)	9.20 ± 3.23	0.234	113.60 ± 14.38	0.255	10.00 ± 2.91	0.082
Unemployed	76 (93.8)	12.35 ± 6.35		101.42 ± 23.99		16.40 ± 9.13	
<b>Income status</b>							
Very high	1 (1.2)	13.00 ± 0.00	0.393	102.00 ± 0.00	0.126	13.00 ± 0.00	0.576
High	15 (18.5)	9.66 ± 6.28		113.46 ± 22.27		12.93 ± 7.64	
Moderate	56 (69.2)	12.62 ± 6.20		99.03 ± 23.86		16.73 ± 9.36	
Low	9 (11.1)	13.33 ± 6.53		102.88 ± 22.27		17.00 ± 9.05	
<b>Place of residence</b>							
City-urban zone	72 (88.9)	12.06 ± 6.25	0.668	101.80 ± 24.41	0.994	15.73 ± 8.87	0.443
Village-rural area	9 (11.1)	12.88 ± 6.65		105.11 ± 16.89		18.22 ± 11.03	
<b>Status of performing personal care</b>							
Can	19 (23.5)	17.94 ± 4.56 <sup>a</sup>	0.000	90.00 ± 28.26 <sup>a</sup>	0.016	25.21 ± 8.21 <sup>a</sup>	0.000
Partially can	27 (33.3)	13.00 ± 4.82 <sup>b</sup>		102.14 ± 16.64 <sup>a</sup>		17.77 ± 6.53 <sup>b</sup>	
Cannot	35 (43.2)	8.37 ± 5.40 <sup>c</sup>		108.80 ± 23.49 <sup>b</sup>		9.65 ± 5.58 <sup>c</sup>	
<b>Patient being cared for</b>							
Yes	45 (55.6)	15.20 ± 5.25	0.000	96.73 ± 22.78	0.020	20.93 ± 8.21	0.000
No	36 (44.4)	8.36 ± 5.30		108.97 ± 23.20		9.86 ± 5.51	
<b>People providing the care (n = 45)</b>							
Caregiver	2 (4.4)	8.00 ± 3.25	0.000	111.00 ± 12.72	0.050	7.00 ± 4.48	0.000
Family members	43 (95.6)	15.25 ± 5.30		96.61 ± 23.03		21.11 ± 8.22	

ANOVA, Kruskal-Wallis and Mann-Whitney U tests were used. Groups with the letters a, b, c are similar.  $\bar{X}$ : Mean, SD: Standard deviation, BDQ: Short Disability Questionnaire, SCAS: Self-care Agency Scale, UPDRS: Unified Parkinson's Disease Rating Scale

**Table 2. Comparison of disability, self-care agency, and activities of daily living total mean scores of the individuals according to their disease characteristics**

Disease characteristics	n (%)	BDQ $\bar{X} \pm SD$	Test and P value	SCAS $\bar{X} \pm SD$	Test and P value	UPDRS $\bar{X} \pm SD$	Test and P value
Disease duration (years)	4.84 ± 1.79						
<b>Hoehn and Yahr stage of the disease</b>							
Stage 1	24 (29.6)	8.58 ± 5.25 <sup>a</sup>	0.001	107.41 ± 19.96	0.392	9.00 ± 5.29 <sup>a</sup>	0.000
Stage 1.5	3 (3.7)	12.00 ± 5.29 <sup>b</sup>		94.12 ± 30.78		13.66 ± 4.50 <sup>b</sup>	
Stage 2	16 (19.8)	11.25 ± 6.02 <sup>b</sup>		101.06 ± 25.30		15.43 ± 8.39 <sup>b</sup>	
Stage 2.5	9 (11.1)	10.33 ± 7.64 <sup>a</sup>		109.44 ± 20.90		15.55 ± 9.46 <sup>b</sup>	
Stage 3	21 (25.9)	16.09 ± 4.83 <sup>c</sup>		95.23 ± 25.01		20.95 ± 7.03 <sup>c</sup>	
Stage 4	8 (9.9)	16.50 ± 4.37 <sup>c</sup>		114.33 ± 8.50		26.62 ± 7.76 <sup>c</sup>	
<b>Has another chronic disease been diagnosed?</b>							
Yes	42 (51.9)	14.23 ± 5.57	0.002	95.73 ± 23.73	0.010	17.71 ± 9.63	0.076
No	39 (48.1)	9.92 ± 6.24		109.10 ± 21.75		14.17 ± 8.00	
<b>Diagnosed diseases (n = 42)</b>							
Diabetes mellitus	13 (30.9)	15.61 ± 5.88 <sup>a</sup>	0.002	93.23 ± 27.43 <sup>a</sup>	0.002	20.23 ± 10.06	0.131
Hypertension	14 (33.3)	14.00 ± 4.55 <sup>a</sup>		100.00 ± 26.37 <sup>b</sup>		16.42 ± 9.07	
Congestive heart failure	5 (11.9)	12.00 ± 6.63 <sup>b</sup>		103.20 ± 12.79 <sup>b</sup>		16.40 ± 9.07	
COPD/asthma	6 (14.3)	15.66 ± 4.92 <sup>a</sup>		79.66 ± 17.25 <sup>c</sup>		22.00 ± 10.35	
Other	4 (9.6)	11.25 ± 8.01 <sup>b</sup>		103.75 ± 12.44 <sup>b</sup>		9.25 ± 6.84	
<b>Disability status</b>							
No disability	13 (16.0)	2.07 ± 1.49 <sup>a</sup>	0.000	122.07 ± 11.10 <sup>a</sup>	0.000	5.69 ± 4.26 <sup>a</sup>	0.000
Mild disability	8 (9.9)	6.50 ± 0.53 <sup>b</sup>		115.50 ± 12.95 <sup>b</sup>		11.00 ± 2.97 <sup>b</sup>	
Moderate disability	21 (25.9)	10.33 ± 1.39 <sup>b</sup>		108.00 ± 17.71 <sup>b</sup>		12.14 ± 4.81 <sup>b</sup>	
Severe disability	39 (48.2)	17.66 ± 2.48 <sup>c</sup>		89.66 ± 24.27 <sup>c</sup>		22.56 ± 7.55 <sup>c</sup>	

