### **Original Article**

# **Predictors of Caregiver Burden in Primary Caregivers of Chronic Patients**

### Gulhan Yigitalp, PhD

Assistant Professor of Community Health Nursing, School of Nursing, University of Dicle, Diyarbakir, **Turkey** 

Hamdiye Arda Surucu, PhD in Internal Medicine Nursing School of Nursing, University of Dicle, Diyarbakir, Turkey

Funda Gumus, PhD in Psychiatric Nursing School of Nursing, University of Dicle, Diyarbakir, Turkey

**Evin Evinc, MSc in Community Health Nursing** School of Nursing, University of Dicle, Diyarbakir, Turkey

Correspondence: Dr. Funda Gumus, School of Nursing, University of Dicle, Diyarbakir, Turkey. 21100/Diyarbakır E-Mail: fcamuz@hotmail.com

#### **Abstract**

Aim: This study was conducted to describe the relationship between the sociodemographic attributes, social support and stress level which are the predictors of caregiver burden in primary caregivers of chronic patients. **Methods:** The descriptive study of 320 primary caregivers in Turkey, was conducted.

**Results:** It has been observed that there is a statistically significant difference with regard to caregivers family type, caregivers training about the disease of patient and the presence of a helper who gives support to caregiver. It has been determined that the care giving burden scale point average of caregiver has high-level positive and statistically significant correlation with caregiver stress level while it has low-level negative and statistically significant correlation with social support (p<0.05). While examining care giving burden in caregivers, it has been determined that stress ( $\beta$ =0.61 p=0.000), social support ( $\beta$ =-0.14, p=0.001), family type ( $\beta$ =0.10, p=0.015) and support status of caregiver ( $\beta$ =0.08, p=0.050) are significant predictors.

Conclusions: It can be said that the increase of perceived social support reduces the care giving burden while the absence of a helper who supports caregiver, living in an extended family and being exposed to high-level stress increase the care giving burden.

**Key Words:** Caregiver burden, stress index, social support perception, nursing

### **Background**

Chronic diseases are lifelong continuing situations that require continuous treatment, periodic monitoring, support and maintenance to maximize the functionality of the individual. Chronic diseases are increasing continuously and reported to be the most common cause of mortality worldwide. These diseases are mainly cardiovascular diseases, cancers, chronic respiratory diseases and diabetes (WHO, 2011).

Along with causing changes in certain aspects of patient's life, chronic diseases bring different responsibilities and burdens to the people who carry on the care giving at home or in the hospital environment (Dokmen, 2012; Chen et al., 2015). Care giving is defined as the process of undertaking the activities and responsibilities of care giving (Stetz & Brown, 1997). Care giving is not limited to a single support type; on the contrary it involves emotional, physical and financial support (Toseland et al., 2001). Issues such as routine health care (drug intake, medication, follow-up), personal care (bathing, feeding, toilet, dressing), transportation, shopping, petty housework, money management etc. are all included in care giving (Toseland et al., 2001). In our country, the care of the sick person is usually given by the parents and this is perceived as family responsibility. Becoming a caregiver is not selectable and can not be planned. For this reason, compliance with this

situation occurs after the situation has emerged (Orak & Sezgin, 2015).

Caregiver burden is defined as the negative objective and subjective outcomes such as "experiencing psychological distress, physical health problems, economic and social problems, breakdown of family relationships and feeling of despair which are brought about by the care giving burden undertaken by the caregiver" (Collins et al., 1994).

Objective care giving results include the changes and frustrations in the lives of caregivers and their families. Furthermore, it is related to physical problems such as experiencing fatigue as a result of care giving, hindrances to the family routine, physical affliction of caregiver etc. As for the subjective care giving outcomes, it is defined as the psychological problems of caregiver which are related to the role of care giving (Kasuya et al., 2000). Alongside many positive attributes it brings to caregivers' lives, such as self improvement, flourishing close relationships within the family, achieving satisfaction, receiving social support from other individuals and developing self-esteem, care giving can also lead to many difficulties (Toseland et al., 2001).

