

# Predictors of caregiver burden in Alzheimer's disease: Caregiver stress, life satisfaction and quality of life levels

<sup>1</sup>Alime Selçuk Tosun, <sup>2</sup>Neslihan Lök, <sup>3</sup>Kerime Bademli

<sup>1</sup>Faculty of Nursing, Public Health Nursing Department, Selcuk University, Konya, Türkiye; <sup>2</sup>Faculty of Nursing, Psychiatric Nursing Department, Selcuk University, Konya, Türkiye; <sup>3</sup>Faculty of Nursing, Psychiatric Nursing Department, Akdeniz University, Antalya, Türkiye

## Abstract

**Objective:** The purpose of this study was to determine the impact of socio-demographic and health characteristics, caregiving stress, life satisfaction, and quality of life on the caregiving burden in caregivers of Alzheimer's patient. **Methods:** This study is a descriptive-correlational type study. A total of 146 individuals who are caregivers of Alzheimer's patient constitute the sampling of the study. The Zarit Burden Interview, Caregiver Strain Index, Satisfaction with Life Scale, and SF-36 Quality of Life. **Results:** The care burden mean score of caregivers was  $61.29 \pm 10.3$ . It was determined that age ( $\beta=0.648$ ), caring duration ( $\beta=0.429$ ), gender ( $\beta=0.672$ ), marital status ( $\beta=0.936$ ), educational status ( $\beta=0.863$ ), the affinity of the caregiver with the patient ( $\beta=0.734$ ), working status ( $\beta=0.524$ ), perceived income adequacy ( $\beta=0.926$ ), perceived health condition ( $\beta=0.682$ ), presence of chronic disease ( $\beta=0.529$ ), caregiving stress ( $\beta=0.633$ ), life satisfaction score ( $\beta=-0.775$ ), physical subscale score ( $\beta=-0.824$ ) and mental subscale score ( $\beta=-0.489$ ) quality of life had an influence on the caregiving burden ( $p < 0.001$ ). It was determined that the effective determining factors account for 76.4% of the variation in the caregiving burden.

**Conclusions:** The caregivers of Alzheimer's disease patients have a high caring burden. In addition to the socio-demographic and health characteristics of caregivers, caregiving stress, life satisfaction, and quality of life are important determinants of the caring burden.

**Keywords:** Caregiving burden, Alzheimer's disease, quality of life, caregiver stress, life satisfaction

## INTRODUCTION

Caregiving involves taking care of another person's health and care needs and assisting with one or more daily life activities. It includes tasks that can be unpleasant and uncomfortable, psychologically stressful, and physically exhausting.<sup>1</sup> Caring for an Alzheimer's disease patient is usually a long and exhausting process for caregivers. Because patients' cognitive skills and functions are impaired in Alzheimer's illness, independence of the patient decreases, and his/her dependence on the caregiver increases. Alzheimer's disease patients often need a high level of care in all aspects of daily life, and this care is mostly provided by family members.<sup>2</sup> It is noted that caregivers of Alzheimer's disease patients often experience social isolation, stress, emotional pressure, depression, anxiety, and

financial problems as a result of providing care.<sup>3</sup> A study conducted with the families of Alzheimer's disease patients found that family members who have a caring role in the family have increased anxiety levels, stress, and depression compared to family members who do not have a caring role.<sup>4</sup> In the study, it is stated that there is a need for a caregiver-centered approach by determining the needs of caregivers to increase the psychological well-being of caregivers and improve the quality of life.<sup>5</sup> Caring for individuals with Alzheimer's disease poses unique challenges, often placing a substantial burden on family caregivers. As the prevalence of Alzheimer's disease continues to rise globally, understanding the factors influencing caregiver burden becomes imperative for the development of effective support strategies.<sup>6</sup> Caregiver burden is defined as a multidimensional

*Address correspondence to:* Alime Selçuk Tosun, Department of Public Health Nursing, Faculty of Nursing, University of Selçuk, Alaaddin Keykubat Campus, Selçuklu 42130, Konya, Turkey. Tel: +903322231631; E-mail: alimetosun@selcuk.edu.tr

