





*Original/Research Paper***Care burden, fatigue, and family functioning among family caregivers of older adults with Alzheimer's disease: A cross-sectional study**Seyyede Mahdiyeh Khastar ^a  | Seyyed Hamid Hoseini ^{b, c}  | Narges Arsalani ^{d*}  | Fateme Mohammadi ^e 

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Abstract

This study aimed to evaluate the relationship between care burden, fatigue, and family functioning among family caregivers of older adults with Alzheimer's disease (AD). This study adopts a cross-sectional research design, employing an available sampling method. The sample comprises 150 caregivers of elderly individuals diagnosed with AD, recruited from the elderly clinic overseen by the Birjand Welfare Organization. Data collection encompassed the administration of multiple instruments, including a demographics form, Zarit Burden Interview, Piper Fatigue Scale, and APGAR family functioning questionnaires. A total of 150 elderly individuals diagnosed with AD, along with their respective caregivers, were included in this study. The mean score for caregiver burden was 24.24 (SD=10.18), fatigue was 32.73 (SD=22.76), and family functioning was 6.58 (SD=7.37). A negative and significant correlation was observed between caregiver burden and family functioning ($r=-0.693$, $P<0.05$). Furthermore, positive and significant correlations were found between caregiver burden and behavioral fatigue ($r=0.720$, $P<0.05$), affective fatigue ($r=0.674$, $P<0.05$), as well as sensory cognitive fatigue ($r=0.484$, $P<0.05$). The association between behavioral fatigue and affective fatigue revealed a positive and significant correlation ($r=0.875$, $P<0.05$), as did the correlation between behavioral fatigue and sensory-cognitive fatigue ($r=0.488$, $P<0.05$). Additionally, a positive and significant relationship was observed between affective fatigue and sensory-cognitive fatigue ($r=0.478$, $P<0.05$). Considering the pronounced relationship between caregiver burden, fatigue, and family functioning, these factors hold utility for researchers and policymakers in the realms of gerontology and intervention planning, serving as pivotal metrics for assessment and intervention design.

Keywords: Alzheimer's Disease, Caregiver Burden, Fatigue, Family Functioning, Older Adults, Family Caregivers.**1 | Introduction**

Alzheimer's disease (AD) is characterized by a progressive degeneration of brain cells, leading to cognitive decline. Early manifestations typically entail mild memory impairment, which subsequently escalates to an incapacity to engage in coherent conversation and perform routine activities. This neurodegenerative condition primarily impacts brain regions associated with cognitive functions such as memory retention, cognitive processing, and linguistic abilities [1].

Advanced medical technologies contribute to the extension of the human lifespan, consequently fostering an aging population, a recognized risk factor for the onset of AD, and resulting in a surge in incident cases [2]. Presently, AD stands as the foremost cause of functional impairment and disability among elderly individuals [3]. Projections by AD international indicate a substantial escalation, foreseeing an additional 152 million individuals globally afflicted with dementia by 2050 compared to figures recorded in 2019 [4]. Iran currently hosts a population of over

700,000 individuals diagnosed with AD, with seventy percent of these patients receiving care within their households by familial caregivers [5]. Recognizing the significance of this issue, the World Health Organization has urged developed nations to prioritize the inclusion of treatment and caregiving for AD patients within their respective national healthcare agendas [6].

With the escalation in the elderly population afflicted by chronic ailments, there is a parallel increase in the count of caregivers dedicated to their support. A report from 2020 indicates that approximately 41.8 million individuals in the United States provided uncompensated care to individuals aged 50 years and above within the preceding year. This trend indicates an ongoing aging of the populace, concomitantly augmenting the demand for caregiving services due to a surge in intricate and persistent health conditions [7]. Informal caregivers, frequently comprising family members, assume a pivotal role in aiding older adults grappling with chronic illnesses [8].

