ORIGINAL RESEARCH

The relationship between care burden and social support in Turkish Alzheimer patients family caregivers: Cross-sectional study

Sabire Yurtsever[1], Aynur Özge[2], Aysun Kara[3], Aslıhan Yandım[4], Simge Kalav[5], Pınar Yeşil[6]

1. Nursing Department, School of Health, Mersin University, Mersin, Turkey. 2. Neurology Department, Health Research and Practice Center, Mersin University, Mersin, Turkey. 3. Anatolia Health High School, Hacı Bozan Bozanoğlu, Urfa, Turkey. 4. Nursing Management Department, Health Research and Practice Center, Mersin University, Mersin, Turkey. 5. Surgical Intensive Care Unit, Aşkım Tüfekçi Public Hospital, Mersin, Turkey. 6. Nursing Department, School of Health, Çukurova University, Adana, Turkey.

Correspondence: Sabire Yurtsever. Address: Mersin Üniversitesi Sağlık Yüksekokulu Çiftlikköy Kampusu, Çiftlikköy, Mersin, Turkey. Telephone: 09-324-361-05-81. Email: sabire00@yahoo.com.

Received: August 9, 2012 **Accepted:** October 8, 2012 **Online Published:** February 25, 2013
DOI: 10.5430/jnep.v3n9p1 **URL:** http://dx.doi.org/10.5430/jnep.v3n9p1

Abstract

Objectives: Most of the Alzheimer's patients are looked after at home by family members. Caregivers who are not prepared for looking after these patients are under pressure because of their increasing needs. Both patients and family members need social support provided by not only healthcare professionals but also family, friends and neighbors in order to cope with their physical, psychological, social and economical problems. This study was conducted in order to determine the relationship between care burden and perceived social support of family caregivers who look after an Alzheimer's patient.

Methods: This study was cross-sectional and conducted at a neurology outpatient clinic of a university hospital. 107 family members who take care of an Alzheimer's patient was included. Personal information form, Barthel Index (BI), Lawton-Brody Index (LBI), Multidimensional Scale of Perceived Social Support (MSPSS), and Zarit Burden Interview (ZBI) were used to collect data. The mean, percentage, Shapiro-Wilk, Student T-test, Mann-Whitney U test, One-way ANOVA, Kruskal-Wallis test, and Pearson's correlation tests were used to evaluate the data.

Results: Family caregivers' average ZBI score was determined to be 53.09 ± 18.19 and average MSPSSS score was 51.78 ± 19.62. Caregivers' age is 51 and above, who were female, who were illiterate, and who were patients' spouse had high ZBI scores and low MSPSS scores. It was determined that there was a negatively significant correlation between the caregivers' ZBI and MSPSS scores ($p < .01$). The patient's LBI mean score was 13.98 ± 3.08, and BI mean score was 43.61 ± 13.52. There was a statistically significant relationship between the patients' LBI and ZBI scores ($p < .01$). Moreover, there was a statistically significant relationship between the patients' BI and ZBI scores ($p < .01$). However, patients' LBI and BI scores are not statistically related to the MSPSS scores.

Conclusions: Motivating family caregivers' social support networks and encouraging caregivers to make use of these networks will be very helpful in coping with caregiving problems.

Key words

Alzheimer disease, Care burden, Family caregiver, Social support

1 Introduction

The frequency of dementia keeps increasing along with that of the elderly population [1]. Fifty percent of all cases of dementia are accompanied by Alzheimer's disease. Alzheimer's disease causes cognitive and behavioral problems resulting from neurodegenerative changes. Its symptoms, amnesia, orientation disorder and physical disability, are progressive [2]. This condition develops over a time frame of 3-20 years; it degrades some of the cerebral functions such as ideation, memory, learning, speaking, logical thinking, judgment, communicating, and activities of daily life [3]. Changes in cognitive function may be observed during the course of this disease, which renders the patient dependent on other people for daily life activities.

In Turkey, as many other countries, a majority of Alzheimer's patients are cared for by family members. Alternative care possibilities, such as visiting caregivers or dedicated inpatient institutions, are not available in Turkey. Worldwide, approximately 8.9 million persons are estimated to be looking after patients over 50 affected by Alzheimer's or dementia from other causes [4]. Caregivers who lack the training needed care for these patients are under pressure because of the increasing needs. Serious problems including financial, personal and marital stress, difficulties in obtaining admission to care centers or schedule for assistance, and various social problems may be observed over the long term [5-8].

The negative impact of the patients' physical, psychological and social problems on family members thus experience social, financial and mental repercussions [9, 10]. This further impairs patient care. These patients need help with most of the daily chores and caregivers also have to cope with inappropriate or violent behavior, which may affect the latter's physical and mental health [11]. Looking after an Alzheimer's patient may be very stressful for caregivers. Varona et al. [12] found that a moderate to high level of burden perception in adult-child caregivers.

