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Website: www.jehp.net
DOI: 10.4103/jehp.jehp_445_19

Stress as a challenge in promoting mental health among dementia caregivers

Shakiba Zahed, Maryam Emami¹, Ahmad Ali Eslami², Majid Barekatin¹, Akbar Hassanzadeh³, Fereshteh Zamani-Alavijeh²

Abstract:

BACKGROUND: Caregiver stress is harmful to the health of both caregivers and people living with Alzheimer's disease or other dementias. The present study was conducted to assess stress and its predictors of people living with Alzheimer's disease or other dementias' caregivers.

METHODS: The present descriptive, analytical, cross-sectional study was conducted in December 2017–June 2018 in Isfahan, Iran. Data were collected by interviewing 99 caregivers had at least 6 months of experience caring for a patient diagnosed with Alzheimer's disease, through questionnaires developed by the researcher. A convenience sample (easy access) of caregivers was recruited from calling the home of formally diagnosed with Alzheimer's patient, that have registered in educational hospitals affiliated to Isfahan University of Medical Sciences and psychiatrists' office both paid caregivers (formal) and unpaid caregivers (family). All caregivers provided informed consent. The type and severity of the relationship between the dependent (stress) and independent variable were assessed using Pearson's and Spearman's correlation coefficients, the independent *t*-test, and the multivariate regression analysis.

RESULTS: The caregivers' mean stress score was 25.4 ± 10.9 (range: 4–54). About 80% of the caregivers were female. Age and stress score was correlated ($P = 0.004$), the mean stress score was significantly higher in female caregivers ($P = 0.04$), informal caregivers ($P < 0.001$), and significantly lower in the caregivers with previous experience of caring for Alzheimer's patients ($P = 0.02$) or those introduced by service companies ($P = 0.005$). Variables including the family relationship with the patient ($P = 0.01$), kind of caregiving ($P = 0.03$), and previous experience of caring for Alzheimer's patients ($P = 0.04$) were stronger predictors of the stress score.

CONCLUSION: Stress is a challenge in promoting mental health among dementia caregivers. Providing social support with an emphasis on physical, mental, and social health is mandatory, especially for female and family caregivers, to promote stress management, mental health in this group, and enable optimal and purposeful care.

Keywords:

Alzheimer's disease, caregivers, dementia, mental health, stress

Introduction

Alzheimer's disease is a type of dementia and one of the main causes of dependence and needs health caregiving in older adults.^[1-3] The increasing prevalence of Alzheimer's disease in older adults, who constitute a vulnerable stratum of the society,

is regarded as a health and social concern.^[4] This disease is associated with cognitive disorders such as impaired memory, perception and learning, personality and mood disorders, and functional disorders such as a disruption in daily activities and social relations.^[5] Some people living with Alzheimer's disease or other dementias with moderate-to-severe degrees of illness require

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How to cite this article: Zahed S, Emami M, Eslami AA, Barekatin M, Hassanzadeh A, Zamani-Alavijeh F. Stress as a challenge in promoting mental health among dementia caregivers. *J Edu Health Promot* 2020;9:65.

Department of Health Education and Promotion, Student Research Committee, School of Health, Isfahan University of Medical Sciences, ¹Department of Psychiatry, School of Medicine, Isfahan University of Medical Sciences, ²Department of Health Education and Promotion, School of Health, Isfahan University of Medical Sciences, ³Department of Epidemiology and Biostatistics, Faculty of Health, Isfahan University of Medical Sciences, Isfahan, Iran

Address for correspondence:

Dr. Fereshteh Zamani-Alavijeh, Department of Health Education and Promotion, School of Health, Isfahan University of Medical Sciences, Isfahan, Iran. E-mail: fe.zamani@hlth.mui.ac.ir; fe.zamani@gmail.com

