

# Caregiver Burden In Dementia: A Study In The Turkish Population

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## Abstract

Caring for someone with dementia is associated with a high level of stress. The term "caregiver burden" is used to describe the physical, emotional and financial cost of providing care. The Zarit Caregiver Burden Scale (ZCBS) is one of the most widely used scales in order to determine the degree of burden in caregivers. Up to this date there is no consensus regarding the predictors of high levels of burden. The objective of this study was to determine the degree of burden in informal caregivers of dementia patients in a Turkish population and to evaluate the possible risk factors associated with higher burden. Fifty two dementia patients and their caregivers were analyzed. The affects of different factors including the patients and caregivers age, gender, years of education, relationship between the patient and caregiver as well as the patients symptom duration, duration of care giving and degree of cognitive impairment and independence of the patient were investigated. Overall 90 % of the caregivers had some degree of burden. There was no significant difference for most of the analyzed factors but the mean ZCBS score was higher in the spouse or adult child, compared to other relatives as the caregiver. The closer the caregiver is to the patient, the care giving emotionally gets harder and the burden is high. The only significant correlation was found for patients age, which was negatively correlated with the degree of burden. This finding might reflect the easy acceptance of dementia for the elderly in the Turkish population, which is related to the fact that there are very few institutions and the aged family members (demented or not) are commonly a part of normal living in many households. As a conclusion low patient age and close relationship between the caregiver and the patient seems to be risk factors correlated with a high degree of caregiver burden.

## INTRODUCTION

Approximately 5 % of people age 65 or older have dementia and the incidence roughly doubles every five years such that nearly half of people aged 85 or older will have dementia. The elderly population forms 5 % of the total Turkish population and community studies have shown mild dementia in 2.6-20 % and severe dementia in 1.3-6.2 % of the elderly population<sup>1</sup>. In Turkey most patients suffering from dementia are cared for at home by an informal caregiver. As the disease progresses it carries with it a tremendous burden both physically and psychologically on the family members who are doing the care giving. It is known that caring for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from other chronic illnesses<sup>2</sup>. The term "caregiver burden" is used to describe the physical, emotional and financial toll of providing care.

Different questionnaires have been developed to quantify the largely subjective domain of caregiver burden, but the Zarit Caregiver Burden Scale (ZCBS) is one of the most widely

used scales<sup>3</sup>. The ZCBS was developed by Zarit and coworkers in 1985 and is a self administered 22-item questionnaire. The questions refer to the caregiver/patient relationship and evaluate the caregiver's health condition, psychological well-being, finances, and social life. The caregiver burden is evaluated by the total score obtained from the sub total of 22 questions and the caregiver distress is higher with higher scores<sup>4</sup>.

The relationship between providing care for a loved one and the experience of psychological distress has been shown to be influenced by a number of factors. There is no consensus regarding the affect of gender differences, the severity of cognitive impairment, patient depression and/or psychosis, as well as the relationship between the patient and the caregiver on the level of burden<sup>5</sup>.

The objective of this study was to determine the level of burden of informal caregivers of dementia patients in a Turkish national sample and to evaluate the possible risk factors associated with higher burden. The affects of different factors including the patients and caregivers age,

gender, years of education, relationship between the patient and caregiver as well as the patients symptom duration and degree of cognitive impairment were investigated.

## MATERIAL AND METHOD

Fifty two patients, diagnosed with dementia according to DSM-IV criteria and their caregivers were included in the study. Patients were administered the Mini-Mental State Examination (MMSE) to evaluate their level of cognitive impairment and the Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL) tests to quantify their level of independence. The level of dementia was classified according to the Global Deterioration Scale (GDS) and Clinical Dementia Rating (CDR)<sup>6,7,8,9,10</sup>. The demographic characteristics of patients and their caregivers as well as the relationship between them and the duration of illness were noted.

The caregivers were given the Zarit's caregiver burden scale (ZCBS) (Table1), which is a self administered 22-item questionnaire with a five-item response set ranging from "never" to "nearly always". 0-20 points mean little or no burden, 21-40 points mean mild to moderate burden, 41-60 points mean moderate to severe burden, 61-88 points mean severe burden<sup>11</sup>.