Persons providing care to Alzheimer's patients are in poor physical health when compared to other caregiver groups, as shown by studies of immune system changes [13] and physical symptoms [14], found to be more frequent in this type of caregivers. Moritz et al. [15] determined that male caregivers who looked after their own wives had a higher systolic blood pressure than controls. Another study reported that caregivers who look after an Alzheimer's patient with little social support evidenced reactive heart rates during emotionally charged conversations [16]. Yet another study emphasized that hostility, anger, avoidance without coping, type A behavior, and emotionality in caregivers of Alzheimer's patients were related to cardiovascular reactivity [17]. Chronic stress increases the risk of hypertension in caregivers of Alzheimer's patients [18, 19]. Shaw et al. [18] in their study determined that 67% of these people are at risk for hypertension. It was also indicated that caregivers of Alzheimer's patients use more medication and get more medical support as compared to caregivers for other types of disease [20]. Especially female spouses of patients have more problems of energy deficit, depression and sleeplessness than male spouses [21]. It was also reported that a patient's disability level is strongly related to the caregiver's energy deficit, emotional reaction frequency and experience of social isolation [21]. In another study, it was noticed that women caregivers of Alzheimer's patients had higher depression scores [22]. Chang et al. [23] found higher levels of physical support to be associated with poorer mental health, a higher care burden, a greater number of illness symptoms and chronic conditions, and a lower self-perceived health score. Mental health and care burden were found to be significantly correlated to the caregivers' health problems in the last mentioned study [23].

Personal damage is not limited to physical and psychological health or family, business and social relationships when looking after an Alzheimer's patient [24, 25]. Extended disease causes financial problems to families [9]. Covinsky et al. [26] reported that caregivers with limited financial resources were more often depressed. It was also observed that it was harder for low-income caregivers to take care of their sick family members [27] and that those caregivers with poor economic status also had a low quality of life [28] and a higher stress level [29]. Caring for people with Alzheimer's disease has been variously characterized as demanding adjustment strategies, constituting threatening events and having a forceful emotional impact [30-32].

As indicated above, in order to cope with their physical, psychological, social and economical problems, both patient and family need social support, to be provided by not only healthcare professionals but also family, friends and neighbors. Some studies indicate the importance of social support for physical and mental health [33, 34]. Social support is available to individuals who have a chance to express positive or negative emotions while coping with hardship [35]. Discussing their problems with other people helps them improve family communication, identify needs, and adjust to a progressive and changing disease [35].

Social support is a complex concept, defined in a multitude of ways [36]. The level of social support of an individual has commonly been examined with metrics such as the size of social network, its density, the frequency of contacts and reciprocity [37]. Social support includes informational, emotional, and instrumental support [38]. Studies confirmed the presence of a strong negative correlation between the availability of support systems and caregiver distress [39, 40]. Drentea et al. [38] determined that 65% of spouse-caregivers reported receiving no physical help. Varona et al. [12] found that caregivers able to receive some social support, even though under more intense stress factors, had a tendency to a lower burden perception compared to those without such social support. The authors also reported that the availability of support from the family and social network mitigates the negative impact of the patient's cognitive and behavioral disturbances [12].

Other studies point to a positive impact of perceived social support on caregiver burden [41, 42]. Some reports suggested that perceived social support can better predict health outcomes and distress among caregivers than the level of effectively received social support [39, 43]. Thompson et al. [44] suggested that instrumental and emotional support were ineffective in reducing the caregiver burden of family members who look after frail, elderly patients.

Aim

This study was conducted to determine the relationship between care burden and perceived social support of family-member caregivers of Alzheimer's patients.

We tried to find answers for the following questions:

- What is the care burden level of family-member caregivers?
- What is the level of social support as perceived by family-member caregivers?
- Do care burden and perceived social support scores of family-member caregivers depend on their socio-demographic characteristics?
- Do care burden and perceived social support scores of family-member caregivers depend on patient characteristics and care requirements?
- Is there a correlation between care burden and perceived social support scores of family-member caregivers?

2 Material and methods

2.1 Sample

This cross-sectional study was conducted at the neurology outpatient clinics of a university hospital. Between February 1 and August 30, 2010, determined as data collection period, 119 Alzheimer patients consulted at the outpatient clinics. Of these, 12 were deemed ineligible due to caregiver characteristics; 107 Alzheimer's family-member primary caregivers were included in the study. The study was restricted to family-member caregivers for Alzheimer's disease, as requirements of patient care may differ among different types of dementia. The caregiving family member was in each case identified among those providing care to the patients recorded at the neurology outpatient clinics where the study was performed.

The 107 subjects included in the study responded to the following criteria: the patient cared for had had a diagnosis of Alzheimer's disease, and the patient had received care from the same primary caregiver, for 3 months or longer, the caregiver requirements were: age over 18, physical and cognitive health status adequate for responding to the study questionnaires, absence of communication problems (speaking, hearing, understanding etc.) and voluntary consent to participate in the study. Cognitive health status was evaluated by one of the investigators, a neurologist, prior to the administration of the questionnaires.

2.2 Measurements

A personal information form was used to determine the sociodemographic characteristics of the caregiver and the care requirements. The Barthel Index (BI) and the Lawton-Brody Index (LBI) were used to evaluate the patient's daily activity; a Multidimensional Scale of Perceived Social Support (MSPSS) was used to determine the caregiver's perceived social support level, and a Zarit Burden Interview (ZBI) to record the caregiver's care burden.

