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The Effect of Lower Urinary Tract Dysfunction on **Quality of Life and Caregiver Burden in Stroke Patients**

İnmeli Hastalarda Alt İdrar Yolu Disfonksiyonunun Yaşam Kalitesi ve Bakım Yükü Üzerine Etkisi

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ABSTRACT Objective: Lower urinary tract dysfunction (LUTD) is an important burden factor for patients and their caregivers. In this study, we aimed to investigate the impact of LUTD on caregiver burden and quality of life of stroke patients. Material and Methods: The study included 75 stroke patients and their caregivers followed in the physical medicine and rehabilitation clinic. Zarit Caregiver Burden Scale (ZCBS) was used to evaluate the caregiver burden, and the Incontinence Quality of Life (I-QOL) Scale was used to evaluate the effect of urinary symptoms on patients' quality of life. Urinary symptoms of the patients were evaluated with Danish Prostatic Symptom Score (DAN-PSS-1), functional status and activities of daily living were evaluated with Functional Independence Measure (FIM) and Barthel Index (BI). The patient's mood status was questioned with Hospital Anxiety and Depression Scale (HADS). Results: A total of 75 stroke patients, 38 (50.7%) women, and 37 (49.3%) men, with a mean age of 61.76±10.6 (37-80) years, and 75 caregivers participated in the study. A statistically significant difference was observed regarding FIM, BI, I-QOL and subgroups, DAN-PSS-1 scores between low/moderate and severe/overburden caregivers (p<0.001). The ZCBS scores of the caregivers of the patients whose HADS were higher than normal were significantly higher (p<0.01 and p<0.001, respectively). A statistically significant correlation was observed between the patients' DAN-PSS-1 and I-QOL-total and subgroups, BI, FIM total, and sub-scores (p<0.01). Conclusion: We found that LUTD in stroke patients reduces the patient's quality of life and increases the caregiver burden.

Keywords: Caregiver burden; quality of life; stroke; lower urinary tract dysfunction

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ÖZET Amac: Alt idrar yolu disfonksiyonu (AİYD), hastalar ve bakım verenleri için önemli bir yük faktörüdür. Bu çalısmada, inmeli hastalarda AİYD bakım veren yükü ve yaşam kalitesi üzerine etkisini araştırmayı amaçladık. Gereç ve Yöntemler: Çalışmaya fizik tedavi ve rehabilitasyon kliniğinde takip edilen 75 inme hastası ve bakım verenleri dâhil edildi. Bakım veren yükünü değerlendirmek için Zarit Bakım Veren Yük Ölçeği (ZBVYÖ), üriner semptomların hastaların yaşam kalitesine etkisini değerlendirmek için İnkontinans Yaşam Kalitesi Ölçeği (İ-YKÖ) kullanıldı. Hastaların üriner semptomları Danimarka Prostat Semptom Skoru (DAN-PSS-1) ile fonksiyonel durum ve günlük yaşam aktiviteleri Fonksiyonel Bağımsızlık Ölçütü (FBÖ) ve Barthel İndeksi (Bİ) ile değerlendirildi. Hastanın duygudurumu Hastane Anksiyete ve Depresyon Ölçeği (HADÖ) ile sorgulandı. Bulgular: Çalışmaya yaş ortalaması 61,76±10,6 (37-80) yıl olan 38'i (%50,7) kadın, 37'si (%49,3) erkek olmak üzere toplam 75 inmeli hasta ve 75 bakım veren katıldı. Düşük/orta ve ağır/aşırı yük bakım verenler arasında FBÖ, Bİ, İ-YKÖ ve alt gruplar, DAN-PSS-1 puanları açısından istatistiksel olarak anlamlı fark gözlendi (p<0,001). HADS normalden yüksek olan hastaların bakım verenlerinin ZBVYÖ puanları anlamlı olarak daha yüksekti (sırasıyla p<0,01 ve p<0,001). Hastaların DAN-PSS-1 ve İ-YKÖ-toplam ve alt grupları, Bİ, FBÖ toplam ve alt puanları arasında istatistiksel olarak anlamlı bir ilişki gözlendi (p<0,01). Sonuç: İnmeli hastalarda AİYD hastanın yaşam kalitesini düşürdüğünü ve bakım veren yükünü artırdığını saptadık.