AD exerts a profound impact not only on the health and well-being of patients but also on that of their caregivers [3]. This phenomenon is encapsulated by the concept of "caregiver burden" [2]. As articulated by Zarit et al., caregiver burden encompasses the degree to which the emotional, physical, social, and financial facets of a caregiver's life are influenced by their provision of care to a family member. Importantly, this burden manifests in both objective and subjective dimensions [3].

The provision of care for AD patients encompasses an extensive array of tasks such as personal care, household assistance, medication administration, and care coordination. However, informal caregivers often encounter challenges in fulfilling these responsibilities due to the overwhelming pressure and magnitude of the caregiving burden [9]. Indeed, a substantial proportion of caregivers experience notable levels of fatigue, depression, social isolation, impaired functioning, and even heightened mortality rates [2].

Research indicates that individuals caring for those with AD, particularly those involved in providing personal care, experience a comparatively higher burden of caregiving than caregivers of individuals with other conditions. A study involving 277 caregivers of dementia patients found that nearly a quarter of them devoted 40 or more hours per week to caregiving duties, in contrast to 16 percent among caregivers of non-AD patients. These caregiving responsibilities encompassed tasks such as bathing, feeding, and assisting with toileting activities. According to recent findings from the Iranian Alzheimer's Association, approximately 7 million family caregivers provided care for individuals with AD and various forms of dementia, dedicating an average of 41 hours per week to caregiving responsibilities [10].

An additional obstacle faced by caregivers of individuals with AD is the experience of fatigue, a phenomenon commonly encountered during the caregiving process and capable of exerting detrimental effects on caregivers' health [11]. Fatigue is characterized as a sensation of tiredness, diminished energy levels, and overall weariness, distinct from feelings of sleepiness or sadness, and often resulting from mental or physical exertion. This pervasive sense of fatigue serves as a symptom of both acute and chronic medical conditions. By impeding the capacity to fulfill caregiving responsibilities, caregiver fatigue poses significant repercussions for both the caregiver and the recipient of care. Indeed, seventy-five percent of AD caregivers report enduring chronic fatigue [12].

The family unit holds substantial potential to contribute significantly to the caregiving dynamics as outlined. Indeed, the family stands as a paramount element in an individual's existence, wielding a pivotal influence in moderating the stress levels experienced by caregivers [13]. However, despite its pivotal role, the significance of family functioning remains relatively underexplored within the scholarly discourse. Existing literature exhibits limited examination of the interrelations and interplay among various factors. Notably, the caregiver burden has the propensity to instigate or exacerbate family distress, while concurrently family functioning may serve to mitigate or accentuate the caregiver burden [14].

Gabriel Smilkstein's model offers a structured framework for assessing the functioning of families, encompassing five key dimensions: adaptation, partnership, growth, affection, and resolve [15]. Within the cultural contexts of Asia, particularly in Iran, where familial ties hold significant cultural and religious importance, family members assume critical roles in the care and support of individuals with AD. However, the effectiveness of these familial caregiving structures in Iran is influenced by various factors, including the deficiency of social security services, community associations, home visitation programs, counseling services, and training sessions [16].

Analyzing the efficacy of family functioning in caring for these patients enables the identification of familial strengths and weaknesses, facilitating targeted interventions aimed at empowering families and enhancing caregivers' mental well-being. Therefore, the objective of this study was to explore the relationship between caregiver burden, fatigue, and family functioning among caregivers of older adults with AD, as no such investigation had been undertaken within the country before this research endeavor.

1.1 | Aims

The study aimed to answer the following research questions:

- How is the care burden in family caregivers of elderly patients with AD?
- How is the fatigue in family caregivers of elderly patients with AD?
- How is the family functioning in family caregivers of elderly patients with AD?
- What is the relationship between care burden, fatigue, and family functioning in family caregivers of elderly patients with AD?