Received: 03-08-2019

Accepted: 26-09-2019

full-time care, and this caregiving role is beyond routine daily tasks and responsibilities.^[6] These care duties are wide-ranging and include feeding, bathing, and dressing, meeting emotional needs, and helping carry out multiple instrumental activities of daily livings, such as paying bills, shopping, and using transportation services. Caregiving is imperative and inevitable for older adults living with Alzheimer's disease or other dementias.^[7,8] The need for healthcare becomes bolder as the disease progresses.^[6] The term "caregiver" refers to a person who provides services and assistance to those who need help or who are not fully capable of carrying out their health and daily activities. The caregivers of people living with Alzheimer's disease or other dementias are mostly family members.^[7,8] Caregivers may be informal, including family members and friends or formal caregivers who were paid for caring the patients.^[9] Being a caregiver for a person living with Alzheimer's disease or other dementias have a significant impact on their mental and physical health.^[10] The care burden experienced as a result of giving care to Alzheimer's patients may adversely affect the caregivers' health and expose them to certain stress and negative consequences of caregiving. The burden of care may be one of the factors that cause stress in caregivers.^[11-13] Many caregivers, especially informal caregivers, have experienced at least one type of depressive disorders.^[6] Given all the emotional and financial expenses imposed on the caregivers and families of Alzheimer's patients, caregiver stress is an issue that cannot be overlooked.^[14] While offering their services, caregivers are themselves exposed to mental, physical and emotional problems caused by the complexity of the disease and the conditions of care.^[14-16] According to many studies, it is clear that the process of caregiving is stressful and challenging for all groups of caregivers, and interventions are thus necessary.^[17-19] Alzheimer's disease is a major health and social problem that affects not only the patient but also several other subjects and people, including caregivers, mortality rates, and health-care expenses.^[20,21] Stress among patients, especially those with known risks, has been more studied than caregivers of patients with particularly unobserved risks.^[22,23] Although the presence of stress has been reported in careers of different patients, according to previous studies, its severity varies with patient and career individual factors.^[24,25] Because of the unknowns of many factors related to caregivers' stress in different societies, researchers believe that further studies should be planned to understand their mental status and related factors to improve the their quality of life of them.^[24,25] These caregivers report a heavier responsibility and poorer physical health than the caregivers of patients with other long-term diseases.^[6] Some studies have argued that caregivers of Alzheimer's patients experience higher perceived stress compared to caregivers of patients with other chronic disease.^[26,27]

According to many caregivers, one of the problems that disrupt their quality of life is the progressiveness of the disease and fear of the future and the stress imposed on the caregiver in the course of the disease.^[28,29] It is important to first address care-related issues such as stress, and then implement health-related programs to assist informal^[30,31] and formal caregivers.^[18] Properly examining Alzheimer's caregivers' stress and related factors is important to understand these problems and address such serious responsibility of greater health for them,^[20,31,32] but they are not accessible easily in Iran since they often perform caring in silence.^[2] Although caregivers can play the main role in creating a suitable environment and providing high-quality health care for Alzheimer's patients.^[16] The feeling of shame and fear of others judgments lead some of them to the isolation from the real world that it may also be a factor of their stress.^[2] Few studies in Iran and some other countries have shown stigma among Alzheimer's caregivers in some countries such as Iran. Thus, they are almost invisible and inaccessible.^[2] For this reason, there is little information about the amount of stress, depending on age, education, gender, work experience, etc., Most of them have not been registered as caregivers. Sampling and studying their problems are difficult. However, since their health status is affected by caring activity, as they are presented as "secret victims,"^[29] their health status is important and cannot be ignored.

The present study was conducted to determine the stress and related factors among Alzheimer's caregivers at patients' homes and nursing and retirement homes.

Methods

The present descriptive, analytical, cross-sectional study was conducted in December 2017–June 2018 in Isfahan, Iran.

A convenience sample (easy access) of caregivers was recruited from calling the home of formally diagnosed with Alzheimer's patient that have registered in governmental health centers in Isfahan within the prior year. To be eligible, caregivers who provided substantial daily care for a patient living with Alzheimer's disease or other dementias in the age of 60 years and older. The caregivers had at least 6 months of experience caring for a patient diagnosed with Alzheimer's disease. Females and males, 18 years of age and older, with all levels of education and economic status, were eligible to participate. All caregivers provided informed consent. Finally, 99 caregivers who volunteered to attend study have completed the questionnaires. They have been invited to the health center. They were two groups^[1] informal caregivers, including family members or friends who voluntarily assumed responsibility for caring for the

patient;^[2] formal caregivers who were paid for the care they give. Some of them sent by service companies, and the other formal caregivers were free from any company.