Anahtar Kelimeler: Bakım veren yükü; yaşam kalitesi; inme; alt idrar yolu disfonksiyonu

Stroke is the most common neurological disease worldwide and is among the most common causes of disability in adults. Stroke is a disease that requires lifelong care, affecting many areas such as walking,

speaking, toilet, bathing, self-care activities. Each of these activities is a burdening factor for caregivers supporting the stroke patients.² Especially, lower urinary tract dysfunction (LUTD) is a significant bur-

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den factor for caregivers of stroke patients and is underestimated compared to other complications. In epidemiological studies conducted on caregivers of stroke patients, bladder and bowel incontinence was evaluated as the most demanding physical stress for caregivers.³

LUTD is one of the most important problems that negatively affect the quality of life and caregiver burden in stroke patients. Although urinary incontinence is the most common LUTD after stroke, urgency, increased frequency, and nocturia are also seen. The prevalence of LUTD after stroke varies from 32-79% at admission, 25-28% at discharge, and 12-19% six months after stroke, it was observed that only 6% of stroke patients did not have LUTD. 4.5

LUTD is an important determining factor in families of stroke patients seeking social assistance support and nursing homes.³ Although there are studies in the literature about the caregiver experiences of stroke patients, there are not enough studies evaluating the relationship between LUTD and caregiver burden.²

In this study, we aimed to investigate the negative effects of LUTD on both the quality of life of stroke patients and their caregivers. The hypothesis of our study is that in stroke patients with LUTD, we expect a decrease in quality of life, an increase in caregiver burden, and a negative impact on patients' mood.

MATERIAL AND METHODS

The cross-sectional study evaluated 75 stroke patients and their caregivers between March 2018 and March 2019 in the Kırıkkale University Physical Medicine and Rehabilitation Clinic. The study was approved by the Institutional Review Board and was conducted in compliance with the Helsinki Declaration. Informed consent was obtained from all participants. The patients aged between 40 and 80 who were followed up in the physical therapy and rehabilitation clinic and diagnosed with stroke by clinical and imaging according to the diagnostic criteria of the World Health Organization, had a stroke at least one month ago and had a normal cognitive level Mini Mental Test (MMT>23), were included in the study.

Patients who had a stroke for a reason other than a cerebrovascular accident, patients who had motor neuron disease or peripheral nerve lesion that could cause incontinence, patients who had symptoms related to the urinary system before the stroke, and patients who had an operation related to the urinary system were not included in the study.

Written informed consent was obtained from stroke patients and their caregivers who agreed to participate in the study, and all the scales used were administered face-to-face. Sociodemographic data such as age, gender, educational status, occupation, marital status, body mass index (BMI), and clinical data such as hemiplegic side, dominant side, lesion type, comorbidities, smoking, duration of hospitalization, and disease duration were recorded. Sociodemographic data of the caregiver, such as age, gender, occupation, education status, marital status, having a child, receiving care allowance, degree of relativity with the patient, and staying at the same home, were recorded.

The Zarit Caregiver Burden Scale (ZCBS) was used to evaluate the caregiver burden, and the Incontinence Quality of Life (I-QOL) Scale was used to evaluate the effect of urinary symptoms on patients' quality of life. Urinary symptoms of the patients were evaluated with Danish Prostatic Symptom Score (DAN-PSS-1), functional status, and activities of daily living were evaluated with Functional Independence Measure (FIM), and Barthel Index (BI), patient's mood was questioned with Hospital Anxiety and Depression Scale (HADS).

The study protocol was approved by the Kırıkkale University Ethics Commission (date: February 08, 2018, no: 03/02).

EVALUATION SCALES

Primary Evaluation Scales

ZCBS: It was developed by Zarit et al.⁶ This scale can be completed by the caregivers themselves or by the researcher. The scale consists of 22 questions that determine the effect of caregiving on the life of the individual.

