

# Yaşlı Bireylere Bakım Veren Aile Bireylerinin Karşılaştığı Sorunların ve Bakım Yükünün Değerlendirilmesi

## Assessment of the Problems and Caregiver Burden of Family Individuals Who Care the Elderly

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### ÖZ

**GİRİŞ ve AMAÇ:** Bu çalışmada yaşlı bireyin bakımını sağlayan aile üyelerinin yaşadığı sorunların ve bakım yükünün değerlendirilmesi amaçlanmıştır.

**YÖNTEM ve GEREÇLER:** Tanımlayıcı tipteki bu araştırma Adana Yüreğir ilçesi Kışla ve Köprülü mahallelerinde yapılmıştır. Kışla mahallesinde 920, Köprülü mahallesinde 298 olmak üzere toplam 1,218 yaşlı olduğu tespit edilmiş ve her iki mahallede yaşayan ve evde bakım verilen tüm yaşlılara ulaşılmaya çalışılmıştır. Toplamda 302 yaşlı ve bu yaşlılara bakım verenler çalışmaya dahil edilmiştir. Araştırmacı tarafından geliştirilen anket formu ve Zarit Bakım Verme Yüğü ölçeği tüm katılımcılara uygulandı.

**BULGULAR:** Bakım verenlerin % 84.8'i bakımda sorun yaşadığını, % 54.6'sı psikolojik, % 64.2'si fiziksel, % 43.0'u sosyal yaşamda, % 53.6'sı ekonomik sorun yaşadığını belirtmiştir. Çalışmaya katılan kadınların, asgari ücret altında aylık geliri olanların, kronik hastalığı olanların, 11 yıl ve üzerinde yaşlıya bakım verenlerin, bakımda sorun yaşadığını ifade edenlerin ve kronik hastalığı olan yaşlıya bakım verenlerin bakım yükü ölçeği (BYÖ) puanı anlamlı olarak yüksek bulunmuştur.

**TARTIŞMA ve SONUÇ:** Bu çalışmada bakım verenlerin fiziksel, psikolojik, sosyal yaşamda ve ekonomik sorunlar yaşadığı görülmüştür. Bakım verenlerin bakım verme güçlüklerinin azaltılması için bakım verenlere yönelik danışmanlık merkezlerinin açılması, yaşlılar için gündüz bakım evlerinin kurulması, kamusal ve özel kurumlar tarafından bakım verenlerin sosyal ve psikolojik yönden desteklenmesi gerekmektedir.

**Anahtar Kelimeler:** yaşlı, bakım verme, bakım yükü

### ABSTRACT

**INTRODUCTION:** In this research, it was aimed to evaluate the problems experienced by family members who provide care for elderly people and assess the caregiver burden.

**METHODS:** This descriptive study was carried out in the districts of Kışla and Köprülü in Adana Yüreğir district. A total of 1,218 elderly people were identified being 920 in Kışla district and 298 in Köprülü district; and it was aimed to reach all elderly people who live in both localities and have home care. A total of 302 elderly and their caregivers were included in the study. A questionnaire form developed by the researchers and The Zarit Burden Interview was applied to all participants.

**RESULTS:** 84.8% of caregivers reported problems in care, 54.6% being in psychological, 64.2% being in physical, 43% being in social life and 53.6% being economic problems. Among the participants in the study, the caregiver burden scores (CBS) were significantly higher in women; in those who have lower income than the minimum wage; in those with chronic illnesses; in those who give care for 11 years or more; in those who express that they have difficulties in giving care and in those who give care for the elderly with a chronic condition.

**DISCUSSION and CONCLUSION:** In this study, caregivers were found to have problems in physical, psychological, social and economic aspects. In order to reduce difficulties in giving care, it is necessary to establish counseling centers for caregivers and day care homes for the elderly and caregivers should be supported by public and private institutions in terms of their social and psychological problems.

**Keywords:** elderly, care giving, caregiver burden.

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## INTRODUCTION

The proportion of the elderly in the world and in our country is steadily increasing. As a result of decrease in population growth rate, development in the field of health, reduction in mortality rates and the rise of life expectancy, the number of elderly in communities increase and societies begin to get older (1).

