

# Evaluation of Caregiver Burden in Patients with Alzheimer's Disease

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## ABSTRACT

**Objective:** This descriptive study was carried out to evaluate the caregiver burden of disease in patients with Alzheimer's disease (pwAD).

**Materials and Methods:** The research was carried out with 30 Alzheimer patients and caregivers followed in the neurology outpatient clinic of a university hospital between July 2021 and September 2021. Alzheimer patient's research data were collected with Patient information form, Neuropsychiatric Inventory, Clinical Dementia Rating Scale, The Physical Self-Maintenance Scale and Activities of Daily Living Scale. Caregivers applied the Caregiver information form, Beck Depression Scale, Beck Anxiety Scale, and Caregiver Burden Scale. Data analyses were done with the SPSS 18.0 computer program.

**Results:** The mean age of Alzheimer's patients was 76.54±7.79 years, 50% were women and the mean year of diagnosis was 2.38±1.98. The mean age of caregivers was 56.50±17.89, 83.3% were women, 83.3% were married and 66.3% were housewives. It was found that the burden of caregiving increased as the patients' behavioral problems, forgetfulness levels, disease stage and dependency level in daily living activities increased ( $p < 0.01$ ).

**Conclusion:** The burden of care in Alzheimer's disease is positively related to the dependence of the patient on the caregiver and higher care burden increases the level of anxiety and depression in caregivers. Therefore, caregivers of AD patients need education and social support to ease the burden of care.

**Keywords:** Alzheimer, caregiver burden, caregivers, patient, care

## INTRODUCTION

Dementia has emerged as a significant health issue due to the world's aging population and rising average life expectancy. The most widespread type of dementia is Alzheimer's Disease (AD) which comprises 50-70% of dementia patients. AD is defined as a progressive neurodegenerative disease that causes cognitive dysfunction, impairment in activities of daily living, and behavioral and psychological disorders (1,2). Over the age of 65, AD prevalence is 6–10%, and over the age of 85, it is 30–47%. After the age of 60, the prevalence doubles the size every five years (3). According to the data of the Ministry of Health; there were approximately 500 thousand patients diagnosed with Alzheimer's disease in our country as of 2018 (4). The early stage of AD is characterized by memory problems.

As the disease progresses, destruction occurs in all cognitive areas. In the last stage, patients often die due to infections and systemic diseases (1,3).

Caregiving is defined as providing care for the physical and emotional needs of a family member at home. Caregivers provide care to individuals who frequently or daily require some level of continuing support with activities of daily living. Assistance with food, personal care, and transportation, as well as support for therapy and medical procedures, may be part of this task (5,6). Caregiver difficulties can be expressed as caregivers' difficulty in giving care to someone in need of care, feeling tense and under pressure. Caregiving difficulty is a multidimensional situation that causes physical, psychological, social, and economic problems in the caregiver (6).

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Clinical observations have reported that most of the people with AD (pwAD) stay with their spouses and children at home (7). Family members serve as the primary informal or unpaid carers for those receiving long-term care in their homes. The devastating process of AD continues for about 8-10 years. As the stage of the disease progresses, the patient's need for care and dependence on the caregiver increases. Familial / social relationships and working life are all negatively affected in individuals who care for pwAD. In addition to having an impact on daily activities, caregivers may also be more vulnerable to adverse health effects like stress, depression, and trouble maintaining a healthy lifestyle. (8,9). Valimaki et al. (2022) reported that depressive symptoms were present in AD caregivers and one-third of the caregivers experienced increasing depressive symptoms for five years. Hellis et al. (2022) found that AD caregivers experienced a lower quality of life due to increased anxiety levels, increased caregiver burden, financial distress, and lack of support. The present study aimed to evaluate the caregiver burden in caregivers of pwAD.

## MATERIALS AND METHODS

### Study Design

The research is a descriptive study that was carried out to evaluate caregiver burden in pwAD.