The higher the total score, the greater the caregiver burden. The scores obtained are evaluated by

grading as (0-20) little/no load, (21-40) moderate load, (41-60) severe load, and (61-88) overload. Turkish validity and reliability study was performed.⁷

I-QOL: It is a specific assessment scale for incontinence developed by Wagner et al. The scale consists of 22 questions and has a 5-point Likert type evaluation system. It includes three domains: avoidance behavior, psychosocial impact, and social embarrassment. Responses to all items are summed in scoring, and a global score is obtained by converting the total score obtained to a 0-100 scale (0-worst/100-best QoL). As the total score increases, the patient's quality of life increases proportionally. The Turkish validity study was conducted.

DAN-PSS-1: First, Meyhoff et al. was conducted in 1993 in stroke patients to evaluate the treatment of prostate-related symptoms. 5,10-12 The Turkish validity and reliability study of this test in stroke patients was performed by Yesil et al. 13 It consists of 12 questions focusing on the frequency and severity of lower urinary symptoms and parts A and B of each question. Part A is related to the frequency and variety of symptoms and gives the "symptom score". In part B, the effect of symptoms on daily life is examined and defined as "bother score". Each question is classified into four stages ranging from 0-3. 0 indicates no symptom, 3 indicates maximum symptom. DAN-PSS-1 total score is calculated by symptom score X bother score. Each question is scored as 0-9 points; the scale's total score varies between 0-108 points. 12,14

Secondary Evaluation Scales

FIM: FIM consists of 6 subdomains: mobility, locomotor function, self-care, sphincter control, communication and social perception, evaluates the functional levels of patients. The first 4 subheadings constitute the FIM-motor score, and the 2 subheadings constitute the FIM-cognitive score. The higher the total score, the higher the patient's functional independence. The Turkish validity and reliability study was performed by Küçükdeveci et al. and it is frequently used in stroke patients.¹⁵

BI: It is used to evaluate patients' activities of daily living. It consists of 10 subdomains: bathing, self-care, eating, bladder control, dressing, bowel control, toilet use, chair/bed transfer, mobility, and

use of stairs. 0-20 points indicate complete dependency, 21-61 points severe dependence, 62-90 points moderate dependence, 91-99 points mild dependence, and 100 points complete independence. The Turkish validity and reliability study of the scale was performed by Küçükdeveci et al.¹⁶

HADS: This scale evaluates the mood of patients. HADS contains a total of 14 questions and odd numbers measure anxiety and even numbers measure depression. The Turkish validity and reliability of the form was made by Aydemir et al. ^{17,18}

STATISTICAL ANALYSIS

SPSS (Version 24.0, Armonk, NY: IBM Corp.) package program was used for statistical analysis. Descriptive statistics were determined as number, percentage, mean and standard deviation. A chisquare test was used to compare qualitative data. The correlation coefficients and statistical significance between the two variables were calculated by the Pearson test for parametric data and the Spearman test for nonparametric data. In the comparison of two independent groups, the t-test was used for parametric variables with normal distribution, and the Mann-Whitney U test was used for parametric variables that did not show normal distribution. In the statistical analysis, comparisons with a p value below 0.05 is considered statistically significant.

RESULTS

A total of 75 stroke patients, 38 (50.7%) women and 37 (49.3%) men, and 75 caregivers participated in the study. The mean age of the patients was 61.76±10.6 (37-80) years, and the mean duration of stroke was 5.80±6.24 (1-36) months. The mean age of the caregivers was 51.02±12.75 (23-72) years, and 48 (64%) were the spouses of the caregivers. The sociodemographic and clinical data of the patients are given in Table 1 and the sociodemographic data of the caregivers are given in Table 2. The mean BI score of the patients was 50.0±30.14 and 58.7% of them were completely and severely dependent on activities of daily living. The mean value of ZCBS was 40.98 ± 23.30 and it was found as 24% (18) little/none, 18.7% (14) moderate, 30.7% (23) advanced and 30.7% and overburden in 26.7% of them.