According to the data obtained from Turkish Statistical Institute in 2017, the population of people over the age of 65 was indicated to be 6 895 385 and the rate of the elderly was determined to be 8.5% (2). According to the population projections, it is estimated that the proportion of elderly will rise to 10.2% in 2023, 20.8% in 2050 and 27.7% in 2075 in Turkey (3).

Dependency and care problems of the elderly become a current issue along with the increase of the elderly population and the rise of life expectancy. Chronic conditions and decrease in vision and hearing prevent most of the elderly from carrying out ordinary functions. Diseases lead to decline of the psychological, physical and cognitive functions of the elderly and make it difficult to conduct daily activities (4)

The care for the elderly provided at home by family members is frequent in many countries worldwide (5). In Turkey, the care of the elderly people is generally undertaken by their family members and institutional care is provided in case the family members are inadequate.

Referring to the studies on issues of elderly care, caregivers undertaking the elderly care are determined to experience many difficulties regarding emotional stress, physical illness, decrease of participation in social activities, relationship with family members, economic and business life (6,7).

Therefore, in this research, it is aimed to assess the problems and caregiver burden of family members undertaking the elderly care.

## METHODS

### Setting and participants

This descriptive research was carried out in the neighborhood of Kışla and Köprülü in Yüreğir district of Adana. The people at the age of 65 or

above and their family members undertaking the elderly care constitute the universe of the research. According to March-2015 statistics of Yüreğir Cumhuriyet Community Health Center, it is determined that a total of 1,218 elderly people live in these neighborhoods; 920 in neighborhood of Kışla and 298 in neighborhood of Köprülü. It was aimed to reach all elderly living in both neighborhoods and getting home care. During the collection of data, a total of 916 elderly could not participate in the study due to the facts that 72 of them were not at home, 51 of them did not agree to conduct a survey, 48 of them temporarily moved out of their houses because of urban regeneration, 5 of them were dead, 162 of them lived alone, 560 of them did not get care since they did need any care and 18 of them did not meet the criteria. A total of 302 elderly people were included in the study, 71 from Köprülü and 231 from Kışla. The criteria for the caregivers to be included in the study is as follows: the caregiver should be 18 or older, there should be a kinship between the caregiver and the elderly individual, the caregiver should give meaningful answers to the questions, the caregiver's mental health should be good and the caregiver should live in the same house with the elderly individual.

### Data collection

Data of the study was collected in March-July 2015. A questionnaire form developed by the researchers and The Zarit Burden Interview was applied to all participants. The questionnaires were gathered using face-to-face interview technique by visiting 65-year-old and older individuals and their caregivers in their own homes.

### The Zarit Burden Interview

The Zarit Burden Interview was developed by Zarit, Reever and Bach-Peterson in 1980. It was adapted to the Turkish society by İnci in 2006 (8). It is a scale used to assess the burden experienced by caregivers or elderly needing care. Each question is scored on a 5 point Likert scale ranging from - never to nearly always present. Total scores range from 0 to 88. The materials included in the scale are generally oriented towards social and emotional areas and high scores in the scale mean that the difficulties experienced are high.

### Statistical analyses

SPSS 20.0 for Windows package program was used for statistical analysis. Mean and standard deviations (SD) of caregiver burden scores (CBS) were calculated using demographic information. The income of the participants were classified and assessed according to the minimum wage of the study date. Student t and Variance analysis (ANOVA) tests were used and Bonferroni and Tamhane post-hoc analyses were conducted to determine the group from which the difference originated among significant variables.

### Ethical considerations

Çukurova University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee approved the study and official permissions were obtained from Adana Public Health Directorate prior to study.

### Funding

Our study was funded by the Scientific Research Project Fund of the University of Çukurova.