2 | Methods

2.1 | Study design and subjects

This study adopts a cross-sectional research design, employing an available sampling method. The sample comprises 150 caregivers of elderly individuals diagnosed with AD, recruited from the elderly clinic overseen by the Birjand Welfare Organization. The inclusion criteria for participants in this study consist of caregivers of elderly individuals diagnosed with AD who have attended geriatric clinics under the auspices of the Birjand Welfare Organization and express willingness to partake in the research. Amidst the COVID-19 pandemic, the distribution of questionnaires was conducted electronically. The original questionnaires, along with the study proposal, underwent submission to both the Security Office and the Research Vice-Chancellorship of the Welfare Organization. Subsequently, a directive was issued through a formal letter to the Welfare Vice-Chancellorship, mandating the dissemination of an SMS containing a hyperlink to the questionnaires among the targeted study population. This formal correspondence was forwarded to the Welfare Statistics Unit, which utilized the RAND function in Excel to randomly dispatch the SMS containing the questionnaire link to 10 times the sample size, totaling 1500 cell phone numbers belonging to the research population. Following a lapse of one week, the researchers received the compiled data in an Excel format via the PressLine website for subsequent analysis on their systems.

2.2 | Ethics consideration

In adherence to ethical guidelines, each questionnaire in this study underwent coding procedures to uphold anonymity and confidentiality standards. The research protocol was assigned the ethical code IR.USWR.REC.1398.091. Subsequently, introduction letters were obtained from the university to facilitate participant engagement. Before participation, individuals were provided with detailed information regarding the study's objectives,

following which written informed consent was obtained from each participant.

2.3 | Data collection

Data collection encompassed the administration of multiple instruments, including a demographics form, Zarit Burden Interview, Piper Fatigue Scale, and APGAR family functioning questionnaires.

2.3.1 | Demographic questionnaire

The demographics form, devised by the researchers, comprised two sections: one focused on the personal attributes of the older adults and the other on those of the caregivers. Within the older adult profile, variables such as age, gender, marital status, level of education, and severity of illness were assessed. The caregiver profile section included variables such as age, gender, marital status, educational background, occupation, relationship with the patient, place of residence, economic status, and duration of caregiving for the patient.

2.3.2 | Zarit burden interview

The Zarit Burden Interview, developed by Zarit et al., in 1998, is a validated questionnaire comprising 22 statements designed to assess caregiver burden and their perception of the caregiving experience. Each statement prompts respondents to indicate their level of agreement using a five-point Likert scale, ranging from 0 (never) to 4 (nearly always). Total scores range from 0 to 88, with scores falling within specific ranges to denote varying levels of burden: 0 to 21 indicating zero to mild burden, 21 to 40 representing mild to moderate burden, 41 to 60 indicating moderate to severe burden, and 61 to 88 reflecting severe burden. The questionnaire's validity has been assessed using Cronbach's alpha, yielding a coefficient of 0.94 [17].

2.3.3 | Piper fatigue scale

The Piper Fatigue Scale, introduced by Barbara Piper in 1990 for clinical trial purposes, comprises 27 items. The average total score for items 2 to 23 on this scale ranges from zero to ten. Additionally, five qualitative questions are included in the questionnaire to enhance its depth, yet these are not factored into the scoring. This scale evaluates four dimensions of fatigue: behavioral, emotional, sensory, and cognitive. Scores range from 0 (indicating no fatigue) to 10 (indicating severe fatigue), with scores between 1 and 4.9 indicative of mild fatigue. In Iran, the reported Cronbach's alpha coefficient for the scale's validity is 0.98. Inter-

nationally, Cronbach's alpha coefficients for determining the validity of the scale yield a value of 0.95 for the entire scale, with coefficients for the subscales ranging from 0.81 to 0.95 [15, 18].

2.3.4 | APGAR family functioning questionnaire

The APGAR Family Functioning Questionnaire, devised by Gabriel Smilkstein in 1978 to aid nurses in evaluating family functioning, comprises 27 items, symbolizing the acronym "Apgar." The questionnaire is structured to assess various aspects of family dynamics: the first four items pertain to adaptation, items 5 to 11 evaluate participation, items 12 to 17 scrutinize family growth, items 18 to 22 assess affection, and items 23 to 27 focus on decision-making. Responses are scored on a scale of 0 (hardly ever), 1 (some of the time), and 2 (almost always). Total scores on the questionnaire range from 0 to 10. Scores falling between 0 and 3 indicate an extremely dysfunctional family, scores ranging from 4 to 6 suggest a moderately dysfunctional family, while scores between 7 and 10 imply a highly functional family. The questionnaire's reliability has been assessed internationally using Cronbach's alpha, yielding a reported coefficient of 0.89 [19, 20].

