

Parkinson Hastalığı Olan Bireylerde Salya Akması Sıklığı ve Şiddeti, Salya Akmasıyla İlgili Yaşam Kalitesi ve Bakım Veren Yükü Arasındaki İlişki: Kesitsel Bir Çalışma

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Özet

Amaç: Salya akması, Parkinson Hastalığı (PH) olan bireylerin yaşam kalitesini ve bakım veren yükünü olumsuz etkiler. Bu nedenle amacımız, salya akması yaşayan bireylerin yaşam kalitesini ve bakım veren yükünü incelemektir.

Gereç ve Yöntem: 65 PH olan bireyi ve 65 bakım vereni içeren prospektif bir çalışma yürütülmüştür. Parkinson hastalığı olan bireyler için Siyalore Klinik Ölçeği (PH-SKÖ) ve Salya Akması Sıklığı ve Şiddeti Ölçeği (SASSÖ) kullanılarak değerlendirilirken, bakım verenler Zarit Bakım Veren Yükü Ölçeği (ZBVYÖ) ile değerlendirilmiştir. Ek olarak, PH'ler hastalık şiddeti ve süresine göre gruplandırılmış ve salya akmasıyla ilişkili yaşam kaliteleri ve bakım veren yükleri karşılaştırılmıştır.

Bulgular: PH-SKÖ, SASSÖ ve ZBVYÖ arasında orta ila yüksek düzeylerde pozitif ve anlamlı korelasyonlar bulunmuştur ($p<0,05$). Daha uzun hastalık süresi ve daha yüksek şiddete sahip gruptaki katılımcılar, daha kısa hastalık süresi ve daha düşük şiddete sahip gruptaki katılımcılara kıyasla sonuç ölçüm araçlarında (PH-SKÖ, SASSÖ ve ZBVYÖ) daha yüksek puanlar göstermiştir ($p<0,01$). Hiç salyası olmayan grupta, orta düzeyde salyası olan ve şiddetli salyası olan gruplar karşılaştırıldığında, şiddetli salyası olan gruptaki katılımcılar diğer iki gruba kıyasla sonuç ölçüm araçlarında daha yüksek puanlar bulunmuştur ($p<0,01$).

Sonuç: Mevcut çalışmada salya akmasıyla yaş, hastalık süresi ve hastalık şiddeti gibi faktörler arasında ilişki bulunmuştur. Bu faktörler salya akması sıklığını ve şiddetini etkileyerek hem PH olan bireylerin salyayla ilgili yaşam kalitesini hem de bakım veren yükünü olumsuz yönde etkilemektedir. Bu nedenle, salyayla ilgili yaşam kalitesini değerlendirmenin yanı sıra bakım veren yükü de ayrıntılı olarak değerlendirilmelidir.

Anahtar kelimeler: parkinson hastalığı, salya akması, siyalore, bakım veren yükü

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The Relationship between Drooling Frequency and Severity, Drooling-Related Quality of Life and Caregiver Burden in Individuals with Parkinson's Disease: A Cross-Sectional Study

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Abstract

Objective: Drooling negatively impacts the quality of life of individuals with Parkinson's Disease (IwPD), and imposes a burden on caregivers. Therefore, our aim is to examine the quality of life and caregiver burden of IwPD experiencing drooling.

Materials and Methods: A prospective study was conducted involving 65 IwPD and their caregivers. IwPD were assessed using the Sialorrhea Clinical Scale for Parkinson's Disease (SCS-PD), and Drooling Frequency and Severity Scale (DFSS), while caregivers were assessed via Zarit Burden Interview (ZBI). Additionally, IwPD were grouped based on disease severity and duration, and their drooling-related quality of life and caregiver burden were compared.