Date of Submission: 17 April 2024; Date of Acceptance: 7 May 2024

<https://doi.org/10.54029/2024idz>

response to physical, psychological, emotional, social, and economic stressors associated with their caregiving experience.<sup>7</sup> Alzheimer's disease caregivers face a myriad of stressors, including the progressive nature of the disease, cognitive and behavioral changes in the care recipient, and the demanding nature of caregiving tasks. Numerous studies have highlighted the profound impact of caregiver stress on overall well-being and the potential for it to contribute significantly to caregiver burden.<sup>6,8,9</sup> In addition to stress, the caregiver's own life satisfaction plays a crucial role in the caregiving experience. Higher life satisfaction has been associated with better coping strategies and resilience in the face of caregiving challenges.<sup>10,11,12</sup> Understanding the interplay between life satisfaction and caregiver burden is essential for designing interventions that address the emotional and psychological aspects of caregiving. Furthermore, caregivers' own quality of life is intricately linked to the burden they experience. A caregiver's quality of life is influenced by various factors, including physical health, social support, and personal fulfillment. Research suggests that interventions promoting improvements in caregiver quality of life may effectively mitigate caregiver burden.<sup>13,14</sup>

While previous studies have explored individual aspects of caregiver burden, few have comprehensively examined the combined influence of caregiver stress, life satisfaction, and quality of life levels. This study seeks to bridge this gap by providing a nuanced understanding of how these factors interact and contribute to the overall burden experienced by caregivers of Alzheimer's disease patients. This study aims to identify and explore the predictors of caregiver burden, specifically examining the roles of caregiver stress, life satisfaction, and quality of life levels.

The research questions were thus: 1. How the caregiving burden of caregivers differ according to sociodemographic characteristics? 2. What is the caregiving burden, stress level, life satisfaction, and quality of life of caregivers? 3. What is the effect of sociodemographic characteristics, stress level, life satisfaction, and quality of life of caregivers on the caregiving burden? 4. What are the determining factors affecting the caregiving burden of individuals?

## METHODS

### *Design, setting and sampling*

This research was planned as a descriptive correlational study. The research was conducted with the caregivers of Alzheimer's patients registered in the population of a Family Health Center located in the Konya province's Selçuk district. There are a total of 146 Alzheimer's patients registered in the Family Health Center. In the study, the full population was reached without doing sample selection. The criteria for participating in the study are that the primary caregiver of the patient must be literate, over the age of 18, primarily responsible for the care and treatment of the patient for more than 6 months, and his/her patient must be diagnosed with Alzheimer's disease for a year and more; The exclusion criterion from the study is that the caregiver has a communication problem.

### *Data collection*

Some of the relatives of the patients were invited to the center by the researcher, and caregivers who could not come to the center for special reasons were paid home visits. The data were collected by face-to-face survey method in January-February 2022.

### *Measures*

The personal information form, the zarit burden interview, the caregiver strain index, the scale of life satisfaction, and the SF-36 quality of life questionnaire were used to collect the research data.

*Personal Information Form:* The Personal Information Form consists of a total of 10 questions (age (years), gender, marital status, education status, affinity with the patient, perceived income status, perceived health status, child-having status, presence of chronic diseases, caregiving duration (month), disease stage of the patient) related to the caregiver. The researcher prepared it based on the literature.<sup>15,16</sup>

*Zarit Caregiver Burden Interview:* It was developed by Zarit *et al.* (1980).<sup>17</sup> It is a scale used to assess caregivers' stress levels.<sup>18</sup> The adaptation of the scale to the Turkish society, the validity and reliability study was conducted by İnci and Erdem (2008). The Cronbach alpha coefficient of the scale was stated as 0.95.<sup>19</sup> The scale consists of 22 items. Each expression has a Likert-type evaluation ranging from "0" to "4". The scale has a minimum score of 0 and a maximum score of 88 points. A score ranging from 0 to 20 indicates little

or no burden, 21–40 indicates mild to moderate burden, 41–60 moderate to severe burden, and finally a score of 61–88 reflects severe burden. The items involved in the scale are often geared towards social and emotional space, with the high scale score indicating that the distress experienced is high.<sup>18,19</sup>

*Caregiver Strain Index:* Robinson (1983) developed the scale to assess caregivers' caring burden. The scale's Cronbach alpha value was specified as 0.86.<sup>20</sup> The Turkish adaptation of the scale was made by Uğur and Fadiloğlu (2010).<sup>21</sup> Cronbach alpha was reported to be 0.75 for the scale. The Caregiver Strain Index (CSI) is a scale that can be used to rapidly detect potential families with concerns about care. Stress measurements in caregiving are made up of 13 items. There is at least one item for each of the main subjects below. The main issues are the working status, financial status, physical status, social status, and time. The scale's lowest score is 0 and its highest score is 13. Positive responses on seven or more scale items (seven points or more) indicate that the caregiver perceives stress as high, indicating the caregiver's burden.<sup>21</sup>