TABLE 1: The demographic and clinical characteristics of stroke survivors.					
Characteristics of stroke survivors	75	%	X±SD		
	n=75	%	(minimum-maximum) 61.76±10.6		
Age (year)			(37-80)		
Duration of stroke (months)			5.80±6.24		
Duration of Stroke (months)			(1-36)		
Duration of hospitalization (mont	hs)		1.40±0.59		
(,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	,		(1-3)		
Body mass index (kg/m²)			25.23±1.82		
, (0)			(21.22-28.58)		
Gender			, ,		
Female	38	50.70			
Male	37	49.30			
Occupation					
Housewife	39	52.00			
Retired	25	33.30			
Officer	7	9.30			
Self-employed	2	2.70			
Unemployed	2	2.70			
Education					
Illiterate	18	24.00			
Primary school	23	30.70			
Secondary school	26	34.70			
High school	8	10.70			
Marital status					
Married	64	85.30			
Single	11	14.70			
Smoking status					
Yes	38	50.70			
No	37	49.30			
Lesion type					
Ischemic	65	86.70			
Hemorrhagic	10	13.40			
Hemiplegic side					
Left hemiplegia	37	49.30			
Right hemiplegia	38	50.70			
Type of house s/he is living					

SD: Standard deviation.

No

Detached Apartment

Lives with caregiver Yes

FACTORS AFFECTING CAREGIVER BURDEN AND THE EFFECT OF LUTD ON CAREGIVER BURDEN

25

50

64

11

33.30

66.70

85.30

14.70

The caregivers were divided into two groups as ZCBS of 0-40 points (less/no and moderate burden) and 41-88 points (high and overburden). Patients' de-

mographic data, FIM, BI, I-QOL and subgroups and DAN-PSS-1 scores were compared between these two groups (Table 3, Table 4). There was no statistically significant difference between the two groups regarding the patient's age, marital status, occupation, education level, BMI, stroke etiology, duration of the stroke, length of stay, side of the lesion, and smoking (p>0.05). The burden on caregivers of patients with high comorbidity was statistically significantly higher (p=0.026). The burden of caregivers in female patients was found to be statistically significantly higher (p=0.003). Age, gender, marital status, education, occupation, the degree to the patient, and having children of the caregivers did not differ statistically in terms of ZCBS (p>0.05).

TABLE 2: The demographic and clinical characteristics of family caregivers.					
Characteristics of			X±SD		
family caregivers	n=75	%	(minimum-maximum)		
Age (year)			51.02±12.75 (23-72)		
Gender					
Female	55	73.30			
Male	20	26.70			
Occupation					
Housewife	54	72.0			
Retired	12	16.0			
Officer	5	6.70			
Self-employed	2	2.70			
Student	2	2.70			
Education					
Illiterate	18	24.00			
Primary school	27	36.00			
Secondary school	25	33.30			
High school	5	6.70			
Marital status					
Married	69	92.00			
Single	6	8.00			
Children					
Yes	65	86.70			
No	10	13.30			
Degree of the caregiver					
Spouse	48	64.00			
Child	23	30.70			
Relative, close	4	5.30			
Does s/he receive care allowance?					
Yes	25	33.30			
No	50	66.70			

SD: Standard deviation.

TABLE 3: Comparison of clinical and demographic characteristics of the patients according to ZCBS. ZCBS 1 group (0-40 points) ZCBS 2 group (41-88 points) **X±SD** X+SD p value FIM-motor 70.75±17.60 30.93±17.65 0.000* 28.87±5.56 FIM-cognitive 20.27±6.04 0.000* FIM-total 51.20±19.88 0.000* 99.62±22.01 75.78±8.71 30.81±21.40 0.000* ΒI

^{*}p<0.05; ZCBS: Zarit Caregiver Burden Scale; SD: Standard deviation; FIM: Functional Independence Measure; BI: Barthel Index.

TABLE 4: Comparison of quality of life and uriner incontinence according to ZCBS.						
	ZCBS 1 group (0-40 points) X±SD	ZCBS 2 group (41-88 points) X±SD	p value			
I-QOL-limiting behaviors	79.30±16.74	49.87±16.27	0.000*			
I-QOL-psychological influence	80.10±16.57	47.89±16.39	0.000*			
I-QOL-social isolation	80.75±13.38	54.60±15.03	0.000*			
I-QOL-total	79.19±15.29	50.44±14.96	0.000*			
DAN-PSS-1	22.53±18.33	67.76±24.32	0.000*			

^{*}p<0.05; ZCBS: Zarit Caregiver Burden Scale; SD: Standard deviation; I-QOL: Incontinence Quality of Life; DAN-PSS-1: Danish Prostatic Symptom Score.