In studies conducted in caregivers because of their caring responsibilities, caregivers have problems such as not taking enough time for themselves, chronic fatigue, sleeping disorder, nutritional deficiency, muscle aches, concentration difficulty, anxiety, depression, substance abuse, fatigue, social isolation, deterioration of family relations and financial problems (Mollaoglu et al., 2011; Atagun et al., 2011; Ozyesil et al., 2014). It was also reported that the burden of care is influenced by the age of the caregiver (Cıtlık Sarılas et al., 2014; Gulpak & Kocaoz, 2014), the educational status (Orak & Sezgin, 2015), having an additional disease (Teel et al. 2001), the duration of care (Palos et al., 2010; Mollaoglu et al., 2011; Gulpak & Kocaoz 2014), getting information about the healthcare (Subgranon, 2000), the presence of an assistant in care (Bugge, 1999), stress and perceived social support. In research on perceived social support, it has been reported that social support in general reduces or eliminates stress, contributes to the development of positive coping skills (Cavkaytar et al., 2008; Guralnick et al., 2008; Tehee et al., 2009) and reduces the burden of care (Hsiao, 2010; Chiou et al., 2009; Varona et al., 2007).

Being sensitive towards the families that undertake the care giving responsibility, being aware of the hardships experienced by caregivers, respecting and supporting them, assigning care giving roles and determining their resilience skills are the roles expected from the nurses because these behaviors increase effectiveness and quality of care giving as well as enhancing the life quality of all the family members (Erdem, 2005). Therefore, first of all it is necessary to determine the difficulties that individuals experience in care giving and the factors related with it. For this reason, this study has been conducted with the purpose of analyzing the relationship among sociodemographic characteristics, social support and stress level which are the predictors of care giving burden in chronic patients' primary caregivers.

**Aims:** The aim of this study was to explore the relationship between the sociodemographic attributes, social support and stress level which are the predictors of caregiver burden in primary caregivers of chronic patients.

### Methodology

# Design

This research, which was conducted with the purpose of examining the predictors of care giving burden in chronic patients' primary caregivers, was realized in descriptive crosssectional design.

# **Sample and Participant Selection**

The sample of this research consists of 320 primary caregivers who lived in the city center of Diyarbakir during March and April 2016, who are 18 or over 18 and provide care at least for the last one year for chronic patients who are 18 or over 18 (patients who are paralyzed or have chronic disease such as cancer, dementia, Parkinson, multiple sclerosis, chronic obstructive lung disease and renal insufficiency) and who accepted to participate in this research. Caregivers who do not comply with any of these criteria, who have a history of psychiatric disorder and who are providing care in return for money were not included in this research. And the individuals who provide primary care for a chronic patient and who have consulted to the family health centers located in Yenisehir, Kayapinar and Baglar districts of Diyarbakır, contributed to this research as samples. The most important factors in selection of these districts are that they are believed to highly represent the

universal and that they are easy to reach for researchers.

#### **Instruments**

In collecting research data "Personal Information Form, Zarit Care Giving Burden Scale (ZCGBS), Multidimensional Scale of Perceived Social Support (MSPSS) and and Caregiver Strain Index (CSI)" are employed.

Personal Information Form: This form is prepared drawing on the literature information. It consists of 23 questions which are related to defining characteristics of patient and caregiver, and care giving experience (Kaufman et al., 2010; Oshodi et al., 2012; Salama, 2012; Tel et al., 2012; Flores Gonzalez & Seguel, 2016). These are related to caregiver's age, gender, degree of kinship to the patient, marital status, number of children if married, educational status, job, health insurance, working status, income level, duration of care giving, patient's diagnosis, age and gender.

Zarit Care Giving Burden Scale (ZCGBS): Zarit was developed by Reever and Bach-Peterson in 1980 (Zarit et al., 1980). It is a tool used for the purpose of evaluating the stress experienced by caregivers who provide care for individuals or elders requiring care. The scale consists of 22 statements which specify the impact of care giving upon individual's life and it can be filled by caregiver or researcher. It has a Likert-type evaluation ranging from 0 to 4 and featuring answers such as "never, seldom, sometimes and very often or almost always". One can get minimum 0 and maximum 88 points from the scale (Inci & Erdem, 2008). A high score indicates a high distress. In this research, the scale's Cronbach's alpha coefficient is calculated as 0.88.