*Satisfaction with Life Scale:* The scale was developed by Diner *et al.* (1985).<sup>22</sup> The Turkish adaptation of the satisfaction with life scale was made by Dağlı and Baysal (2016).<sup>23</sup> The scale is used to measure the life satisfaction of adult individuals. The Cronbach alpha internal consistency of the scale was determined as 0.88 and the test-retest reliability was 0.97. The scale consists of 5 items. The items of the seven-point Likert scale are answered ranging from (1) absolutely disagree to (7) absolutely agree. The scale's lowest score is 7 and its highest score is 35. The high score taken from the scale indicates that life satisfaction is high.<sup>23</sup>

*SF-36 Quality of Life Questionnaire:* It was developed by Ware and Sherbourne (1992).<sup>24</sup> This scale is one of the most widely used scales for measuring the quality of life. Its validity and reliability study was made and the scale was adapted to the Turkish society by Koçyiğit *et al.* (1999). Cronbach alpha values of the subscale scores were found to be between 0.73-0.76.<sup>25</sup>

The SF-36 consists of 2 main dimensions and 8 sub-dimensions: The scale has a Likert-type rating. Of the 36 statements included in the scale, 35 are evaluated taking into account the last 4 weeks. The score for each subdivision and two

main dimensions ranges from 0 to 100. SF-36, which has a positive score, is scored in such a way that the quality of life associated with health increases as the score of each dimension increases. As well as the 8 sub-dimensions can be evaluated separately with the scale, the quality of life can also be evaluated in two main dimensions: The physical and mental dimensions. In the calculation of the main dimension scores, the sub-dimension scores below each main dimension are added up and divided by the number of dimensions, so the score is calculated. For example, when calculating the physical dimension score, the physical function, role restriction-physical, physical pain, and general health perception scores are summed up and divided by 5. SF-36 evaluates both positive and negative aspects of the state of health. It is not possible to obtain a total score for the SF-36 quality of life questionnaire. Instead, summary scores can be obtained for the physical and mental components of health on the SF-36 questionnaire. The physical health components of the scale are the physical function, physical role, pain, and general health perception subscales, while the mental health components are the vitality, social function, emotional role, and mental health subscales. The lowest "0" and the highest "100" scores are obtained in the summary scores, and the high score indicates good health.<sup>25</sup>

#### *Variables of the study*

*The independent variables* of the study are the caregiver and patient characteristics (gender, age, marital status, education status, the affinity of the caregiver with the patient, perceived income adequacy, perceived health status, having a child, presence of chronic disease, working status, duration of care, disease stage of the patient) and the caregiver's stress level, life satisfaction level, and quality of life level. *The dependent variable* is the level of care burden

#### *Data analysis*

The IBM SPSS 25 package software was utilized to analyze the research data. The study's data were analyzed in a computer setting, and descriptive statistics such as number, percentage, mean, and standard deviation were used. The Kolmogorov-Smirnov test and Q-Q plot graphs were used to assess the data's suitability for normal distribution. Since the data is normally distributed, the relationship between care burden and socio-demographic and health disease characteristics was evaluated by t-test and analysis of variance

in independent groups. Multiple regression analysis was performed in the study to examine the caregiver stress, life satisfaction, quality of life, demographic and disease-health variables that may affect the care burden. In the analysis, categorical variables were assigned a value of "1" for groups containing risk factors. The risk group encodings were determined based on the significance values of the literature, t-test, and ANOVA tests.

#### *Ethical considerations*

The study began after receiving ethical approval from a university hospital's ethics committee. (Number of Decisions: 2021/12-227) and corporate permission from the family health center. In addition, the informed consent form was read aloud to the individuals, and the written consent of the individuals was obtained before the questionnaire forms were filled out.

## RESULTS

When we examined the descriptive characteristics of caregivers, it was determined that 45.4% was in the 50-64 age range, 60.1% was women, 39.9% was men, 53.1% was married, 49.7% was Primary School/Secondary School graduates, 55.9% was the patient's daughter, 44.1% perceived their incomes as poor, 53.1% had children, 55.9% had chronic diseases, 70.6% cared for their patient for 8-23 months and 43.4% were in stage 2 (Table 1).

When assessing the mean scores of caregivers' care burden, stress level, life satisfaction, and quality of life scale, the mean score of care burden was found to be  $61.29 \pm 10.31$ , the mean score of caregiver stress index was  $8.42 \pm 1.49$ , the mean score of satisfaction with life scale was  $15.80 \pm 4.04$ , the mean score of physical sub-dimension of quality of life was  $39.39 \pm 11.67$  and the mean score of mental sub-dimension was  $37.71 \pm 11.74$  (Table 2).

