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Arastırma Makalesi / Research Article

Relationship Between Caregiver Burden and Compassion Levels and the Affecting Factors in Caregivers of Patients with Alzheimer's Disease: A Cross-Sectional Study

Alzheimer Hastalarına Bakım Verenlerin Bakım Yükleri ile Merhamet Düzeyleri Arasındaki İlişki ve Etkileyen Faktörler: Kesitsel ve Tanımlayıcı Bir Çalışma

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Abstract:

Aim: *This cross-sectional study aims to identify the relationship between caregiver burden and compassion levels and the affecting factors in caregivers of patients with Alzheimer's disease.*

Methods: *The research was carried out in Turkey Alzheimer's Association Elderly Life Center in one of our provinces between February and May 2018. The target population was composed of 58 caregivers of patients with Alzheimer's disease who were registered in the related center. Data were collected through the Socio-demographic Form, the Compassion Scale (CS), and the Caregiver Burden Scale (CBS). Mean and standard deviation, median [minimum-maximum], student t test/Mann Whitney U test, one-way ANOVA/Kruskal Wallis test, and Pearson correlation analysis were used to evaluate the data. Statistical comparisons were evaluated at p<0.05 significance level.*

Findings: *The average age of the participants was found 45.53±15.88, and the average duration of caregiving was 3.60 ±3.19 years. The CS total mean score of the caregivers was 94.60±15.83, and their CBS total mean score was 39.14 ±11.59. No significant relationships were detected between the CBS and CS subscale and total scores (p>0,05). Participants' education level, marital status, having a child, working status, being a relative, getting help, experiencing fear and anxiety, experiencing social difficulties, meeting the basic needs of the patient, providing mobility support to the patient, needing information about care it was determined that there was a factor affecting the sense of compassion (p<0.05).*

Conclusion: *Although the participants were found to have a moderate-level caregiver burden, their compassion level was high and the compassion towards patients with Alzheimer's disease was affected by some factors. It is recommended to plan trainings to reduce the caregivers' burden of care and the negative emotions they experience and to improve them positively.*

Key Words: *Caregiver, patient with Alzheimer's disease, caregiver burden, compassion.*

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Özet:

Amaç: *Araştırma, Alzheimer hastalarına bakım verenlerin bakım yükleri ile merhamet düzeyleri arasındaki ilişkinin ve etkileyen faktörlerin belirlenmesi amacıyla kesitsel olarak yapıldı.*

Yöntem: *Araştırma Şubat -Mayıs 2018 tarihleri arasında bir ilimizdeki Türkiye Alzheimer Derneği Yaşlı Yaşam Merkezi'nde yapıldı. Araştırmanın evrenini araştırmanın yapıldığı merkeze kayıtlı 58 Alzheimer hastası ve bu hastalara bakım veren bir bakıcı oluşturdu. Veriler, Kişisel Bilgi Formu, Merhamet Ölçeği (MÖ) ve Bakım Verme Yükü Ölçeği (BVYÖ) ile toplandı. Verilerin değerlendirilmesinde ortalama ve standart sapma, medyan [minimum-maksimum], student t testi/Mann Whitney U testi, tek yönlü ANOVA/Kruskal Wallis testi ve Pearson korelasyon analizi kullanıldı. İstatistik karşılaştırmalar p<0,05 anlamlılık düzeyinde değerlendirildi.*

Bulgular: *Katılımcıların yaş ortalaması 45.53±15.88, hastalara bakım verme süresi ortalaması 3.60±3.19 yıldır. Bakım vericilerin MÖ toplam puan ortalaması 94.60±15.83 ve BVYÖ toplam puan ortalaması 39.14 ±11.59'dır. Çalışmada BVYÖ ve MÖ alt boyut ve toplam puanları arasında istatistiksel olarak anlamlı bir ilişki saptanmadı (p>0,05).*

Katılımcıların öğrenim düzeyi, medeni durum, çocuğa sahip olma, çalışma durumu, akraba olma, yardım alma, korku ve endişe yaşama, sosyal açıdan güçlük yaşama, hastanın temel gereksinimlerini karşılama durumu, hastaya hareket desteği verme durumu, bakımla ilgili bilgiye ihtiyaç duyma durumunun katılımcıların merhamet duygusunu, etkileyen faktör olduğu (p<0.05) belirlendi.

Sonuç: *Bakım vericilerin bakım yüklerinin orta düzeyde olmasına rağmen, merhamet düzeylerinin yüksek ve merhamet duygularını etkileyen faktörlerin olduğu belirlendi. Bakım verenlerin bakım yüklerini ve yaşadıkları olumsuz duyguları azaltmaya ve olumlu yönde geliştirmeye yönelik eğitimlerin planlanması önerilir.*

Anahatar Sözcükler: *Bakım verici, Alzheimer hastası, Bakım yükü, Merhamet.*

INTRODUCTION

Alzheimer's disease is a life-threatening disease that progresses slowly and starts years before symptoms are seen. Alzheimer's Association 2023 Report in the United States of America indicates the number of patients diagnosed with Alzheimer's disease as 6.7 million and points that Alzheimer's disease is ranked fifth among the causes of death in individuals aged 65 and over (1). The Turkish Statistical Institute data reported that while the ratio of deaths from Alzheimer's disease was 4.6% in 2017, it was 3.0% in 2021 (2).

