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Exploring Caregiver Burden in Alzheimer's Disease: The Predictive Role Of Psychological Distress

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Abstract:

Background: Alzheimer's Disease (AD), the most prevalent form of dementia, is on the rise in terms of its prevalence. Individuals affected by this condition typically require extensive care across all aspects of daily living. The mental well-being of caregivers for those with dementia stands as a significant public concern. Therefore, the current study aimed to investigate the association between the burden of caregiving and the psychological distress experienced by family caregivers of individuals with AD.

Methods: This cross-sectional study employed a census method and involved the participation of 150 caregivers of Alzheimer's patients in Shahroud, Iran. To assess the eligibility of family caregivers, the inclusion criteria comprised minimal literacy in reading and writing and at least six months of care for an individual with AD. Exclusion criteria included being a formal caregiver or employed in healthcare, having mental disorders, or using neuroleptic drugs among family caregivers. Data collection tools consisted of the Zarit Care Burden Inventory (ZBI) and Lovibond's Depression, Anxiety, and Stress Scale (DASS-21). Information was gathered online and through self-reporting, followed by analysis using descriptive statistics [frequency, percentage, mean, and standard deviation], as well as inferential statistical tests [multivariate linear regression].

Results: In this study, the mean scores for caregiver burden, anxiety, stress, and depression were 28.09 ±13.01, 4.50 ±4.53, 8.12 ±4.98, and 4.69 ± 4.86, respectively. The study's findings revealed that with each additional hour spent on daily patient care, the burden score for caregivers increased by 0.327 units ($p=0.025$, $\beta=0.327$). Furthermore, for every one-unit rise in stress ($p<0.001$, $\beta=1.087$) and depression scores ($p=0.015$, $\beta=0.671$), the burden score also increased by 1.087 and 0.671 units, respectively.

Conclusion: Caregivers of individuals with AD experienced notable levels of caregiving burden, particularly correlated with the duration of daily patient care and the manifestation of stress and depression symptoms. Hence, the study suggests the implementation of tailored interventions, such as psychoeducational programs, to provide vital support for these individuals.

Keywords: Caregiver burden, Alzheimer's disease, Stress, Anxiety, Depression, Psychoeducational programs.

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1. INTRODUCTION

Alzheimer's Disease (AD), a progressive and degenerative brain condition, stands as the most prevalent form of dementia, contributing significantly to the burgeoning burden on healthcare systems. In 2015, the global prevalence of dementia was approximately 46 million individuals, with 70% being affected by AD [1, 2]. Examining specific data from Iran, a study reported a 2.3% prevalence of AD among individuals aged 67-78 [3]. Genetics is known to be one of the most effective factors in Alzheimer's disease [4]. The primary clinical symptoms of AD encompass memory impairment and cognitive dysfunction, including substantial deficits in memory, orientation, and, at times, challenges in judgment and insight. These symptoms significantly curtail the social activities of both patients and their family members. Notably, aging stands as the primary risk factor for AD, and with the global aging population on the rise, the prevalence of affected individuals is increasing worldwide. Thus, AD has emerged as a significant social challenge in recent years [5]. Genetics contribute to about 70% of the overall risk of developing AD. However, acquired factors such as cerebrovascular diseases, diabetes, hypertension, obesity, and dyslipidemia further elevate the risk of developing the disease [6]. Research suggests that sleep deprivation and circadian rhythm disruption may interact to intensify the risk of AD [7]. Moreover, sleep disturbances and symptoms of depression and anxiety are directly linked to the severity of AD. Mitigating the risk of experiencing psychological symptoms might offer a way to delay the onset of AD [8].

In addition to the numerous challenges experienced by those with AD, it's crucial to recognize the negative impact it has on family caregivers. As a result, dementia stands out as one of the most demanding age-related diseases for both caregivers and healthcare professionals [9]. Individuals with AD typically require extensive care across all daily activities, with much of this care being provided by informal caregivers such as family members or friends [10]. The family and spouses of older adults with dementia play crucial roles in providing care. The majority of caregivers are engaged in full-time care, allocating minimal time for themselves [11]. Given the progressive nature of dementia, family caregivers are required to assume more responsibilities as the condition of the dementia patient deteriorates. Caregivers also encounter escalating symptoms associated with dementia, given the increased life expectancy and longevity observed in societies today. The rising life expectancy, coupled with the gradual advancement of dementia, contributes to heightened stress and caregiving burdens experienced by caregivers [12]. In this context, Zarit *et al*. (1986) define caregiving burden as “'the extent to which a caregiver's emotional or physical well-being, social life, or financial status has been affected as a result of caring for their relative” [13-15]. Moreover, family caregivers of Alzheimer's patients face substantial caregiving challenges, evident in the experience of symptoms of depression, anxiety, and sleep disturbances [11, 16]. Factors contributing to the caregiving burden encompass the caregivers' functional status, the severity of the patient's dementia, low life satisfaction, and the presence of symptoms of depression and anxiety [17].