### Sampling and Participants

The study was conducted with patients diagnosed with AD and their relatives/caregivers who applied to the neurology outpatient clinic in a research hospital. Patients diagnosed with Alzheimer's to be included in the study were determined retrospectively by scanning their files for the last 2 years. Then, in July 2021 and September 2021, the patients and their caregivers were called to the neurology outpatient clinic, and the data were collected by face-to-face interview method. The study was carried out with 30 caregivers and 30 patients who agreed to participate in the study and could speak Turkish.

### Measures

The data were collected in two separate forms: prepared for pwAD and prepared for the caregiver.

### Data Collection Tools for pwAD

**Patient Information Form:** Created by the researchers the form included questions about socio-demographic and clinical characteristics (1,10,11).

**Neuropsychiatric Inventory-Questionnaire (NPI-Q):** The caregiver answers questions about twelve behavioral domains (delusions, hallucinations, aggression, depression/dysphoria, anxiety, elation, apathy, disinhibition, irritability/lability, abnormal motor behavior, nocturnal/sleeping behavior, appetite, and eating changes) of the pwAD. The Neuropsychiatric Inventory Questionnaire (NPI-Q), which has been cross-validated with the conventional NPI, was created to provide a quick evaluation of neuropsychiatric

symptomatology in common clinical practice settings (12). The NPI-Q is a validated informant-based interview that evaluates neuropsychiatric symptoms over the past month and is based on the NPI (13). The NPI-Q contains both additions. The NPI-Q is an intended survey that informants complete regarding the patients they care about. There is a survey question for each of the 12 NPI-Q domains, reflecting the key symptoms of that domain. Each domain query receives an initial "Yes" (present) or "No" response (absent). If the answer is "Yes," the informant then rates the severity of the symptoms that have been present over the past month on a 3-point scale and the impact of the symptom presentations on them (i.e., caregiver distress) on a 5-point scale. The NPI-Q offers ratings for each symptom's severity and distress, as well as overall severity and distress scores that represent the total of each domain's scores. More severe symptoms are indicated by higher ratings. The NPI-Q version was employed in the research (14).

**Clinical Dementia Rating Scale – CDR:** The scale used possible phases of cognition and function to determine. According to the results of the interview and exam, six separate categories (memory, orientation, judgment and problem-solving, home and hobbies, community affairs, and personal care) are evaluated over 5 points. Only impairment resulting from cognitive impairment is scored, and each domain is rated using one of five categories of impairment. Ratings of 0, 0.5, 1, 2, and 3 for each domain correspond to very mild, mild, moderate, and severe impairment, respectively. The global CDR score was computed with the system recommended by Morris (1997). Summarizing the results from all six areas results in box scores that range from 0 (no inadequacy) to 18. (maximal inadequacy). Global CDR ratings for dementia range from 0 (cognitively normal), 0.5 (very mild), 1 (mild), 2 (moderate), and 3 (severe). The widely used algorithm is accessible at <http://alzheimer.wustl.edu/>, the Knight ADRC website (14,16).

**The Physical Self-Maintenance Scale (PSMS):** The scale is based on the information provided by carers/caregivers in patients. Reliability has been reported in the 0.90 range. It is a scale that includes 6 items related to basic daily living activities (toilet, self-care, nutrition, physical ambulation, dressing, bathing). For each item, independence is scored as 1 and other parameters as 0 (14, 17).

**Activities of Daily Living Scale (ADCS-ADL):** It consists of 23 questions questioning the activities performed by the individual in the last month and to what extent the patient does these activities on individual own. It is performed with a score between 0-78 points, low scores indicate addiction (6). In our country, the internal consistency coefficient of the scale for Alzheimer's patients was reported as 0.93 by Ince et al. (18).

### Data Collection Tools for Caregivers

**Caregiver information form:** Created by the researchers the form included sociodemographic characteristics, degree of kinship with the patient, and duration of cohabitation (1,10,11).

