

## An Investigation of Caregiver Burden and Quality of Life Among Individuals Providing Care to Patients with Alzheimer's Disease\*

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### Abstract

**Aim:** This study aimed to determine the levels of caregiver burden and quality of life among individuals providing care for patients with Alzheimer's disease and to examine the relationship between these two variables.

**Method:** This descriptive and correlational study was conducted between May 2024 and February 2025, starting at the neurology outpatient clinic of a private hospital located in the Black Sea Region and completed with 191 participants through snowball sampling. Participants were administered a sociodemographic information form, the Caregiver Burden Scale, and the Quality of Life in Alzheimer's Disease Scale. In addition to descriptive statistics, t-test, ANOVA, and Pearson correlation analysis were used for data analysis.

**Results:** Most participants were women, employed, and university graduates. Caregiver burden levels were found to be moderate, whereas quality of life levels were found to be relatively low. Differences in caregiver burden and quality of life levels were identified according to age and income levels. In addition, a significant negative relationship between caregiver burden and quality of life was identified.

**Conclusion:** The findings indicate that the quality of life of individuals caring for patients with Alzheimer's disease is significantly affected by their perceived caregiver burden. It is essential that nurses holistically assess the needs of caregivers, develop individualized care strategies, and expand access to support services to improve caregiver well-being.

**Keywords:** Alzheimer's disease, caregiver burden, quality of life, nursing.

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*ETHICAL STATEMENT: This study was approved by the Ethics Committee of Istanbul Arel University on 5 April 2024 with decision number 2024/08.*

## Alzheimer Hastalarına Bakım Veren Bireylerde Bakım Yüğü ve Yaşam Kalitesinin İncelenmesi

### Öz

**Amaç:** Bu çalışma, Alzheimer hastalarına bakım sağlayan bireylerin bakım yüğü ve yaşam kalitesi düzeylerini belirlemek ve aralarındaki ilişkiyi değerlendirmek amacıyla gerçekleştirilmiştir.

**Yöntem:** Tanımlayıcı ve ilişki arayıcı türde planlanan bu araştırma, Mayıs 2024–Şubat 2025 tarihleri arasında Karadeniz Bölgesi'nde yer alan özel bir hastanenin nöroloji polikliniğinde başlayarak Kartopu örnekleme yöntemiyle 191 katılımcıya ulaşıldı. Katılımcılara, sosyo-demografik bilgi formu, Bakım Verme Yük Ölçeği ve Alzheimer Hastalığında Yaşam Kalitesi Ölçeği uygulanmıştır. Verilerin analizinde tanımlayıcı istatistiklere ek olarak t-testi, ANOVA ve Pearson korelasyon analizi kullanıldı.

**Bulgular:** Katılımcıların çoğu kadın, çalışan ve üniversite mezunudur. Bakım veren yüğü düzeylerinin orta düzeyde olduğu, yaşam kalitesi düzeylerinin ise görece düşük olduğu belirlendi. Bakım veren yüğü ve yaşam kalitesi düzeylerinin yaş ve gelir düzeyine göre farklılık gösterdiği saptandı. Ayrıca, bakım veren yüğü ile yaşam kalitesi arasında anlamlı ve negatif yönlü bir ilişki olduğu belirlendi.

**Sonuç:** Araştırma bulguları, Alzheimer hastalarına bakım sunan bireylerin yaşam kalitelerinin, algıladıkları bakım yükünden önemli ölçüde etkilendiğini göstermektedir. Hemşirelerin bu bireyleri çok boyutlu değerlendirmesi, bireyselleştirilmiş müdahaleler planlaması ve destekleyici hizmetleri yaygınlaştırması önerilmektedir.