Caring for individuals with dementia is often an arduous and taxing responsibility. Consequently, caregivers bear a significant care burden, leading to psychological distress and potential mental health disorders [18, 19]. Termed as the “invisible second patients,” family caregivers of individuals with dementia play a crucial role in shaping the quality of life for their patients. While the family caregiver role may yield some positive effects, it often engenders negative outcomes and is linked to heightened levels of psychological burden and complexities such as depression, social isolation, physical ailments, and financial struggles [20]. Due to the prolonged nature of the illness, the care burden on these individuals can give rise to pressing social challenges, including intra-family conflicts, erosion of the patient-caregiver relationship, mistreatment of the patient, and caregiver suicide [21].

The mental well-being of caregivers for those with dementia emerges as a critical public concern, making this investigation particularly pertinent in addressing these multifaceted challenges. Given the escalating life expectancy rates, the substantial prevalence, and the expanding trajectory of AD, along with its notable impact on the living circumstances of caregivers and the degree of caregiving burden, the current study seeks to examine the relationship between caregiving burden and psychological distress experienced by family caregivers of individuals with AD.

2. METHODS AND MATERIALS

2.1. Study Settings and Participants

This cross-sectional study was undertaken in 2023 among caregivers of individuals with AD in Shahroud, Northeast Iran. The target sample was comprised of 150 family caregivers of Alzheimer's patients who were accessing healthcare centers. Participants were selected through a census sampling approach. All of the participants considered primary family caregivers assessed based on the following inclusion and exclusion criteria. Inclusion criteria involved possessing a minimum level of reading and writing proficiency to complete the questionnaires and providing care for an individual with AD for a minimum of six months [22, 23]. Exclusion criteria included being a formal caregiver or employed in healthcare, having psychiatric disorders, and using neuroleptic medications among family caregivers, based on self-reported information. Four participants were excluded from the study as they had been providing care for less than six months.

2.2. Data Collection Tools

To gather data, we used a demographic information form, the Zarit Care Burden Inventory (ZBI), and the Lovibond Depression, Anxiety, and Stress Scale (DASS-21) for self-reporting. The caregiver demographic profile form included details such as age, gender, educational level, employment status, marital status, presence of underlying disease, relationship with the patient, daily caregiving hours [24, 25] as well as demographic information for the patient, including age, gender, marital status, employment status, insurance status, and the presence of underlying diseases.

The Zarit Care Burden Inventory (ZBI), developed by Zarit and colleagues in 1980, serves to assess the level of caregiver burden and is administered through interviews. This inventory comprises 22 items, gauging the burden experienced by the caregiver due to the care of a patient. Responses are rated on a Likert scale from never [0], rarely [1], sometimes [2], often [3], to always [4]. The total score obtained by each individual determines their level of caregiving burden. A score of less than 30 indicates mild psychological burden, while 31 to 60 signifies moderate burden, and 61 to 88 indicates severe care burden. Each individual's minimum and maximum score on this questionnaire ranges between 0 and 88, with higher scores reflecting elevated caregiver burden [26]. Smith and Schwirian assessed the ZBI's stability favorably using the test-retest method, reporting an Intraclass Correlation Coefficient (ICC) of 0.71 [27]. Moreover, the Persian version's internal consistency was examined by Mousaei *et al*. in 2022, showing a Cronbach's alpha coefficient estimate of 0.85 [28]. In our study, we evaluated the reliability of ZBI through an assessment of internal consistency, yielding a Cronbach's alpha coefficient of 0.72.