Results: Moderate to high positive and significant correlations between SCS-PD, DFSS, and ZBI were found ($p<0.05$). Participants in the group with longer disease duration and greater severity exhibited higher scores on the outcome measurement tools (SCS-PD, DFSS, ZBI) compared to those in the group with shorter disease duration and lower severity ($p<0.01$). When comparing the groups with no drooling, moderate drooling, and severe drooling, participants in the severe drooling group showed higher scores on the outcome measurement tools compared to the other two groups ($p<0.01$).

Conclusion: In the present study, relationships were found between drooling and factors such as age, disease duration, and disease severity. These factors influence the drooling frequency and severity, thereby negatively affecting both the drooling-related quality of life of IwPD and the caregiver burden. Therefore, in addition to assessing drooling-related quality of life, caregiver burden should also be evaluated in detail.

Keywords: parkinson's disease, drooling, sialorrhea, caregiver burden

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Introduction

Parkinson's disease (PD) is the most common neurodegenerative movement disorder characterized by the degeneration and loss of dopaminergic neurons due to damage to the substantia nigra (Armstrong & Okun, 2020; Balestrino & Schapira, 2020). Communication, drooling, and swallowing difficulties in which Speech-Language Therapists (SLTs) play a role in assessment and therapy processes are frequently observed in individuals with Parkinson's Disease (IwPD) (de Araújo et al., 2023; Miller et al., 2015). Drooling is considered one of the top five most serious symptoms reported by IwPD, with a prevalence estimate of approximately 56% (Kalf et al., 2009; Politis et al., 2010). It is associated with clinical problems such as perioral skin damage, eating, and speech difficulties. Additionally, it can lead to aspiration, increasing the risk of pneumonia, a leading cause of death (Fasano et al., 2015). It also causes feelings of shame and social isolation, reducing the quality of life for IwPD (Arboleda-Montealegre et al., 2021; Nascimento et al., 2021).

Studies indicate that drooling is prevalent among IwPD, with drooling being common even at mild to moderate levels (Kalf et al., 2009; Kalf et al., 2007; Mao et al., 2018). A study examining the causes of drooling noted that factors such as male gender and disease severity contribute to the increased severity of drooling (Mao et al., 2018). Another study emphasizes that, beyond its high prevalence, drooling is highlighted as a significant problem due to its clinical impact. The severe physical and emotional consequences of drooling in IwPD negatively affect social functioning (Kalf et al., 2009). Additionally, it is emphasized that many individuals remain untreated, and there is a need for treatment, underscoring the importance of conducting a detailed and specific assessment to understand its impact on IwPD (Kalf et al., 2007). In a study examining the quality of life of IwPD and caregiver burden, there appears to be a relationship between drooling and the quality of life of IwPD (Rajiah et al., 2017).

IwPD often require assistance from their caregivers in terms of medical, emotional, and social support. Furthermore, as the disease progresses, motor impairments worsen, and as individuals age, the role of the caregiver becomes increasingly significant (Rajiah et al., 2017). The burden of caregiving for IwPD, defined as the perception of strain and stress resulting from the perceived obligation to provide care, can adversely affect the quality of life of IwPD (Sham et al., 2022). It is necessary to comprehend the factors that contribute to the burden on caregivers and develop strategies to minimize it (Macchi et al., 2020). Therefore, caregiver burden is one of the critical steps in comprehensive assessment and treatment

processes for clinicians working with IwPD (Mosley et al., 2017). However, as far as the authors' knowledge, there is currently no existing study revealing the impact of the severity and frequency of drooling in IwPD on the burden of caregivers. Therefore, our first aim was to investigate the relationship between the drooling severity and frequency, quality of life-related to drooling, and caregiver burden in IwPD. The second aim was to compare the quality of life related to drooling and caregiver burden according to the disease duration, disease severity, and amount of drooling.