**Anahtar Sözcükler:** Alzheimer hastalığı, bakım yüğü, yaşam kalitesi, hemşirelik.

### Introduction

Alzheimer's disease (AD) is a progressive neurodegenerative disorder, predominantly observed in older adults, that leads to cognitive and functional decline<sup>1</sup>. These impairments affect not only the individual with the disease but also significantly impact their caregivers<sup>2</sup>. As the disease advances, patients lose the ability to perform daily living activities, resulting in an increasingly demanding caregiving process, typically undertaken by family members<sup>3</sup>.

Caregiving encompasses not only physical responsibilities but also psychological, social, and economic burdens<sup>1</sup>. This multidimensional strain, defined as the "caregiver burden" can negatively affect the caregiver's quality of life<sup>4</sup>. Various demographic variables such as age, gender, income level, and the caregiver's relationship with the patient may influence both the degree of burden and the caregiver's overall well-being<sup>5</sup>. Research has shown that as caregiver burden increases, quality of life decreases, and issues such as depression, anxiety, and social isolation become more prevalent<sup>6-9</sup>. Recent studies have consistently demonstrated that this negative association between caregiver burden and quality of life is observed across different stages of Alzheimer's disease and is accompanied by increased psychological distress among caregivers<sup>8,9</sup>.

Quality of life, which has been conceptually defined and measured among caregivers in previous studies<sup>10</sup>, is a multidimensional concept that includes physical, psychological,

and social domains<sup>1,10</sup>. The literature indicates that the presence of social support, educational interventions for caregivers, and technology-based tools such as mobile health applications are effective in reducing caregiver burden and enhancing quality of life<sup>11-13</sup>. Recent evidence further suggests that educational and psychosocial support interventions enhance caregivers' coping capacity, while technology-based tools facilitate access to information, emotional support, and continuity of care<sup>11,12</sup>.

Although numerous studies have explored caregiver burden and quality of life among caregivers of individuals with Alzheimer's disease<sup>14</sup>, many of these studies focus more broadly on the general dementia population<sup>4,6,14</sup>. They often fail to sufficiently address the unique experiences of Alzheimer's caregivers or to examine in depth the relationships between key variables<sup>14</sup>. Moreover, sociodemographic characteristics are frequently evaluated in a limited manner, overlooking the complex dynamics that influence the caregiving process. This study aims to evaluate the relationship between caregiver burden and quality of life among individuals caring for patients with Alzheimer's disease in Türkiye and to examine how this relationship varies according to key sociodemographic factors, including age, income level, social security status, gender, and educational level<sup>15,16</sup>. By focusing on an Alzheimer's-specific caregiver population within the Turkish context, where caregiving responsibilities are predominantly assumed by family members, this study seeks to provide a more comprehensive understanding of caregiving dynamics and to inform culturally appropriate nursing and public health interventions<sup>16,17</sup>.

## **Material and Methods**

### ***Study Design***

This study was designed as a descriptive and correlational study to determine the relationship between caregiver burden and quality of life among individuals providing care to patients with Alzheimer's disease.

### ***Population and Sample***

The research was conducted between March 2024 and February 2025 with caregivers of patients diagnosed with Alzheimer's disease who were admitted to the neurology department of a private hospital located in the Black Sea Region of Türkiye. Using the snowball sampling method, individuals with similar caregiving characteristics were subsequently included. The study was completed with a total of 191 participants.

The sample size power analysis was calculated using the G Power 3.1.9.2 software. To examine the difference between two dependent means, the point-biserial correlation model (Correlation: Point-Biserial) was employed, and standardized direct effect sizes were taken into account. At a 95% confidence level, with a calculated effect size of 0.324 and a sample size of  $N = 191$ , the statistical power of the study was found to be 0.998. This result indicates that the study has a high level of statistical power and that the sample size is sufficient.

### ***Inclusion Criteria***

- No communication barriers.
- Being 18 years of age or older.
- Currently providing care for an individual diagnosed with Alzheimer's disease.

### ***Data Collection Tools***

Three instruments were used for data collection.

Firstly, a sociodemographic data form consisting of 10 items such as age, gender, and social security status was developed by the researcher to describe the characteristics of the participants.