When the relationship of sociodemographic, health characteristics and the care burden of caregivers was evaluated, it was found between age, gender, educational status, marital status, the affinity of the caregiver with the patient, perceived income adequacy, perceived health status, presence of chronic disease, caregiving duration, stage of illness of the patient and the burden of care significant difference ( $p < 0.05$ ). Those aged 65 and over, high school and above graduates, caregivers being the patient's daughter, those with poor perceived income, those with poor perceived health, those with any chronic disease,

those with a caregiving period of 24 months and above, caregivers of the patients with the 3rd level of the disease had higher care burden (Table 3).

It was observed that the mean scores of the strain, life satisfaction, and quality of life scale and sub-dimensions of the caregivers had a very significant effect on the burden of care ( $P < 0.001$ ). According to the regression analysis, the total scores of caregiver stress level ( $\beta = 0.623$ ), life satisfaction level ( $\beta = 0.412$ ), physical sub-dimension of quality of life ( $\beta = 0.506$ ), and mental sub-dimension of quality of life ( $\beta = 0.389$ ) were found to account for 87.3% (Adjusted  $R^2 = 0.873$ ) of the variation in care burden (Table 4).

Caregivers age ( $\beta = 0.648$ ), time to care ( $\beta = 0.429$ ), gender ( $\beta = 0.672$ ), marital status ( $\beta = 0.936$ ), educational status ( $\beta = 0.863$ ), affinity of the caregiver with the patient ( $\beta = 0.734$ ), working status ( $\beta = 0.524$ ), perceived income ( $\beta = 0.926$ ) and perceived health status ( $\beta = 0.682$ ), presence of chronic disease ( $\beta = 0.529$ ), caregiver's stress level ( $\beta = 0.633$ ), total score of satisfaction with life scale ( $\beta = 0.775$ ), physical sub-dimension score of quality of life scale ( $\beta = 0.824$ ) and mental sub-dimension score averages of quality-of-life ( $\beta = 0.489$ ) were found to have an impact on the care burden ( $p < 0.001$ ). The effective determining factors accounted for 76.4% of the variation in care burden (Adjusted  $R^2 = 0.764$ ) (Table 5).

## DISCUSSION

Taking care of an Alzheimer's patient is often a grueling and difficult process. Being responsible for the care of Alzheimer's patients causes negative outcomes, particularly depression, anxiety, sleep disorders, but also increases the burden of caregiving.<sup>15,26</sup> Adverse conditions experienced by caregivers of Alzheimer's patients have been cited in many studies.<sup>15,16,27</sup> In the present study, it was determined that caregivers had an average care burden of  $61.29 \pm 10.31$  and had a moderate care burden. Similar to the study findings, it was stated in the studies that caregivers have a moderate level of care burden.<sup>16,28</sup>

The contribution of family members to care is important in providing care. Especially women often take on the job of caring for them. In the present research, the care burden of female caregivers was found to be higher than that of men. In studies similar to the current study results, it was reported that women have a greater burden of care than men.<sup>15,16,29</sup> In a study, it was reported that women are 75% more likely to experience

**Table 1: Distribution of descriptive properties of caregivers**

Variables	Number	Percent
Age (years)		
32-49	55	38.5
50-64	65	45.4
65 years and older	23	16.1
Gender		
Woman	86	60.1
Man	57	39.9
Marital status		
Married	76	53.1
Single	67	46.9
Education Status		
Literate	32	22.4
Elementary+middle school graduate	71	49.7
High school graduate and above	40	28.0
Affinity with the patient		
Wife	36	25.2
Daughter	80	55.9
Son	27	18.9
Perceived income satatus		
Good	38	26.6
Medium	42	29.4
Poor	63	44.1
Perceived health status		
Good	27	18.9
Medium	62	43.4
Poor	54	37.8
Child-having status		
Having	76	53.1
Not having	67	46.9
Presence of chronic diseases		
Yes	80	55.9
No	63	44.1
Caregiving duration (month)		
8-23 months	101	70.6
24 months and above	42	29.4
Disease stage of the patient		
Stage 1	44	30.8
Stage 2	62	43.4
Stage 3	37	25.9

serious stress than male caregivers.<sup>30</sup> In the current study, it was determined that the care burden of the patient was higher among those who had daughters and those who were married. The gradual deterioration of the patient's cognitive functions makes it difficult for married caregivers

to maintain their marital roles and responsibilities. In these cases, it is possible that the care load on women has increased further.<sup>31,32</sup> On the other hand, in the current research, it was found that the age of the caregiver had an effect on the burden of care. At the same time, chronic diseases of