2.4 | Sample size

The sample size calculation utilized the correlation formula, with an alpha value of 0.05 and a power of 80%. A correlation coefficient (r) of 0.3 between family functioning and quality of life was adopted based on the findings of Sanchez et al. [21]. Furthermore, a 10% attrition rate was accounted for during the sampling process, resulting in the inclusion of 150 individuals in the study.

2.5 | Statistical analysis

Statistical analyses were conducted using the SPSS software package (version 23.0, SPSS Inc., Chicago, IL, USA). Descriptive statistics were employed to present continuous variables, expressed as mean (standard deviation [SD]), while categorical variables were represented as frequency (percentage). Assumptions of the research involved conducting skewness and kurtosis tests to assess the normality of score distributions. Pearson's correlation coefficient was utilized for inferential analysis to examine relationships between variables. The predetermined significance level for all statistical tests was set at 0.05.

3 | Results

3.1 | Participants' characteristics

As depicted in Table 1, a total of 150 elderly individuals diagnosed with AD, along with their respective caregivers, were included in this study. Among the elderly, 54.67% were aged over

80 years, with 63.0% being male and 60.0% being illiterate. Additionally, 86.67% resided in urban areas, with 72.0% experiencing AD for less than six years, and 47.20% having mild severity of the disease. Among the caregivers, 48.0% were aged between 49 to 59 years, with 63.33% being female and 55.33% possessing a bachelor's degree or higher. Furthermore, 84.0% of caregivers were adult children of the elderly patients. In terms of caregiving commitment, 66.67% of caregivers dedicated over 18 hours per week to their duties, with 63.33% providing care at the patient's place of residence.

3.2 | The relationship between care burden, fatigue, and family functioning among family caregivers of older adults with AD

As indicated in Table 1, the mean score for caregiver burden was 24.24 (SD=10.18), fatigue was 32.73 (SD=22.76), and family functioning was 6.58 (SD=7.37). As illustrated in Table 2, a negative and significant correlation was observed between caregiver burden and family functioning ($r = -0.693$, $P < 0.05$). Furthermore, positive and significant correlations were found between caregiver burden and behavioral fatigue ($r = 0.720$, $P < 0.05$), affective fatigue ($r = 0.674$, $P < 0.05$), as well as sensory cognitive fatigue ($r = 0.484$, $P < 0.05$). The association between behavioral fatigue and affective fatigue revealed a positive and significant correlation ($r = 0.875$, $P < 0.05$), as did the correlation between behavioral fatigue and sensory-cognitive fatigue ($r = 0.488$, $P < 0.05$). Additionally, a positive and significant relationship was observed between affective fatigue and sensory-cognitive fatigue ($r = 0.478$, $P < 0.05$).

4 | Discussion

The results suggest that the caregiver burden experienced by older adults affected by AD exhibits a moderate association with various dimensions of fatigue, including behavioral, affective, and sensory-cognitive. These findings align with prior research, as exemplified a study by Szabo et al., (2019), which highlighted that caregivers of AD patients typically endure greater burdens compared to individuals not involved in caregiving activities [22]. Notably, a key disparity between the two investigations lies in the choice of measurement instrument and the timing of assessment. Specifically, the assessment of caregiver burden in the referenced study tended to adopt an economic perspective. Consistent with our findings, Yildizhan et al., (2019) demonstrated a significant positive correlation between caregiver burden among caregivers of elderly AD patients and burnout [23].

Table 1. The demographic attributes of patients and their caregivers, along with the average levels of fatigue, caregiver burden, and family functioning in elderly individuals with AD (N=150).