## RESULTS

### Socio-demographic Characteristics of Caregivers and Elderly Individuals

It was determined that 81.1% of the caregiving individuals participating in the study were female, 34.4% of them were primary school graduate, 70.2% of them were married, 73.5% of them had children, 85.1% of them did not work and 42.0% of them had income over the minimum wage (Table 1). It was also found that 50.7% of the elderly participating in the study were female, 34.4% of them had poor financial status, 44.7% of them did not graduate from any school and 90.1% of them had at least one chronic illness (Table 2). The most common chronic diseases were hypertension with 59.6%, other cardiovascular diseases with 37.1%, and diabetes mellitus with 32.1%.

**Table 2. Comparison of the Sociodemographic Characteristics of the Elderly with Caregivers' CBS**

		Num ber	%	Mean±SD	F/t	p
Sex	Female	153	50.7	27.94±17.21	0.582	0.561
	Male	149	49.3	26.81±16.67		
Educational status	Below primary school	135	44.7	30.11±17.92	3.767	0.024 <sup>a</sup>
	Primary school graduate	114	37.7	26.09±15.71		
	Middle school or higher	53	17.6	23.21±15.96		
Economic status	Bad	104	34.4	34.09±17.19	5.200	<0.001
	Moderate/ good	198	65.6	23.86±15.72		
Having any chronic disease	Yes	272	90.1	28.22±16.98	2.609	0.01
	No	30	9.9	19.80±14.56		

<sup>a</sup> =  $p < 0.05$  for below primary school group versus all other groups

### Comparison of Sociodemographic Characteristics of Caregivers with CBS

The mean CBS of the caregivers is  $27.38 \pm 16.93$ .

The CBS of women, caregivers that have a monthly income under the minimum wage, those with chronic illness and those giving care for 11 years and more were found to be significantly high. The CBS of the caregivers with the age of 18-29 and those that graduate from university were found to be significantly low. There was no statistically significant difference between the relationship with caregivers and elderly people and their CBS (Table 1)

**Table 1. Comparison of sociodemographic characteristics of caregivers with CBS**

Sociodemographic characteristics	Number	%	Mean±SD	F/t	p
<b>Sex</b>					
Female	245	81.1	28.60±17,01	0.253	<b>0.009</b>
Male	57	18.9	22.12±15,62		
<b>Age group (years)</b>					
18-29	29	9.6	16.34±9,44	6.042	<b>&lt;0,001<sup>a</sup></b>
30-39	42	13.9	25.69±16,98		
40-49	86	28.5	30.57±16,15		
50-59	69	22.8	31.96±18,53		
60 or above	76	25.2	24.76±16,32		
<b>Educational status</b>					
Illiterate	41	13.6	25.22±13,68	3.058	<b>0,01<sup>b</sup></b>
Literate	17	5.6	31.00±16,66		
Primary school graduate	104	34.4	29.96±18,42		
Middle school graduate	44	14.6	31.09±17,84		
High school graduate	65	21.5	25.18±16,20		
University/junior college graduate	31	10.3	18.94±12,43		
<b>Marital status</b>					
Married	212	70.2	27.41±16,51	0.470	<b>0.963</b>
Single	90	29.8	27.31±17,96		
<b>Having children</b>					
Yes	222	73.5	27.95±16,76	-0.982	<b>0.327</b>
No	80	26.5	25.79±17,39		
<b>Occupational status</b>					
Working	45	14.9	25.31±16,46	-0.889	0.375
Not working	257	85.1	27.14±17,02		
<b>Monthly income</b>					
Lower than minimum wage	26	8.6	34.58±16,05	2.815	0.039 <sup>c</sup>
Minimum wage	111	36.8	28.90±16,19		
More than minimum wage	127	42	25.34±17,97		
Twice minimum wage or more	38	12.6	24.84±14,65		
<b>Having any chronic disease</b>					
Yes	161	53.3	29.77±17,82	2.672	0.008
No	141	46.7	24.65±15,47		
<b>Kinship between the elderly</b>					
Children				1.536	0.217
Spouse	130	43	28.46±16,98		
Second degree	97	32.1	24.91±16,40		
Relative	75	24.8	28.71±17,37		
<b>Time spent with the elderly (After the 65 age or later)</b>					
1-5 years	148	49.0	23.91±15,11	7.954	<b>&lt;0.001<sup>d</sup></b>
6-10 years	62	20.5	27.85±17,42		
11 years or more	92	30.5	32.65±18,11		