**Table 2: Distribution of caregiving burden, stress level, life satisfaction and quality of life scale score averages of caregivers**

Variables	Mean (SD)*	Min/Max
Caregiving Burden Total Points	61.29 (10.31)	38/83
Caregiver Strain Index Total Score	8.42 (1.49)	6/12
Total Score of Satisfaction with Life Scale	15.80 (4.04)	9/25
Sub-dimensions of quality of life		
Physical Dimension	39.39 (11.67)	23/74
Mental Dimension	37.71 (11.74)	27/72

\*Standart deviation

**Table 3: Distribution of caregiving burden by sociodemographic characteristics**

Variables	Score of Caregiving Burden Mean (SD)***	p Value
Age (years)		
32-49	52.50 (10.99)	0.003**
50-64	60.04 (9.44)	
65 years and older	71.91 (11.04)	
Gender		
Woman	65.90 (10.91)	0.003**
Man	56.36 (9.35)	
Marital status		
Married	72.23 (11.35)	0.002**
Single	50.22 (8.95)	
Educational Status		
Literacy	52.38 (10.14)	0.001**
Primary school+secondary school graduate	59.37 (9.47)	
High school graduate and above	70.90 (11.23)	
Affinity with the patient		
Wife	59.13 (9.39)	0.003**
Daughter	70.69 (11.69)	
Son	55.18 (10.37)	
Perceived income adequacy		
Good	51.28 (10.56)	0.040*
Medium	60.05 (10.75)	
Poor	72.04 (9.96)	
Perceived health status		
Good	52.62 (10.05)	0.002**
Medium	61.50 (10.55)	
Poor	67.88 (9.88)	
Presence of chronic diseases		
Yes	65.42 (11.12)	0.030*
No	57.39 (9.15)	
Caregiving time		
8-23 months	59.99 (9.88)	0.002**
24 months and above	64.42 (10.78)	
Disease stage of the patient		
stage 1	54.86 (9.46)	0.003**
stage 2	60.90 (10.86)	
stage 3	67.97 (10.45)	

\*p&lt;0,05, \*\*p&lt;0,01 \*\*\*Standart deviation

**Table 4: The Effect of caregivers' stress, life satisfaction and quality of life sub-dimensions on caregiver burden**

Determinants	$\beta$	t	P	Collinearity	
				Tolerance	VIF
Caregiver Stress Level	0.623	2.519	0.000*	0.238	3.662
Level of Satisfaction with Life	-0.412	2.712	0.000*	0.492	2.428
Physical Sub-Dimension of Life Quality	-0.506	1.028	0.000*	0.619	5.231
Mental Sub-Dimension of Life Quality	-0.389	3.629	0.000*	0.527	2.708
		R <sup>2</sup> =0.672	Adjusted R <sup>2</sup> = 0.873	F=6291.182	p<0.000*

\*p<0,001

the caregiver increase the burden of providing care. With increasing age, the prevalence of chronic diseases is also rising. Similarly, in the present study, it was determined that the burden of care increases with increasing age. The studies conducted on the subject also support the current research finding in this aspect.<sup>15,16</sup>

Another factor that increases the burden of care is the duration of providing care to the

patient. In the present study, it was determined that the longer the care period (in months), the higher the care burden. The findings of the studies conducted on the subject support the current research finding in this aspect.<sup>8,28,30</sup> Other factors affecting the care burden include the educational status of the caregiver and the perceived income adequacy. The current study results indicated that caregivers with a high level of education

**Table 5: Determining factors for caregiving burden of caregivers**

Determinants	$\beta$	t	P	Collinearity	
				Tolerance	VIF
Age (1=65 years and over)	0.648	1.035	0.000*	0.482	1.773
Caregiving duration (1=24 months and above)	0.429	2.938	0.000*	0.297	1.082
Gender (1=female)	0.672	3.904	0.000*	0.442	2.943
Marital status (1=married)	0.936	3.257	0.000*	0.754	1.035
Education status (1=high school graduate and above)	0.863	0.583	0.000*	0.721	0.833
Affinity with the patient (1=daughter)	0.734	1.702	0.000*	0.834	1.773
Working status (1=Working)	0.524	1,834	0.000*	0.348	0.438
Perceived income adequacy (1=poor)	0.926	4.488	0.000*	0.045	0.582
Perceived health status (1=poor)	0.682	1.356	0.000*	0.823	1.734
Presence of chronic disease (1=yes)	0.529	3.043	0.000*	0.562	1.024
Caregiver's Strain Index Total Score (Continuous)	0.633	0.951	0.000*	0.939	0.664
Total Score of the Satisfaction with Life Scale (Continuous)	-0.775	2.475	0.000*	0.801	0.457
Physical Subscale Score of Quality of Life (Continuous)	-0.824	1.045	0.000*	0.723	0.927
Mental Subscale Score of Quality of Life (Continuous)	-0.489	2.931	0.000*	0.589	0.926
		R <sup>2</sup> =0.883	Adjusted R <sup>2</sup> = 0.764	F=7445.223	p<0.000*