The DASS-21 scale, a shortened version of the DASS-42 introduced by Lovibond in 1995, is designed for self-administration [29]. It consists of 21 items, including seven for stress evaluation (items 2, 6, 8, 11, 12, 14, 18), seven for anxiety assessment (items 1, 4, 7, 9, 15, 19, 20), and seven for depressive symptoms evaluation (items 3, 5, 10, 13, 16, 17, 21). The scale for interpretation is as follows: scores from 0 to 4 are considered normal, 5 to 11 reflect moderate levels, and scores above 12 indicate severe symptoms. Lovibond's analysis confirmed the reliability of the scale, with Cronbach's alpha values reported as 0.81 for stress, 0.73 for anxiety, and 0.81 for depression. Additionally, Antony *et al*. reported Cronbach's alpha coefficients of 0.95, 0.92, and 0.97 for stress, depression, and anxiety, respectively. In Iran, Mirhosseini *et al*. (2022) evaluated the tool's reliability, reporting Cronbach's α coefficients of 0.86, 0.87, and 0.92 for stress, anxiety, and depression, respectively [30, 31]. In our study, the internal consistency of the DASS-21 subscales was examined, yielding Cronbach's alpha coefficients ranging from 0.78 to 0.71.

2.3. Data Analysis

We utilized the Statistical Package for the Social Sciences (SPSS) for data analysis, employing descriptive statistics [frequency, percentages, mean, and standard deviation] and inferential statistical tests [multivariate linear regression analysis]. A significance level of less than 0.05 was adopted for all statistical tests.

2.4. Ethics

This study adhered to the principles outlined in the Declaration of Helsinki, ensuring participants' rights to freely engage in the research, avoidance of harm, the right to withdraw from the study, and preservation of data confidentiality. Furthermore, the research team maintained compliance with the guidelines of the Council on Publication Ethics (COPE) for publication. Prior to the commencement of the study, both oral and written informed consent were obtained from all participants. The results of the evaluations were presented to the participants. In case of high levels of psychological distress or caregiving burden, family caregivers were referred to expert counselors for counseling. This study was approved by the Shahroud University of Medical Sciences under code IR.SHMU.REC.1401.084.

3. RESULTS

According to the findings, on average, patients had been diagnosed with AD for approximately 2.77 years (±2.89). Nearly four-fifths of the patients (n=119) had a parental relationship with their caregiver, and the majority of them (n=144) had health insurance coverage. Caregivers provided an average of 8.78 hours (±5.63) of daily care, with around a third of them (n=50) being employed. Further results are detailed in Table **1**.

Based on the findings of this study, the average scores for anxiety, stress, and depression were 4.50 (±4.53), 8.12 (±4.98), and 4.69 (±4.86) respectively (Each subscale allows for minimum and maximum scores of 0 and 21, respectively. Scores falling between 5 and 11 indicate a moderate level for each dimension.) Additionally, the average caregiver burden score was reported as 28.09 (±13.01), with the potential for minimum and maximum scores of 0 and 88, respectively. A score between 0 and 30 denotes a mild level of caregiving burden. Further details are provided in Table **2**.

Table 1. Demographic characteristics of patients with AD and their caregivers.

Variables		Caregiver		Patient	
		n	%	n	%
Gender	Male	33	22.0	61	40.7
	Female	117	78.0	89	59.3
Marital status	Married	115	76.7	16	10.7
	Single	35	23.3	134	89.3
Level of education	Elementary school	66	44.0	148	98.7
	Secondary school	65	43.4	2	1.4
	High school	19	12.6	0	0.0
Secondary supports	Yes	17	11.3	25	16.7
	No	133	88.7	125	83.3
Underlying disease	Yes	121	80.7	59	39.3
	No	29	19.3	91	61.7
-		**Mean**	**SD**	**Mean**	**SD**
Age [year]	-	43.38	14.29	73.64	12.37

Abbreviations: AD: Alzheimer's disease; n: Frequency; %: Percent; SD: Standard deviation.

Table 2. Mean and standard deviation scores of care burden, stress, anxiety, and depression in caregivers of patients with AD.

Variable	Mild	Moderate	Severe	Mean	SD
	n (%)	n (%)	n (%)		
Care burden	92 (61.3)	55 (36.7)	3 (2.0)	28.09	13.01
Stress	40 (26.7)	79 (52.7)	31 (20.7)	8.12	4.98
Anxiety	96 (64.0)	41 (27.3)	13 (8.7)	4.50	4.53
Depression	112 (74.7)	29 (19.3)	9 (6.0)	4.69	4.86

Abbreviations: AD: Alzheimer's disease; n: frequency; %:percent; SD: Standard deviation.

Table 3. Evaluation of the effect of associated variables of the care burden based on multivariate linear regression analysis.

Variables	β	SE	t	p
Intercept	13.248	2.026	6.53	< 0.001
Stress	1.087	0.265	4.10	< 0.001
Depression	0.671	0.272	2.47	0.015
Daily care hours	0.327	0.145	2.25	0.025

Abbreviations: SE: Standard error; p: P value.