Multidimensional Scale of Perceived Social Support (MSPSS): This tool was developed by Zimmet and colleagues in 1988 (Zimet et al., 1988) and it is dedicated to identifying the individuals' perception of social support factors. The validity and reliability of MSPSS was verified in Turkey, in 1995 (Eker et. al., 2001). The tool was revised in 2001 by the same authors and its sub-scale Cronbach's alfa coefficient was found between 0.80 and 0.95 (Eker & Arkar, 1995). It is a Likert-type scale which is comprised of a total of 12 items ranging from "definitely no" to "definitely yes" (1-7 points). The tool has 3 sub-scales, each comprised of 4

items in order to determine family (3rd, 4th, 8th, 11th items), colleagues (6th, 7th, 9th, 12th items) and significant other (1st, 2nd, 5th, 10th items) support. The minimum point that can be scored in each sub-scale is 4 and the maximum is 28. The minimum point that can be obtained from the scale as a whole is 12, the maximum is 84. A high score indicates a high perceived social support (Arkar et al., 2004). In this research, the Cronbach's alpha coefficient of the scale is calculated as 0.91.

Caregiver Strain Index (CSI): It was developed by Robinson in 1983 (Robinson 1983) and its validity and reliability was verified in Turkey (Ugur & Fadiloglu, 2010). CSI is a tool that can be used to quickly identify families with potential care giving concerns. The measurements of strain related to care provision consist of 13 items and each item represents a stressor. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social state and Time. This tool is reported as suitable for individuals of any age who have assumed the role of caregiver. The responses are in the form of short answers "yes" (1) and "no" (0), and the scoring is minimum 0 to maximum 13. Positive responses to seven or more items on the index indicate a greater level of strain. Its Cronbach's alpha coefficient is reported as 0.86.<sup>36</sup> The Cronbach's alpha of the tool in this research is calculated as 0.69.

#### **Ethical Consideration**

A written consent was received from the authors of the tools used in the planning stage of this research and from the Non-invasive Clinical Research Ethics Committee of Dicle University (26.02.2016\102). Before starting to collect data, primary caregivers were informed about the purpose and content of the research and their verbal consent was received.

# Data analysis

The data was analyzed in electronic environment using SPSS 15.0 (Statistical Package for Social Sciences, SPSS Inc., Chicago, IL, Kolmogorov-Smirnov test was employed to analyze the missing values in the data of research group and normality of distribution. The crosssectional descriptive analysis was made among the independent variables (age, education, social support etc.) that would be related to preregression caregiver burden of caregivers. Pearson correlation coefficient Test, Student T Test, Mann-Whitney U Test and Kruskal-Wallis Test were implemented as descriptive statistics. Before composing the Stepwise linear regression model, standardized residual for variables and multicollinearity for independent variables were examined (Hair et al., 2010). Variance inflation factor (VIF) was tested in Multicollinearity Assessment and no multicollinearity was found among independent variables. As the family type, caregiver's support, caregiver's training on patient's disease and its treatment are categorical variables, they were included in the Regression analysis as dummy variables (Powers Daniel & Xie, 2000). The statistical significance level was accepted as p<0.05 in order that variables could be brought into the regression equation.

#### **Results**

Sociodemographic Characteristics of Patients and Caregivers: It has been found that 77.5% of caregivers who have participated in the research are women, 29.4% are illiterate, 82.2% have no chronic disease, 32.2% did not receive training about the disease of his/her patient, 45.3% have no helper who supports them in care giving, the average age of caregivers is 39.97(±11.4) and the average care giving duration is 4.96 years (±5.23). When looked at the characteristics of patients receiving care. it has been determined that 56.6% of the patients are women, 40.6% have more than one chronic disease, 87.5% are the first degree relatives of caregivers, 92.2% live together with the caregiver and the average age of patients receiving care is  $63.17 (\pm 18.55)$  (see Table 1).

Comparison of Primary Caregivers' Burden with Sociodemographic Characteristics, Social Support and Stress Level of Patients and Caregivers: In this research, caregiver burden of primary caregivers was determined 41.37±14.21 (min-max: 7-83), perceived social support as 48.07±15.92 (min-max: 12-84) and stress level as 8.99±2.70 (min-max: 2-13).

When the caregiver burden of caregivers were examined according to their sociodemographic characteristics, it was found that there would be a statistically significant difference based on the caregiver's family type (t: 2.062; p: 0.040), caregiver's training on his/her patient's disease and its treatment (t:-2.0513; p: 0.012) and the presence of a helper who supports care giving (t:-2.960; p: 0.003). It was observed that caregiver

burden point average of caregivers has a high level positive correlation with caregiver's stress level (r:0.639; p:0.000) while on the other hand it has a low level negative correlation with social support (r:-0.217; p:0.000) which is statistically significant (Table 2).