Caregiver burden includes the physical, emotional, and financial challenges, stress, and pressure felt by caregivers providing care to individuals who require care, who are older, and who have a chronic disease/ disability (3, 4-8). Physical regression in the process of the disease limits elderly individuals' autonomy, independence, and quality of life (9). In this case, caregiving responsibility increases in individuals providing care to patients with Alzheimer's disease. Cultural features and personal values sometimes affect the relationship between the caregiver and the patient. Caregivers of Alzheimer's disease generally include the patient's spouse-children, friends, or acquaintances (3, 4, 6, 7). Sousa et al. (2016) reported the important factors affecting caregiver burden as the family structure, spending more time with the patient, family member as the caregiver, and living with the patient (10).

In the study conducted by Gilbert (2009), compassion is defined as "a deep awareness of the suffering of another coupled with the wish to relieve it" (11). Strauss et al (2016) reported five components of compassion as 1) recognizing suffering; 2) understanding the universality of suffering in human experience; 3) feeling empathy for the person suffering and connecting with the distress; 4) tolerating uncomfortable feelings aroused in response to the suffering person; and 5) motivation to act/acting to alleviate suffering (12). By promoting positive emotions, compassion enhances healthy communication and increases the quality of the care provided (13-15). Compassion fatigue is one of the factors affecting care negatively. When the caregiver experiences compassion fatigue, the quality of care decreases, which could lead to psychosocial problems and burnout to be experienced by the caregiver. Depending on the strength of the connection between the patient and the caregiver, compassion and care could be affected when the caregiver is the patient's relative.

Alzheimer's disease causes loss of autonomy and independence, the patient becomes more and more dependent in the progressive stages, which could cause the caregiver to experience some psychological and physical difficulties. Vashon (2016) states that the intention that feeds compassion is based on the ethical orientations of not giving harm, doing kindness, and helping others (16). Lyncha et al., (2018) conducted a study with caregivers who are family members of Alzheimer's patients, and the 71% had a high level of caregiver burden, 59.5% burnout and that half of them had moderate compassion fatigue. (15). In the study, it was found that caregivers who felt more compassionate love towards people diagnosed with Alzheimer's reported less caregiving burden and more positivity in their caregiving roles (17). Hence, it is important to identify the relationship between caregiver burden and compassion levels and the affecting factors in caregivers of patients with Alzheimer's disease.

METHODS

Purpose and study design

This study, which is cross-sectional and descriptive in nature, aims to identify the relationship between caregiver burden and compassion levels and the affecting factors in caregivers of patients with Alzheimer's disease.

Setting of the study

The study was conducted in an Elderly Living Center of the Turkish Alzheimer's Society. Alzheimer's Society has 13 branches in Turkey. The center where this study was conducted provides service to 58 registered patients with Alzheimer's disease and caregivers.

Target population and the sample

The target population of the study is the caregivers of 58 patients with Alzheimer's disease who are registered in an Elderly Living Center of the Turkish Alzheimer's Society. No sampling was performed; the study included all the target population. All the registered caregivers in the center were accessed.

Measures

The Socio-demographic Form: The Socio-demographic Form that was prepared in line with the literature is composed of 23 questions that aimed to identify the descriptive characteristics of the participants and the patients and the characteristics of the care provided by the participants (4, 8, 17, 18).

The compassion scale (CS): The Compassion Scale was developed by Pommier in 2011, and its Turkish validity and reliability were performed by Akdeniz and Deniz in 2016 (19). The scale is composed of 24 items and 6 subscales that include kindness, indifference, common humanity, disengagement, mindfulness, and separation. The scale is responded on a 5-point scale. The total compassion score is obtained by adding all the subscales after scoring the subscales scored reversely. Higher scores from the scale mean a higher compassion level. Cronbach's Alpha reliability coefficient of the total scale is 0.85 (19). In this study Cronbach's Alpha score is 0.896.

The caregiver burden scale (CBS): The Caregiver Burden Scale was developed by Zarit, Reeverve Bach-Peterson in 1980, and its reliability and validity for Turkish were performed by İnci in 2006 (20). The scale is composed of 22 items that are rated on a 5-point Likert scale ranging from 0 to 4. A minimum of 0 and a maximum of 88 points can be obtained from the scale. Higher scores indicate higher levels of problems experienced. Cronbach's alpha reliability coefficient of the total scale is 0.95 (20). In our study Cronbach's Alpha score is 0.798.

Data collection

Data were collected between the 1st of February and 1st of May 2018 from the caregivers of patients with Alzheimer's disease who are registered in an Elderly Living Center of the Turkish Alzheimer's Society in a metropolitan city in Turkey. Institutional permission was obtained for the research after obtaining permission from the non-invasive ethics committee. When the patient's relatives came to visit their patients at the center, I was interviewed by the researcher. Data were collected through interviews conducted face-to-face with the caregivers who agreed to participate, about 20 minutes.

