



Self-Compassion in Caregivers of Cancer Patients in Respect of Psychological Resilience, Distress and Quality of Life

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OBJECTIVE

This study aimed to determine the relationship between self-compassion and psychological resilience, quality of life, depression, anxiety, and stress levels of informal caregivers of inpatient palliative care oncology patients.

METHODS

The study involved 72 caregiver relatives (39 females, 33 males) of cancer patients receiving inpatient palliative care. Data were collected through Sociodemographic Information Forms, the Self-Compassion Scale, the Psychological Resilience Scale for Adults, the Caregiver Quality of Life Index Cancer Scale, and the Depression Anxiety Stress-21.

RESULTS

The most challenging issues for caregivers were grief about the patient's health and trying to manage the patient's psychological reactions or changes in behavior. The correlation analysis indicated statistically significant associations between resilience, depression, anxiety, stress, quality of life, and self-awareness. Psychological resilience and quality of life were found to be significantly predictive of self-understanding, while depression, anxiety, and stress levels were not found to have any predictive role.

CONCLUSION

It would be useful to focus on increasing the levels of self-compassion and psychological resilience in psychological intervention programs to be developed to protect and treat the mental health of caregivers of cancer patients in the palliative treatment period.

Keywords: Cancer; caregiver; distress; palliative period; psychological resilience; quality of life; self-compassion.

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INTRODUCTION

Palliative care is an approach that seeks to prevent or at least alleviate suffering by providing early assessment and treatment of pain, psychological and other problems, as

well as medical problems, to improve the quality of life of patients and their families facing problems related to a life-threatening illness.[1,2] In diseases with severe treatment processes such as cancer, some patients may need palliative care as their medical conditions may vary.

Received: November 14, 2023

Revised: December 11, 2023

Accepted: April 03, 2024

Online: June 14, 2024

Accessible online at:

www.onkder.org

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In the palliative approach, the well-being of the patient's family members, a vital component of the process, is also considered, in addition to that of the patient. The World Health Organization (WHO) has identified as a goal of palliative care, provision of support to the patient's relatives throughout the progression of illness and also during the grieving process that follows.[2] During the palliative period, caregiving duties often fall to the patient's relatives. The transition to the role of caregiver holds significant importance for the relatives of the patient, affecting them physically, mentally, and socially, and caregivers have even been described as "hidden patients".[3] As the patient relies on their relative, caregiving tasks become increasingly difficult and time-consuming, and at some point the carer realizes that they have devoted their life to caring. As the demands increase, the physical and mental health of the patient's relatives is negatively affected due to constant pressure.[4] As the disease progresses and the patient enters the palliative period, relatives may become more distressed and become prone to psychiatric problems such as depression and anxiety.[5,6] In a study conducted with caregivers of cancer patients, it was found that 13% of caregivers met the diagnostic criteria for psychiatric disorders according to DSM-4 and only 46% of these individuals had access to mental health services.[7] Psychological and physical strain on caregivers may lead to poor quality care and adverse health outcomes, including neglect and abuse.[8]

Psychological resilience is defined as the potential to successfully maintain and restore mental health when faced with risk factors.[9,10] Psychological resilience has important effects on the ability of both survivors and caregivers to overcome the difficulties they experience during the cancer process. Negative experiences such as inability to cope effectively with difficulties, inadequacy in solving problems, and having chronic stress levels are considered to be associated with low levels of psychological resilience.[10]

The physical, psychological, and social changes caused by chronic diseases such as cancer in patients and their relatives have brought the discussion of the quality of life of these people to the agenda. In a study conducted with 200 family members caring for cancer patients receiving health care services in Hematologic Oncology Service, it was revealed that family members experienced high levels of stress, their lives were negatively affected during the process of caring for their patients and their quality of life decreased.[11] In another study, it was stated that many needs of family members of cancer patients, most of which were not adequately met, caused psychological distress and decreased the quality of life.[12]

In a study conducted on primary caregivers of cancer patients, it was found that self-compassion, which is a new concept, is a protective factor for the mental health and quality of life of the caregiver.[13] Self-compassion has been shown to be associated with concepts such as optimism, increased happiness, individual initiative, and commitment; it has been observed to reduce anxiety, depression, and rumination, and there is a significant relationship between understanding and psychopathology.[14,15] When the studies conducted in foreign and domestic literature were examined, no study was found to reveal the predictive role of psychological resilience, quality of life, depression, anxiety, and stress variables together with self-comprehension levels. The aim of this study was to identify problem areas encountered by caregivers of palliative oncology patients during the care process, as well as to determine the relationship between psychological resilience, quality of life, depression, anxiety, and stress levels, and self-compassion.