Predictors of Primary Care Providers' Care Burden: Stepwise linear regression analysis was made for the purpose of determining the contribution of factors related with caregiver burden. A statistically significant correlation was observed between caregiver burden caregiver's family type, caregiver's training on patient's disease and its treatment, presence of a helper who supports caregiver, social support and stress level of caregiver. And they were included in the regression model. When the care giving burden in caregivers is examined, it is understood that stress ( $\beta$ =0.61;p=0.000), social support ( $\beta$ =-0.14; p=0.001), family type( $\beta$ =0.10, p=0.015)and caregiver's social support status ( $\beta$ =0.08; p=0.050) are significant predictors for caregiver burden, and these variables explain 45% of the common variance (see Table 3).

It was found that the increase of caregivers' stress levels, living in large families and not having someone who supports primary care increase the burden of care. However, as the level of social support of caregivers increases, the burden of care decreases.

#### Discussion

Sociodemographic Characteristics of Patients and Caregivers: In this research, the majority of primary caregivers consist of illiterate women who have no social security, no wage-earning employment, who are married and much younger than the patients, and living in the extended families. In the Turkish Family Structure Study (2006) of Turkish Statistical Institute (TUIK), it is stated that there are similar findings concerning the status of women and domestic work is mostly done by women (TUIK, 2006). The majority of caregivers is women, and this can be associated with the fact that the responsibility of care giving is attributed to women and it is a role naturalized both by women and the society. When the characteristics of caregivers from previous researches are examined, they can be said to have similarities with the findings of this research (Kaufman et al., 2010; Oshodi et al., 2012; Tel et al., 2012; Flores Gonzalez & Seguel, 2016).

**Table 1. Identifying Characteristics of Caregivers and Patients** 

Variables (Caregivers)	n	%
Gender Female	248	77.5
Male	72	22.5
Educational level İlliterate	94	29.4
Literate	51	15.9
Primary school	71	22.2
Secondary school	38	11.9
High school	43	13.4
College and more	23	7.2
Marital status Married	235	73.4
Single	85	26.6
Family type Extended family	162	50.6
Nuclear family	158	49.4
Have a child? Yes	232	72.5
No	88	27.5
Employment status Unemployed	250	78.1
Employed	70	21.9
Social security Yes	72	22.5
No	248	77.5
Chronic disease Yes	57	17.8
No	263	82.2
Gender of patient Female	181	56.6
Male	139	43.4
Patients have multiple chronic		
<b>Diseases</b> ? Yes	130	40.6
No	190	59.4
Patients –caregiver relation		
<b>status</b> First-degree relative	280	87.5
Second-degree relative	35	10.9
Other	5	1.6
<b>Living with patient</b> Yes	295	92.2
No	25	7.8
Receive education about the		
patient's disease Yes	217	67.8
No	103	32.2
<b>Anyone that helps caregivers</b> Yes	175	54.7
No	145	45.3
Age of caregivers (years)	39.97±11.4 (min-max:18-80)	
Caregiving period (years)	4.96±5.23 (min-max:1-35)	
Age of patient	63.17±18.55 ( min-max:18-100)	
ZCGBS total score	41.37±14.21 ( min-max:7-83)	
CSI total score	8.99±2.70 ( min-max:2-13)	
MSPSSI Support total score	48.07±15.92 ( min-max:12-84)	
* 7CGRS: Zarit Care Giving Rurden Sc	ale MSPSS: Multidimensional Scale of	Darcaived Social Support CSI: Caraciver

<sup>\*</sup> ZCGBS: Zarit Care Giving Burden Scale, MSPSS: Multidimensional Scale of Perceived Social Support, CSI: Caregiver Strain Index

Table2. Burden Comparison of Caregivers and Patients Based on the Identified **Characteristics** 