The analysis of the data was performed in IBM SPSS V25 statistical package program. Shapiro Wilk test was utilized to determine whether the data distributed normally. When normality assumptions were met, descriptive characteristics were presented using means and standard deviations, and they were presented with median (minimum-maximum) values when normality assumptions were not met. The comparison of the independent two groups was done using the student's test /Mann Whitney U test. Multiple independent group comparisons were performed using the one-way ANOVA/ Kruskal Wallis test. The analysis of the continuous variables was performed using the Pearson Correlation analysis. The significance level taken in statistical comparisons was $p<0.05$.

Ethical considerations

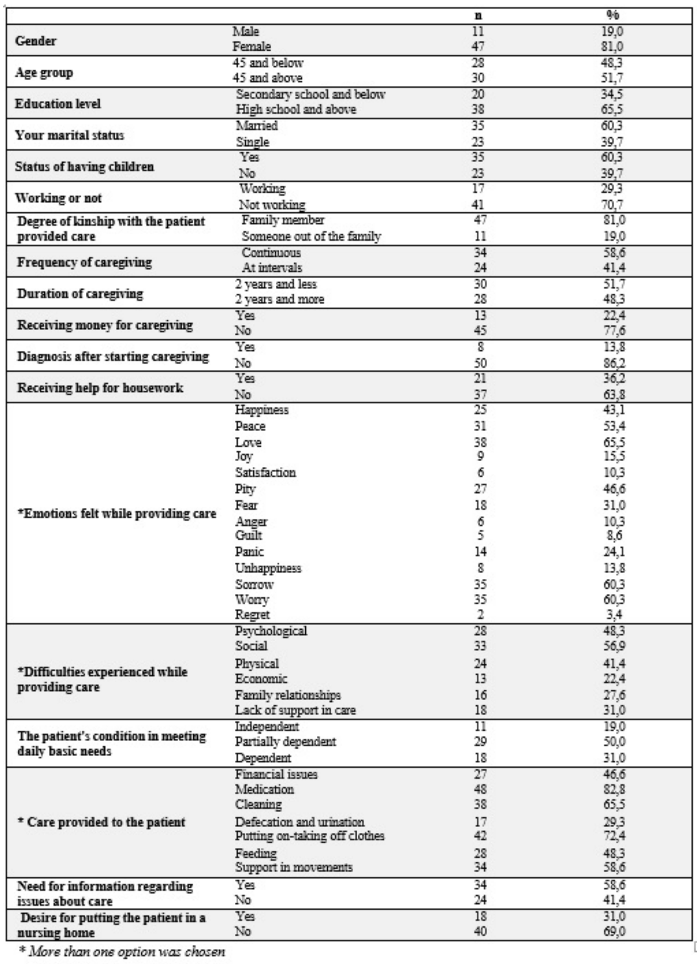
In line with the standards for national ethics rules, ethics committee approval was obtained from the ethics committee of a university (Number: 2017-70/25, Date: 10.11.2017). Written permission was obtained from the Alzheimer's Society. Consent was received from the participants after they were given information about the study.

FINDINGS

The average age of the participants was 45.53±15.88, and the average duration of providing care was 3.60 ±3.19 years. Of all the participants, 81% were females, 65.5% graduated from high school or above, 60.3% were married and had children, and 70.7% did not work in another job. Besides, 81.0% were the relatives of the patient who was provided care (spouse, children, etc.), 58.6% provided continuous care, 51.7% provided care for 2 years and less, 86,2% stated that the patient was diagnosed with Alzheimer's before they started to provide care, 50% of the patients provided care were partially dependent, 22.4 % received money for caregiving, and 36.2% received help for housework. While providing care to the patient, 57,8 % reportedly experienced negative emotions such as pity, fear, panic, sorrow, and worry; 56.9% had social difficulties, 52.2% provided care about daily living activities (maintaining body hygiene, helping defecation and urination, putting on-taking off clothes, feeding, supporting in movements); 58.6% needed information regarding issues about care; and 31% thought about putting the patient in a nursing home.

The average age of the patients who were provided with care by the participants was 77.29±9.39, and 69% were females, 32.8% graduated from primary school, and 62.1% had the middle stage of the disease.