MATERIALS AND METHODS

Study Population

This study was conducted with family caregivers of palliative cancer patients who were hospitalized at Istanbul University Oncology Institute. The study was conducted with a total of 72 relatives of 72 patients, 39 of whom were female and 33 of whom were male. The data collection phase of the study lasted for 5 months between December 2018 and April 2019. Clinical Research Ethics Committee approval dated 24.12.2018 and numbered 1735 was obtained for the research. The data of 80 relatives of the patients included in the study were invited, and the data of 8 relatives were not included in the analysis because they did not accept to participate in the study or the data collection process was interrupted. It was conducted in adherence to the principles outlined in the Declaration of Helsinki.

In the selection of the sample group, the following criteria were sought: knowing how to read and write, being older than 18 years of age, having the cognitive competence to understand the statements in the scales, not having any mental (developmental retardation, psychosis, mania, dementia, delirium, alcohol-substance addiction) or physical health impairment that would prevent them from continuing the study, and being willing to participate in the study. The interview was interrupted when the patient's relative did not feel well during the application. Participants were included in the study through random sampling.

Sociodemographic and Caregiving Data Collection Form

The form consists of two parts. The first part aims to collect basic demographic information such as age, gender, marital status, and socio-economic status of the participants. The second part, which was developed by the researchers based on the literature[5,7,8,11] to collect information about the care process, includes questions such as the degree of closeness of the caregiver to the patient, the duration of care for the patient, how many hours per day he/she devotes to himself/herself, whether he/she receives support during the care process, and whether he/she finds the support given to him/her sufficient. In addition, the relatives were asked about a number of items that the patient's relatives found difficult in caring for the patient, and they were asked to respond by choosing one of the following options: not at all/a little, moderately, and very much. The form consists of two parts. The first part aims to collect basic demographic information such as age, gender, marital status, and socio-economic status of the participants. The second part, which was developed by the researchers based on the literature[5,7,8,11] to collect information about the care process, includes questions such as the degree of closeness of the caregiver to the patient, the duration of care for the patient, how many hours per day he/she devotes to himself/herself, whether he/she receives support during the care process, and whether he/she finds the support given to him/her sufficient. In addition, the relatives were asked about a number of items that the patient's relatives found difficult in caring for the patient, and they were asked to respond by choosing one of the following options: not at all/a little, moderately, and very much.

Self-Compassion Scale (SCS)

SCS was developed by Neff and the Turkish reliability and validity study of the scale was conducted by Deniz, Kesici, and Sümer on a sample of university students.[16,17] The scale consists of 6 sub-dimensions and 26 items. In the scale, respondents are asked to rate how often they act in a given situation on a five-point Likert-type scale ranging from "Almost never=1" to "Almost always=5". The internal consistency coefficient of the scale was 0.89 and the test-retest correlation was 0.83. The criterion-related validity of the self-compassion scale showed that there were correlations of $r=0.62$ between the self-compassion scale and self-esteem scale, $r=0.45$ between self-compassion and life satisfaction, $r=0.41$ between positive emotion and $r=-0.48$ between negative emotion.[17]

The Resilience Scale for Adults (RSA)

The RSA was developed by Friborg et al.[18] and adapted into Turkish by Basım and Çetin[19]. The sub-dimensions of the scale, which has a total of 33 items, are self-perception, future anxiety, structural style, social competence, family cohesion, and social resources. The Cronbach alpha values of the sub-dimensions calculated for the reliability of the scale are between 0.66 and 0.81 (student sample) and between 0.68 and 0.79 (employee sample). The overall Cronbach's alpha coefficient was 0.86 for both samples. In addition, the test-retest reliability was between 0.68 and 0.81.[19]

The Caregiver Quality of Life Index Cancer Scale (CQOLC)