Materials and Methods

Study design and participants

This study was conducted between March 2023 and January 2024 as a prospective cross-sectional study at the Neurology outpatient clinics of Ondokuz Mayıs University. The current study complies with human studies guidelines and was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. The Ondokuz Mayıs University Clinical Research Ethics Committee reviewed and approved this study protocol with decision number 2023/68. Sixty-five IwPD and their caregivers were included in the study based on the inclusion criteria. Inclusion criteria for IwPD were: 1) being 18 years of age or older and 2) being able to complete the information forms and scales. 3) Meeting the diagnostic criteria of the UK Parkinson's Disease Society Brain Bank. 4) Receiving support from a caregiver for at least one year. Inclusion criteria for caregivers were: 1) providing care for the IwPD for at least one year, 2) being 18 years of age or older, and 3) being able to complete the information forms and scales. Exclusion criteria for IwPD were: 1) illiteracy, 2) presence of additional neurological diagnoses as these can cause drooling as well, 3) not being a native Turkish speaker, and 4) scoring below 24 on the Mini-Mental State Examination (MMSE) (Folstein et al., 1975) as an indicator of cognitive impairment and could potentially influence participation of the study. Exclusion criteria for caregivers were: 1) illiteracy, 2) not being a native Turkish speaker, 3) having a neurological disorder, as these can cause drooling as well, and 4) providing care for more than one individual.

A total of 87 individuals diagnosed with PD were referred to our center for evaluation. Of the IwPD, three were not included in the study because they were illiterate, four because they had additional neurological diagnoses, six because they scored below 24 on the MMSE, and a total of 74 individuals were deemed suitable. Of these individuals, four were not included in the study because their caregivers were illiterate, two because they had

neurological diseases, and three because they provided care to more than one individual. As a result, 65 IwPD and their caregivers were included in the study.

Assessments

Firstly, IwPD underwent clinical evaluation by a neurologist using the Unified Parkinson's Disease Rating Scale, a revised by the Movement Disorder Society (MDS-UPDRS) (Goetz et al., 2008), and the Hoehn and Yahr (H&Y) scale (Goetz et al., 2004). Subsequently, IwPD and their caregivers were referred to the Ondokuz Mayıs University Speech and Language Disorders Education, Research, and Training Center to be assessed by speech and language therapists (SLTs). SLT first administered a Demographic Information Form (DIF) which collected data on gender, age, education level, employment status, medication usage, disease duration of IwPD, caregiving duration, and working status. Following the administration of DIF, MMSE, Sialorrhea Clinical Scale for Parkinson's Disease (SCS-PD) (Perez Lloret et al., 2007), Drooling Frequency and Severity Scale (DFSS) (Thomas-Stonell & Greenberg, 1988), and Zarit Burden Interview (ZBI) (Zarit et al., 1980) were administered.

Outcome Measurement Tools

Sialorrhea Clinical Scale for Parkinson's Disease (SCS-PD)

SCS-PD is the seven-item clinical scale that evaluates problems related to drooling (sialorrhea) based on patient-reported outcomes. The seven items assess the following aspects: (A) diurnal sialorrhea, (B) nocturnal sialorrhea, (C) severity of drooling, (D) speech impairment, (E) eating impairment, (F) frequency of drooling, and (G) social discomfort. On the scale where each item is scored between 0 and 3, the total score ranges from 0 to 21. An increase in scores indicates more severe discomfort related to sialorrhea (Genç & Atalar, 2023; Perez Lloret et al., 2007).

Drooling Frequency and Severity Scale (DFSS)

The DFSS is a scale used to assess the severity and frequency of drooling through observation. The severity section is scored on a scale of 1-5, while the frequency section is scored on a scale of 1-4. Higher scores indicate worse drooling (Thomas-Stonell & Greenberg, 1988). A total score of 2 indicates no drooling, whereas scores above 6 indicate severe drooling (Nienstedt et al., 2018).

Zarit Burden Interview (ZBI)

The ZBI is used to assess the level of stress and perceived burden experienced by caregivers while providing care for different health conditions. This consists of 22 items, each

scored between 0 and 4. The total scores on the scale range from 0 to 88. Scores between 0 and 24 indicate "mild burden," scores between 25 and 33 indicate "moderate burden," and scores between 34 and 88 indicate "severe burden" (Özer et al., 2012; Zarit et al., 1980).