The personal information form was designed for the carer's sociodemographic characteristics as well as factors specific to the disease and its care. These are presumed to have an influence on the care burden and social support levels. This form included information on variables such as age, gender, marital status, economic status (categories: income lower than expenses, equal to expenses, and exceeding expenses), educational status, caregiver health and presence of chronic disease, patient's disease status, other care-related factors such as disease duration and care duration, and level of dependence on caregiver.

The BI was developed by Barthel and Mahoney in 1965. It evaluates mobility and self-care activities, and its reliability has been validated in various patient populations and societies. The BI consists of 10 items evaluating a person's daily functioning and more specifically the activities in daily life and the patient's mobility grade. Single items include feeding, moving from wheelchair to bed and vice versa, grooming, transferring to and from the toilet seat, bathing, walking on a level surface, going up and down the stairs, dressing, and bowel and bladder continence. The score ranges from 0 to 100, where 0-20 points indicate a fully dependent, 21-61 highly dependent, 62-90 semi-dependent, 91-99 almost independent and 100 points a fully independent patient [45].

The LBI instrumental daily life activity scale was developed by Lawton and Brody. It is evaluating independent living in society. This index consists of 8 questions that aim to determine a person's instrumental daily life activities, such as using a phone, cooking, shopping, daily household chores, laundry, using public transportation, taking pills and managing one's finances. For each activity, three points are awarded for independent performance, two points if some help is needed and one point if no performance is possible. A total score of eight indicates a fully dependent, 9-16 points semi-dependent, and 17-24 points a fully independent patient [46].

The ZBI, developed by Zarit, Reever and Bach-Peterson in 1980 aims to evaluate the stress level of caregivers. This interview can be filled out by either the caregiver or an investigator. The interview consists of 22 questions to determine the impact of caring on the caregiver's life. The evaluation uses a Likert-type scale where 0 indicates never, 1, seldom, 2, sometimes, 3, usually and 4 always. The ZBI was checked for validity and reliability by İnci [47] after translation into Turkish and adaptation to Turkey. The total minimum score is 0 and the maximum 88. Questions in this interview generally relate to social and emotional issues. A high total score indicates a heavy care burden [48].

The MSPSS was developed by Zimet and his friends in 1988 [49]; it aims to determine how social support factors are perceived by individuals. Eker and Akar [50] conducted its reliability and validity studies for Turkey. The evaluation uses a

Likert-type scale, with 12 questions each of which offer 7 reactions to choose from, ranging from 1 that corresponds to "very strongly disagree" to 7, meaning "very strongly agree".

This scale has three subscales to evaluate support by family, friends and significant others. All three subscales have 4 questions. Individual subscale scores vary between 4 and 28, and the total score varies from 12 to 84. The higher the score, the more perceived social support the person is reporting.

2.3 Data collection

A statement of the study purpose and methods was sent prior to starting the study to the hospital direction of the study facilities to obtain formal authorization to perform the research. The study was started subsequent to the granting of this authorization. Family-member caregivers provided their written informed consent after being informed of the aims, purpose and procedures. Family-member caregivers were informed by the investigating team they were free to withdraw their voluntary participation at any moment. The BI and LBI were essentially applied to the patients in the neurology outpatient clinics to evaluate daily activities. The personal information form, ZBI and MSPSS were filled out for caregivers during a one-to-one interview in another room. Forms were filled by the investigating team members over approximately 30 minutes.

2.4 Data analysis

Data coding and evaluation was performed with the help of the Statistical Package for the Social Sciences (SPSS) 11.5. Descriptive statistics such as mean, standard deviation, and percentiles were used for all variables. The Shapiro-Wilk normality test was used to check the distribution of scores. Two independent groups were compared according to their scores. Student *t*-test was used for normally distributed variables (age, gender, marital status, and presence of chronic disease-ZBI and MSPSS scores) and the Mann-Whitney U test for the others (age –MSPSS score). A one-way ANOVA was performed to compare simultaneously two or more variables with normal distribution (income level, live-in with the patient, care duration and patient's dependence- ZBI and MSPSS score) and the Kruskal-Wallis test for variables without a normal distribution (educational level- MSPSS score, patient's degree of relationship- ZBI and MSPSS score). Pearson's correlation was used to evaluate linear correlations between two continuous variables (BI, LBI, ZBI and MSPSS scores). *P*-values below 0.05 were considered statistically significant.

We did not conduct regression analysis. In accordance with the objectives of our study, we present subgroup ZBI and MSPSS scores.

3 Results

3.1 Family-member caregiver characteristics: ZBI and MSPSS scores

Table 1 shows the caregivers' sociodemographic characteristics and their ZBI and MSPSS mean scores. The ZBI mean score was 53.09 ± 18.19 and MSPSS mean score was 51.78 ± 19.62. Caregivers over 51 had a statistically significantly higher ZBI score and lower MSPSS score than younger family-member caregivers ($p< 0.05$). Women's ZBI scores were higher and their MSPSS scores lower when compared to men ($p< 0.05$). Married caregivers had higher ZBI mean scores than single caregivers ($p< 0.05$), while the latter's MSPSS scores were higher than those of the married, all differences being statistically significant ($p< 0.05$) (see Table 1). The educational level was inversely correlated with the ZBI score and. income level correlated positively with MSPSS score (both $p< 0.05$) (see Table 1).