The Zarit Burden Interview (ZBI)<sup>18</sup>, originally developed by Zarit et al.<sup>18</sup> and adapted to Turkish by İnci and Erdem (2008)<sup>17</sup>, was used to measure caregiver burden. It consists of 22 items in a Likert-type format. In this study, the Cronbach's alpha coefficient of the scale was found to be 0.91.

The Quality of Life in Alzheimer's Disease Scale (QOL-AD), developed by Gibbons et al.<sup>19</sup> and adapted to Turkish by Akpınar Söylemez and Küçükgüçlü (2012)<sup>7</sup>, was used to assess the quality of life. This scale contains 13 items and is rated on a 4-point Likert scale. In the present study, the Cronbach's alpha coefficient was calculated as 0.88.

### ***Ethical Statement***

Prior to the commencement of the study, ethical approval was obtained from the Ethics Committee of Istanbul Arel University on April 5, 2024, with protocol number 2024-08. Before administering the data collection forms, participants were informed about the purpose of the study and their right to withdraw from the research at any time without providing a reason. Completion of the forms by the participants was considered an indication of their voluntary consent to participate in the study.

### ***Data Analysis***

The data were analyzed using IBM SPSS Statistics version 26.0. Descriptive statistics were used to summarize the data, with categorical variables presented as frequencies and percentages, and continuous variables expressed as means and standard deviations. The normality of continuous variables was assessed using skewness and kurtosis values, and the data were found to be normally distributed. Accordingly, parametric tests were applied. Independent samples t-tests were used to compare scale scores across binary variables, while one-way analysis of variance (ANOVA) was conducted for variables with more than two categories. Post hoc analyses were performed using the Tukey or Games-Howell tests, as appropriate. Pearson correlation analysis was used to examine the relationship between caregiver burden and quality of life. In addition, simple linear

regression analysis was conducted to evaluate the effect of caregiver burden on quality of life among caregivers of patients with Alzheimer's disease. The assumptions of linearity and normal distribution of residuals were assessed using histogram and Q-Q plot analyses. Statistical significance was set at  $p < .05$ .

## Results

A total of 191 caregivers of patients with Alzheimer's disease were included in the study. Participants were predominantly female, had a relatively high educational level, and were actively employed. The distribution of participants according to age groups, income levels, educational status, and caregiving relationship categories indicated a heterogeneous caregiver sample (Table 1).

**Table 1.** Sociodemographic characteristics of individuals providing care for patients with Alzheimer's disease (n=191)

Variables	Mean±SD	Min–Max
Age (Years)	33.72±11.62	18–82
<b>Variables and Subgroups</b>	<b>Number (n)</b>	<b>Percent (%)</b>
<b>Age</b>		
18–25 years	37	19.4
26–35 years	94	49.2
36–45 years	28	14.7
46 years and older	32	16.8
<b>Gender</b>		
Female	130	68.1
Male	61	31.9
<b>Marital Status</b>		
Married	92	48.2
Single	99	51.8
<b>Education Level</b>		
High school or below	52	27.2
University degree or above	139	72.8
<b>Employment Status</b>		
Employed	149	78.0
Unemployed	42	22.0
<b>Occupation</b>		
Civil servant	52	27.2
Worker	79	41.4
Retired or housewife	16	8.4
Self-employed/tradesperson	27	14.1
Not working	17	8.9

<b>Health Insurance</b>		
Present	176	92.1
Absent	15	7.9
<b>Income Level</b>		
Able to meet expenses, lives comfortably	81	42.4
Able to meet expenses, manages with difficulty	93	48.7
Unable to meet expenses, experiences hardship	17	8.9
<b>Relationship to the Patient</b>		
Spouse or child	21	11.0
Parent	21	11.0
Relative	125	65.4
Professional caregiver	24	12.6

*Frequency Analysis and Descriptive Statistical Findings*

**Mean:** Average; **SD:** Standard deviation; **Min:** Minimum; **Max:** Maximum

Caregiver burden scores differed significantly according to age and income level. Post hoc analyses showed that caregivers aged 46 years and older and those with lower income levels reported higher caregiver burden scores. No significant differences were observed for caregiver burden in relation to other sociodemographic variables. Regarding quality of life, income level was the only variable that demonstrated a statistically significant association, whereas differences according to education level, employment status, and social security coverage were not statistically significant (Table 2).