Based on the data in Table **3**, we first examined the relationship between all research variables and care burden using univariate linear regression models. Variables showing a significance level below 0.2 were included in the multivariate model. When we used a backward method for linear regression, we found that the variables in the model could explain 42.7% of the variation in the total care burden score. This analysis revealed that for each hour of daily patient care, the care burden score increased by 0.327 units. Additionally, an increase of one unit in stress and depression scores resulted in 1.087 and 0.671 unit increases in the care burden score.

4. DISCUSSION

The relentless progression of AD results in an increasing demand for care, triggering negative repercussions for those providing the care [32]. In the context of Alzheimer's, “care burden” encapsulates the adverse outcomes linked to tending to dementia patients, spanning psychological, physical, and economic realms, all observed from the vantage point of caregivers. This concept is not solely applicable to caregivers of Alzheimer's patients but extends to those tending to individuals with other enduring or incapacitating conditions as well [33, 34]. Our current study endeavored to explore the relationship between caregiving burden and psychological distress (in the form of stress, anxiety, and depressive symptoms) experienced by caregivers of Alzheimer's patients.

In the context of AD, patients experience a diminishing sense of independence, necessitating an increased involvement of caregivers in their daily care [35]. Our findings revealed that roughly a third of caregivers contended with a moderate caregiving burden, with the overall average burden being characterized as mild. In a study by Gamze Bozgeyik *et al*. in 2019, 50.7% of individuals exhibited a mild care burden [36]. Similarly, in a study by Anna Pudelewicz *et al*. in 2019, 73% of caregivers of Alzheimer's patients reported an average care burden [35]. Discrepancies in these percentages may be attributed to differences in the sample sizes, with the latter study consisting of 55 caregivers. It's crucial to recognize that caregiver burden significantly influences the well-being of both the patient and the caregiver. Consequently, it becomes imperative to comprehend the factors associated with caregiver burden [37]. Caregiver burden is defined as the stress or onus encountered by an individual caring for a chronically ill, disabled, or older adult family member [38].

The prevalence of depression in individuals with AD and their caregivers is notably high. Caregivers often harbor concerns about potential declines in their own quality of life and frequently manifest inadequate coping strategies [36]. Bozgeyik *et al*.'s study among caregivers of Alzheimer's patients in Turkey revealed that 43.7% of caregivers experienced depression, with 19.7% enduring mild depression, 19.7% grappling with moderate depression, and 4.2% contending with severe depression [36]. In our study, we found that 74.7% of caregivers faced mild depression, 19.3% reported moderate depression, and 6% faced with severe levels of depressive symptoms. Smyth A. *et al*.'s investigation of caregivers of Alzheimer's patients showed that 56.3% of caregivers experienced depression, with 21.1% enduring mild depression and 19.7% reporting depression at an average level [39]. The outcomes of our current study were found to align closely with the results of the aforementioned studies.

Moreover, our study's findings revealed that 64% of caregivers experienced mild levels of anxiety symptoms. In a study by García-Alberca JM *et al*. in Spain, over 50% of caregivers of Alzheimer's patients exhibited high scores for anxiety and depression [40]. Additionally, research conducted by Sansoni J *et al*. indicated that roughly three-quarters of caregivers of Alzheimer's patients displayed elevated levels of anxiety symptoms, with around half reporting symptoms of depression [41]. The prevalence of depressive and anxiety symptoms within various societies can be influenced by cultural, social, demographic, and clinical variables. Given these variations and the differences in measurement tools and sample sizes, our study authors believe that these factors may contribute to distinct study outcomes.

Caregiving for individuals with AD or other forms of dementia significantly impacts the mental and physical well-being of both the caregivers and those with AD [42]. The stress experienced by caregivers has been identified as detrimental to their health and that of individuals with AD [43]. Qualitative studies have underscored the enduring stress and frustration experienced by caregivers of Alzheimer's patients [44]. The results of our study indicate that caregivers' stress levels were at a moderate level. Similarly, Zahed *et al*.'s 2020 study highlighted that caregivers of Alzheimer's patients experienced moderate levels of stress, aligning with our current findings [43]. Moderate stress levels pose a considerable concern for caregivers, as this stress can disrupt their quality of life [45]. In a study by Huang H *et al*. in 2019, caregivers of individuals with AD similarly reported moderate stress levels [46]. Furthermore, Messina A *et al*. noted that more than half of caregivers of individuals with AD experienced only mild to moderate levels of stress and depressive symptoms [47]. These studies' findings are consistent with the results of our present study, emphasizing the pervasive nature of moderate stress levels among caregivers of Alzheimer's patients.