Table 1. Descriptive and caregiving-related characteristics of the participants

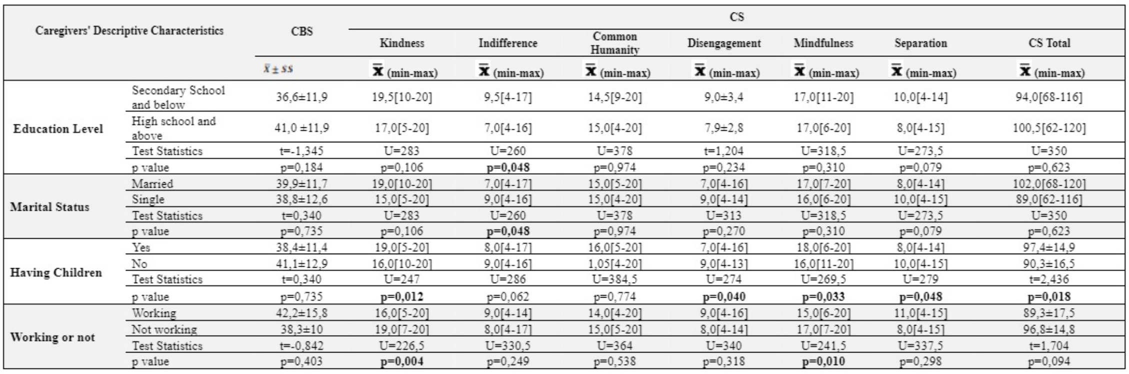


		n	%
Gender	Male	11	19,0
	Female	47	81,0
Age group	45 and below	28	48,3
	45 and above	30	51,7
Education level	Secondary school and below	20	34,5
	High school and above	38	65,5
Your marital status	Married	35	60,3
	Single	23	39,7
Status of having children	Yes	35	60,3
	No	23	39,7
Working or not	Working	17	29,3
	Not working	41	70,7
Degree of kinship with the patient provided care	Family member	47	81,0
	Someone out of the family	11	19,0
Frequency of caregiving	Continuous	34	58,6
	At intervals	24	41,4
Duration of caregiving	2 years and less	30	51,7
	2 years and more	28	48,3
Receiving money for caregiving	Yes	13	22,4
	No	45	77,6
Diagnosis after starting caregiving	Yes	8	13,8
	No	50	86,2
Receiving help for housework	Yes	21	36,2
	No	37	63,8
***Emotions felt while providing care**	Happiness	25	43,1
	Peace	31	53,4
	Love	38	65,5
	Joy	9	15,5
	Satisfaction	6	10,3
	Pity	27	46,6
	Fear	18	31,0
	Anger	6	10,3
	Guilt	5	8,6
	Panic	14	24,1
	Unhappiness	8	13,8
	Sorrow	35	60,3
	Worry	35	60,3
	Regret	2	3,4
***Difficulties experienced while providing care**	Psychological	28	48,3
	Social	33	56,9
	Physical	24	41,4
	Economic	13	22,4
	Family relationships	16	27,6
	Lack of support in care	18	31,0
The patient's condition in meeting daily basic needs	Independent	11	19,0
	Partially dependent	29	50,0
	Dependent	18	31,0
*** Care provided to the patient**	Financial issues	27	46,6
	Medication	48	82,8
	Cleaning	38	65,5
	Defecation and urination	17	29,3
	Putting on-taking off clothes	42	72,4
	Feeding	28	48,3
	Support in movements	34	58,6
Need for information regarding issues about care	Yes	34	58,6
	No	24	41,4
Desire for putting the patient in a nursing home	Yes	18	31,0
	No	40	69,0

** More than one option was chosen*

The CS total mean score of the caregivers was 94.60±15.83. This study found the CS Cronbach's α reliability coefficient as 0.896. CBS total scores was 39.14±11.59. This study found the Cronbach's α reliability coefficient of the CBS as 0.798. Although the participants were found to have a moderate-level caregiver burden and their compassion level was high.

Table 2. The analysis of the CBS and CS scores according to the caregivers' descriptive