**Table 2.** Comparison of scale scores according to the socio-demographic characteristics of individuals providing care to patients with Alzheimer's disease (n = 191)

Variable	Caregiver Burden Mean				Post Hoc	QoL Mean			Post Hoc
	n	Mean±SD	Test	p	Tukey/ Games Howell	Mean±SD	Test	p	Tukey/ Games Howell
<b>Gender</b>									
Female	130	37.4±14.35	t=0.824	.411	-	27.6±5.27	t=1.105	.271	-
Male	61	35.5±16.92				28.7±8.53			
<b>Age (Years)</b>									
18–25 (A)	37	33.3±14.85	<b>F=3.016</b>	<b>.031</b>	<b>D &gt; A;</b> <b>p=.024</b>	28.4±7.03	F=0.217	.884	-
26–35 (B)	94	36.1±15.20				28.0±6.96			
36–45 (C)	28	36.0±11.19				27.8±5.04			
46 years and older (D)	32	43.7±17.08				27.2±5.67			
<b>Marital Status</b>									
Married	92	38.6±14.56	t=1.524	.129	-	27.0±6.00	t=1.859	.065	-
Single	99	35.2±15.67				28.8±6.83			
<b>Education Level</b>									

High school or below	52	33.7±14.70	t=1.767	.079		29.3±7.30	t=1.752	.081	-
University or above	139	38.0±15.26				27.4±6.11			
<b>Employment Status</b>									
Employed	149	37.0±15.63	t=0.309	.757	-	27.6±6.40	t=1.264	.208	-
Unemployed	42	36.2±13.69				29.0±6.74			
<b>Occupation</b>									
Civil servant	52	39.6±16.13	F=1.011	.403	-	27.0±6.13	F=0.821	.514	-
Worker	79	36.0±14.67				28.0±6.43			
Retired or housewife	16	39.7±13.81				29.2±7.50			
Self-employed / tradesperson	27	33.5±17.15				29.4±7.44			
Not working	17	35.0±12.21				27.3±5.19			
<b>Health Insurance</b>									
Present	176	36.8±15.58	t=0.239	.812	-	27.7±6.46	t=1.330	.185	-
Absent	15	37.7±9.90				30.1±6.66			
<b>Income Level</b>									
High(E)	81	33.5±15.21	F=4.815	.009	<b>H &gt; E;</b> <b>p=0.015</b>	29.3±7.01	F=3.577	.030	<b>E &gt; G;</b> <b>p=0.022</b>
Moderate(G)	93	38.3±15.19				26.7±5.76			
Low(H)	17	44.7±11.17				28.2±6.69			
<b>Relationship to the Patient</b>									
Spouse or child	21	39.5±17.63	F=1.233	.299	-	27.5±4.39	F=0.730	.535	-
Parent	21	40.4±16.69				29.0±8.29			
Relative	125	36.6±14.92				27.5±6.61			
Professional caregiver	24	32.6±12.60				29.3±5.62			

**N:** Number of participants; **Mean:** Average; **SD:** Standard deviation; **A, B, C, D :** Group difference indicators; **Post Hoc:** Inter-group differences based on Tukey or Games–Howell method; **QoL:** Quality of Life; **A:** 18–25 years; **B:** 26–35 years; **C:** 36–45 years; **D:** ≥46 years; **E:** High; **F:** One-way ANOVA test; **G:** Moderate; **H:** Low; **t:** Independent Samples T test.