Statistical Analysis

Statistical analysis was performed using IBM SPSS V23. Normality of continuous variables was assessed using the Kolmogorov-Smirnov test. Variables that followed a normal distribution were presented as mean \pm SD, while non-normally distributed variables were expressed as median (IQR). For participant characteristics, age, MDS-UPDRS-2.2, SCS-PD, and DFSS were reported as mean \pm SD or median (IQR), depending on their distribution. Gender, disease duration, education level, Hoehn & Yahr stage, drooling frequency, and severity were presented as n (%). For caregiver characteristics, age, duration of caregiving, and ZBI were reported as mean \pm SD or median (IQR), based on their distribution. Gender, working status, and education level were presented as n (%). The relationship between the age of IwPD, duration of caregiving, MDS-UPDRS-2.2, SCS-PD, DFSS, and ZBI were calculated using Pearson correlation for normally distributed data, and Spearman's ρ (rho) was used for not normally distributed data. Results were reported as significant for $p < 0.05$. IwPD was grouped according to disease duration, drooling frequency and severity, and disease severity. Subsequently, the Kruskal-Wallis test was used to determine differences between groups. Following the Kruskal-Wallis test, Dunn's post-hoc analysis with Bonferroni correction was conducted to identify specific group differences. Results were considered significant at $p < 0.0021$.

Results

Descriptive analysis of IwPD is presented in Table 1. Individuals consisted of 33 males (50.8%) and 32 females (49.2%), and the mean age was 68.40 ± 6.71 years. Disease severity classified according to Hoehn and Yahr stages was distributed as follows: 33.8% (n=22) in Stage 1, 30.8% (n=20) in Stage 2, 23.1% (n=15) in Stage 3, and 12.3% (n=8) in Stage 4. The median score for MDS-UPDRS-2.2 was 2 (range: 0-4), while the mean SCS-PD score was 9.70 ± 6.36 . The median DFSS score was 4 (range: 2-9).

Table 1. Descriptive Analysis of Individuals with Parkinson's Disease

Parameters (N=65)	
Gender, n (%)	
Male	33 (50.8)
Female	32 (49.2)
Age (years), mean \pm sd	68.40 \pm 6.71
Disease duration, n (%)	
≤ 5 years	22 (33.8)
6-9 years	24 (36.9)
10 \geq years	19 (29.2)
Disease severity, n (%)	
Stage 1	22 (33.8)
Stage 2	20 (30.8)
Stage 3	15 (23.1)
Stage 4	8 (12.3)
Drooling Frequency and Severity, n (%)	
without drooling (DFSS = 2)	14 (21.5)
with mild drooling (2 < DFSS < 6)	32 (49.2)
with severe drooling (DFSS \geq 6)	19 (29.2)
MDS – UPDRS – 2.2, median (min-max)	2 (0 – 4)
SCS – PD, mean \pm sd	9.70 \pm 6.36
DFSS, median (min-max)	4 (2 – 9)

Note. MMSE: Mini-Mental State Examination, MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale

Descriptive analysis of caregivers of IwPD is presented in Table 2. The individuals consisted of 26 males (40.0%) and 39 females (60.0%), and the mean age was 52.38 \pm 13.93 years. The mean caregiving duration of the caregivers was 5.40 \pm 2.38 years. The median Zarit Burden Interview (ZBI) score was 20 (range: 0-80).