3.2 Patient and care characteristics

Table 2 shows patient and care characteristics and their mean ZBI and MSPSS scores. The patients' LBI mean score was 13.98 ± 3.08, and BI mean score was 43.61 ± 13.52.

No significant correlation could be established between any of patient age, caregiver's degree of relationship to the patient, duration of care or caregiver's experience and the ZBI and MSPSS scores. Caregivers of dependent patients had higher ZBI mean scores than those taking care of semi-dependent patients ($p < 0.05$). The MSPSS scores were comparable between these two groups (see Table 2).

Table 1. The Caregiver Characteristics and ZBI and MSPSS Mean Scores

Characteristics	n	%	ZBI Mean ±SD	*P* value	MSPSS Mean ±SD	*P* value
Age*						
25-50 years	52	48.60	48.63±18.74	.006	54.43±18.77	.037
51 and above	55	51.40	54.68±16.84		49.28±14.73	
Gender						
Female	91	85.05	55.93±19.23	.003	50.58±16.64	.009
Male	16	14.95	46.64±16.51		53.69±18.73	
Marital Status						
Single	22	20.56	46.33±15.48	.007	54.75±13.21	.045
Married	85	79.44	53.57±18.83		48.92±19.79	
Educational Level						
Illiterate	8	7.48	54.97±19.24	.027	32.59±75.73	.009
Primary School	27	25.23	52.67±51.89		41.09±19.79	
Secondary School	19	17.76	46.59±19.64		54.83±17.27	
High School	31	28.97	43.77±16.99		56.11±20.05	
University	22	15.49	37.91±15.15		57.02±17.48	
Income Level						
High	12	11.21	54.96±17.78	.081	59.61±19.27	.049
Middle	46	42.99	52.71±09.91		45.89±20.11	
Low	49	45.79	55.04±20.51		44.28±19.58	
Lived With Patient						
With AD Patient	26	24.30	55.01±15.08	.088	46.94±24.85	.091
AD Patient and Family Members	53	49.53	54.06±14.39		49.71±16.37	
AD Patient, Family Members and Relatives	9	8.41	49.83±15.72		51.20±14.46	
Only Family Member (AD Patient at Separate Home)	19	17.76	44.72±14.44		47.70±21.02	
Chronic Disease						
Yes	61	57.01	54.08±17.19	.091	47.91±16.52	.217
No	46	42.99	52.87±17.25		49.09±19.26	

*Grouped with a cut-off of 50 years, as younger people are actively occupied

Table 2. The Patients Characteristics and Care Requirements and ZBI and MSPSS Mean Scores

Characteristics	**n**	**%**	**ZBI Mean ±SD**	***P* value**	**MSPSS Mean ±SD**	***P* value**
Patients Age						
54-75 years	39	36.45	52.31±14.93		49.52±19.06	
76 and above	68	63.55	51.94±19.73	.872	50.89±19.98	.392
Patient's Affinity Degree						
Spouse	31	28.97	56.31±17.79		39.84±19.74	.078
Children	66	61.68	51.76±15.78		50.83±18.90	
Relative/Friend	10	0.93	42.00±22.44	.022	46.50±25.79	
Care Duration						
3-12 months	29	27.10	49.45±15.39		51.72±20.60	
1-3 years	47	43.93	54.67±16.81		50.79±21.49	.
4 years and above	31	28.97	55.09±18.31	.054	53.93±17.52	393
Patient's Dependence Level						
Independent*	1	0.93	18.00		36.00	
Semi-dependent	59	55.14	52.22±15.02		53.45±19.42	
Dependent	47	43.93	56.79±17.78	.027	53.24±21.76	.860

* No statistical evaluation was performed.

3.3 Relationships between ZBI and MSPSS scores

There was a negative, significant correlation between the caregivers' ZBI and MSPSS scores ($p< 0.01$) (see Table 3).

Table 3. Correlation Between ZBI, MSPSS, LBI, and BI Scores

	ZBI Score	**MSPSS Score**	**BI Score**	**LBI Score**
ZBI Score	1	-.676*	-.483*	.629*
MSPSS Score		1	-.291	.189
BI Score			1	-.745*
LBI Score				1

*Significant .01 level

4 Discussion

In Turkey, family-member caregivers play an essential role in the care of patients with dementia. The ZBI and MSPSS scores of caregivers were higher than average in our study. A previous study had showed that 18 of 24 centers had ZBI scores between 23 and 37 [51]. ZBI scores in this report were lower than in our study (53.09 ± 18.19). We believe that the absence of a home care organization in our country to ensure the continuity of care plays a role in this higher ZBI score. Previous publications reported that behavioral problems such as night wandering, incontinence, agitation, and increasingly impaired memory, which ultimately causes the patient to be unable to recognize his or her caregiver, can be especially difficult for the latter [52, 53].