The CQOLC was developed by Weitzner et al.[20] to measure the quality of life of cancer caregivers, including the dimensions of emotional functioning, family functioning, physical functioning, and social functioning. The total score obtained from the scale and its sub-dimensions ranges from 0 to 140. The higher the score on the scale, the better the quality of life. In the Turkish adaptation study, the Cronbach's alpha coefficient was found to be 0.88 for the total scale; the test-retest correlation coefficient was found to be between 0.84–0.95 for the sub-dimensions of the scale and 0.96 for the total scale.[21]

The Short-Form Version of the Depression Anxiety Stress Scales (DASS-21)

The 42-item scale developed by Lovibond and Lovibond [22] was later converted into a 21-item short form.[23] In this scale, depression, stress, and anxiety sub-dimensions consist of 7 items each. In the Turkish validity study, Cronbach's alpha internal consistency reliability coefficient was found to be $\alpha=0.87$ for the depression subscale, $\alpha=0.85$ for the anxiety subscale, and $\alpha=0.81$ for the stress subscale in the clinical sample, while the test-retest correlation coefficients were found to be $r=0.68$ for the depression subscale, $r=0.66$ for the anxiety subscale, and $r=0.61$ for the stress subscale in the healthy sample.[24]

Statistical Analysis

Quantitative analysis methods were used in the analysis of the data by using SPSS 25.0 program. In this context, frequency and percentage analyses and descriptive analyses such as mean, standard deviation, etc. were used to determine descriptive findings about the participants and scales. Chi-square analysis was used to determine the effect of sociodemo-

graphic characteristics on dependent and independent variables. The effects of psychological resilience, depression, anxiety, stress, and quality of life on self-understanding were determined by multiple linear stepwise regression. In the multiple correlation analyses, it was determined that there was no multicollinearity problem between the independent variables by examining the correlation and VIF values. In all of the analyses, the significance level was accepted as $p < 0.05$ and the confidence interval as 95%.

RESULTS

Sociodemographic and Caregiving Characteristics

The mean age of the participants was 43.64 ± 13.10 years (19–69), 54.2% were female and 45.8% were male. The time elapsed since the diagnosis of the relatives of the participants varied between 1–120 months, with a mean and standard deviation of 20.44 ± 24.25 months. Approximately 40% of the participants included in the study have been caring for the patient for more than 6 months. Two-thirds of them were children or spouses of the patient, and approximately 70% of them lived with the patient. While 54.3% of the participants stated that they shared the responsibility of caregiving equally with other relatives of the patient, approximately 38% stated that they were the main caregivers who took all the responsibility and did not find the support they received sufficient. As a matter of fact, although the rate of receiving care support was approximately 80%, the rate of receiving information support, psychological/emotional support, and financial assistance remained below 40%. The sociodemographic and caregiving characteristics of the participants are shown in detail in Table 1.

In addition, the most difficult situations in the caregiving process for relatives of oncology patients were, respectively, feeling sorry for the patient's condition (94.5% moderate or above) and trying to cope with changes in the patient's psychology or behavior (84.7% moderate or above), physical fatigue (77.8% moderate and above), financial issues (70.9% moderate and above), not having time for oneself (66.7% moderate and above), coping with treatment side effects (65.3% moderate and above), and making decisions about treatment (54.1% moderate and above) (Table 2).

Correlation Between Scale Points

The mean scale scores obtained from the participants and the correlation coefficients between the scale

scores are presented in Table 3. A negative correlation was determined between SCS scores and RSA ($r = -0.629$, $p < 0.001$), CQOLC ($r = -0.608$, $p < 0.001$), depression ($r = -0.521$, $p < 0.001$), anxiety ($r = -0.508$, $p < 0.001$), and stress ($r = -0.502$, $p < 0.001$) scores.

The Predictive Role of Psychological Resilience, Quality of Life, Depression, Anxiety, and Stress in Respect of Self-Compassion

Multiple linear stepwise regression analysis showed that "Psychological Resilience" and "Quality of Life" variables explained 47% of the total variance in "Self-compassion" levels in the relatives of palliative period oncology patients ($R = 0.69$, $R^2 = 0.47$, $F = 30.751$, $p < 0.001$). The predictive role of the scores obtained from the "Depression Anxiety Stress Scale-21" form could not be determined. The stepwise multiple linear regression analysis was completed in two stages. Firstly, the psychological resilience variable entered the analysis. It is seen that psychological resilience, which is the independent variable of the study, predicts self-compassion, which is the dependent variable, significantly and positively and explains approximately 40% of the variance in self-compassion by itself. The first model with a single independent variable was found statistically significant. The second model with two independent variables was found statistically significant ($R = 0.63$, $R^2 = 0.39$, $F = 45.870$, $p = 0.000$) (Table 4).