	Frequency (%) or Mean (SD)
<u>Demographic characteristics of older adults</u>	
Age	
70-79	68 (45.33)
≥80	82 (54.67)
Gender	
Male	55 (37.00)
Female	95 (63.00)
Education level	
Illiterate	90 (60.00)
Primary	26 (17.33)
Junior high school	22 (14.67)
High school and above	12 (8.00)
Place of residence	
Urban	130 (86.67)
Rural	20 (13.33)
History of AD (years)	
<6	108 (72.00)
≥7	42 (28.00)
AD severity	
Mild	67 (47.20)
Moderate	40 (28.20)
Severe	35 (24.60)
<u>Demographic characteristics of caregivers</u>	
Age	
38-48	53 (35.33)
49-59	72 (48.00)
≥60	25 (16.67)
Gender	
Male	55 (36.67)
Female	95 (63.33)
Employment status	
Employed	53 (35.33)
Homemaker	67 (44.67)
Retired	30 (20.00)
Education level	
High school or lower	67 (44.67)
Bachelor's degree and higher	83 (55.33)
Relationship with patient	
Spouse	12 (8.00)
Child	126 (84.00)
Grandchild	12 (8.00)
Length of care per week (hour)	
<18	50 (33.33)
≥18	100 (66.67)
Location of care provision	
Patient's residence	95 (63.33)
Caregivers' residence	55 (36.67)
<u>Caregiver's burden</u>	
	24.24 (SD=10.18)
<u>Fatigue</u>	
Behavioral	9.05 (SD=9.58)
Affective	6.99 (SD=6.89)
Sensory cognitive	16.69 (SD=9.73)
Total	32.73 (SD=22.76)
<u>Family functioning</u>	
Adaptation	1.18 (SD=1.24)
Partnership	1.29 (SD=2.31)
Growth	1.36 (SD=2.17)
Emotional growth	1.45 (SD=1.28)
Resolve	1.30 (SD=1.75)
Total	6.58 (SD=7.37)

Values are given as Mean (SD) for continuous variables and frequency (%) for categorical variables.

Table 2. The demographic attributes of patients and their caregivers, along with the average levels of fatigue, caregiver burden, and family functioning in elderly individuals with AD (N=150).

	Caregiver burden	Family functioning	Behavioral fatigue	Affective fatigue	Sensory-cognitive fatigue
Caregiver burden	1				
Family functioning	-0.693*	1			
Behavioral fatigue	0.720*	-	1		
Affective fatigue	0.674*	-	0.875*	1	
Sensory-cognitive fatigue	0.484*	-	0.488*	0.478*	1

P-value was obtained by the Pearson correlation coefficient test.

*P<0.05

Furthermore, a study by Bastani *et al.*, (2015) identified a significant inverse relationship between caregiver burden and the overall health status of caregivers [24]. These findings suggest that caregivers of elderly patients with AD encounter numerous mental and physical challenges in their caregiving role. Such challenges may stem from caregiver burden or may be exacerbated by factors such as fatigue, depression, and general health issues [25]. Dedicating substantial time to the care of older adults with AD can lead to alterations in the caregiver's lifestyle. The cumulative physical, emotional, and financial strains associated with caregiving can adversely affect both the caregiver's and the patient's health, potentially leading to feelings of exhaustion. Consequently, the importance of respite care provided by formal caregivers, such as nurses, in alleviating the fatigue experienced by family caregivers of elderly individuals with AD is underscored.

Other findings indicate that caregivers' family functioning is compromised, both overall and across the five specific domains. Adaptation emerged as the most affected dimension, followed by partnership, resolve, growth, and affection. Furthermore, it was observed that as caregiver burden escalated, so did the deterioration in family functioning. In conjunction with the outcomes of this study, the research by Tramonti *et al.*, (2019) noted that the family functioning of caregivers for individuals with Alzheimer's, Parkinson's, and multiple sclerosis exhibited greater dysfunctionality, particularly in communication, role allocation, emotional responsiveness, behavior management, and overall functioning [26]. A study by Arshi *et al.*, (2016) illustrated in their research a positive and statistically significant correlation between caregiver burden and all domains of family functioning [27]. The congruence observed between these studies and the current investigation lies in the disruption of overall family functioning caused by the diseases under consideration. Moreover, the mean scores for family functioning in the present study were notably diminished.