In our study, caregivers below 50 years of age had lower ZBI scores and higher MSPSS scores than younger subjects, while a published study reports the contrary, i.e. a higher care burden in younger caregivers [27]. Younger caregivers, having more extensive social networks and higher educational levels, can cope more with problems more effectively.

Most of the caregivers in our study were women, which is similar to previous published studies [27, 54] Women had higher ZBI scores and lower MSPSS scores than men. Since caregiving is seen as a feminine duty in Turkish culture, as is the case for many cultures around the world, it is regarded as a follow-up to women's domestic responsibilities. Perception of caregiving as a simple duty may lead to insufficient social support. Therefore, women's role in caregiving, coupled with other domestic responsibilities and lack of sources of support, brings about increased burden of caregiving.

Single caregivers had lower ZBI scores as compared to married ones. Similarly, single caregivers had higher MSPSS scores than the married. Single persons may have fewer responsibilities, while married caregivers have to cope with their family's problems in addition to those of their patients.

The study here presented found that ZBI scores are inversely related to the educational level of caregivers, while MSPSS scores are directly related to it. This may indicate the importance of education in coping with problems. Our study also found a positive correlation between education level and income level. Well-educated caregivers usually have higher income levels. Their social support networks and their ability to access information may be better. Previous studies have reported that caregivers with a higher level of education have more extensive social networks [55, 56]; a correlation with lower caregiver burden was also established [57, 59].

We found that a majority of the caregivers live with their Alzheimer's patient, which is also the finding reported in published studies [12, 54]. Caregivers living only with the Alzheimer's patient had higher ZBI and lower MSPSS scores than those living with other relatives in addition to the Alzheimer's patient. This observation underlines the significant support provided to caregivers by other family members. The caregiving function may possibly be shared among family members.

In this study, caregivers who look after their spouses had higher ZBI and lower MSPSS scores than those who look after their friends or relatives. Another report observed that caregiving spouses had more health problems and work burdens when compared to looking after other [21]. Caregiving spouses have smaller social networks and higher ZBI scores because they are alone in looking after their patients.

In the present study, it was observed that ZBI scores increased with the length of the caregiving relationship. Similarly Covinsky et al. [26] indicated that a longer duration of caregiving affects the progression of depression in caregivers. The duration of caregiving has been found to be related to burden [12, 57, 58]. It is thought that, as the duration of caregiving increases, caregivers start to have more problems in providing care. It was also found, however, that caregivers with more than four years of experience had higher MSPSS scores; when diseases are progressive by nature, patients will be more and more dependent in time, a significant factor in increased burden of caregiving. Another cause of increased burden of caregiving is the tension brought about by long periods of caregiving.

Zarit Burden Inventory scores of caregivers who looked after dependent patients were higher than the scores of caregivers who were taking care of semi-dependent patients. As the needs of a patient increased, care burdens increased as well. However, MSPSS scores of both groups were very close to each other. Several studies indicate that patients need help in most of their daily activities. Additionally, caregivers have to cope with the patients' inappropriate or violent behavior [59, 60]. Therefore, their care burden increases. The caregivers indicated that providing support for self-care and coping with problematic behavior, physical symptoms and health problems do increase the care burden [14, 61]. Another publication reported that patient health status and daily activity index were related to care burden [21]. Various conditions of care recipients, including functional or cognitive impairment with behavioral disturbances, were found to be associated with the caregiver's burden [62].

Our study subjects showed a significant relationship between the ZBI and MSPSS scores of the caregivers. Other studies similarly indicate a negative correlation between social support and caregiver burden [63, 64]. Other authors confirm that perceived social support has a positive effect on caregiver burden [39, 41, 42]. Pinquart and Sörensen [62] similarly did not find a strong correlation between the amount of care provided and caregiver burden.

Improving social support networks to help caregivers remains, at any rate, an important requirement. Caregivers should be taught how to manage the stress caused by their taking care of patients. They should also be encouraged to join caregiver support groups and spare time for themselves. Probable bio-psycho-social problems might thus be minimized; caregivers who get professional support appear to have better physical health, less care burdens and better quality of life [58].

5 Conclusions

Family-member caregivers' ZBI and MSPSS scores were higher than average in our study. Support by professional medical staff appears to be very important for permanent family-member caregivers, especially so if they are over 50, female, married, women, with a low educational level, a spouse of the patient cared for, providing care for four years or longer, or caring for a dependent patient. It is essential that the needs of caregivers, as well as their health status and sources of support, should be identified in accordance with the holistic approach, that particular plans should be made to reduce the burden of caregiving and that these plans should be monitored regularly.

Providing supportive care with a consideration into the factors in the burden of caregiving will result in reduced burden of caregiving. Being in constant communication with other family members may decrease problems. Discussing problems with nurses will allow caregivers to improve family-internal communication, identify needs and adjust to a disease that keeps progressing and changing [35]. Sharing caregiving experiences in family meetings may be beneficial and relaxing for caregivers. Motivating the social support networks and encouraging caregivers to make use of these should prove helpful in coping with the problems of patient care, helping the caregivers adapt to their roles and providing relief from isolation. Sharing news, interacting the friends and neighbors, discussing problems and feelings may all help relieve the stress of caring for a patient. Providing social support to caregivers will decrease the use of nursing homes, which have very high costs.