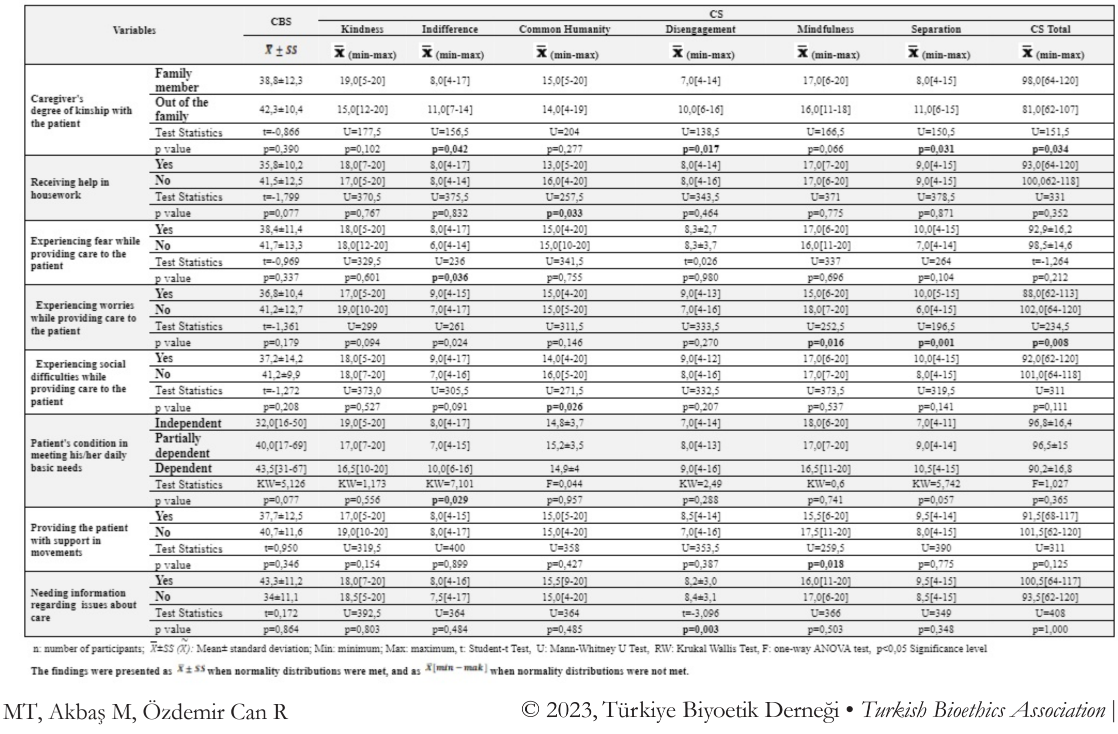
Caregivers' Descriptive Characteristics		CBS	CS						
			Kindness	Indifference	Common Humanity	Disengagement	Mindfulness	Separation	CS Total
		$\bar{X} \pm SS$	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)
Education Level	Secondary School and below	36,6±11,9	19,5[10-20]	9,5[4-17]	14,5[9-20]	9,0±3,4	17,0[11-20]	10,0[4-14]	94,0[68-116]
	High school and above	41,0 ±11,9	17,0[5-20]	7,0[4-16]	15,0[4-20]	7,9±2,8	17,0[6-20]	8,0[4-15]	100,5[62-120]
	Test Statistics	t=-1,345	U=283	U=260	U=378	t=1,204	U=318,5	U=273,5	U=350
	p value	p=0,184	p=0,106	**p=0,048**	p=0,974	p=0,234	p=0,310	p=0,079	p=0,623
Marital Status	Married	39,9±11,7	19,0[10-20]	7,0[4-17]	15,0[5-20]	7,0[4-16]	17,0[7-20]	8,0[4-14]	102,0[68-120]
	Single	38,8±12,6	15,0[5-20]	9,0[4-16]	15,0[4-20]	9,0[4-14]	16,0[6-20]	10,0[4-15]	89,0[62-116]
	Test Statistics	t=0,340	U=283	U=260	U=378	U=313	U=318,5	U=273,5	U=350
	p value	p=0,735	p=0,106	**p=0,048**	p=0,974	p=0,270	p=0,310	p=0,079	p=0,623
Having Children	Yes	38,4±11,4	19,0[5-20]	8,0[4-17]	16,0[5-20]	7,0[4-16]	18,0[6-20]	8,0[4-14]	97,4±14,9
	No	41,1±12,9	16,0[10-20]	9,0[4-16]	1,05[4-20]	9,0[4-13]	16,0[11-20]	10,0[4-15]	90,3±16,5
	Test Statistics	t=0,340	U=247	U=286	U=384,5	U=274	U=269,5	U=279	t=2,436
	p value	p=0,735	**p=0,012**	p=0,062	p=0,774	**p=0,040**	**p=0,033**	**p=0,048**	**p=0,018**
Working or not	Working	42,2±15,8	16,0[5-20]	9,0[4-14]	14,0[4-20]	9,0[4-16]	15,0[6-20]	11,0[4-15]	89,3±17,5
	Not working	38,3±10	19,0[7-20]	8,0[4-17]	15,0[5-20]	8,0[4-14]	17,0[7-20]	8,0[4-15]	96,8±14,8
	Test Statistics	t=-0,842	U=226,5	U=330,5	U=364	U=340	U=241,5	U=337,5	t=1,704
	p value	p=0,403	**p=0,004**	p=0,249	p=0,538	p=0,318	**p=0,010**	p=0,298	p=0,094

n: number of participants; $\bar{X} \pm SS\ (\tilde{X})$: Mean± standard deviation; Min: minimum; Max: maximum, t: Student-t Test, U: Mann-Whitney U Test, p<0,05 Significance level

The findings were presented as $\bar{X} \pm SS$ when normality distributions were met, and as $\tilde{X}[min-mak]$ when normality distributions were not met.

No significant relationships were detected between the Caregiver Burden Scale and the Compassion Scale subscales and total scores (p>0.05). The CS indifference subscale score median of the participants who had an education level of secondary school and below was significantly that of the participants who graduated from high school and above (p=0.048). The CS indifference subscale score median of single individuals was significantly that of the participants who were married (p=0.048). The comparison of the score median according to the variable of having children showed that the groups indicated significant differences in kindness (p=0.012), disengagement (p=0.040), mindfulness (p=0.033), separation (p=0.048), and the total score (p=0.018). The participants' CS kindness (p=0.004) and mindfulness (p=0.010) subscale score medians demonstrated significant differences according to the working variable. No significant relationship was found between the caregivers' descriptive characteristics and the Caregiver Burden Scale total scores (p>0.05). (Table 2).

Table 3. Caregivers' characteristics related to caregiving and the analysis of CBS and CS scores