Variables	Mean	Test	р
Caregiver's gender			
Female	42.08±14.15	t:1.646	0.101
Male	14.22±1.67		
Educational level of caregivers			
İlliterate	41.94±13.39		
Literate	41.33±14.18		
Primaryschool	43.35±13.76	KW:9.125	0.104
Secondaryschool	43.47±14.71		
High school	38.60±13.99		
College and more	34.78±17.01		
Marital status of caregivers			
married	41.52±14.43	t:0.304	0.762
Single	40.97±13.65		
Family type of caregivers			
Extended family	42.98±14.49	t:2.062	0.040
Nuclear family	39.72±13.76		
Employment status of caregivers			
Unemployed	41.71±14.19	t:0.803	0.422
Employed	40.17±14.31		
Social security of caregivers			
Yes	41.07±14.77	t:-0.704	0.482
No	42.41±12.08		002
Chronicdisease of caregivers	12.11=12.00		
Yes	43.36±13.96	t:1.167	0.244
No	40.94±14.25	1.1.107	0.211
Gender of thepatient	10.9 121 1.23		
Famele	42.06±13.59	t:0.980	0.328
Male	40.48±14.98	1.0.700	0.320
Multiplechronicdiseases of	+0.+0±14.70		
thepatient	40.91±15.02	t:-0.481	0.631
Yes	40.91±13.02 41.69±13.65	10.401	0.031
No	41.09±13.03		
Patients –caregiver relation status			
First-degree relative	41.22±14.04		
Second-degree relative	42.48±15.42	KW:0.049	0.976
_		KW.0.049	0.970
Other Living with nations of congressions	42.00±17.80		
Living with patient of caregivers	11 55 : 11 15	11.2116 000	0.198
Yes	41.55±14.15	U:3116.000	0.198
No	39.24±15.03		
Caregivers status receive			
education about the	40.01 - 14.25	4. 2.512	0.012
patient'sdisease	40.01±14.25	t:-2.513	0.012
Yes	44.25±13.75		
No			
Anyone that helps caregivers	20.26.12.14	4.000	0.002
Yes	39.26±13.14	t:-2.960	0.003
No	43.93±15.05		
The age of caregivers (years)	r:-0.049		0.386
Caregivers caregiving period (years)	r:0.064		0.253
The age of patient	r:-0.035		0.535
CSI total score	r:0.639		0.000
MSPSS Support total score	r:-0.217		0.000

	_					
	Beta	SE	р	PartialCorrelation	VIF	$\mathbb{R}^2$
ZCGBS						0.450
CSI	0.614	0.221	0.000	0.635	1.014	
MSPSS	-0.148	0.040	0.001	-0.185	1.124	
Family type of caregivers	0.103	1.198	0.015	0.136	1.021	
Anyone that helps caregivers	0.086	1.250	0.050	0.110	1.102	

Table 3. Predictors of Zarit Care Giver Burden of Caregivers

Comparison of Primary Caregivers' Caregiver Burden with Sociodemographic Characteristics, Social Support and Stress Level of Patients and Caregivers: The first step to reduce caregiver burden is to determine the content of the burden. Identifying caregiver burden contribute to enhancing the life quality of both caregivers and patients (Kucukguclu et al., 2009). In this research, which was conducted for determining the predictors of caregiver burden in primary caregivers of chronic patients, it was indicated that caregiver burden and perceived social support level in primary caregivers are moderate, whereas the stress level is high. In the research conducted by Mollaoglu and colleagues (2011) caregiver burden has also been reported as medium level (33.02  $\pm$  15.92) (Mollaoglu et al., 2011). In a research conducted in Japan on the caregivers of paralyzed patients, caregiver burden scale point average is reported as 28.33 ± 13.07 (Morimoto et al., 2003). In another research, this ratio is found to be  $28.321 \pm 2.7$  (Schreiner et al., 2006; Flores Gonzalez & Seguel, 2016), and the perceived effective social support level in these researches is reported to be low. Similarly, in another study perceived social support level of caregivers is reported to be low (Chiou et al., 2009). In a research on the caregivers of patients with Parkinson disease, caregiver burden scale point average is found as 16±13.9 and stress level average as 2.1±2.3 (Flores Gonzalez & Seguel, 2016). In Turkey, caregiver burden, stress level and perceived social support level of chronic

patients' caregivers are reported to be higher than the other countries. The reason why caregiver burden of paralyzed patients in Turkey is higher than the other countries is thought to be related with many factors such as inter-country differences in family structures, differences in social support and health care delivery etc. Furthermore, the fact that caregiver burden level perceived by caregivers is moderate can be linked to the Turkish society's embracing care giving role and perceiving this role as "help" rather than "burden" (Mollaoglu et al., 2011).