AD constitutes a chronic, progressive, and incapacitating neurological condition characterized by profound cognitive impairments in memory and cognition, alongside behavioral abnormalities in afflicted individuals. Due to their cognitive and behavioral challenges, AD patients often encounter difficulties in meeting their daily needs. Consequently, the responsibility for providing round-the-clock care typically falls heavily upon family members. This circumstance exerts multifaceted repercussions on various facets of both the personal and familial domains of caregivers of elderly individuals affected by AD [28].

The resultant caregiver burden disrupts the functioning of family members, thus establishing a detrimental cycle that exacerbates the burden on family caregivers. Consequently, evaluating or improving the level of family functioning among those caring for elderly patients with AD is recognized as a critical aspect of caregiver health and well-being [29]. Essentially, as the caregiving burden intensifies, caregivers allocate less time to their personal needs and devote more time to tending to the requirements of older adults with Alzheimer's [30, 31]. This, in turn, impairs caregivers' functioning and family dynamics. Hence, it is logical to infer that caregiver burden is significantly correlated with family functioning among caregivers of older adults with AD.

4.1 | Limitations

This study is subject to several limitations. The utilization of a cross-sectional design restricts the capacity to infer causality between variables. Additionally, the reliance on self-report measures to evaluate caregiver burden, fatigue, and family functioning may introduce response bias, potentially leading to underreporting or overreporting of experiences due to social desirability or recall bias. Furthermore, the absence of longitudinal data precludes the examination of changes in caregiver burden, fatigue, and family functioning over time, thereby impeding a comprehensive understanding of the dynamic nature of these factors.

4.2 | Recommendations for future research

The study suggests the implementation of longitudinal research endeavors to monitor the evolution of caregiver burden, fatigue, and family functioning across time, thereby facilitating a more comprehensive comprehension of their temporal dynamics and potential causal associations. Additionally, it recommends the development and appraisal of interventions intended to mitigate caregiver burden and fatigue, while concurrently fostering family functioning. These interventions may include support groups, respite care initiatives, or psychoeducational programs. Furthermore, the study proposes an investigation into the determinants of resilience and effective coping mechanisms among caregivers of elderly individuals with AD, exploring their role in ameliorating caregiver burden and fatigue, and fostering positive family dynamics.

5 | Conclusions

The current investigation unveiled a moderate correlation between caregiver burden, caregiver fatigue, and the family functioning of caregivers of elderly individuals with AD. To mitigate the burden on caregivers, heightened attention should be directed toward assessing caregiver fatigue levels and evaluating the functionality of their families. Considering the pronounced relationship between caregiver burden, fatigue, and family functioning, these factors hold utility for researchers and policymakers in the realms of gerontology and intervention planning, serving as pivotal metrics for assessment and intervention design.

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Authors' contributions

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work: SMK, SHH, NA, FM; Drafting the work or revising it critically for important intellectual content: SMK, SHH, NA, FM; Final approval of the version to be published: SMK, SHH, NA, FM; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: SMK, SHH, NA, FM.

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Ethics approval and consent to participate

The study obtained ethical approval from the Ethics Committee of University of Social Welfare and Rehabilitation Sciences, identified by the code IR.USWR.REC.1398.091. Before participation, all individuals provided informed consent after receiving detailed information about the study's aims. Participants were explicitly informed of their right to withdraw from the study at any time if they chose to do so.

Competing interests

We do not have potential conflicts of interest with respect to the research, authorship, and publication of this article.

Availability of data and materials

The datasets used during the current study are available from the corresponding author on request.

Using artificial intelligent chatbots

None.

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