It was found that the type of house in which the patient lived, with whom he lived, living in the same or different house with the caregiver, having own room, and receiving care allowance by the caregiver did not have any effect on ZCBS (p>0.05).

The ZCBS of the caregivers of the patients whose HADS were higher than normal were statistically significantly higher (p<0.01 and p<0.001, respectively).

COMPARISON OF LUTD AND QUALITY OF LIFE, FUNCTIONAL AND PSYCHOLOGICAL STATUS OF PATIENTS

A statistically significant correlation was observed between the patients' DAN-PSS-1 and I-QOL-total and subgroups, BI, FIM total, sub-scores (p<0.01) (Table 5).

In patients with high HADS, the DAN-PSS-1 score was found to be statistically significantly higher, while the values of I-QOL-total and its subgroups were found to be statistically significantly lower (p<0.001). The quality of life of patients whose LUTD level increased significantly decreased, at the same time it negatively affected their mood.

TABLE 5: Correlation between DAN-PSS-1 and quality of life. DAN-PSS-1 r р FIM-motor 0.928 0.000* FIM-cognitive 0.668 0.000° FIM-total 0.925 0.000* 0.876 0.000*I-QOL-limiting behaviors 0.963 0.000* I-QOL-psychological influence 0.000* 0.962 I-QOL-social isolation 0.896 0.000* 0.000* I-QOL-total 0.979

*p<0.05; DAN-PSS-1: Danish Prostatic Symptom Score; FIM: Functional Independence Measure; BI: Barthel Index;

I-QOL: Incontinence Quality of Life.

DISCUSSION

Our study is important since it is the first study to examine the effect of LUTD on quality of life and caregiver burden in stroke patients. In our study, in which we investigated the burden of LUTD on caregivers in stroke patients and its effect on the patient's quality of life; we found that LUTD increases the burden of caregivers and decreases the quality of life of pa-

tients by increasing the level of dependency in daily living activities.

When we examined the patients and caregivers in terms of sociodemographic characteristics, it was found that 73.3% of the caregivers were female, the mean age was 51, 65% had children, the majority of them were primary and secondary school graduates (69.3%), housewives (72%), married (92%) in our study. It was determined that 73.3% of the patients lived with their spouses, 64% of the caregivers were the spouse of the patient, and 66.7% did not receive care allowance.

In a study examining the sociodemographic characteristics of stroke patients and their caregivers, it was stated that the caregivers were between the ages of 40-64 and most of them were women, married, primary school graduates, housewives, and a high rate of first-degree relatives of the patient. ¹⁹ In another study, 40% of the caregivers were children of the patients and most of the caregivers were unemployed, which is consistent with the sociodemographic data in our study. ²⁰ Unlike our study, there are also studies in which most of the caregivers are male. ²¹

In our study, similar to the study of Mollaoğlu et al. and Ogunlana et al. in the literature, no relationship was found between the patient's age, education, whom he/she lives with, disease duration, marital status, smoking, and caregiver burden.²⁰ In the study of these researchers, unlike ours, it was observed that the burden of caregivers was lower in young women, and that of sibling caregivers was the highest, that the burden of child caregivers was the lowest. In our study, the burden on caregivers of women stroke patients with high comorbidities was found to be high in line with the literature.²¹

It is thought that the education level of the caregiver may be a factor affecting the caregiver burden. In accordance with our study, although there are studies showing that the education level of the caregiver is unrelated to the caregiver burden; in another study, it was stated that the low education level of the caregiver increased the caregiver burden.²⁰⁻²³ They explained this with the low level of education, lack of knowledge and skills, the ability to reach the correct

information, and the inability to effectively cope with stress due to financial inadequacy.

In our study, it was found that 66.7% of the patients did not receive care allowance, and there was no relationship between care allowance and caregiver burden. In our country, receiving care allowance requires having a stroke duration of at least six months to one year and, receiving active rehabilitation during this period. We can explain the reason why those receiving care allowance are low, with the average duration of stroke of the patients being less than one year.