<sup>a</sup>=  $p < 0.05$  for 18-29 age groups versus all other age groups

<sup>b</sup>=  $p < 0.05$  for university/junior college graduate group versus all other groups, <sup>c</sup>=  $p < 0.05$  for lower than minimum wage group versus all other groups, <sup>d</sup>=  $p < 0.05$  for 1-5 years group versus 11 years or more group

### Comparison of the Sociodemographic Characteristics of the Elderly People with the CBS of the Caregivers

The CBS of the caregivers giving care to elderly people who did not graduate from any school, those with bad financial situation and those with chronic illness were found to be significantly high (Table 2). The highest CBS were observed in those giving care to elderly with Alzheimer's disease, cerebrovascular diseases and psychiatric diseases; scores being  $41.50 \pm 17.89$ ,  $37.72 \pm 16.93$  and  $35.63 \pm 15.74$ , respectively.

### Problems experienced by caregivers during care

54.6% of the caregivers participating in the study were found to have psychological problems, 64.2% of them were found to have physical problems, 43.0% of them were found to have problems in social life and 53.6% of them were found to have economic problems. During the caregiving, 53.0% of the caregivers declared to need consultancy and 63.9% of them declared to need help (Table 3).

**Table 3. Problems experienced by caregivers during care**

		Number	%
<b>Psychological problems</b>	Yes	165	54.6
	No	137	45.4
<b>Physical problems</b>	Yes	194	64.2
	No	108	35.8
<b>Social problems</b>	Yes	130	43.0
	No	172	57.0
<b>Economic problems</b>	Yes	162	53.6
	No	140	46.4
<b>Need for help</b>	Yes	193	63.9
	No	109	36.1
<b>Need for consultancy</b>	Yes	160	53.0
	No	142	47.0

### DISCUSSION

81.1% of the caregivers in our study were females. It is firmly established that, the caregivers giving care to elderly individuals are generally females. Considering other studies made in this respect, 80.7% of the caregivers were females in the study of Limpawattana and 87.6% of the caregivers were females in the study of Önür (9,10).

The reasons for the females to be appropriate for caregiving are considered as housework being seen as natural for females, females being more compassionate and sensitive, females having better communication, females coping with problems better than males and females entering the working life less than males.

70.2% of the caregivers were found to be married and 49.0% of them were found to be primary school graduate. 78.8% of the caregivers were determined to be married and 43.3% of them were determined to be primary school graduate in the study of Özkan Tuncay and his colleagues (11). 81.7% of the caregivers were stated to be married in the study of Cabral and his colleagues made in Spain (12). Evaluating the results of similar studies, the majority of caregivers are married and primary school graduate similar to our study.

The CBS scores of females were found to be statistically higher than males. Referring to other studies, the CBS scores of females were indicated to be higher than that of males, which supports our study (13,14). The reason for caregiver burden to be higher in females is thought to be related with the facts that females spend more time with the elderly they give care and that females have other responsibilities such as children, housework etc. other than caregiving.

In our study, university/college graduates were found to have lower caregiver burden. In the research of Mollaoğlu and his colleagues similar to our study, high school and above graduates were indicated to suffer lower level of care burden compared to other educational groups (15). The reasons for caregivers having higher level of education to suffer lower level of caregiver burden may be the facts that they are aware of how they can access and use the resources, that they are able to cope with problems and that they have good communication.

In our study, caregivers with chronic illness were found to have a significantly higher CBS than those without chronic disease. Referring to other studies, the CBS of the caregivers with chronic illness were indicated to be high, similar to our study (16,17). The caregiver burden for the caregivers with chronic illness is possibly higher

due to the fact that they also deal with their own diseases during care. In the literature, it is also reported that the caregivers' health problems and the difficulties they experience during care may lead to a decrease in the quality of care provided and an increase in the caregiver burden (18).