Table 2. Descriptive Analysis of Caregivers of Individuals with Parkinson's Disease

Parameters (N=65)	
Gender, n (%)	
Male	26 (40.0)
Female	39 (60.0)
Age (years), mean \pm sd	52.38 \pm 13.93
Caregivers, n (%)	
Partner	25 (38.5)
Child	26 (40.0)
Brother or sister	10 (15.4)
Other	4 (6.2)
Working status, n (%)	
Full	20 (30.8)
Part-time	14 (21.5)
Unemployed	16 (24.6)
Retired	15 (23.1)
Education level, n (%)	
Primary education	14 (21.5)
High school	25 (38.5)
Graduate	21 (32.3)
Postgraduate	5 (7.7)
Duration of caregiving	5.40 \pm 2.38
ZBI, median (min-max)	20 (0 – 80)

Note. MMSE: Mini-Mental State Examination, ZBI: Zarit Burden Interview

Table 3 displays the relationship between the parameters of IwPD and their caregivers. The highest correlation was highly positive and significant between MDS-UPDRS-2.2 and SCS-PD ($\rho = 0.937$, $p < 0.01$). Conversely, the lowest significant correlation was very weak and positive between caregiving duration and ZBI ($\rho = 0.252$, $p < 0.05$). Notably, there was no significant relationship between caregiving duration and most parameters.

Table 3. Relationship between Parameters

	Age of IwPD	Duration of Caregiving	MDS-UPDRS-2.2	SCS – PD	DFSS	ZBI
Age of IwPD	$r = 1.000$					
Duration of Caregiving	$\rho = .224$	$\rho = 1.000$				
MDS-UPDRS-2.2	$\rho = .316^*$	$\rho = -.031$	$\rho = 1.000$			
SCS – PD	$r = .307^+$	$\rho = -.014$	$\rho = .937^{**}$	$\rho = 1.000$		
DFSS	$\rho = .260^*$	$\rho = .127$	$\rho = .758^{**}$	$\rho = .804^{**}$	$\rho = 1.000$	
ZBI	$\rho = .397^{**}$	$\rho = .252^*$	$\rho = .523^{**}$	$\rho = .510^{**}$	$\rho = .419^{**}$	$\rho = 1.000$

Note. ρ = Spearman's ρ (rho), r = Pearson correlation, MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview, $^{**}p < 0.01$ by Spearman's ρ (rho), $^*p < 0.05$ by Spearman's ρ (rho), $^+p < 0.05$ by Pearson correlation

The evaluation parameters of groups with disease duration of five years and below, 6-9 years, and ten years and above were compared according to the results of the Kruskal-Wallis test (Table 4). Upon examining the comparison results of the three groups based on disease duration, a statistically significant difference was found among the median of MDS-UPDRS-2.2, SCS-PD, DFSS, and ZBI (respectively, $p < 0.001$, $p < 0.001$, $p < 0.001$, $p < 0.01$). According to the Dunn's post-hoc analysis following the Kruskal-Wallis test, significant differences were observed in MDS-UPDRS-2.2, SCS-PD, DFSS, and ZBI scores across all pairwise group comparisons (Table 5).

Table 4. Comparison of Values According to Disease Duration

Parameters	≤ 5 years (n=22)	6-9 years (n=24)	10 ≥ years (n=19)	<i>p</i>
MDS-UPDRS-2.2, median (min-max)	1.0 (0.0-3.0)	2.0 (0.0-4.0)	3.0 (2.0-4.0)	<0.001*
SCS – PD, median (min-max)	2.0 (0.0-16.0)	9.0 (3.0-20.0)	15.0 (7.0-21.0)	<0.001*
DFSS, median (min-max)	2.0 (2.0-9.0)	4.0 (2.0-9.0)	6.0 (3.0-9.0)	<0.001*
ZBI, median (min-max)	10.5 (0.0-46.0)	21.0 (3.0-78.0)	31.0 (12.0-80.0)	<0.001*

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview, *: Kruskal–Wallis test

Table 5. Post-Hoc Pairwise Comparisons of Parameters According to Disease Duration Using Dunn's Test

Comparison	MDS-UPDRS-2.2 p-value	SCS – PD p-value	DFSS p-value	ZBI p-value
≤ 5 years vs. 6-9 years	0.001	0.002	<0.001	0.008
≤ 5 years vs. 10 ≥ years	<0.001	<0.001	<0.001	<0.001
6-9 years vs. 10 ≥ years	0.015	0.006	0.092	0.053