The linear regression analysis in our study revealed that as the number of daily care hours increased, the caregiving burden score also increased. Similar findings were reported in a study by Hongmei Yu *et al*. in 2015, which demonstrated a direct impact of caregiving hours on the escalation of caregiving burden among caregivers of individuals with AD. These results align with our present study's findings [48]. Likewise, the study conducted by Anna Pudelewicz *et al*. also corroborated this outcome [35]. In support of this conclusion, Mirhosseini *et al*. (2023) found that the daily hours of patient care are directly and significantly linked to the levels of care burden experienced by caregivers [49]. Based on the author's viewpoint, when caregivers spend extended hours providing care, it can disrupt their personal lives, affecting their ability to engage in activities they enjoy or attend to their own needs. This disruption can add to their sense of burden. Moreover, the greater the amount of time devoted to caregiving, the greater the level of responsibility and commitment. This unrelenting pressure and responsibility can contribute to a heightened sense of burden and stress.

The subjective burden on caregivers may indicate clinical depression in that caregiving for frail older adults. Moreover, individuals caring for people with dementia tend to experience a more significant level of burden [50]. The results of this study indicate that as depression symptoms intensify, the caregiving burden also rises. This aligns with a prior study in Turkey (2019), which demonstrated a direct link between caregiver burden for Alzheimer's patients and their experience of depressive symptoms [36]. Similarly, an Australian study indicated that the perceived burden was directly and significantly associated with depression among family caregivers of individuals with dementia [51]. These results echo the findings of the current study. Based on the current findings, there is a correlation between higher levels of stress symptoms in caregivers and worsened caregiving burdens. A study conducted by Manee Pinyopornpanish *et al*. (2021) highlighted a direct association between heightened perceived stress levels and increased caregiving burden [52]. Additionally, a study revealed that Brazilian caregivers tending to individuals with neuropsychiatric diseases face a heightened risk of experiencing depression, anxiety, insomnia, and related issues [53]. These results align with the outcomes observed in the present study.

4.1. Strengths and Limitations

The data collection in this study relied on a questionnaire and self-reporting method, potentially introducing bias into the results. The study's scope was also constrained by the need to prevent sample loss due to incomplete questionnaire responses, limiting the evaluation of additional variables. In this study, we attempted to gather data from patients' medical records or the self-reported information of family caregivers. However, the stage of Alzheimer's Disease (AD) was not investigated due to the significant amount of missing data in the medical records. Furthermore, being localized in a northeastern Iranian city with a cross-sectional design raises concerns about the generalizability of findings to other cultures or geographical regions. Despite employing a census method for sampling, the study's sample size was limited. To address these limitations, future research is recommended to adopt a longitudinal approach with a larger sample size or carry out a multicenter cross-sectional study in the different regions of Iran. It's important to note that, despite these constraints, the present study contributes novel insights into the experiences of caregivers of Alzheimer's patients in Iranian society.

CONCLUSION

Caregivers of Alzheimer's patients experienced a substantial caregiving burden, correlating with the duration of daily patient care and the psychological distress manifested in stress and depression symptoms. To alleviate this burden, it is advisable to introduce psycho-educational interventions and provide essential training for managing daily care programs.

AUTHORS' CONTRIBUTION

S.M. and H.E.: Contributed to the study's concept and design; M.S.: Collected data; M.H.B.: Analyzed the data and interpreted the results; and F.A. and H.R.: Drafted the manuscript.

LIST OF ABBREVIATIONS

DASS-21 = Depression, Anxiety, and Stress Scale
ICC = Intra-class Correlation Coefficient
SPSS = Statistical Package for the Social Sciences
ZBI = Zarit Burden Inventory
COPE = Committee on Publication Ethics
AD = Alzheimer's disease

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the Ethics Committee of Shahroud University of Medical Sciences, Iran under code IR.SHMU.REC.1401.084.

HUMAN AND ANIMAL RIGHTS

All procedures performed in studies involving human participants were in accordance with the ethical standards of institutional and/or research committees and with the 1975 Declaration of Helsinki, as revised in 2013.

CONSENT FOR PUBLICATION

Informed consent was obtained from participants.

STANDARDS OF REPORTING

STROBE guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from the corresponding author, (H.E), on special request.

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None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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