In the first stage of the analysis, the standardised regression coefficient (β) of the psychological resilience variable was found to be 0.63. In the second stage of the analysis, the quality of life variable was included in the model in which the psychological resilience variable was included. The quality of life variable contributed to the total variance and increased the R^2 variance ratio to 47% ($R = 0.68$, $R^2 = 0.47$, $F = 30.751$, $p = 0.000$). The standardised regression coefficient (β) of the quality of life variable at this stage was 0.35 (Table 5).

Psychological resilience and quality of life explain the change in the total variance of "self-compassion" scores at a good level. The regression equation model is as follows: "SELF-COMPASSION = $13.975 + 0.46 \times$ PSYCHOLOGICAL RESILIENCE + $0.35 \times$ QUALITY OF LIFE". When the regression equation is examined, when "Quality of Life" scores are kept constant, a 1 (one) unit increase in "Psychological Resilience" scores causes a 0.46 unit increase in "Self-Compassion" scores. Similarly, when "Psychological Resilience" scores are kept constant, a 1 (one) unit increase in "Quality of Life" level causes a 0.35 unit increase in "Self-compassion" scores.

Table 1 Sociodemographic and caregiving characteristics of the participants

Variable	Group	n (72)	%
Gender	Woman	39	54.2
	Male	33	45.8
Age, mean±SD (min-max)		43.64±13.10 (19–69)	
Education status	Literate	2	2.8
	Primary school graduate	27	37.5
	High school graduate	18	25.0
	University graduate	24	33.3
Marital status	Postgraduate graduate	1	1.4
	Married	49	68.1
Having children	Single	23	31.9
	Yes	46	63.9
Employment status	No	26	36.1
	Not working	29	40.3
	Working	19	26.4
	Resigned due to caring	11	15.3
Income level	Pensioner	8	11.1
	Leave of absence/report due to caring	5	6.9
	Middle	53	73.6
	Good	10	13.9
Degree of kinship to the patient	Bad	9	12.5
	Child	29	40.3
	Spouse	17	23.6
	Parent	11	15.3
	Bride/groom	5	6.9
Living with the patient	Relative	4	5.6
	Brother/sister	4	5.6
	Grandson	2	2.8
	Yes	50	69.4
Duration of care provided	No	22	30.6
	0–6 months	45	62.5
	7–11 months	14	19.4
	1–3 years	9	12.5
Receiving support for caregiving	3 years and over	4	5.6
	Shares equal tasks with other family members in the care process	39	54.2
	Other family members provide support from, but he/she is the main caregiver	27	37.5
Finding the support received adequate	No support from anyone	6	8.3
	Sufficient	27	41.5
	Partially sufficient	14	21.5
Total	Unsufficient	24	36.9
		72	100

SD: Standard deviation

DISCUSSION

Cancer can cause many negative changes not only in the patient, but also in the life of the patient's family and especially in the life of the patient's relatives, who play a primary role in the patient's care. Difficulties increase over time and can lead to serious psychological problems.

The patient's relatives experience many complex emotions such as fear, anger, helplessness, denial, and guilt in the face of the illness. They have to try to cope with these complex emotions and provide support and care to the patient.[25] This study addressed the problems experienced by palliative oncology caregivers during the care process and aimed to determine the relationship

Table 2 Situations in which the participants experienced difficulties in the care-giving process

Difficulties	Not at all/ somewhat		Moderate		Very much	
	n	%	n	%	n	%
Feeling sorry for the patient's condition	4	5.6	11	15.3	57	79.2
Trying to cope with changes in the patient's psychology or behaviour	11	15.3	15	20.8	46	63.9
Not having time for yourself	24	33.3	20	27.8	28	38.9
Making decisions about treatment	33	45.8	15	20.8	24	33.3
Financial matters	21	29.2	29	40.3	22	30.6
Dealing with treatment side effects	25	34.7	25	34.7	22	30.6
Feeling lonely	39	54.2	13	18.1	20	27.8
Physical fatigue	16	22.2	37	51.4	19	26.4
Feeling psychologically exhausted	36	50.0	20	27.8	16	22.2
Problems in the field of work/career	42	58.3	14	19.4	16	22.2
Understanding the procedures involved in treatment	36	50.0	22	30.6	14	19.4
Changing the city due to maintenance	57	79.2	3	4.2	12	16.7
Problems with caring for their own children	31	68.9	7	15.6	7	15.6
Lack of support from the spouse	28	84.8	2	6.1	3	9.1
Problems with other family members	54	75.0	12	16.7	6	8.3
Communication problems with the treatment team	55	76.4	11	15.3	6	8.3