The mean, median, and interquartile range values of the caregiver burden and quality of life scales were calculated. Caregiver burden levels were found to be moderate, while quality of life levels were identified as moderate to low among the participants (Table 3).

**Table 3.** Levels of caregiver burden and quality of life among individuals providing care to patients with Alzheimer's disease

Scale	Observed Min-Max Values	Mean±SD	Median (IQR)
Caregiver Burden Scale	0.00–88.00	36.83±15.20	37 (20)
Quality of Life in Alzheimer's Disease Scale	13.00–51.00	27.93±6.49	27 (8)

*Descriptive Statistical Analysis*

**Mean:** Average; **SD:** Standard deviation; **Min:** Minimum value; **Max:** Maximum value; **Median (IQR):** Interquartile range.

A moderate, statistically significant negative correlation was found between caregiver burden and quality of life scores ( $r = -0.324$ ,  $p < .01$ ) (Table 4).

**Table 4.** Relationship between caregiver burden and quality of life among individuals providing care to patients with Alzheimer's disease

Variables	Correlation Coefficient (r)	(1)	(2)
(1) Caregiver Burden Scale	r	1	
	p		
(2) Quality of Life in Alzheimer's Disease Scale	r	-0.324**	1
	p		

*Pearson Correlation Analysis*

\* $p < .05$ ; \*\* $p < .01$ ; **r:** Pearson correlation coefficient.

Simple linear regression analysis showed that caregiver burden was a significant predictor of quality of life among caregivers of patients with Alzheimer's disease. Higher caregiver burden scores were associated with lower quality of life scores. The model explained 10.5% of the variance in quality of life (Adj.  $R^2 = 0.105$ ) (Table 5).

**Table 5.** The effect of caregiver burden on quality of life among individuals providing care for patients with Alzheimer's Disease

Variable	B	SE	$\beta$	t	p	95% CI	
						Upper	Lower
Alzheimer's Disease Quality of Life Scale (Constant)	33.020	1.170		28.213	0.000	35.328	30.711
Caregiver Burden Scale	-0.138	0.029	-0.324	-4.701	0.000	-0.080	-0.196

$R = 0,324$ , Adj.  $R^2 = 0,105$ ,  $F(1,189) = 22,098$ ,  $p = 0,000$ ,  $p < 0,001$  **SE:** Standard error,  **$\beta$ :** standardized regression coefficient, **CI:** Confidence Interval.