**Table 1: Descriptive characteristics of Alzheimer's patients and their caregivers.**

Variables	Alzheimer patient		Caregiver		
	n	%	n	%	
Age Mean $\pm$ SD(Min.,Max.)	76.54 $\pm$ 7.79 (57- 89)		56.50 $\pm$ 17.89 (20- 83)		
Gender	Female	15	50	25	83.3
	Male	15	50	5	16.7
Marital status	Married	18	60	25	83.3
	Single	12	40	5	16.7
Education Status	Middle school and under	28	93.3	20	66.7
	High school and above	2	6.7	10	33.3
Professional status	Working	1	3.3	6	20
	Housewife	12	40	19	63.3
Place of life (1/3)	Retired	17	56.7	5	16.7
	Village- small- town	14	46.7	10	33.3
Live together	Province- town	16	53.3	20	66.7
	Wife	11	36.7	12	40
Children	Wife and children	15	50	18	60
	alone/ children	4	13.3	0	0
Income	Two and under $\leq$ 2	13	43.3	21	70
	Three and above $\geq$ 3	17	56.7	9	30
Chronic Disease	Medium-bad moderate / low	20	66.7	25	83.3
	Good / high	10	33.3	5	16.7
Alzheimer's patient's diagnosis year	Yes	20	66.7	15	50.0
	No	10	33,3	15	50.0
The proximity of the caregiver with the patient	Mean $\pm$ SD(Min.-Mak.)	2.38 $\pm$ 1.98 (1- 8)		-	-
The duration of living together with Alzheimer's patient and caregivers	Children (son-daughter)	-	-	12	40.0
	Wife	-	-	12	40.0
	Other (bride, groom, grandchild)	-	-	6	20.0
	Mean $\pm$ SD(Min.-Max.)	21.90 $\pm$ 22.09 (0- 62)			

**Beck Depression Scale:** It evaluates depressive symptoms in the last week with 21 questions. As the score increases, the degree of depression increases (19). Its validity and reliability in our country were performed by Teğin (1987) and Hisli (1988). The cut-off points for the scale were determined as 17 points and the internal consistency coefficient was reported as 0.80 (20).

**Beck Anxiety Scale:** It evaluates anxiety symptoms in the last week with 21 questions. Higher scores indicate a higher degree of anxiety (15). The validity and reliability study for the Turkish population was conducted by Ulusoy et al (1996). The internal consistency coefficient of the scale was reported as 0.93 (21).

**Caregiver Burden Scale:** The scale developed by Zarit et al. in 1980 was adapted to Turkish society by İnci and Erdem in 2006. The internal consistency coefficient of the scale was reported

as 0.95. The scale consists of 22 statements. It evaluates the impact of caregiving on an individual's life. The scale is likert type and scored from 0 to 4 (rarely, sometimes, often, and always). A minimum of 0 and a maximum of 88 points are obtained from the scale. As the scale score increases, the burden of caregivers increases (22).

### Ethical consideration

Approval was obtained for the study by the Ethics Committee of Tekirdağ Namık Kemal University Faculty of Medicine with reference number 13/04/2021(2021.102.04.20) The study's participants were told about it, and their written agreement was obtained, attesting to their voluntary participation.

### Statistical Analysis

Data analyses were performed with the SPSS 18.0 program. Mean, standard deviation, percentage, and minimum-maximum expressions were used to express the variables. The distribution of the data was analyzed with the Kolmogorov-Smirnov test of normality of distribution. Nonparametric tests (Mann Whitney U test or Kruskal Wallis test) were used in the analysis of the study due to the variables were not distributed normally. The evaluation of the relationships between the variables was used in Spearman's Correlation analysis because of data abnormal

**Table 2: The relationship between caregiver burden of care and Beck depression scale and Beck anxiety scores.**

	Caregiver Burden Scale	
Beck Depression Scale	r	0.732
	p	0.000
Beck Anxiety Scale	r	0.535
	p	0.002

r: Spearman's rank correlation test \*p<.001

**Table 3: The relationship between caregiver burden scale with Alzheimer patients' neuropsychiatric inventory, physical self-maintenance scale clinical dementia rating scale, and activities of daily living scale.**

	Caregiver Burden Scale	
	r	p
Neuropsychiatric inventory (NPI-Q)	0.611	0.000
Physical self-maintenance scale (PSMS)	-0.706	0.000
Clinical dementia rating scale (CDR)	0.578	0.001
Activities of daily living scale (ADCS-ADL)	-0.495	0.005

r: Spearman's rank correlation test \*p<0.01

distributions. P value less than 0.05 was considered significant.