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview

Evaluation parameters were compared among three groups categorized based on the frequency and severity of drooling (without, Mild, and Severe) using the Kruskal-Wallis test (Table 6). According to the comparison results, statistically significant differences were found among the median of MDS-UPDRS-2.2, SCS-PD, and ZBI for the three groups (respectively, $p < 0.001$, $p < 0.001$, $p < 0.001$). According to the Dunn's post-hoc analysis following the Kruskal-Wallis test, significant differences were observed in MDS-UPDRS-2.2, SCS-PD, and ZBI scores across all pairwise group comparisons based on drooling frequency and severity (Table 7).

Table 6. Comparison of Values According to Drooling Frequency and Severity

Parameters	Without drooling (n=14)	Mild drooling (n=32)	Severe drooling (n=19)	<i>p</i>
MDS-UPDRS-2.2, median (min-max)	0.0 (0.0-2.0)	2.0 (0.0-4.0)	3.0 (1.0-4.0)	<0.001*
SCS – PD, median (min-max)	1.0 (0.0-7.0)	9.5 (1.0-19.0)	15.0 (6.0-21.0)	<0.001*
ZBI, median (min-max)	7.0 (0.0-25.0)	22.0 (3.0-80.0)	31.0 (4.0-78.0)	<0.001*

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview, *: Kruskal–Wallis test

Table 7. Post-Hoc Pairwise Comparisons of Parameters According to Drooling Frequency and Severity using Dunn's Test

Comparison	MDS-UPDRS-2.2 p-value	SCS – PD p-value	ZBI p-value
Without drooling vs. Mild drooling	<0.001	<0.001	<0.001
Without drooling vs. Severe drooling	<0.001	<0.001	<0.001
Mild drooling vs. Severe drooling	<0.001	<0.001	<0.001

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, ZBI: Zarit Burden Interview

Finally, the evaluation parameters of IwPD were classified into four groups based on the severity determined by Hoehn & Yahr stages (Stages 1, 2, 3, 4) and were compared using the Kruskal-Wallis test (Table 8). According to the comparison results, significant differences were found among the median of MDS-UPDRS-2.2, DFSS, SCS-PD, and ZBI for the four groups (respectively, $p < 0.001$, $p < 0.001$, $p < 0.001$, $p < 0.001$). According to the Dunn's post-hoc analysis following the Kruskal-Wallis test, significant differences were observed in MDS-UPDRS-2.2, SCS-PD, DFSS, and ZBI scores across all pairwise comparisons based on disease severity stages (Table 9).

Table 8. Comparison of Values According to Disease Severity

Parameters	Stage 1 (n=22)	Stage 2 (n=20)	Stage 3 (n=15)	Stage 4 (n=8)	<i>p</i>
MDS-UPDRS-2.2, median (min-max)	1.0 (0.0-3.0)	2.0 (0.0-4.0)	2.0 (2.0-4.0)	3.0 (2.0-4.0)	<0.001*
SCS – PD, median (min-max)	4.5 (0.0-16.0)	8.0 (0.0-20.0)	13.0 (7.0-19.0)	16.0 (7.0-21.0)	<0.001*
DFSS, median (min-max)	2.5 (2.0-9.0)	4.0 (2.0-9.0)	5.0 (3.0-8.0)	5.0 (4.0-9.0)	<0.001*
ZBI, median (min-max)	8.5 (0.0-28.0)	18.0 (0.0-66.0)	38.0 (15.0-75.0)	67.0 (24.0-80.0)	<0.001*

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview, *: Kruskal–Wallis test

Table 9. Post-Hoc Pairwise Comparisons of Parameters According to Disease Severity Using Dunn's Test