\*p<0.001

and income adequacy perceived as good have lower care burden levels. This can be explained by the fact that caregivers with a higher level of education have improved more effective skills cope with care problems as well as their own stress. Other studies on the subject have shown similar results to current study results.<sup>8,28</sup> Balbim *et al.* (2020) reported that the economic situation is effective in the care burden.<sup>33</sup> It is stated that low-income caregivers perceive more distress than high-income caregivers.<sup>34</sup> In line with these results, the disadvantage of the caregiver in terms of individual and health characteristics negatively affects the care burden.<sup>30,33,34</sup>

Another factor that causes a sense of increased burden is the stage of Alzheimer's disease. In the present study, it was determined that the caregiver burden increases as the disease stage progress, and the patient's stage is an important determinant of the care burden. The burden of care continues to increase at each stage of the disease. With progressive Alzheimer's disease, there is an increase in difficulty performing daily life activities, an increase in psychiatric symptoms, so various behavioral symptoms also occur.<sup>34</sup> The increase in these symptoms also increases the caregiver burden, and it is reported to exert an intermediary influence on the care burden for the Alzheimer patient's behavioral and psychological symptoms.<sup>27,35</sup> In another study, the patient's behavioral problems that the caregiver has were reported as important individual variable of the caregiving burden.<sup>8</sup> In this context, the stage of the disease and the presence of behavioral and psychological symptoms of the disease may worsen the caregiver's burden.<sup>27,34,36</sup>

Other factors that affect the care burden are care stress, life satisfaction, and quality of life. In the present study, it was seen that these variables account for 87.3% of the variation in the care burden. It was found that these variables, together with socio-demographic and health characteristics, account for 76.4% of the variation in the care burden. The level of caregiver stress and the care burden were found to have a positive relationship in this study. The caregiver's stress level rises as the care burden rises. A study found that as the caregiver's burden increases, the stress level also increases.<sup>30</sup> Monteiro *et al.* (2018) reported that the use of emotion-focused coping strategies, religion and spirituality-related strategies, and methods of effective coping with stress in caregivers can be effective in reducing the care burden.<sup>2</sup> In line with these results, improving effective coping skills in caregivers can reduce the level of stress in the

care provider as well as reduce the caregiving burden.<sup>11,12</sup>

The care burden of caregivers negatively affects their life satisfaction and quality of life.<sup>4,16</sup> In the present study, it was found that there is a negative and significant relationship between the care burden and the physical and mental sub-dimensions of life quality and life satisfaction. In line with the present study findings, it has been stated that the caregiving burden has a negative relationship with the physical, psychological, social, and environmental sub-dimensions of quality of life.<sup>37</sup> It can be said that the quality of life has an effect on the care burden of the caregiver. In studies related to the subject, it has also been reported that the poor functional status of caregivers causes low life satisfaction and increases the care burden.<sup>15,16</sup> Khusaifan & El Keshky (2017) stated that informal social support in caring for Alzheimer's patients may play a role as an intermediary variable in the relationship between depression and life satisfaction.<sup>10</sup> As the severity of Alzheimer's disease increases, it may become harder for caregivers to cope, and caregivers may feel exhausted and worn out. This situation may negatively affect the caregiver's quality of life and life satisfaction with the increased care burden.<sup>10,32</sup>

The current study has some limitations that may restrict the validity of the findings. One of the study's limitations is that it only included caregivers of Alzheimer's patients who registered with a family health center. As a result, the findings cannot be applied to other caregivers of Alzheimer's disease patients. The second limitation of the study is that only primary caregivers were included in this study. This study was not specifically designed to compare Caregiver Stress, Life Satisfaction and Life Quality Levels of primary and non-primary caregivers. The third limitation of the study is that the patients included in the study resided in a wide area and each of the patients received their Alzheimer's disease diagnosis from different hospitals. For this reason, detailed information about the patients' Alzheimer's disease diagnostic criteria (such as, NIA-AA, DSM) is not included. Additionally, biomarkers were not used to diagnose Alzheimer's disease in the patient receiving care. Because there are many subtypes of dementia and each has different symptoms, it may lead to different burden to caregiver. For this reason, it is recommended to provide detailed information about the Alzheimer's disease diagnostic criteria of the patient being cared for future studies. The



fourth limitation of the study is that the stage of Alzheimer's disease was determined based on the information the caregiver received from the neurologist during the patient's previous examination. It is recommended to use rating scales to determine the stage of Alzheimer's disease in future studies.