## RESULTS

A total of 30 AD patients and caregivers were included in the study. The descriptive characteristics of the patients and caregivers are presented in Table 1. Caregivers were mostly female and married. Although all patients had social health security, 66.2% defined their monthly income as moderate or low. The mean year of diagnosis of Alzheimer's was  $2.38 \pm 1.98$  years and 66.7% of them had at least one concomitant chronic disease. 40% of the caregivers were the patient's child. The duration of living together with Alzheimer's patients and caregivers was found 21.90 years.

In this study, the relationship between the descriptive characteristics of the caregiver and the caregiver burden scale, Beck anxiety, and Beck depression scale was examined. There was no significant relationship between age, education level, employment status, where the caregiver lives, presence of chronic illness, degree of closeness to the patient, and duration of living with the patient ( $p > 0.05$ ). However, the burden of care scale scores was found to be higher in single caregivers than married ones, and depression scale scores were higher in women than men ( $p < 0.05$ ). The relationship between the caregiver burden scale Beck depression scale and Beck anxiety scores in the study are given in Table 2. A positive and highly significant correlation was found between the caregiving burden scores and the depression scores ( $r = 0.732$   $p < 0.01$ ). A positive and moderately significant relationship was found between the caregiving burden scores and the anxiety scores ( $r = 0.535$   $p < 0.01$ ).

The relationship between the caregiver burden scale with Alzheimer patients' neuropsychiatric inventory, physical self-maintenance scale, activities of daily living scale, and clinical dementia rating scale score is given in Table 3. A positive and moderately significant correlation was found between the caregiver burden scale and the neuropsychiatric inventory scale scores ( $r = 0.611$   $p < 0.01$ ). As the neuropsychiatric characteristics (delusions, hallucinations, agitation, depression, elevation, apathy, disinhibition, irritability, abnormal motor behavior, sleep changes, appetite changes) of the patient increased,

the caregiver burden scale score increased. A negative and moderately significant relationship was found between the caregiver burden scale and the physical self-maintenance scale scores ( $r = -0.706$   $p < 0.01$ ). It was observed that as the physical self-maintenance increased, the caregiver burden also increased. A positive and moderately significant relationship was found between the caregiver burden scale and the clinical dementia rating scale ( $r = 0.578$   $p < 0.01$ ). A negative and moderately significant correlation was found between the caregiver burden scale and the activities of daily living scale ( $r = -0.495$   $p < 0.01$ ). It was determined that as the individual's ability to do daily life activities (eating, dressing, shopping, etc.) increased, the caregiver burden decreased in caregiver.

## DISCUSSION

In this study, we aimed to evaluate the sociodemographic and clinical features related to caregiver burden in pwAD. The results of socio-demographic features were like previous reported studies (8,23,24). The majority of pwAD were living with their family, the majority of the caregivers were women, and income levels were moderate or low. 40% of the caregivers were children, 40% were spouses, and 20% were daughter-in-law, groom, or grandchild. The reason can be associated with the fact that older adults' care is seen as a woman's duty in Turkish society (24). In the studies of Pudelewicz et al. (2019) 49% of the caregivers and 49.3% of the caregivers in the studies of Kalinkara and Kalaycı (2017) were stated as sons or daughters. A reason may be that in traditional societies, children are brought up as a guarantee of care for their parents (1,26).

In this study, we examined the relationship between the descriptive characteristics of the caregiver and the caregiver burden scale, Beck anxiety, and Beck depression scale. There was no significant relationship between age, education level, employment status, place of life, with whom the caregiver lived, chronic illness, degree of closeness to the patient, and the duration of living with the patient. However, the care burden was determined higher in singles caring for Alzheimer's patients than in married people and depression levels were higher in women than men. Altay et al. (2018) reported that caregivers who are not employed have a higher burden of care than those who are employed (26). Sallim et al. (2015) reported that 34% of caregivers of Alzheimer's patients had anxiety and 43% had depression. Most of the studies mentioned that depression and anxiety were higher in female caregivers and their spouses (27). According to our results supported by previous studies in the literature, we thought that the reason for the high level of depression in women may be related to the burden of multiple responsibilities on women in our society (such as homework, childcare, etc.). The reason why the burden of care is higher for singles may be that the responsibility is not shared with the spouse. In other words, it can be thought that the burden of the caregiver increases when different responsibilities are included in daily functions or as the time spent by the individual decreases and social communication decreases.