Acknowledgements

We would like to thank to the Mersin University Health Research and Practice Center and the family caregivers who participated in this study.

References

[1] Malmgren R, Coffey CE, Cummings JL. Epidemiology of aging. Textbook of Geriatric Neuropsychiatry. The American Psychiatric Press, 2000.

[2] Folstein MF, Basset SS, Anthoniy JG, Ramanoski AJ, Nestadt GR. 1991. Dementia: case ascertainment in a community survey. J Gerontol. 1991; 46: 132-138. http://dx.doi.org/10.1093/geronj/46.4.M132

[3] Smeltzer SC, Bare BG. Textbook of Medical Surgical Nursing. (5th ed.). New York: Lippincott Company, 1996.

[4] Gaugler JE, Roth Dl, Haley WE, Mittelman MS. Can counselling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Result from the New York University Caregiver Intervention Study. J Am GeriatrSoc. 2008; 56: 421-428. PMid:18179495 http://dx.doi.org/10.1111/j.1532-5415.2007.01593.x

[5] Garity J. 2006. Caring for a family member with Alzheimer's disease: coping with caregiver burden post-nursing home placement. J Gerontol Nurs. 2006; 32: 39-48. PMid:16773862

[6] Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology. 2006; 67: 1592-1599. PMid:17101889 http://dx.doi.org/10.1212/01.wnl.0000242727.81172.91

[7] Mittelman MS, Roth DL, Clay OJ, Haley WE. Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention. Am J Geriatr Psychiatry. 2007; 15: 780-789. PMid:17804831 http://dx.doi.org/10.1097/JGP.0b013e31805d858a

[8] Beard RL, Fox PJ. Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss. SocSci Med. 2008; 66: 1509-1520. PMid:18222581 http://dx.doi.org/10.1016/j.socscimed.2007.12.024

[9] Wimo A. Jönsson B, Karlsson I. Winblad B. Health Economics of Dementia. New York: Wiley, 1998.

[10] Arai Y, Kumamoto K, Washio M, Ueda T, Miura H, Kudo K. Factors related to feelings of burden among caregivers looking after impaired elderly in Japan under the longterm care insurance system. Psychiatry Clin Neurosci. 2004; 58: 396-402. PMid:15298653 http://dx.doi.org/10.1111/j.1440-1819.2004.01274.x

[11] Qureshi H, Patmore C, Nicholas E, Bamford C. Outcomes in community care practice. Overview: outcomes of social care for older people and caregivers. York, The University of York, 2000.

[12] Varona R, Saito T, Takahashi M, Kai I. Caregiving in the Philippines: A Quantative survey on adult-child caregivers' perceptions of burden, stressors, and social support. Arch Gerontol Geriatr. 2007; 45: 27-41. PMid:16982103 http://dx.doi.org/10.1016/j.archger.2006.07.007

[13] Kiecolt-Glaser JK, Glaser R, Shuttleworth EC, Dyer CS, Ogrocki P, Speicher CE. Chronic stres and immunity in family caregivers of Alzheimer's Disease victims. Psychosom Med. 1987; 49: 523-535. PMid:3671639

[14] Baumgarten M, Battista R, Infante-Rivard C, Hanley J, Becker R, Gauther S. The psychological and physical health of family members caring for an elderly person with dementia. J Clin Epidemiol. 1992; 45: 61-70. http://dx.doi.org/10.1016/0895-4356(92)90189-T

[15] Moritz DJ, Kasl SV, Berkman L. The health impact of living with a cognitively impaired elderly spouse: depressive symptoms and social functioning. J Gerontol. 1989; 44 (suppl.): 17-27. http://dx.doi.org/10.1093/geronj/44.1.S17

[16] Uchino, B.N., Kiecolt-Glaser, J.K., &Cacioppo, J.T. Age related changes in cardiovascular response as a function of a chronic stressor and social support. J Personal Soc Psychol. 1992; 63 (5): 839-846. PMid:1447696 http://dx.doi.org/10.1037/0022-3514.63.5.839

[17] Vitaliano PP, Russo J, Bailey SL, Young HM, McCann BS. Psychosocial factors associated with cardiovascular reactivity in older adults. J Psychosom Med. 1993; 55: 164-177.