Variables		CBS	CS						
			Kindness	Indifference	Common Humanity	Disengagement	Mindfulness	Separation	CS Total
		$\bar{X} \pm SS$	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)	$\bar{X}$ (min-max)
Caregiver's degree of kinship with the patient	**Family member**	38,8±12,3	19,0[5-20]	8,0[4-17]	15,0[5-20]	7,0[4-14]	17,0[6-20]	8,0[4-15]	98,0[64-120]
	Out of the family	42,3±10,4	15,0[12-20]	11,0[7-14]	14,0[4-19]	10,0[6-16]	16,0[11-18]	11,0[6-15]	81,0[62-107]
	Test Statistics	t=-0,866	U=177,5	U=156,5	U=204	U=138,5	U=166,5	U=150,5	U=151,5
	p value	p=0,390	p=0,102	**p=0,042**	p=0,277	**p=0,017**	p=0,066	**p=0,031**	**p=0,034**
Receiving help in housework	**Yes**	35,8±10,2	18,0[7-20]	8,0[4-17]	13,0[5-20]	8,0[4-14]	17,0[7-20]	9,0[4-15]	93,0[64-120]
	No	41,5±12,5	17,0[5-20]	8,0[4-14]	16,0[4-20]	8,0[4-16]	17,0[6-20]	9,0[4-15]	100,062-118]
	Test Statistics	t=-1,799	U=370,5	U=375,5	U=257,5	U=343,5	U=371	U=378,5	U=331
	p value	p=0,077	p=0,767	p=0,832	**p=0,033**	p=0,464	p=0,775	p=0,871	p=0,352
Experiencing fear while providing care to the patient	**Yes**	38,4±11,4	18,0[5-20]	8,0[4-17]	15,0[4-20]	8,3±2,7	17,0[6-20]	10,0[4-15]	92,9±16,2
	No	41,7±13,3	18,0[12-20]	6,0[4-14]	15,0[10-20]	8,3±3,7	16,0[11-20]	7,0[4-14]	98,5±14,6
	Test Statistics	t=-0,969	U=329,5	U=236	U=341,5	t=0,026	U=337	U=264	t=-1,264
	p value	p=0,337	p=0,601	**p=0,036**	p=0,755	p=0,980	p=0,696	p=0,104	p=0,212
Experiencing worries while providing care to the patient	**Yes**	36,8±10,4	17,0[5-20]	9,0[4-15]	15,0[4-20]	9,0[4-13]	15,0[6-20]	10,0[5-15]	88,0[62-113]
	No	41,2±12,7	19,0[10-20]	7,0[4-17]	15,0[5-20]	7,0[4-16]	18,0[7-20]	6,0[4-15]	102,0[64-120]
	Test Statistics	t=-1,361	U=299	U=261	U=311,5	U=333,5	U=252,5	U=196,5	U=234,5
	p value	p=0,179	p=0,094	p=0,024	p=0,146	p=0,270	**p=0,016**	**p=0,001**	**p=0,008**
Experiencing social difficulties while providing care to the patient	**Yes**	37,2±14,2	18,0[5-20]	9,0[4-17]	14,0[4-20]	9,0[4-12]	17,0[6-20]	10,0[4-15]	92,0[62-120]
	No	41,2±9,9	18,0[7-20]	7,0[4-16]	16,0[5-20]	8,0[4-16]	17,0[7-20]	8,0[4-15]	101,0[64-118]
	Test Statistics	t=-1,272	U=373,0	U=305,5	U=271,5	U=332,5	U=373,5	U=319,5	U=311
	p value	p=0,208	p=0,527	p=0,091	**p=0,026**	p=0,207	p=0,537	p=0,141	p=0,111
Patient's condition in meeting his/her daily basic needs	**Independent**	32,0[16-50]	19,0[5-20]	8,0[4-17]	14,8±3,7	7,0[4-14]	18,0[6-20]	7,0[4-11]	96,8±16,4
	Partially dependent	40,0[17-69]	17,0[7-20]	7,0[4-15]	15,2±3,5	8,0[4-13]	17,0[7-20]	9,0[4-14]	96,5±15
	Dependent	43,5[31-67]	16,5[10-20]	10,0[6-16]	14,9±4	9,0[4-16]	16,5[11-20]	10,5[4-15]	90,2±16,8
	Test Statistics	KW=5,126	KW=1,173	KW=7,101	F=0,044	KW=2,49	KW=0,6	KW=5,742	F=1,027
	p value	p=0,077	p=0,556	**p=0,029**	p=0,957	p=0,288	p=0,741	p=0,057	p=0,365
Providing the patient with support in movements	**Yes**	37,7±12,5	17,0[5-20]	8,0[4-15]	15,0[5-20]	8,5[4-14]	15,5[6-20]	9,5[4-14]	91,5[68-117]
	No	40,7±11,6	19,0[10-20]	8,0[4-17]	15,0[4-20]	7,0[4-16]	17,5[11-20]	8,0[4-15]	101,5[62-120]
	Test Statistics	t=0,950	U=319,5	U=400	U=358	U=353,5	U=259,5	U=390	U=311
	p value	p=0,346	p=0,154	p=0,899	p=0,427	p=0,387	**p=0,018**	p=0,775	p=0,125
Needing information regarding issues about care	**Yes**	43,3±11,2	18,0[7-20]	8,0[4-16]	15,5[9-20]	8,2±3,0	16,0[11-20]	9,5[4-15]	100,5[64-117]
	No	34±11,1	18,5[5-20]	7,5[4-17]	15,0[4-20]	8,4±3,1	17,0[6-20]	8,5[4-15]	93,5[62-120]
	Test Statistics	t=0,172	U=392,5	U=364	U=364	t=-3,096	U=366	U=349	U=408
	p value	p=0,864	p=0,803	p=0,484	p=0,485	**p=0,003**	p=0,503	p=0,348	p=1,000