ANOVA, Kruskal-Wallis and Mann-Whitney U tests were used. Groups with the letters a, b, c are similar.  $\bar{X}$ : Mean, SD: Standard deviation, BDQ: Short Disability Questionnaire, SCAS: Self-care Agency Scale, UPDRS: Unified Parkinson's Disease Rating Scale, COPD: Chronic obstructive pulmonary disease

**Table 3. Distribution of individuals' disability, self-care agency, and activities of daily living total mean scores**

Scales and subgroups	( $\bar{X} \pm SD$ )	Min-max values
BDQ	12.0 ± 6.25	0-22
SCAS	104.0 ± 23.63	0-140
UPDRS	15.0 ± 9.00	0-51

$\bar{X}$ : Mean, SD: Standard deviation, BDQ: Short Disability Questionnaire, SCAS: Self-care Agency Scale, UPDRS: Unified Parkinson's Disease Rating Scale

**Table 4. Correlation between disability, self-care agency, and activities of daily living scores**

Scales	SCAS	UPDRS	BDQ
SCAS	-	-0.506 0.000	-0.596 0.000
UPDRS	-0.506 0.000	-	0.782 0.000
BDQ	-0.596 0.000	0.782 0.000	-

Pearson correlation analysis was used. BDQ: Short Disability Questionnaire, SCAS: Self-care Agency Scale, UPDRS: Unified Parkinson's Disease Rating Scale



## Discussion

There is a strong correlation between health and self-caring. When a person cares for themselves, their health and wellbeing can improve. People with PD have difficulty in or become incapable of doing what they did before, experience disability, and become dependent on others. Since disability directly affects the independence of the individual, it may cause them to feel useless and dependent on others, decrease their self-esteem, and lead to depression (23,24,25). In this case, it negatively affects the life quality of both the individuals with PD and the caregivers (26).

This study evaluated the effects of disability and the self-care agency of patients with PD on their ADL and found that although the self-care agency and ADL scores were higher in men than in women, the difference between them was not statistically significant. Since the burden in family life (such as household chores and childcare) tends to be greater on women in our society and they also experience stress in their working life, it can be expected that women are affected more negatively. In their study of patients with PD, Behari et al. (12) found that male patients had a higher quality of life than women, but the difference was not statistically significant. This result is consistent with that of the present study. Other studies also found that the quality of life of female patients was lower compared with that of men (27,28).

Often with increasing age, individuals' health problems increase, losses are experienced in body functions, and some changes are experienced in physiological, psychological, and cognitive areas. These changes can limit, or even hinder, ADL. As a result, individuals can become more dependent while performing their ADL. Some studies have reported that as age increased, disability increased, whereas self-care agency, life satisfaction, status of performing ADL, and quality of life decreased, which is compatible with the present study (23,24,25,29). However, other studies have found that patients with early-onset PD were prone to depression associated with having this disease at a young age, and their quality of life is lower than that of patients with late-onset PD (24).