[18] Shaw WS, Patterson TL, Ziegler MG, Dimsdale JE, Semple SJ, Grant I. Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. J Psychosom Res. 1999; 46: 215-227. http://dx.doi.org/10.1016/S0022-3999(98)00084-1

[19] Shaw WS, Patterson TL, Semple SJ, Dimsdale JE, Ziegler MG, Grant I. Emotional expressiveness, hostility and blood pressure in a longitudinal cohort of Alzheimer caregivers. J Psychosom Res. 2003; 54: 293-302. http://dx.doi.org/10.1016/S0022-3999(02)00412-9

[20] Haley WE, Levine E, Brown S, Berry J, Hughes G. Psychological, social, and health consequences of caring for a relative with senile dementia. J Am Geriatr Soc. 1987; 35: 405-411. PMid:3571789

[21] Colvez A, Joel ME, Ponton-Sanchez A, Royer AC. Health status and work burden of Alzheimer patients' informal caregivers comparisons of five different care programs in the European Union. Health Policy. 2002; 60: 219-233. http://dx.doi.org/10.1016/S0168-8510(01)00215-9

[22] Sivrioğlu EY. Alzheimer hastalarına bakım verenlerin desosyodemografik özellikler ve bakım verme biçiminin depresyon düzeyi ile ilişkisi (Alzheimer disease caregiverssociodemographic characteristics and the relationship between care and depression). Yeni Symposium (New Symposium). 2004; 42: 55-59.

[23] Chang HY, Chiou CJ, Chen NS. Impact of mental health and caregiver burden on family caregivers' physical health. Arch Gerontol Geriatr. 2010; 50: 267-271. PMid:19443058 http://dx.doi.org/10.1016/j.archger.2009.04.006

[24] Karlawish JH, Zbrozek A, Kinosian B, Gregory A, Ferguson A, Low DV, et al. Caregiver's assessments of preference-based quality of life in Alzheimer's disease. Alzheimers Dement. 2008; 4: 203-211. PMid:18631969 http://dx.doi.org/10.1016/j.jalz.2007.11.018

[25] MacRae H. Self and other: the importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. J Aging Stud. 2011; 25: 101-109. http://dx.doi.org/10.1016/j.jaging.2011.06.001

[26] Covinsky K, Newcomer R, Fox P, Wood J, Sands L, Dane K, Yaffe K. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. J Gen Intern Med. 2003; 18: 1006-1014. PMid:14687259 http://dx.doi.org/10.1111/j.1525-1497.2003.30103.x

[27] Andren S, Elmstahl S. Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: A cross-sectional community-based study. Int J Nurs Stud. 2007; 4: 435-446. PMid:17078957 http://dx.doi.org/10.1016/j.ijnurstu.2006.08.016

[28] Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's disease: patient and caregiver reports. J Ment Health Aging. 1999; 5: 21-32.

[29] Williams A, Forbes D, Mitchell J, Essar M, Corbett B. The influence of income on the experience of informal caregiving: policy implications. Health Care Women Int. 2003; 24: 280-291. PMid:12746001

[30] Dang S, Badiye A, Kelkar G. The dementia caregiver—a primary care approach. South Med J. 2008; 101: 1246-1251. http://dx.doi.org/10.1097/SMJ.0b013e318187cccc

[31] Cooper C, Katona C, Orrell M, Livingston G. Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. Int J Geriatr Psychiatry. 2008; 23: 929-936. PMid:18383189 http://dx.doi.org/10.1002/gps.2007

[32] Papastavrou E, Kalokerinou A, Papacostas S. Caring for relative with dementia: family caregiver burden. J Adv Nurs. 2007; 58: 446-457. PMid:17442030 http://dx.doi.org/10.1111/j.1365-2648.2007.04250.x

[33] Cohen S, Syme SL. Social Support and Health. Orlando: Academic Press, 1985.

[34] Berkman LF, Glass T, Brissette I, Seeman TE. From Social Integration to Health: Durkheimin the new millennium. Soc Sci Med. 2000; 51: 843–857. http://dx.doi.org/10.1016/S0277-9536(00)00065-4

[35] Spiegel D, Kimerling R. Group psychotherapy for women with breast cancer: relationships among social support, emotional expression, and survival. In emotion, social relationships, and health. Ed. C. D. Ryff and B.H. Singer, New York: Oxford University Press, 2001.

[36] Vaux A. Social and emotional loneliness: the role of social and personal characteristics. Pers Soc Psychol Bull. 1988; 14: 722-734. http://dx.doi.org/10.1177/0146167288144007

[37] House JS, Kahn RL, McLeod JD, Williams D. Measures and concepts of social support. In S. Cohen and S.L. Syme (Eds), Social support and health. Orlando, FL: Academic Press, 1985.

[38] Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social support: Five year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. Soc Sci Med. 2006; 63: 957-967. PMid:16616406 http://dx.doi.org/10.1016/j.socscimed.2006.02.020

[39] Sander AM, High WMJ, Hannay HJ, Sherer M. Predictors of psychological health in caregivers of patients with closed head injury. Brain Injury. 1997; 11: 235-249. PMid:9134198 http://dx.doi.org/10.1080/026990597123548

[40] Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with Parkinson's disease. J Neuro Sci Nurs. 2002; 34: 184-190. PMid:12197259 http://dx.doi.org/10.1097/01376517-200208000-00003

[41] Li LW, Seltzer MM, Greenberg JS. Social support and depressive symptoms: differential patterns in wife and daughter caregivers. J Gerontol- Series B Psychol Sci Soc Sci. 1997; 52: 200-211. http://dx.doi.org/10.1093/geronb/52B.4.S200