Table 3 Descriptive statistics and pearson correlation coefficients for the relationships between variables

Scale/subdimension	Mean	SD	1	2	3	4	5	6
1. SCS	83.43	18.08	1	0.629** p=0.000				
2. RSA	130.96	22.34	0.629* p=0.000	1				
3. DASS-21 Depression	6.10	4.80	-0.521* p=0.000	-0.555* p=0.000	1			
4. DASS-21 Anxiety	4.69	3.69	-0.508* p=0.000	-0.497* p=0.000	0.694** p=0.000	1		
5. DASS-21 Stress	6.78	4.19	-0.502* p=0.000	-0.464* p=0.000	0.777** p=0.000	0.766** p=0.000	1	
6. CQOLC	75.14	18.28	0.608* p=0.000	0.627 p=0.000	0.711** p=0.000	0.619* p=0.000	-0.683* p=0.000	1

*: 0.29<r<0.70: Moderate relationship; **: 0.69<r: Strong relationship (Büyüköztürk, vd., 2011: 92). SD: Standard deviation; SCS: Self-compassion scale; RSA: The Resilience Scale for Adults; DASS: Depression Anxiety Stress Scales; CQOLC: The Caregiver Quality of Life Index Cancer Scale

between psychological resilience, quality of life, depression, anxiety, and stress levels, and self-compassion.

The study identified physical fatigue, lack of personal time, financial issues, coping with treatment side effects, and loneliness as the most challenging situations faced by relatives caring for cancer patients in the palliative period. The high percentage of participants (70%) living with the patient may contribute to the

physical fatigue and lack of personal time. It is important to address these issues to support the well-being of both the patient and their caregivers. The literature reports that caregivers who live with the patient experience a higher care burden compared to those who do not. Constantly being with the patient results in the neglect of the caregiver's self-care and social life. This can lead to an inability to spare time for themselves.[26] It

Table 4 R and R2 change regarding the effect of psychological resilience and quality of life on self-compassion

Variable	R	R ²	R ² change	F change	p	SD	SD2
Psychological resilience	0.629	0.396	0.387	45.873	0.000	1	70
Quality of life	0.686	0.471	0.456	30.751	0.000	2	69

SD: Standard deviation

Table 5 Multiple stepwise linear regression results related to self-compassion

Variable	Non-standardised parameters		Standardised parameters		p	VIF
	B	SD	β	T		
Model 1 fixed	16.740	9.987		1.676	0.098	
Psychological resilience	0.509	0.095	0.629	6.773	0.000	1.000
Model 2 fixed	13.975	9.452		1.479	0.144	
Psychological resilience	0.330	0.091	0.458	3.632	0.001	1.648
Quality of life	0.349	0.111	0.352	3.136	0.003	1.648

SD: Standard deviation; VIF: Variance Inflation Factor

has been revealed that caregivers of patients often experience problems such as fatigue, neglect of personal care, lack of interest in previously enjoyed activities, sleep problems, and loss of appetite.[27] These difficulties are expected due to the continuous care required for the patient. Similar results have been reported in the literature regarding the employment status of caregivers. In their study, Çivi et al.[27] also found a 60% decrease in work and 58.2% decrease in daily functioning among cancer caregivers. Caregivers may also experience emotional effects in addition to the time they need to allocate for the patient's care.