In this research, it was found that caregiver's training about his/her patient's disease and its treatment reduces caregiver burden. In the research conducted by Selen and Kav (2014) on the primary caregivers of patients with Chronic Obstructive Lung Disease, it is stated that caregiver burden scale point is higher in caregivers who did not get information about the disease and home oxygen therapy (Selen & Kav, 2014). In Sirzai and colleagues' research (2015) it was observed that the majority of caregivers (58,3%) were not informed about the disease and treatment of their patients but they wanted to receive information from health care staff (Sirzai et. al., 2015). In another study, it was observed that 84.2% of caregivers are inexperienced in care giving and 32.8% need training on care giving (Tasdelen & Ates, 2012). In the study of Hinojosa and Rittman (2007), caregivers stated that they need information about the disease (Hinojosa & Rittman, 2007). Subgranon and

<sup>\*</sup>Regression analysis; family type (Extended:1, Nuclear:0), the training status (yes:0, no:1), The presence of one of the support (yes:0, no:1), It is taken as a dummy variable.

ZCGBS: Zarit Care Giving Burden Scale, MSPSS: Multidimensional Scale of Perceived Social Support, CSI: Caregiver Strain Index

Lund (2000) stated that caregivers are not informed by health care staff about home care when their patients are discharged from the hospital, therefore caregivers develop their own solutions for the problems they encounter in care giving (Subgranon & Lund, 2000). Studies revealed that caregivers who receive training experience less stress and anxiety, and their life quality remains higher compared to caregivers who do not receive training (Lutz & Young, 2010). Nowadays, the structure of health care services are changing, duration of hospital stay is diminishing and self-care responsibilities of patient and his/her family is growing each day. As a consequence, this situation requires patients and families to receive the necessary training and apply this training in a systematic, practical and analytical way. Accordingly, provision caregivers' educational needs can increase gratification of caregivers while reducing their caregiver burden.

Predictors of Caregiver Burden of Primary Caregivers: According to our research, while belonging to an extended family increases caregiver burden, having a helper who supports caregiver reduces caregiver burden. In the research conducted by Mollaoglu and colleagues (2011), it was indicated that the majority of caregivers (73.1%) meet all the needs of patients alone (Mollaoglu et al., 2011). In another research made by Sirzai and colleagues (2015), it was found that the majority of caregivers receive support from a third person and in general this person is caregiver's first degree relative such as his/her siblings or children (Sirzai et al., 2015). Selen and Kav (2014) stated that 82% of caregivers have helpers who support them in care giving and the numbers of these helpers are 3 or more (42.3%). They also reported that as the number of helpers who support primary caregivers' increases, caregiver burden scale point decreases (Selen & Kav, 2014). The presence of helpers who support caregivers is considered to be reducing caregiver burden of primary caregivers. Similar to our research results, in the research conducted by Tel and colleagues (2012), it was reported that caregiver burden of caregivers living in extended families is higher. This finding shows that, an increase in the number of family members would extend the responsibilities of the women contrary to the expectation that caregiver burden would decrease as the responsibility would be shared among family members (Tel et al., 2012). Even though

the number of caregivers who receive support from other individuals is high, the ratio of undertaking care giving responsibility alone is also considerable.

Care giving is the source of stress for caregivers and it adversely affects caregiver's health (Iwamoto et al., 2008; Leggett et al., 2010). Stress level was found as a significant predictor for caregiver burden in our research. It is proved that as the caregiver burden increases, the stress level of caregiver also increases. In Schulze and Rossler's study (2005), it was stated that caregivers' health is adversely affected due to the caregiver burden in the first place, and they face high level stress (Schulze & Rossler, 2005). Numerous studies revealed that caregiver burden is linked to depressive disorder symptoms and care giving stress can worsen caregivers' situation (Hamama-Raz et al., 2012; Kim et al., 2012; Wang et al., 2016). In their meta-analysis study on caregiver burden, Aoun and colleagues (2013) observed that caregiver burden causes stress and the perceived support resources play an important role in overcoming stress (Aoun et al., 2013).