[42] Pohl JM, Given CW, Collins CE, Given BA. Social vulnarability and reactions to caregiving in daughters and daughters- in- law caring for disabled aging parents. Health Care Women Int. 1994; 15: 385-395. PMid:8002423 http://dx.doi.org/10.1080/07399339409516131

[43] Ergh TC, Rapport LJ, Coleman RD, Hanks RA. Predictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. J Head Trauma Rehabil. 2002; 17: 155-174. PMid:11909512 http://dx.doi.org/10.1097/00001199-200204000-00006

[44] Thompson EH, Futterman AM, Gallagher-Thompson D, Rose JM, Lowett SB. Social support and caregiving burden in family caregivers of frail elders. J Gerontol. 1993; 48: 245-254. http://dx.doi.org/10.1093/geronj/48.5.S245

[45] Mahoney FJ, Barthel DW. Functional evaluation: The Barthel Index. Md State Med J. 1965; 14: 61-65. PMid:14258950

[46] Lawton MP, Brody EM. Assessment of older people: self maintaining and instrumental activities of daily living. Gerontologist. 1969; 9: 179-186. PMid:5349366 http://dx.doi.org/10.1093/geront/9.3_Part_1.179

[47] İnci FH. BakımVermeYüküÖlçeğininTürkçe'yeuyarlanması, geçerlikvegüvenirliği (Validity and reliability of The Burden Interview and its adaptation to Turkish). Atatürk Üniversitesi HemşirelikYüksekokulu Dergisi. 2008; 11: 76-84.

[48] Zarit SH, Zarit JM. The memory and behavior problems checklist and the burden interview. University Park, PA:Penn State University Gerontology Center, 1990.

[49] Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of of perceived social support. J Pers Assess. 1988; 52: 30-41. http://dx.doi.org/10.1207/s15327752jpa5201_2

[50] Eker D, Akar H. Çok Boyutlu Algılanan Sosyal Destek Ölçeği'nin factor yapısı, geçerlik ve güvenirliği (Factorial structure, reliability and validity of Multidimensional Scale of Perceived Social Support in Turkish population). Türk Psikoloji Dergisi (J Turk Psychol). 1995; 34: 45-55.

[51] The 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries. Int J Geriatr Psychiatry. 2004; 19: 170-177. PMid:14758582 http://dx.doi.org/10.1002/gps.1046

[52] Mittelman MS, Roth DL, Haley WE, Zarit SH. Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: results of a randomized trial. J Gerontol Psychol Sci. 2004; 59B: 27-34. http://dx.doi.org/10.1093/geronb/59.1.P27

[53] Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. Psychol Ageing. 2005; 20: 634-644. PMid:16420138 http://dx.doi.org/10.1037/0882-7974.20.4.634

[54] Mafullul YM, Morriss RK. Determinants of satisfaction with care and emotional distress among informal carers of demented and non-demented elderly patients. Int J Geriatr Psychiatr. 2000; 15: 594-599. http://dx.doi.org/10.1002/1099-1166(200007)15:7<594::AID-GPS154>3.0.CO;2-T

[55] Keller BK, Magnuson TM, Cernin PA, Stoner JA, Potter JF. The significance of social network in a geriatric assessment population. Aging Clin Experiment Res. 2003; 15: 512-517.

[56] Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stres process: an overview of concepts and their measures. Gerontologist. 1990; 30: 583-594. PMid:2276631 http://dx.doi.org/10.1093/geront/30.5.583

[57] Choi HK. Cultural and noncultural factors as determinants of caregiver burden for the impaired elderly in South Korea. Gerontologist. 1993; 33: 8-15. PMid:8440505 http://dx.doi.org/10.1093/geront/33.1.8

[58] McConaghy R, Caltabiano ML. Caring for a person with dementia: exploring relationships between perceived burden, depression, coping and well-being. Nurs Health Sci. 2005; 7: 81-91. PMid:15877684 http://dx.doi.org/10.1111/j.1442-2018.2005.00213.x

[59] Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: An updated mata-analysis. J Gerontol. 2006; 61: 33-45. http://dx.doi.org/10.1093/geronb/61.1.P33

[60] Sörensen L, Waldorf F, Waldemar G. Coping with mild Alzheimer's disease. Dementia. 2008; 7: 287-289. http://dx.doi.org/10.1177/1471301208093285

[61] Bedard M, Koivuranta A, Stuckey A. Health impact on caregivers of providing informal care to a cognitively impaired older adult: rural versus urban settings. Can J Rur Med. 2004; 9: 15-23. PMid:15603671

[62] Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. Psychol Aging. 2003; 18: 250-67. PMid:12825775 http://dx.doi.org/10.1037/0882-7974.18.2.250

[63] Chiou CJ, Chang HY, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. Arch Gerontol Geriatr. 2009; 48: 419-424. PMid:18602706 http://dx.doi.org/10.1016/j.archger.2008.04.001

[64] Okamoto K, Harasawa Y. Emotional support from family members and subjective health in caregivers of the frail elderly at home in Japan. Arch Gerontol Geriatr. 2009; 49: 138-141. PMid:18674826 http://dx.doi.org/10.1016/j.archger.2008.06.003