In conclusion, the caregivers' care burden was determined to be moderate. Care stress, life satisfaction, quality of life, and sociodemographic and health characteristics of caregivers were determined to have an effect on the care burden. Those aged 65 and over, high school graduate and above, caregivers being the patient's daughter, those with poor perceived income, those with poor perceived health, those with any chronic disease, those with a caregiving period of 24 months and above, caregivers of the patients with the 3rd level of the disease had higher caring burden. In line with these results, appropriate support and services are needed to reduce the caring burden of caregivers. It is thought that receiving the support of official institutions in patient care and providing patient care at certain times during the day will reduce the burden of the caregiver. In the first step health care services, in addition to the follow-up of patients, caregivers should be followed up.

## ACKNOWLEDGMENTS

We would like to thank all the participants.

## DISCLOSURE

Financial support: None

Conflict of interest: None

## REFERENCES

1. Abreu W, Tolson D, Jackson GA, Costa N. A cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia. *Dementia* 2020;19(2):301-18. doi:10.1177/1471301218773842
2. Monteiro AMF, Santos RL, Kimura N, Baptista MAT, Dourado MCN. Coping strategies among caregivers of people with Alzheimer disease: a systematic review. *Trends Psychiatry Psychother* 2018;40(3):258-68. doi:10.1590/2237-6089-2017-0065
3. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA* 2014; 311(10):1052-60. <https://doi.org/10.1001/jama.2014.30>
4. Farina N, Page TE, Daley S, et al. Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimers Dement* 2017; 13(5):572-81. doi:10.1016/j.jalz.2016.12.010.
5. Cross AJ, Garip G, Sheffield D. The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychol Health* 2018; 33(11):1321-42. doi:10.1080/08870446.2018.1496250.
6. Hellis E, Mukaetova-Ladinska EB. Informal caregiving and Alzheimer's Disease: the psychological effect. *Medicina* 2023;59(1):48. doi:10.3390/medicina59010048
7. Bozgeyik G, Ipekcioglu D, Yazar MS, Ilnem MC. Behavioural and psychological symptoms of Alzheimer's disease associated with caregiver burden and depression. *Psychiatry Clin Psychopharmacol* 2019; 29(4):656-64.
8. Park M, Sung M, Kim SK, Kim S, Lee DY. Multidimensional determinants of family caregiver burden in Alzheimer's disease. *Int Psychogeriatr* 2015;27(8):1355-64. doi:10.1017/S1041610215000460
9. Yu H, Wang X, He R, Liang R, Zhou L. Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. *PLoS One* 2015; 10(7):e0132168. doi:10.1371/journal.pone.0132168
10. Khusaifan SJ, El Keshky ME. Social support as a mediator variable of the relationship between depression and life satisfaction in a sample of Saudi caregivers of patients with Alzheimer's disease. *Int Psychogeriatr* 2017;29(2):23948. doi:10.1017/S1041610216001824
11. Fernández-Calvo B, Castillo IC, Campos FR, Silva JCD, Torro-Alves N. Resilience in caregivers of persons with Alzheimer's disease: A human condition to overcome caregiver vulnerability. *Estudos de Psicologia (Natal)* 2016;21:125-33.
12. Teahan A, Lafferty A, McAuliffe E, et al. Resilience in family caregiving for people with dementia: A systematic review. *Int J Geriatr Psychiatry* 2018;33(12):1582-95. doi:10.1002/gps.4972
13. Domingues NS, Verreault P, Hudon C. Reducing burden for caregivers of older adults with mild cognitive impairment: a systematic review. *Am J Alzheimers Dis Other Demen* 2018; 33(7):401-14. doi:10.1177/1533317518788151
14. Lee M, Ryoo JH, Crowder J, Byon HD, Williams IC. A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. *J Adv Nurs* 2020;76(2):475-89. doi:10.1111/jan.14262.
15. Liu S, Li C, Shi Z, et al. Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *J Clin Nurs* 2017;26(9-10):1291-300. doi:10.1111/jocn.13601
16. Pudelewicz A, Talaraska D, Bączyk G. Burden of caregivers of patients with Alzheimer's disease. *Scand J Caring Sci* 2019;33(2):336-41. doi:10.1111/scs.12626
17. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649-55. doi:10.1093/geront/20.6.649