The study found a strong positive correlation between the stress levels of patients' relatives and their depression and anxiety levels. Additionally, a negative correlation was observed between quality of life and depression. These findings are consistent with existing literature. Depression and anxiety are prevalent psychiatric disorders that are often comorbid. Posluszny et al.[28] observed that caregivers had higher anxiety rates and were more emotionally fragile than cancer patients. The literature has shown a strong relationship between the quality of life and depression in the relatives of cancer patients.[29] The research results suggest that psychological resilience levels primarily explain the levels of self-compassion, followed by quality of life levels. The results of our study align with previous research that highlights the correlation between self-compassion and psychological resilience,[30] as well as quality of life.[13,31]

A multiple regression analysis was conducted to determine the extent to which psychological resilience, depression, anxiety, stress, and quality of life predicted levels of self-understanding. The results showed that psychological resilience and quality of life significantly predicted self-understanding levels, explaining 47% of the variance. Upon analysis of the results, it was found that changes in psychological resilience and quality of life scores were associated with changes in self-compassion levels. However, changes in depression, anxiety, and stress levels did not significantly affect self-compassion levels. The regression analysis results suggest that self-compassion levels in caregivers of cancer patients in palliative care are explained by their psychological resilience levels and quality of life levels. Increasing the resilience levels of patients' relatives against challenging life events can play an important role in increasing their self-compassion levels. It is expected that psychological resilience levels have a positive predictive power in this regard. When considering the positive predictive power of quality of life on self-compassion levels, it was found that increasing the quality of life levels of patients' relatives may have a low-level effect on self-compassion scores.

Numerous studies have revealed the relationship between psychological resilience and self-compassion. [15,30,32] Self-compassion is based on establishing a better relationship with oneself, particularly during difficult life events and feelings of inadequacy.[32] Therefore, it is expected that psychological resilience would predict

self-compassion. The use of participants' quality of life as a predictor of self-compassion levels is consistent with the literature. A study conducted on primary caregivers of cancer patients' relatives found that self-compassion was a protective factor for caregiver mental health and quality of life. Low self-compassion was associated with increased depression and stress symptoms, as well as low quality of life scores in cancer patients.[13,31] The current study found that depression, anxiety, and stress levels of palliative period oncology patient relatives were not significant predictors of self-compassion levels. However, there was a moderate and negative relationship between the participants' depression, anxiety, and stress levels and their self-compassion levels. Although this finding cannot predict self-compassion, it suggests that caregivers of palliative period oncology patients with low levels of depression, stress, and anxiety may have high levels of self-compassion. Previous studies have linked higher levels of self-compassion with lower levels of depression, anxiety, and stress.[15,31,33] In a study with 72 lung cancer patients and their caregivers, Hsieh et al.[34] demonstrated that self-compassionate action can mitigate the impact of caregiving stress on depressive symptoms. This was shown after controlling for patients' factors such as treatment status, symptom distress, and depressive symptoms, as well as caregivers' health status.

CONCLUSION

The depression, anxiety, and stress levels of the patient's relatives, who are responsible for the care of the cancer patient and are an important and integral part of the treatment, are among the important factors influencing the patient care process. This highlights the importance of investigating the relationship between psychological problems such as depression, anxiety, and stress, and self-compassion in the relatives of palliative period oncology patients. The results suggest that caregivers of palliative period oncology patients may experience a decrease in their quality of life and psychological resilience, which could have a negative impact on their self-compassion levels. Therefore, during the palliative period, when the quality of life and psychological resilience of both caregivers and patients are crucial, intervention programmes can be developed to increase individuals' self-compassion levels while also aiming to improve their psychological resilience. For instance, in these supportive approaches, the aim may be to equip the patient's relatives with skills that enhance their psychological resilience, such as self-efficacy, problem-solving ability, optimism, and auto-regulation, to help them develop greater self-compassion.

Ethics Committee Approval: The study was approved by the İstanbul Faculty of Medicine Clinical Research Ethics Committee (no: 1735, date: 24/12/2018).

Authorship contributions: Concept – S.A., D.A., M.Ö.; Design – S.A., D.A., M.Ö.; Supervision – S.A., D.A., M.Ö.; Funding – S.A., D.A., M.Ö.; Materials – S.A., D.A., M.Ö.; Data collection and/or processing – S.A., D.A., M.Ö.; Data analysis and/or interpretation – S.A., D.A., M.Ö.; Literature search – S.A., D.A., M.Ö.; Writing – S.A., D.A., M.Ö.; Critical review – S.A., D.A., M.Ö.

Conflict of Interest: All authors declared no conflict of interest.

Use of AI for Writing Assistance: Not declared.

Financial Support: None declared.

Peer-review: Externally peer-reviewed.

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