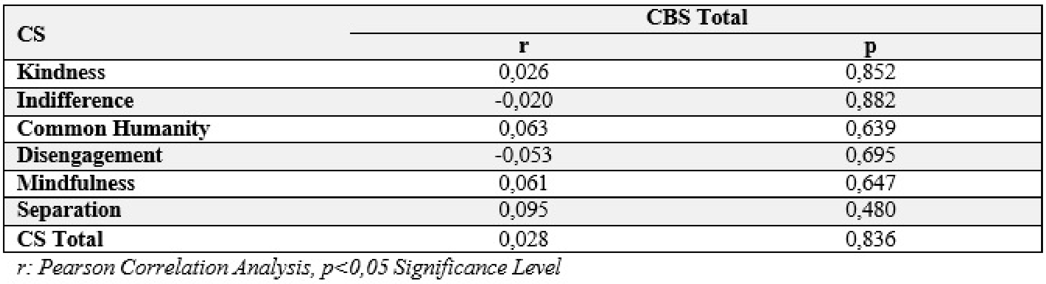
n: number of participants; $\bar{X} \pm SS\ (\tilde{X})$: Mean± standard deviation; Min: minimum; Max: maximum, t: Student-t Test, U: Mann-Whitney U Test, RW: Krukal Wallis Test, F: one-way ANOVA test, p<0,05 Significance level

The findings were presented as $\bar{X} \pm SS$ when normality distributions were met, and as $\tilde{X}[min-mak]$ when normality distributions were not met.

Comparisons of the subscale scores between the groups according to the degree of kinship with the patient indicated significant differences in the indifference (p=0.042), disengagement (p=0.017), separation (p=0.031), and CS total (p=0.034) score medians. While significant differences were detected between the groups according to receiving help in housework (p=0.033), the median of the common humanity subscale score of the participants who did not receive help was found to be higher than that of the participants who received help.

A significant difference was found in the caregivers' indifference subscale score median according to experiencing fear (p=0.036). The median of the participants who experienced fear was found to be high. Significant differences were detected in the mindfulness (p=0.016), separation (p=0.001) medians, and CS total score (p=0.008) according to experiencing worries while providing care to the patient. Hence, while mindfulness and CS total score medians were found to be higher in the participants who had worries, they were found to be low in the separation subscale. The common humanity subscale median score was found to be significantly lower in the participants who experienced social difficulties while providing care to the patient (p=0.026). The indifference subscale demonstrated significant differences between the groups according to patients meeting daily basic needs (p=0.029). According to providing the patient with support in movements, the mindfulness subscale median score was found to be significantly lower in individuals who provided this care (p=0.018). The disengagement subscale mean score of the individuals who needed information regarding issues about care was found to be significantly lower than the individuals who did not need information (p=0.003). No significant relationships were detected between a family member providing care and the Caregiver Burden Scale total scores; however, the caregiver burden score decreased when the care was given by a family member but it increased when the care was given by someone out of the family (p>0.05) (Table 3).

Table 4. Correlation analysis of the CBS and CS subscale and total scores

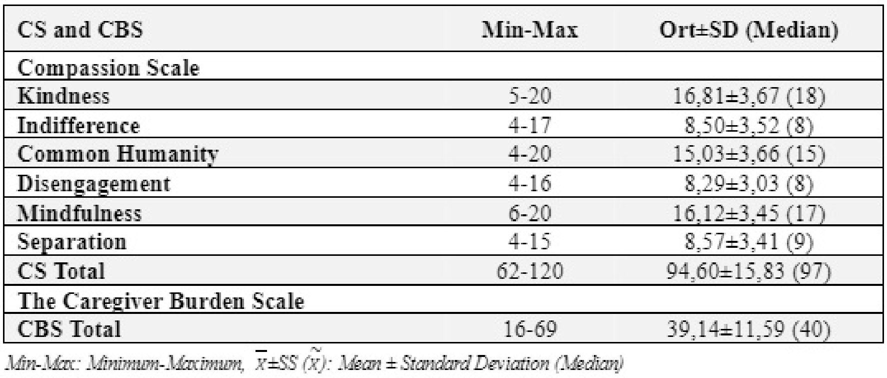


CS	CBS Total	
	r	p
Kindness	0,026	0,852
Indifference	-0,020	0,882
Common Humanity	0,063	0,639
Disengagement	-0,053	0,695
Mindfulness	0,061	0,647
Separation	0,095	0,480
CS Total	0,028	0,836

r: Pearson Correlation Analysis, p<0,05 Significance Level

There was no significant correlation between the Caregiving Burden Scale and Compassion Scale sub-dimension and total scores (p>0.05) (Table 4).

Table 5. The participants' compassion scale and caregiver burden scale scores



CS and CBS	Min-Max	Ort±SD (Median)
Compassion Scale		
Kindness	5-20	16,81±3,67 (18)
Indifference	4-17	8,50±3,52 (8)
Common Humanity	4-20	15,03±3,66 (15)
Disengagement	4-16	8,29±3,03 (8)
Mindfulness	6-20	16,12±3,45 (17)
Separation	4-15	8,57±3,41 (9)
CS Total	62-120	94,60±15,83 (97)
The Caregiver Burden Scale		
CBS Total	16-69	39,14±11,59 (40)

Min-Max: Minimum-Maximum, $\overline{x}$±SS ($\tilde{x}$): Mean ± Standard Deviation (Median)

CBS total scores of the caregivers ranged between 16 and 69, and the average score was 39.14±11.59 with the median being 40 (Table 2).