Data were collected by completing questionnaires developed by the researcher using the results of a relevant qualitative study conducted on the stress and by the experience of caregiving to older adults with dementia as well as the standard Perceived Stress Scale (PSS).^[33] Caregivers whose patients had recorded at a psychiatrist's office or an educational hospital were selected through convenience sampling for participation in the study. Some of the formal caregivers provided their services in the patients' home and some in nursery homes. The other caregivers included the patients' family or friends who had at least 6 months of experience in giving care to Alzheimer's patients and who were willing to take part in the study. The caregivers reserved the right to discontinue their cooperation at any time. It took 15–20 min to complete each questionnaire by interviewing with caregivers.

The questionnaires contained demographic items (sex, age, marital status, hours of daily caregiving, the overall duration of caring for the patient, education level, previous experience of caring for Alzheimer's patients, kind of caregiving, and sending by service companies), plus 16 Likert-based items for assessing the stress experienced by dementia patients' caregivers. Instances include "When you are taking care of the patient, you feel stressed and nervous," and the items were scored as follows: never = 0; almost never = 1; sometimes = 2; fairly often = 3; very often = 4. Higher scores meant a higher stress level. The items did not require recoding. The PSS is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. The standard questionnaire contained 14 and 10 items.^[33,34] The Cronbach's alpha for the questionnaire was found as 0.92 in the present study. The collected data were analyzed in SPSS version 18 (SPSS Inc; an IBM Company, Chicago, IL) using descriptive statistics (central and dispersion indexes such as mean and standard deviation as well as graphs and data tables). The type and severity of the relationship between the dependent variable (stress) and independent quantitative variables (age, hours of daily caregiving, and overall duration of caring for the patient) were assessed using the Pearson's correlation coefficients. Spearman's correlation coefficients were used for determining of relationship between stress and ordinal variable (education level). The independent *t*-test used to compare the stress mean score in two groups based on sex; marital status, kind of caregiving; previous experience of caring for Alzheimer's patients; service companies. To multivariate regression analysis,

stress as the dependent variable and age; sex; kind of caregiving; family relationship with the patient; previous experience of caring for Alzheimer's patients; and service companies as the independent variables were entered by forward method.

Results

All of 99 (100%) participated caregivers completed the questionnaires. Participants' age ranged from 18 to 80 years, with a mean and standard deviation of 46.9 ± 15.5 years. The mean hours of daily caregiving were 13.8 ± 8.1 , and the overall duration of caring for the patient was 32.8 ± 22.6 months. Table 1 presents the other details of the caregivers. The caregivers' mean stress score was 25.4 ± 10.9 . According to the Pearson's correlation coefficient, the caregivers' stress score had a direct relationship with their age ($r = 0.295$, $P = 0.004$) but had no significant relationships with their hours of daily caregiving ($r = 0.109$, $P = 0.29$) or their duration of caring for the patient ($r = 0.110$, $P = 0.28$). Spearman's correlation coefficient test showed no significant relationships between the caregivers' stress score and their education level ($r = 0.086$, $P = 0.40$). According to the independent *t*-test, the mean stress score was significantly higher in the female than in the male caregivers. This means the score also significantly was higher in the family caregivers. Meanwhile, this mean score was significantly lower in caregivers with previous

Table 1: Sociodemographic characteristics of participants

Variable	Number of respondents (%)
Sex	
Female	79 (79.8)
Male	20 (20.2)
Education level	
<12 years	39 (39.4)
High school diploma	27 (27.3)
University education levels	33 (33.3)
Marital status	
Married	76 (76.8)
Single	19 (19.2)
Widow	2 (2.0)
Divorced	2 (2.0)
Previous experience of caring for Alzheimer's patients	
Yes	25 (25.3)
No	74 (74.7)
Kind of caregiving	
Formal caregivers	52 (52.5)
Family caregivers	47 (47.5)
Caregivers were sent by service companies	
Yes	19 (19.2)
No	80 (80.8)
Total	99 (100)

experience of caring for Alzheimer’s patients and those sent by service companies. As shown in Table 2, no significant differences were observed in the mean stress score between single and married caregivers.

The multivariate linear regression analysis showed that, out of the variables with a significant relationship with the stress score, family relations with the patient, family caregiving and a previous experience of caring for Alzheimer’s patients were stronger predictors of the stress score, and the other variables were not significant predictors of the stress score in the presence of these three variables [Table 3].