Comparison	MDS-UPDRS-2.2 p-value	SCS – PD p-value	DFSS p-value	ZBI p-value
Stage 1 vs. Stage 2	0.047	0.103	0.016	<0.001
Stage 1 vs. Stage 3	<0.001	<0.001	0.002	<0.001
Stage 1 vs. Stage 4	<0.001	<0.001	<0.001	<0.001
Stage 2 vs. Stage 3	0.064	0.029	0.686	0.009
Stage 2 vs. Stage 4	0.008	0.013	0.438	<0.001
Stage 3 vs. Stage 4	0.028	0.120	0.693	0.031

Note. MDS – UPDRS: Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SCS – PD: Sialorrhea Clinical Scale for Parkinson's disease, DFSS: Drooling Frequency and Severity Scale, ZBI: Zarit Burden Interview

Discussion and Conclusion

Drooling in PD is an important symptom that clinicians need to recognize, as it significantly affects the daily lives of individuals with PD and leads to a decrease in their quality of life (Leibner et al., 2010). On the other hand, caregivers play an essential role, especially in the late stages of PD. Recognizing the caregiver burden is crucial for conducting a detailed and specific assessment. A high caregiver burden can lead to problems among the patient, healthcare provider, and caregiver, adversely affecting treatment options (Mosley et al., 2017). Therefore, this study aims to investigate the relationship between drooling frequency and severity in IwPD and drooling-related quality of life and caregiver burden. Due to the limited number of studies in the literature examining caregiver burden, our study investigated drooling in 65 IwPD and the caregiver burden in 65 caregivers. According to the results, relationships were found between drooling frequency and severity, disease severity, and quality of life of IwPD and caregiver burden.

The current study found a weak but statistically significant correlation between the age of IwPD and the drooling frequency and severity, drooling-related quality of life, and caregiver burden. In a study investigating the pathophysiology of drooling in IwPD, it was suggested that the age factor should be further explored, as increasing age in IwPD was considered a potential risk factor for drooling (Kalf et al., 2011). In the current study, a weak relationship was found between increasing age in IwPD and the drooling frequency and severity, supporting the notion that age, while not a standalone factor, may be a potential risk factor. In a study on caregiver burden in IwPD, a weak positive relationship was found between caregiver burden and the age of IwPD (Razali et al., 2011). In our study, a similarly weak positive relationship was found between the age of IwPD and caregiver burden. This suggests that, similar to the drooling frequency and severity, the increasing age of IwPD also

contributes to a higher caregiver burden. Furthermore, the current study revealed a decline in drooling-related quality of life with increasing age in IwPD. Therefore, age is considered one of the factors that can negatively impact drooling frequency and severity, drooling-related quality of life, and caregiver burden. It should be taken into consideration in the evaluation processes as IwPD age.

In our study, similar to the study conducted by Genç and Atalar, we found a high-level correlation between drooling severity and frequency and self-assessment measurements (MDS-UPDRS-2.2 and SCS-PD) related to drooling in IwPD (Genç & Atalar, 2023). In this case, increasing drooling frequency and severity may have a negative impact on the quality of life of IwPD. In a study examining the quality of life and caregiver burden in IwPD, a moderate correlation was found between saliva and drooling, caregiver burden, and overall quality of life (Rajiah et al., 2017). In our study, a similar moderate correlation was found between drooling and caregiver burden, while a strong correlation was observed between drooling frequency and severity, and drooling-related quality of life. This suggests that an increase in drooling frequency and severity may have a greater impact on drooling-related quality of life than on overall quality of life. In a study examining the factors contributing to caregiver burden in IwPD, it was noted that both motor and non-motor symptoms can contribute to caregiver burden. Therefore, healthcare professionals should pay close attention to caregiver burden and provide caregivers with detailed information about the disease (Grün et al., 2016). We can argue that increased frequency and severity of drooling expose caregivers to a greater burden. Therefore, the caregiving burden could be considered more critical in IwPD who complain of drooling symptoms. We did not find a high correlation between drooling severity and frequency and caregiver burden because ZBI gives general information about caregiver burden, not specifically related to drooling.