A study comparing caregivers of stroke patients and caregivers of other chronic diseases showed that the caregiver burden of stroke patients with depression and low quality of life was high, in line with our study.²⁴ Previous studies that found a significant relationship between depression and physical independence and caregiver burden are also consistent with our study.^{25,26} It makes us think how important it is to psychologically support stroke patients and increase their quality of life to reduce caregivers' burden.

Our study observed that as the level of physical dependence in patients increased, their daily life activities worsened, which increased the burden of caregivers significantly. In our study, it was concluded that as the physical dependence of the patients increased, the burden of the caregivers increased at the same rate. ^{2,20,27,28} In one study, a negative relationship was found between caregiver burden and quality of life. Besides, it was observed that the disability of the patients and the increase in the level of dependence in daily living activities negatively affected the caregiver burden. ²¹

Our study observed that the quality of life of patients with high LUTD decreased, and the level of addiction, depression, and anxiety increased in activities of daily living. We think that deterioration in the quality of life due to LUTD in stroke patients may cause an increase in depression and anxiety. A study examining patients with chronic stroke stated that bladder dysfunction affects disability status, daily life activity, and quality of life in patients.²⁹

As in our study, in the study in which Tibaek et al. evaluated the urinary function in male patients

after stroke with DAN-PSS-1 and evaluated the quality of life with QoL, it was found that the urinary functions and quality of life of the patients were significantly impaired compared to the control group.³⁰

In a study in which Akkoç et al. investigated the relationship between bladder problems, quality of life, and functional level in stroke patients with urinary symptoms, a significant negative correlation was found between DAN-PSS-1 total scores and I-QOL total and subgroups.³¹ Similarly, in our study, a significant negative correlation was found between I-QOL-total and its subgroups, DAN-PSS-1 and BI, FIM total and sub-scores, and HADS. Similarly, Tibaek and Dehlendorff found a significant correlation between urinary incontinence and DAN-PSS-1 in stroke patients.³²

When the literature is examined, studies on caregivers of stroke patients with incontinence are limited.⁴ One of the most important studies on this subject was done by Tseng et al.³ Although caregivers lack the knowledge and skills to provide incontinence care, it was observed that they develop various strategies to cope with incontinence. Many studies are showing that caregivers of stroke patients experience hypervigilance and fatigue.^{33,34} Previous studies have reported that caregivers experience shame when dealing with incontinence.^{35,36} In our study, we used the ZCBS as an evaluation scale, and especially fatigue, burnout, inability to spare time for oneself, and financial problems of caregivers were evaluated.

In the study of Kohler et al. in which they investigated the stroke patients, it was found that patients did not answer questions about urinary incontinence because they were embarrassed. Stroke patients refrained from expressing their urinary complaints and did not share their concerns about urinary incontinence with anyone because their needs were not taken into account.^{37,38} In our study, the increase in LUTD was found to be directly related to anxiety and depression.

We consider that fighting with LUTD, which is a part of rehabilitation, is a team effort, and that the education and awareness of the rehabilitation team, especially the patient, patient relatives, rehabilitation nurse, should be created. The limitations of the study were that it was single-center, and the patients were evaluated with a self-report scale and clinical examination. Multicenter studies with more patients participating in the study and objective data such as urodynamics can be evaluated in future studies.

CONCLUSION

Our study is the first in the literature to evaluate the impact of LUTD on caregiver burden and quality of life in stroke patients. Caregiver experiences in stroke patients have started to attract attention in recent years, and studies have increased. However, LUTD is a negative experience for the caregiver, which is overlooked in the evaluation of the patient, affects the rehabilitation process. Since this issue creates stigma in society, patients and caregivers are reluctant to talk and seek different ways of coping. We think that studies should be conducted to evaluate LUTD from multiple perspectives and focus on caregiver experiences since stroke affects the patient and the family members negatively. LUTD is a condition that significantly reduces the quality of life of stroke patients and should be evaluated in the rehabilitation program.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Design: Hatice Ağır, Müyesser Aras, Esra Dilek Keskin; **Data Collection and/or Processing:** Hatice Ağır; **Analysis and/or Interpretation:** Hatice Ağır, **Writing the Article:** Hatice Ağır. All authors read and approved the final manuscript.

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