Discussion

The present study was conducted to determine the mean of stress score and its predictors among a group of Alzheimer’s patients’ caregivers. As some previous researchers have reported, many of caregivers’ experience many problems, such as stress.^[35] Caregiver

stress in the population under study can, therefore, be considered a serious health problem. Alzheimer’s patients require assistance and supervision in their daily activities, and the burden of this care often falls on informal caregivers (family members), who undergo significant amounts of stress and experience heavy workloads.^[12,35] According to several studies, Alzheimer’s patients need caregivers’ help for living and their daily activities, and due to the burden of care and their relationship with the patient, the caregivers of dementia patients often experience chronic and emotional strains that may lead to emotional fatigue and occupational burnout.^[36] Some qualitative studies have even noted sustained stress and despair in Alzheimer’s caregivers.^[37] According to the stress score obtained in the present study (25.4 ± 10.9), caregivers’ stress was classified as moderate and is considered a serious problem. Given that formal caregivers were also assessed in the present study, and based on the results of previous studies, nursing can be considered a very stressful profession. Even formal nurses experience certain levels of stress due to their heavy workloads and responsibilities, and this stress is considered a health problem.^[38] In the present study, the caregivers’ stress score had a direct relationship with their age. The direct relationship between age and stress appears logical, since the majority of caregivers are middle-aged, and many family caregivers thus have to simultaneously support their children and their parents and experience some age-related problems of their own as well. The term “sandwich generation” seems to be true of these people. Emotional and physical fatigue can affect women’s family life. Many women who are engaged in caregiving, including caregiving for patients with dementia, often look after their children and older parents at the same time, which interferes with their ability to provide family care and affects the quality of life in their family.^[10] The duration of caregiving varied from one to several years in the present study, and some of the participants were family members who provided 24-h care, which can be a factor contributing to stress. Some studies have referred to caring for dementia patients as a 36-h/day job that causes physical, mental, and emotional problems for the caregivers.^[36] In the present study, 80% of the caregivers were female. As noted, the majority of caregivers in the present study were women with primary school education. Other studies have reported nearly similar results to the present study and have proposed neuropsychiatric symptoms as a predictor of the caregiving burden. Reports show that female caregivers experience overall higher levels of care burden, depression, and stress compared to men in many different countries and settings.^[10] All of these factors predict anxiety disorder.^[35] Caregiver stress increases as the Alzheimer’s patient’s conditions worsen, especially in the case of female caregivers, and their health deteriorates, and their quality of life and care

Table 2: Differences in mean score with sex, marital status, kind of caregiving, previous experience of caring for Alzheimer’s patients and sent by service companies

Variables	Mean±SD	P	Statistics
Sex			
Female	26.4±10.6	0.04	t=2.18, df=97
Male	21.5±11.4		
Marital status			
Single	25.1±9.2	0.82	t=0.22, df=97
Married	25.7±11.5		
Kind of caregiving			
Family caregivers	29.5±10.8	<0.001	t=3.73, df=97
Formal caregivers	21.8±9.7		
Previous experience of caring for Alzheimer’s patients			
Yes	20.8±8.2	0.02	t=2.44, df=97
No	26.9±11.3		
Caregivers were sent by service companies			
Yes	19.1±10.5	0.005	t=2.90, df=97
No	26.9±10.5		

SD=Standard deviation

Table 3: The multivariate linear regression model to predict stress score based on different variables

Variables	Raw coefficients	Standard coefficients	P
Age	0.092	0.131	0.23
Sex	-1.289	-0.048	0.64
Kind of caregiving	-3.684	-0.348	0.03
Family relationship with the patient	14.043	0.616	0.01
Previous experience of caring for Alzheimer’s patients	-2.639	-0.311	0.04
Caregivers were sent by service companies	1.051	0.038	0.76