In our study, IwPD was divided into three groups based on disease duration, and differences between groups were examined with outcome measurements. In the literature, studies examining disease duration and drooling in IwPD have compared groups with and without drooling, finding that the group with drooling had a longer disease duration (Ou et al., 2015). In a study on the prevalence and progression of drooling in individuals with PD, it was noted that an increase in disease duration was associated with a higher prevalence of drooling (van Wamelen et al., 2020). Additionally, in a study investigating risk factors associated with drooling in individuals with PD, a comparison between groups with and without drooling revealed that the disease duration was significantly longer in the group with drooling (Mao et

al., 2018). It was indicated that the longer the duration of the disease, the higher the risk of drooling, and with the duration of the disease, the overall clinical condition tends to worsen, including drooling (Nascimento et al., 2021; van Wamelen et al., 2020). In our study, consistent with the literature, we observed significant differences in the outcome measurements among groups with different disease duration (short, medium, and long). In this context, it will be important to plan a comprehensive assessment and treatment process, including both drooling-related quality of life and caregiver burden, before the disease duration increases.

In our study, another comparison was made based on the drooling frequency and severity. We divided IwPD into three groups (without drooling, mild drooling, and severe drooling) and analyzed the differences between these groups based on various parameters. Previous studies have indicated that drooling reduces the quality of life of IwPD and increases caregiver burden (Arboleda-Montealegre et al., 2021; Ozdilek & Gunal, 2012; Rajiah et al., 2017; Srivanitchapoom et al., 2014). In our study, similar findings were observed, where an increase in drooling frequency and severity were associated with decreased drooling-related quality of life of IwPD and increased caregiver burden. A study also found that the quality of life of IwPD decreased, and the caregiver burden increased due to motor symptoms, including drooling. Therefore, it was suggested that treatment options aimed at reducing caregiver burden should be developed (Ozdilek & Gunal, 2012). Another study also highlighted the negative impact of drooling on quality of life and recommended integrated rehabilitation programs (Arboleda-Montealegre et al., 2021). Our study revealed that caregiver burden increased with the increase of drooling frequency and severity. Consequently, it is crucial to comprehensively examine caregiver burden for integrated assessment and rehabilitation options.

Our study grouped participants according to disease severity and examined the differences between outcome measurement tools. Disease severity was categorized using the Hoehn & Yahr stages. Studies have indicated that disease severity negatively impacts drooling frequency and severity, caregiver burden, and quality of life (Kalf et al., 2009; Karakoc et al., 2016; Mao et al., 2018; Santos-García & De la Fuente-Fernández, 2015; van Wamelen et al., 2020). In our study, like other studies, disease severity appeared to have a negative impact on the drooling frequency and severity, the drooling-related quality of life of IwPD, and the caregiver burden. Therefore, the late stages of PD, drooling frequency and

severity, drooling-related quality of life, and caregiver burden should be considered in comprehensive evaluation and treatment processes.

As drooling is a significant burden for caregivers, the lack of a questionnaire assessing the caregiver burden related to drooling is a limitation of our study. Also, caregiver burden with caregivers responsible for more than one individual should be investigated in future research. As a strength, this study has demonstrated that drooling negatively impacts the drooling-related quality of life of IwPD and the caregiver burden in different conditions (disease duration, disease severity, drooling frequency, and severity). Consequently, the caregiver burden should be emphasized in PD as it is affected by different parameters. SLTs should consider the caregivers and include them in their assessment protocol.

The increase in age, disease duration, and disease severity in IwPD increases the drooling frequency and severity, negatively affecting drooling-related quality of life of IwPD and general caregiver burden. Therefore, it is believed that attention should be paid to variables such as age, duration of disease, and severity in the evaluation processes of drooling in IwPD. Also, caregivers' thoughts about the burden of drooling should be considered during the assessment process.

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