The present study found that disability was higher in unemployed individuals than in those who were employed; their self-care agency was lower and their dependency levels were higher, but this was not statistically significant. In a similar study, the dependency level and mobility limits of unemployed individuals in ADL were found to be higher, and this was statistically significant (26). This result suggests that individuals with high income have no financial stressors and can access health institutions more readily, whereas the financial problems experienced by individuals with a low income affect their adaptation to the disease and their ability to cope; thus, disability influences self-care and ADL. Other recent studies have stated that individuals with regular income have a better quality of life and they perform ADL better (27,28).

In this study, a statistically significant difference was found between the status of fulfilling daily work and ADL scores. People who are not dependent on others in their daily work are more likely to have greater self-care agency. The result of the present study is compatible with the literature, where studies revealed a positive and highly significant correlation between life satisfaction and self-care agency and that life satisfaction increased as self-care agency and physical competence increased (29).

The present study also revealed that in the case of the presence of a caregiver, disability was higher, self-care agency was lower, and dependence level in ADL was higher. This was thought to be related to the increase in the need for caregivers as the disease progresses. A previous study found that individuals who needed assistance for care had high dependency levels in their ADL (6). The study showed that if those providing care were family members and not caregivers, disability was higher, self-care agency was lower, and the dependency level in ADL was higher. A study conducted in India found that the presence of a family member providing care for each patient with PD due to their culture positively affected the course of the disease (12).

Studies have shown that the dependency level in ADL increased and the quality of life decreased as the duration and stage of the disease increased (27,28,29). The present study found that the stage of the disease significantly affected the disability and ADL score, and disability increased and ADL decreased as the disease progressed.

In the present study, disability increased and self-care agency decreased statistically significantly with the presence of another chronic disease in patients with PD. The disability and dependency level in ADL increased and self-care agency decreased, particularly in patients with COPD. One study stated that the presence of chronic diseases caused disability and dependency in ADL (23,25).

Most people with PD need the assistance of others. Many studies have found that the quality of life of people is impaired as their dependency levels increase while performing ADL (12,26). In the present study, a statistically significant correlation was found between disability, self-care agency, and dependency level in ADL. As disability in patients with PD increased, their self-care agency decreased, and the dependency level in ADL also increased. It was stated in the study conducted with patients with PD that the quality of life of the individual was impaired as the dependence level on ADL increased and self-care agency decreased (16).

The present study found that the patients' ADL increased as their self-care agency increased. In a study conducted with patients with osteoarthritis, individuals with low self-care agency were found to have a relatively high dependence level in ADL (3). In the present study, high self-care agency and ADL mean score, meeting their own needs, moving independently, and being together with people similar to themselves can be considered as factors increasing the life satisfaction of individuals. This result was associated with the fact that individuals with PD included in our sample preferred to live with their families, as they need more help from their families because they have a disability. People become dependent when performing their ADL, as PD causes insufficiency in mobility and functional activities at different levels. Social support received from the family can be expected to have a large effect, as family members are tied together, live together, know the importance of being a family, and have strong solidarity and ties within the family in Turkish society.

### Study Limitations

Although the number of samples was sufficient in the research, taking patients from institutions other than university hospitals could increase the generalizability of the findings.

## Conclusion

Nurses and other healthcare professionals providing care should be informed about practices that increase the positive correlation between disability, ADL, and self-care agency in individuals with PD. Furthermore, they should be supported in reflecting this information in healthcare practices. The authors recommend that healthcare professionals evaluate the disability, self-care agency, and ability to perform ADL of individuals with PD and plan to prevent or reduce their effects on the life of the individual. Individuals with PD should be supported in maintaining ADL, and studies should be conducted to investigate the care burden in families providing care for individuals with PD.

## Ethics

**Ethics Committee Approval:** Approval to conduct the study was obtained from the Erciyes University Faculty of Medicine Ethics Committee and written permission from the Erciyes University Health Research and Application Center Gephver Nesibe Hospital (2017/324, date: June 18, 2017).

**Informed Consent:** Obtained.

**Peer-review:** Externally peer-reviewed.

## Authorship Contributions

Surgical and Medical Practices: S.G., M.G., Concept: S.G., M.G., Design: S.G., M.G., Data Collection or Processing: A.Ç., A.E., Analysis or Interpretation: S.G., M.G., A.Ç., A.E., Literature Search: S.G., A.Ç., Writing: S.G., A.Ç.

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