## Discussion

Caregivers of individuals with Alzheimer's disease experience considerable physical, emotional, and social burden, which has important implications not only at the individual level but also for public health<sup>1,3,4,14</sup>. Previous studies have consistently shown that caregivers of patients with Alzheimer's disease commonly experience moderate levels of burden accompanied by limitations in quality of life. These findings are consistent with the results of the present study, in which caregivers reported moderate caregiver burden and moderate-to-low quality of life. A significant negative relationship was identified between caregiver burden and quality of life, indicating that increasing caregiving demands are associated with decreased well-being<sup>4,14,20</sup>. This relationship may be explained by the cumulative physical strain and persistent psychological stress associated with long-term caregiving<sup>1,3,18</sup>. Caregivers experiencing higher burden often report emotional exhaustion, depressive symptoms, and reduced life satisfaction, which further compromise their quality of life<sup>5,8,9</sup>. Although caregiver burden explained a modest proportion of the variance in quality of life, this finding is consistent with the multifactorial nature of quality of life in caregivers of patients with Alzheimer's disease<sup>1,3,14</sup>. The adjusted R<sup>2</sup> value indicates that caregiver burden represents a significant, yet not exclusive, determinant of quality of life, suggesting that additional psychological, social, and environmental factors also contribute to caregivers' well-being<sup>4,20,21</sup>. This result supports the need for comprehensive, multidimensional nursing interventions rather than approaches targeting a single factor<sup>12,13</sup>. Age emerged as a significant factor influencing caregiver burden, with higher burden observed among caregivers aged 46 years and older<sup>20,21</sup>. Advancing age may be associated with declining physical capacity, increased health problems, and prolonged exposure to caregiving responsibilities, all of which may intensify perceived burden<sup>1,3,18</sup>. These findings highlight the need for age-sensitive support strategies for older caregivers<sup>12,13,16</sup>. Income level was another important determinant of caregiver burden and quality of life<sup>14</sup>. Caregivers with lower income levels reported higher burden and poorer quality of life<sup>15,16,22</sup>. Financial difficulties may exacerbate caregiving stress by limiting access to formal care services, respite care, and supportive resources<sup>3,13,22</sup>, thereby increasing both objective and perceived caregiving demands<sup>14</sup>. Although female caregivers reported higher caregiver burden scores than males, the difference was not statistically significant<sup>15,16</sup>. Nevertheless, existing evidence suggests that women often assume greater caregiving responsibilities due to traditional social roles, which may increase emotional strain and stress levels<sup>6,7,23</sup>. These findings underscore the importance of considering gender-related factors when designing caregiver support interventions<sup>12,13,24</sup>. Social support plays a crucial protective role in the caregiving process<sup>1,14</sup>. Caregivers who perceive adequate social support tend to experience lower levels of burden and better quality of life<sup>13,20,25</sup>. In addition, educational and psychosocial interventions can strengthen caregivers' coping abilities and resilience<sup>3,12</sup>. Recent advances in technology-based interventions, including mobile health applications and online counseling services, offer promising opportunities to reduce caregiver burden and enhance psychosocial well-being<sup>11,24</sup>. From a nursing perspective, these findings emphasize the importance of a holistic and caregiver-centered approach in Alzheimer's disease care<sup>1,3</sup>. Nurses are in a

key position to assess caregivers' physical, psychological, and social needs, identify high-risk groups, and facilitate access to appropriate support services<sup>3,12,13</sup>. Integrating psychosocial support, caregiver education, and digital health tools into nursing practice may contribute to reducing caregiver burden and improving quality of life<sup>11,12,24</sup>. One limitation of this study is the use of snowball sampling, which may limit the generalizability of the findings. However, this approach was considered appropriate due to the difficulty in accessing caregivers of patients with Alzheimer's disease<sup>1,3,14</sup>. Moreover, post hoc power analysis supported the adequacy of the sample size, indicating sufficient statistical power to detect the observed relationships.

## **Conclusion and Recommendations**

This study demonstrated that caregiver burden is a key determinant of quality of life among individuals caring for patients with Alzheimer's disease. By focusing specifically on an Alzheimer's disease caregiver population, the findings emphasize that caregiver burden should be addressed as a core component of dementia care and public health strategies, rather than as a secondary outcome.

From a nursing perspective, these findings highlight the necessity of extending care beyond a patient-centered approach to a comprehensive, caregiver-centered model. Nurses play a critical role in the early identification of caregivers at risk and in the systematic assessment of caregivers' physical, psychological, and social needs. Nurse-led psychosocial support, counseling, and referral services are particularly essential for caregivers who are vulnerable due to advanced age, limited economic resources, or prolonged caregiving responsibilities associated with the progressive nature of Alzheimer's disease.

Community-based and home care nursing practices may facilitate continuity of care and strengthen communication with caregivers throughout the disease trajectory. In addition, integrating digital health technologies into nursing practice and guiding caregivers toward technology-based support systems may contribute to reducing caregiver burden and improving quality of life. Incorporating Alzheimer's disease-specific caregiver support content into nursing education programs may further enhance nurses' capacity to support this population.

In conclusion, recognizing caregivers of patients with Alzheimer's disease as a priority group for nursing interventions is essential for improving caregiver well-being and sustaining long-term care. Future research should focus on developing and evaluating nursing-based intervention models tailored to Alzheimer's disease and examining their applicability across different care settings and regional contexts.

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