In our research, social support level was determined as a significant predictor for caregiver burden of caregivers. The regression analysis findings in the research indicate that as the perceived social support level increases caregiver burden decreases. According to the previous studies, social support given to caregivers is also reported to be effective in reducing the caregiver burden (Rodakowski et al., 2012; Shieh et al., 2012; Ozkan et al., 2015). Chiou and colleagues' research (2009) points out significant negative correlation between perceived social support and caregiver burden (Chiou et al., 2009). Undertaking the care burden of a patient with chronic disease affects the lives of family members and causes physical, emotional, social and economic problems (Hayes et al., 2015). For this reason, caregivers need support from their families and colleagues. They need to feel that they are not alone, receive help in terms of money, information and education as well as social and emotional support. Increasing social support reduces the negative effects of care giving and enhances caregivers' gratification (Chiou et al., 2009; Dokmen, 2012; Chen et al., 2015). Moreover, it is known that social support can prevent stress, change the perception of situation, help person in handling difficulties and it affects caregiver's coping skills (Ardahan,

2006). In addition to this, Turkish society has strong social support mechanisms and social support mechanisms are substantial resources that reduce caregiver burden (Yildirim et al., 2012).

In principle, the treatment of chronic diseases has become a community-based practice in Turkey, as well. Thus, it is important for caregivers to be informed beforehand about the problems awaiting them and to help them develop coping strategies. Studies on this topic have been gaining significance and any information will be guiding in terms of developing correct approaches for patients and their relatives. However, resources reserved for rehabilitation programs insufficient and they should be increased. In psychosocial care, nurses should aid patient's and family's adaptation to lifestyle changes, help them avoid unnecessary adaptations, improve patient's and family's coping skills and support their adaptation to disease. In addition, they should ensure that patients and families are informed about the problems awaiting them and guide them to develop correct approaches and attitudes (Asiret & Kapucu, 2012).

### **Implication for Nursing**

Care giving is among the major tasks of nursing profession. In the case of requiring long-term care, this task belongs to patient's family. The majority of family members do not have the required knowledge and skills to provide long term care. As the members of professional health care team, starting from the diagnostic phase, nurses should prepare the caregivers for home care after discharge from hospital. Nurses have to fulfill their tasks such as providing training, care, counseling, guidance and organizing their work etc. in this process. They should observe caregiver's communication with the patient, his/her knowledge, attitude and behaviors about the disease and care giving. In addition, they should help caregiver develop positive attitudes, focusing on caregiver's abilities. While providing required care additional to caregivers, nurses should not put their own physical and psychological health in danger. They should receive support and connect with proper support groups in order to avoid extra caregiver burden. It is considered that if the nurses provide training for caregivers about the skills necessary for care giving, practices to facilitate patient's daily life and basic nursing applications, they can reduce the care giving burden and enhance both patient's

and caregivers life quality (Asiret & Kapucu, 2012).

# Study Limitation

The limitation of this study is investigating the cases which require different care giving in the same research even though its feasibility is limited due to the qualitative differences of cases. Even so, this study was realized in order to transformation of caregiver analyze the responsibilities into caregiver burden and the development mechanism of secondary cases.

The strength of this research comes from one-tointerview with participants communication with caregivers.

### **Conclusion and Suggestions**

In this research, it was found that level of caregiver burden and perceived social support in primary caregivers is moderate, while stress level is high. Additionally, it was observed that as the social support increases caregiver burden decreases, the more stress level increases the more care giving burden increases or as the care giving burden increases, the caregiver's stress level increases. Furthermore, belonging to an extended family increases the caregiver burden, while on the other hand having training on the patient's disease and its treatment and the presence of a helper who supports the caregiver reduce the caregiver burden.

In parallel with these results, it can be suggested that caregiver burden of chronic patients' caregivers should be dealt with a holistic approach. Reducing the care burden by activating social support resources, which is one of the important factors effecting the dimension of caregiver burden, determining the stress factors and planning the initiatives to diminish these stressors, doing the planning within the family in order to give responsibilities about care giving to each individual and regularly monitoring the applications also efficiency of can recommended.

### References

Aoun SM., Bentley B., Funk L., Toye C., Grande G. & Stajduhar KJ. (2013) A 10-year literature review of family caregiving for motor neurone disease: moving from caregiver burden studies to palliative care interventions. Palliative medicine 27(5): 437-446.