also decreases.^[39] According to the latest information from some countries, >84% of unprofessional caregivers are women. The pressure of caregiving increases the incidence of physical and psychological problems in them and affects their ability to provide care.^[40] According to the results obtained, family relations were the strongest predictor of the stress score in this group. In one study, the majority of nurses were female and professional stress had no significant relationship with social-demographic factors such as age, marital status, number of children, and the nurse's gender.^[38] In the present study, the majority of the caregivers were also female, and the stress had a significant relationship with gender and age, but not with education or marital status. Many studies have investigated the caregiving experiences of both family and formal caregivers. A qualitative study on this subject reported stress and problems caused by caregiving in the family and demonstrated the various challenges and complexities of family and formal caregiving at home. These results are indicative of the need to improve course, training, and support for caregivers.^[41,42] In the present study, the mean stress score was significantly higher in family caregivers compared to formal caregivers [Table 2]. Informal caregivers are categorized as family caregivers and are mostly made up of the patients' spouses, daughters, etc., as demonstrated both in this study and in others.^[10,41,42] Given the nature of Alzheimer's disease, the patients' challenging behaviors contribute to caregiving stress. Different countries and cultures have different expectations of women for assuming the caregiving role. Female caregivers of spouses with dementia rarely introduce themselves as "caregiver;" instead, the caregiver is a label that is used for service providers. The caregiving role is regarded as a lifelong commitment to family care. Family caregivers of dementia patients experience mental health problems such as depression and anxiety disorders. Female caregivers report higher levels of responsibility, stress and depression symptoms than their male counterparts.^[10] The mean stress score was significantly higher in family caregivers, which seems a logical finding. The emotional relationship between the caregiver and the recipient of these services and the progressive nature of the disease and its anticipated outcome are factors contributing to caregiving stress. Other studies have also noted the relationship between the caregiving experience and factors such as the emotional relationship between the caregiver and the patient.^[12] Some studies have also mentioned the experience of stress informal caregivers. Supporting nurses is thus strictly recommended. Since some of the participants in the present study were formal caregivers and this group also experienced caregiving stress, it is mandatory to also support formal caregivers and help them prevent stress caused by their work with patients and potential negative health outcomes.^[38] The mean

stress score among formal caregivers and caregivers sent by service companies to provide care for Alzheimer's patients was significantly lower compared to the other caregivers.

It appears that caregivers who provide care within the framework of a service company consider their responsibilities a job and are therefore less stressed compared to family caregivers who regard caregiving as a lifelong commitment. Dementia care is primarily undertaken in the community. In less indebted middle-income countries, this is often a much higher figure, although difficult to quantify. Care is typically provided by family members (often daughters or daughters-in-law) at home.^[10] According to the present findings, people with previous experience of caregiving to Alzheimer's patients had less stress than those who had assumed this responsibility for the first time. Since they had encountered the challenging and high-risk behaviors of the patients in their previous experience and had learned how to deal with them. Other studies have also confirmed this finding. Caregivers, especially female caregivers, need to be individually trained on how to understand and manage the behaviors of their relatives with dementia and how to deal with their own emotions so that they can be less stressful when coping with their patient.^[10, 43]

Study limitations

There were some limitations to this study. One of the limitations of this study was nonrandom sampling. Another limitation was the small sample sizes of dementia caregivers in the study. Smaller samples make it more difficult to reach generalizability of results. The management of retirement homes and other care facilities for older adults with dementia were not always cooperative due to the heavy burden involved in caring for these patients.

Conclusion

In the present study, the majority of the caregivers of people living with Alzheimer's disease or other dementias were formal, female, and their health was threatened with moderate stress that constituted a significant problem. Therefore, stress is a challenge in promoting mental health among dementia caregivers. Their stress had a direct relationship with age and gender, and the stress score was significantly higher in female and family caregivers. In contrast, the stress score was significantly lower in, formal caregivers sent by service companies with previous experience of caring for dementia patients.

These findings demonstrated the need for educational, emotional, and financial support from better coordinated

and compassionate services for the female family caregivers of Alzheimer's and dementia patients to promote stress management and mental health in this group.

Acknowledgments

The authors would like to express their gratitude to Isfahan University of Medical Sciences for funding this project, and to the patients, their families and caregivers, and the staff at the selected retirement homes, for their cooperation and help in conducting this study.

Financial support and sponsorship

This article is part of a Ph.D. thesis by Shakiba Zahed in the field of Health Education and Promotion and was funded by the Student Research Center, School of Health, Isfahan University of Medical Sciences, Isfahan, Iran.

Conflicts of interest

There are no conflicts of interest.

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