In our study, it is determined that as the income level of caregivers increases, the care burden decreases, which is consistent with the relevant studies (19-21). Furthermore the CBS of the caregivers giving care to the elderly with low level of financial status were found to be significantly higher than that of the caregivers giving care to the elderly with moderate/good level of financial status. In the study of Yaşar, it was found that there was a significant difference between the income status of the elderly and CBS and the caregiver burden of the elderly individuals having income that meets the expenditure is found to be lower than those having income that does not meet the expenditure (22). High income is thought to decrease the care burden because of the facts that caregivers benefit from other sources and they are able to purchase other materials regarding the care.

It is found that there is no significant difference between the degree of relationship with the caregiver and the elderly individual and CBS. In the study of Işık unlike our study, the care burden of daughter-in-law was found to be higher than that of elderly's wife, daughter and son (16). The discrepancy between the results of that study and our study may be due to regional differences.

It is established that the care duration of the caregivers increases the CBS and there is a significant difference between them. In other studies, it is also seen that as the duration of care increases, the care burden also increases (20,23). The reasons why the care burden increases as the duration of care increases are considered to be due to the progresses in the chronic illness of the elderly individual and rise in the level of dependency.

The CBS of the caregivers giving care to the elderly people having no school diploma were found to be significantly higher. In the study of Selçuk and Avcı, it was also found that the level of education of the elderly influenced the caregiver burden and that as the level of education decreased,

the care burden increased (23). The elderly people with high level of education are thought to affect caregiver burden by having less problems in communication.

The mean of care burden was indicated to be 27.38 in our study. Türkoğlu determined the CBS as 36.65 for the family members caring for cancer patients (24). In the study of Yıldız, the average CBS of family members giving care to chronic psychiatric patients was found to be 59.33 (25). In the studies mentioned above, caregivers giving care to the elderly individuals in need of care with certain diseases were examined. Therefore, the factors affecting the care burden of the caregivers dealing with elderly people with various health problems may change. Our study was conducted on caregivers living in the same house with the elderly people at the age of 65 and over and it was thought that the results might be unique to our study group. The reasons, why the mean score of care burden of caregivers is low, are thought to be caregivers' perception of the elderly care as help other than as burden, caregivers' avoidance of sharing the difficulty they have with others and caregivers' thought of being condemned by others.

54.6% of the caregivers participating in the study stated that they had psychological problems, 64.2% of them had physical problems, 43.0% of them had problems in social life and 53.6% of them had economic problems. In the study of Kılıç Akça and Taşçı, 62.5% of the caregivers stated that caregiving hampered social communication, 22.5% of the caregivers stated caregiving affected physical health, 34.4% of the caregivers stated caregiving affected their mental health and 16.4% of the caregivers stated that physical complaints started due to mental problems (26). Unver and his colleagues indicated that 26.0% of the caregivers suffered economic problems, 64.0% of them suffered social isolation and 33.0% of them experienced negative feelings such as anger, frustration due to caregiving (27). In a study carried out in India, it was stated that 42.4% of the caregivers had economic problems, 23.8% of them had problems in social life, 34.1% of them had sleep disorder, 21.2% of them couldn't spare time for themselves, 20.1% of them didn't fulfill their responsibilities due to caregiving and 63.5% of

them were unhappy (28). All of these studies suggest that caregivers had some sort of physical, psychological, social and economic problems.

The study had certain limitations. This study was conducted on caregivers giving care on elderly and living in only two neighborhoods in an urban area which may obstruct the extrapolation of the results to general population. Since the data was collected by applying questionnaires, individuals with low level of education had difficulty in understanding and answering the questions. This problem was tried to be resolved by using face-to-face interview method and making explanation to them for the questions with which they have difficulty.

Consequently, considering the results obtained from the study, it is seen that caregivers experience physical, psychological, social and economic problems and many characteristics of caregiver and the elderly affect the caregiver burden. In order to reduce caregiver burden, the provision of specific supportive approach to each caregiver, the establishment of daycare centers for elderly people and social and psychological support for caregivers are recommended by examining the problems of the caregivers and the personal factors affecting the caregiver burden.

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