Depression and anxiety are among the main difficulties faced by caregivers of pwAD. Low life satisfaction, depression and anxiety levels of caregivers affect caregiver burden (28). In this study, we found a positive correlation between caregiver burden and the levels of depression and anxiety. Depression and anxiety were higher in caregivers with higher caregiver burden. This result, which is also supported in the literature, can be expected as a natural result of the increase in the burden of care (6,12). For example, in one study, anxiety and depression symptoms were found in less than half of the caregivers of Alzheimer's patients (30); in another study conducted with caregivers of elderly patients, it was reported that there was a moderate relationship between anxiety and care burden (31). In the study conducted by Akyar and Akdemir (2009), 74% of AD caregivers were diagnosed with depression after they started to give care. In line with these results, the point we want to emphasize is that the increase in the level of anxiety and depression can create a vicious circle, affect the level of quick and correct decision-making, negatively affect the caregiver's ability to cope with problems, and self-efficacy levels, and increase the burden of caregiving. Community-based organizations are typically poorly integrated into the medical visit and the healthcare system, although they can provide support and knowledge. The co-management programs are staffed by advanced practice nurses who are trained to understand the issues faced by people with dementia and their families are required to provide dementia care.

Our analysis also revealed that the burden of caregiving was higher in the caregivers of pwAD with higher disease stage, worse neuropsychiatric symptoms, and more dependent on the caregiver. When functionality is impaired, the patient's to perform daily activities increases (14,32). The emergence of behavioral problems increases caregiver burden more than cognitive disorders (32). Caregivers reported that they experienced the greatest difficulty when behavioral problems arose. Because these behaviors are defined as difficult and shameful behaviors to be managed by the caregiver and negatively affect the emotional bond between the patient and the caregiver (33). In addition, the control of behavioral changes affects the daily life of the caregiver negatively (not leaving him alone at home, worrying about exhibiting inappropriate behavior in public, hallucinations of the sick individual, etc.). We think that the caregiver's feeling/necessity of keeping the Alzheimer's patient under constant control and trying to explain that the problems in his/her environment are caused by the disease increase the caregiver burden and the level of anxiety and depression in the individual.

**Limitation:** The study was carried out in a single center. The results of the study cannot be generalized to Alzheimer's disease and caregivers but can provide an idea about the subject.

## CONCLUSION AND RECOMMENDATIONS

The burden of care was found higher in singles than in married people and as caregiver burden increased, depression and

anxiety levels increased. Depression level was determined to be higher in women than men. Alzheimer's patients were determined that the caregiver burden increased as the stage of demands, forgetfulness, neuropsychiatric disorder, and dependence on the caregiver in activities of daily living increased. Recommend because of findings.

- Alzheimer's disease awareness increase will arrange the organization of training programs,
- Performing the necessary screening tests by healthcare professionals in individuals who apply to a healthcare institution with a complaint of forgetfulness,
- Providing patient and family counseling to reduce the burden of care,
- Caregivers to directed to social support by health workers (care fees, free care centers, etc.) and recommend increasing the number of day care homes.

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**Informed Consent:** Written consent was obtained from the participants.

**Peer Review:** Externally peer-reviewed.

**Author Contributions:** Conception/Design of Study- F.D., A.Ü., D.Ş.; Data Acquisition- F.D., A.Ü., D.Ş.; Data Analysis/Interpretation- D.Ş., A.Ü., F.D.; Drafting Manuscript- F.D., A.Ü., D.Ş.; Critical Revision of Manuscript- A.Ü., F.D., D.Ş.; Final Approval and Accountability- A.Ü., F.D., D.Ş.

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