18. Zarit SH, Zarit JM. The memory and behavior problems checklist and the Burden Interview. University Park, PA: Pennsylvania State University Gerontology Center,1990.
19. İnci FH, Erdem M. Validity and reliability of the burden interview and its adaptation to Turkish. *J Anatolia Nursing Health Sci* 2008;11(4): 85-95.
20. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983;38(3): 344-8. doi:10.1093/geronj/38.3.344
21. Ugur O, Fadiloğlu C. "Caregiver Strain Index" validity and reliability in Turkish society. *Asian Pac J Cancer Prev* 2010;11(6):1669-75.
22. Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. *J Pers Assess* 1985;49(1):71-5. doi:10.1207/s15327752jpa4901\_13
23. Dağlı A, Baysal N. Adaptation of the satisfaction with life scale into turkish: the study of validity and reliability. *Electronic J Social Sci* 2016;15(9):1250-62. doi:10.17755/esosder.75955
24. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30(6): 473-83.
25. Koçyiğit H, Aydemir Ö, Fişek G, Ölmez N, Memiş A. Form-36 (KF-36)'nın Türkçe versiyonunun güvenilirliği ve geçerliliği. *İlaç ve Tedavi Dergisi* 1999;12:102-6. (in Turkish).
26. Ghezalje TN, Rafii F, Ladani FK. The caregiver burden of Alzheimer's patients: an evolutionary concept analysis. *Revista Latinoamericana de Hipertensión* 2020;15(1):36-43.
27. Kim B, Noh GO, Kim K. Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. *BMC Geriatr* 2021;21(1): 160. doi:10.1186/s12877-021-02109-w
28. Zhang M, Chang YP, Liu YJ, Gao L, Porock D. Burden and Strain among Familial Caregivers of Patients with Dementia in China. *Issues Ment Health Nurs* 2018;39(5): 427-32. doi:10.1080/01612840.2017.1418034
29. Hernández-Padilla JM, Ruiz-Fernández MD, Granero-Molina J, Ortíz-Amo R, López Rodríguez MM, Fernández-Sola C. Perceived health, caregiver overburden and perceived social support in family caregivers of patients with Alzheimer's: Gender differences. *Health Soc Care Community* 2021;29(4):1001-9. doi:10.1111/hsc.13134
30. García-Mochón L, Peña-Longobardo LM, Del Río-Lozano M, Oliva-Moreno J, Larrañaga-Padilla I, García-Calvente MDM. Determinants of burden and satisfaction in informal caregivers: Two sides of the same coin? The CUIDAR-SE Study. *Int J Environ Res Public Health* 2019;16(22):4378. doi:10.3390/ijerph16224378
31. Meyer J, Mc Cullough J, Berggren I. A. A phenomenological study of living with a partner affected with dementia. *Br J Community Nurs* 2016;21(1):24-30. doi:10.12968/bjcn.2016.21.1.24
32. Tulek Z, Baykal D, Erturk S, Bilgic B, Hanagasi H, Gurvit IH. Caregiver burden, quality of life and related factors in family caregivers of dementia patients in Turkey. *Issues Ment Health Nurs* 2020;41(8):741-9. doi:10.1080/01612840.2019.1705945
33. Balbim GM, Magallanes M, Marques IG, et al. Sources of caregiving burden in middle-aged and older Latino caregivers. *J Geriatr Psychiatry Neurol* 2020;33(4):185-94. doi:10.1177/0891988719874119
34. Tsai CF, Hwang WS, Lee JJ, et al. Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatr* 2021;21:1-9. doi:10.1186/s12877-021-02007-1
35. Isik AT, Soysal P, Solmi M, Veronese N. Bidirectional relationship between caregiver burden and neuropsychiatric symptoms in patients with Alzheimer's disease: A narrative review. *Int J Geriatr Psychiatry* 2019;34(9):1326-34. doi:10.1002/gps.4965
36. Schumann C, Alexopoulos P, Perneckzy R. Determinants of self- and carer-rated quality of life and caregiver burden in Alzheimer disease. *Int J Geriatr Psychiatry* 2019;34(10):1378-85. doi:10.1002/gps.5126
37. Dawood S. Caregiver Burden, quality of life and vulnerability towards psychopathology in caregivers of patients with dementia/Alzheimer's disease. *J Coll Physicians Surg Pak* 2016;26(11): 892-5.