DISCUSSION

The results of this study showed that the average age of the participants was 45, more than ¾ of them were females and almost ¾ of them did not work in another job. Studies in the literature report the increased risk factors for caregivers' burden while giving care to patients with Alzheimer's as follows: being female, having spare time, duration allocated to care and working in another job (17, 21-25). The ratio of female caregivers in the present study was higher than other studies in the literature (22,25). This result is considered to result from the patriarchal family structure in Turkey; the majority of caregivers are females, which is associated with cultural support and appreciation.

Of all the participants in the study, more than half felt negative emotions and more than half had social difficulties. Studies show that caregivers frequently experience one or some of the problems including hopelessness, fatigue, anxiety, pain, and depression as well as caregiver burden (physical, psychological, social, and economic) (8, 9, 25). Garre-Olmo et al. (2016) reported that the increase in the dependence level and behavioral disorders could increase the caregiver's stress level and workload, which in turn increases the caregiver burden (22). A study reported that the positive experiences of caregivers in the caring process had effects on their coping with difficulties, fondness and pleasure more in their relationship with the patients (18). The fact that some of the participants had a medium level of caregiver burden score may be associated with the fact that caring for the elderly is considered important and honorable in our cultural values.

In this study, half of the participants were found to provide care about daily life activities. Liu et al. reported that caregivers spent 2.8±2.1 hours/day meeting the basic needs of the patients such as eating, putting on clothes, having a bath, and using the bathroom (25). Half of the patients in this study were partially dependent, and the caregivers had a moderate level of caregiver burden; the need for help in daily life activities increases with the increase in the patient's dependence level.

More than ¾ of the patients in this study were patient relatives; more than half of them provided the patient with continuous care; only 1/5 received money for the care they provided. Studies on patients with Alzheimer's disease showed that more than ¾ of caregivers were the patient's relatives, and almost 1/3 provided care for 4-6 years (18, 21). It is reported that when caregivers are relatives, they could experience compassion fatigue caused by the emotional confusion due to the dependence level of the patient and the course of the disease (26). The caregivers in this study were mainly composed of the patients' relatives and thus the results are in line with the other studies in the literature. The average age of the patients with Alzheimer's disease who were provided care was over 70 age and education level of primary school or above (18, 21, 25). Medium age and education level of the patients with Alzheimer's disease is in line with this study.

The CS total mean score was found 94.60±15.83in this study, indicating high compassion levels. Caregivers with high compassion levels are reported to have more positive attitudes towards patients and experience less caregiver burden (17, 27). The results of this study are in line with other studies in the literature in that the caregiver burden score decreased with the increase in the compassion level.

The Caregiver Burden Scale mean score of the participants was found 39.14±11.59 in this study, indicating a moderate level of caregiver burden. The caregiver burden score decreases when care is given by a family member, but it increases if the caregiver is out of the family. In studies reported that when the caregiver is the spouse in patients with dementia, the caregiver burden was perceived less, and compassion affected care positively (10, 28, 29). One of the most important factors affecting the Caregiver Burden Scale score was found to be kinship in this study, which is parallel to the related literature.

The mindfulness subscale and the Compassion Scale total scores of the participants who did not have worries while providing care were found to be higher and statistically significant than the scores of the participants who experienced worries while providing care (p<0.05). Compassion fatigue while providing care is reported to cause nurses to experience worries, fear, lack of confidence, and a decrease in emphatic skills (27, 30-32). A study on the attitudes of health professionals towards compassion reported that the doctor's barriers to showing compassion included external distracting factors such as burnout or work overload, time pressure, "difficult" patients/families, uncertainties in the treatment process, and treatment failure (33). This study found that a negative emotion such as worry increased the compassion score, which is in line with other studies in the literature.

The CBS scores of the participants who experienced social difficulties while providing care to the patient did not indicate any significant differences according to those who reportedly did not have difficulties. Studies showed that the caregiver burden was felt less and the quality of life was better when caregivers of patients with Alzheimer's disease had good social skills and good skills for coping with depression/anxiety (7,8,21,34-36). In a study, 55.93% of caregivers stated that they felt inadequate in providing care and this caused them to feel unwell (37). Physical, psychological, and social support to be provided to caregivers in line with their interests and needs could decrease their burnout and help them to provide better care and produce fast and effective solutions to the problems experienced.

Although the CBS scores of those who need information related to the issues about care were higher than those who did not need information. An important factor that could decrease caregivers' burden could be health professionals identifying caregivers under risk and providing them with education programs that could enhance care (22). Our study results showed that education programs parallel to their needs could substantially decrease caregivers' caring burden.

CONCLUSION

Although the participants were found to have a moderate-level caregiver burden, their compassion level was high and the compassion towards patients with Alzheimer's disease was affected by some factors. These results could be useful for designing policies focusing on forming education programs for caregivers of patients with Alzheimer's disease and enhancing their well-being to increase their quality of life.

Limitations: This study was conducted with a group of caregivers of patients with Alzheimer's disease and thus the results might not represent all caregivers. All the participants were Turkish citizens, so the results cannot be generalized to caregivers from other ethnic origins.

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