Statistics: Along with the descriptive and frequency statistics, Student's t test was used for the comparison of mean values between two different groups. The correlation between the ZCBS and other possible factors was calculated with the Spearman's rho correlation test.

## RESULTS

There were 27 male (51.9 %) and 25 female (48.1 %) patients. One patient was diagnosed with frontotemporal dementia and 3 patients were diagnosed with vascular dementia, the remaining were diagnosed with Alzheimer's disease. Most caregivers were females (n=44, 84.6 %) with only 8 male (15,4 %) caregivers. The age of the patients ranged between 59-84 with a mean of 73,9 and the age of the caregivers ranged between 31-84 with a mean of 53,6. The duration of illness was between 12-72 months with a mean 30 months. The mean MMSE, ADL, IADL scores as well as CDR and GDS are shown in table 2. Thirty two of the patients (61.5 %) had behavioral problems such as aggression or agitation.

**Figure 1**

Table 2: The mean MMSE, ADL, IADL, CDR and GDS results

	Mean	Std. Deviation
MMSE	16,50	6,913
ADL	4,84	4,173
IADL	9,75	3,751
GDS	4,63	1,221
CDR	1,779	,7236

MMSE: mini mental state examination, ADL= activity of daily living,IADL=Instrumental activity of daily living, GDS=global deterioration scale, CDR= Clinical dementia rating scale

The majority of the caregivers were spouses, closely followed by adult children. (Table 3),

**Figure 2**

Table 3: The caregivers relationships and the mean ZCBS points in different groups.

	n	%	Mean ZCBS Score	Std. Deviation
Spouse	23	44,2	42,96	17,434
Adult child	21	40,4	41,00	15,063
Daughter in law	7	13,4	30,50	14,432
Niece	1	1,9	29,00	.
Total	52	100,0	37,60	15,445

The degree of burden in the caregivers is shown in table 4. The mean ZCBS scores were compared in different groups according to the caregiver and patient characteristics (table 5). The results of the Spearman's rho correlation test for ZCBS and the other tests are shown in table 6. Only patients age was found to be negatively correlated with the degree of burden.

**Figure 3**

Table 4: The degree of burden in 52 caregivers

	<20	21-40	41-60	61-88
n	5	22	18	7
%	9,6 %	42,3 %	34,6 %	13,4 %

Figure 4

Table 5: The comparison of ZCBS scores in different groups

		n	Mean	Std.	p
Gender of patient	Male	27	44,22	16,890	0,068
	Female	25	35,96	14,890	
Gender of caregiver	Male	8	39,63	19,690	0,908
	Female	44	40,36	15,926	
Age of the caregiver	>= 50	26	37,42	13,057	0,396
	< 50	16	41,56	18,162	
Caregiving duration	>= 30	24	43,54	15,007	0,152
	< 30	26	37,04	16,494	
psychiatric symptom	+	20	41,15	13,967	0,757
	-	32	39,69	17,862	

p<0,05 is considered to be significant

Figure 5

Table 6: The Spearman's rho analysis between the ZCBS and other possible correlated factors

Independent variable	r	p
Age of patient	-,380**	,005**
Age of caregiver	-,032	,841
Gender of patient	-,228	,103
Gender of caregiver	-,043	,764
Duration of illness	,278	,051
Duration of caregiving	,221	,122
Behavioral problems	,094	,509
Education of caregiver	,143	,322
Relationship to the patient	-,189	,179
MMSE	-,088	,534
ADL	,243	,086
IADL	,244	,084
GDS	,109	,441
CDR	,244	,082
IADL	,143	,322

\* Correlation is significant at the 0,05 level (2-tailed)

\*\* Correlation is significant at the 0,01 level (2-tailed)

• MMSE= Mini mental state examination, ADL= Activities of daily living, IADL= Instrumental activities of daily living, GDS= Global deterioration scale, CDR= Clinical dementia rating scale

## DISCUSSION

The burden upon informal caregivers of mentally ill patients was first acknowledged by Grad and Sainbury in 1963<sup>12</sup>.

Today it is widely accepted that providing care for a relative with dementia can be a potent source of chronic stress and can cause deleterious consequences for both the physical and emotional health of caregivers. The incidence of depression among caregivers ranges between 18-47 % in different studies, therefore most of the research has focused on the psychologic well-being of the caregivers<sup>2</sup>. The immune function of caregivers are also reduced and cellular immunity has been shown to be lower in caregivers than in controls. Furthermore the relative risk for all-cause mortality

among older spousal caregivers experiencing caregiver strain is reported to be 63% higher than noncaregiving control subjects<sup>13</sup>.

Caregiving may impact physical health by producing alterations in the sympathoadrenalmedullary axis which is activated in the presence of a stressor. Short-term activation of this system results in a rise in plasma epinephrine and norepinephrine, which in turn act to speed metabolism, alter immune functioning, and increase heart rate and blood pressure in a transient manner. However, long-term or repeated acute activation of this system, as can occur in the context of caregiving, may lead to alterations in the set point of these systems that promote the development of pathophysiological conditions, such as hypertension<sup>14</sup>.

In this study 90% of the caregivers had some degree of burden. The degree of caregiver burden may be exacerbated or reduced by a number of factors. Spouses have consistently been found to be more depressed than other relatives, and in some studies, female spousal caregivers had significantly higher levels of stress<sup>15,16,17</sup>. We did not find any significant difference for the relationship or genders, but the mean ZCBS score was close to 42 for the spouse or adult child while it was 30 for other caregivers. The spouse or the adult child caregiver probably spends more time with the patient, puts more effort into helping the patient, the caregiving gets emotionally harder and the burden is high.

Older age has been associated with increased psychological distress in some studies while younger age has been associated in others<sup>15,18</sup>. In our study although not significant the burden was higher in the younger aged caregivers.

The only significant correlation we found was a negative correlation between the patient's age and the degree of burden. This finding might reflect the easy acceptance of dementia for the elderly in the Turkish population, which is related to the fact that there are very few institutions and the aged family members (demented or not) are commonly a part of normal living in many households. The acceptance is harder for the unexpected therefore the burden is high when the patient is younger.

Surprisingly according to most studies the level of burden does not correlate with the duration of time spent as a caregiver or the degree of memory loss in the patient<sup>2</sup>. On the contrary Andrieu et al studied caregivers of 531 dementia patients and concluded that low MMSE, behavioral problems and female gender were associated with a high

level of burden. However neither the illness duration nor the functional disabilities in activities of daily living affected the level of burden<sup>19</sup>. In other studies the functional disabilities as well as behavioral disturbances were found to be correlated with the level of burden<sup>20,21</sup>. In our study although not significant the burden level was higher in patients with behavioral problems. The reason for different results in different studies might be related to the different size of the samples.

Research has shown that caregivers of demented patients are nearly twice as likely to have symptoms of depression compared with caregivers of non-demented people. In addition, rates of chronic illness are higher in caregivers of demented patients and they are also twice as likely to be using psychotropic medications than the caregivers of non-demented subjects. Therefore we can see reflections of burden directly using the Zarit scale, but also indirectly in terms of depression, illness and use of medications<sup>22</sup>. Although the caregiving experience differs from individual to individual, it is evident that providing in-home care for a relative with dementia is a very difficult process.

The caregivers should be advised to protect their personal time, watch out for symptoms of depression such as crying more, sleeping/eating more or less than usual, lack of interest in usual activities, and join a support group for caregivers of dementia.

### CONCLUSION

Advances have been made in the clinical diagnosis and treatment of dementia. The physical and emotional health of the caregiver is critical for the optimal management of a patient with dementia. Almost all caregivers of dementia patients (90%) have some degree of burden. Our data support the literature which there is no correlation of caregiver burden with the degree of cognitive impairment or independence. According to this study low patient age and a close relationship between the caregiver and the patient seems to be correlated with a higher degree of caregiver burden.

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