- Ardahan M. (2006) Social support and the nursing. Journal of Anatolia Nursing and Health Sciences 9(2): 68-75.
- Arkar H., Sari O. & Fidaner H. (2004) Relationships between quality of life, perceived social support, social network and loneliness in a Turkish sample. New Symposium, 42(1): 20-27.
- Asiret GD. & Kapucu S. (2012) Burden of caregivers of stroke patients. Turkish Journal of Research & Development in Nursing 19:5-10.
- Atagun MI., Balaban OD., Atagun Z., Elagoz M., Ozpolat AY. (2011) Caregiver Burden in Chronic Diseases. Current Approaches in Psychiatry 3(3):513-552.
- Bugge C., Alexander H., & Hagen S. (1999) Stroke patients' informal caregivers patient, caregiver, service factors that affect caregiver strain. Stroke 30(8): 1517-1523.
- Cavkaytar A., Batu S. & Cetin OB. (2008) Perspectives of Turkish mothers on having a child developmental disabilities. International Journal of Special Education 23(2): 101-109.
- Chen HM., Huang MF., Yeh YC., Huang WH. & Chen C S. (2015) Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. Psychogeriatrics 15(1): 20-25.
- Chiou CJ., Chang HY., Chen IP. & Wang HH. (2009) Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. Archives of gerontology and geriatrics 48(3): 419-424.
- Citlik Saritas S., Bayır K., Saritas S., Ucuzal M. (2014) Caregivers Of Patients Undergoing Liver Transplantation Determination The Burden Of Care. Yildirim Beyazıt University Journal of Nursing 2:17–25.
- Collins CE., Given BA. & Given CW. (1994) Interventions with family caregivers of persons with Alzheimer's disease. The Nursing Clinics of North America 29(1): 195-207.
- Dokmen Z. (2012) The relations between mental health and perceived social support of family caregivers. Ankara University Journal of Institute of Social Sciences 3(1): 3-38.
- Eker D. & Arkar H. (1995) Factorial structure, validity, and reliability of the multidimensional scale of perceived social support. Turkish Journal of Psychology 34: 17-25.
- Eker D., Arkar H. & Yaldiz H. (2001) Factorial structure, validity, and reliability of revised form of the multidimensional scale of perceived social support. Turkish Journal of Psychiatry 12(1): 17-25.
- Erdem M. (2005) The caregiver for elderly. Journal of Anatolia Nursing and Health Sciens 8(3): 101-106.
- Flores Gonzalez E. & Seguel Palma F. (2016) Functional social support in family caregivers of adults with severe dependence. Investigación Educación У Enfermería 34(1): 68-73.

- Gulpak M. & Kocaoz S. (2014) The care burden and the affecting factors of individuals receiving hemodialysis treatment. TAF Preventive Medicine Bulletin 13(2):99-108.
- Guralnick MJ., Hammond MA., Neville B. & Connor RT. (2008) The relationship between sources and functions of social support and dimensions of child-and parent-related stress. Journal Intellectual Disability Research 52(12): 1138-1154.
- Hair JF., Black WC., Babin BJ., Anderson RE. (2010) Multivariate data analysis. Seventh Edition. Prentice Hall, Upper Saddle River, New Jersey, US.
- Hamama-Raz Y., Rot I. & Buchbinder E. (2012) The coping experience of parents of a child with retinoblastoma-malignant eye cancer. Journal of Psychosocial Oncology 30(1): 21-40.
- Hayes J., Chapman P., Young LJ. & Rittman M. (2015) The prevalence of injury for stroke caregivers and associated risk factors. Topics in Stroke Rehabilitation 16(4):300-308.
- Hinojosa MS. & Rittman MR. (2007) Stroke caregiver information needs: Comparison of mainland and puerto rican caregivers. Journal of rehabilitation research and development 44(5): 649-658.
- Hsiao CY. (2010) Family demands, social support and caregiver burden in Taiwanese family caregivers living with mental illness: the role of family caregiver gender. Journal of Clinical Nursing 19(23-24): 3494-3503.
- Inci FH. & Erdem M. (2008) Validity and reliability of the burden interview and its adaptation to Turkish. Journal of Anatolia Nursing and Health Sciences 11(4):85-95.
- Iwamoto V., dos Santos SH., Skare TL. & Spelling PF. (2008) Evaluation of psychological stress in primary caregivers of patients with juvenile idiopathic arthritis. Jornal de pediatria 84(1): 91-
- Kasuya RT., Polgar-Bailey MP. & MPH Robbyn Takeuchi, MSW. (2000) Caregiver burden and guide burnout for primary care physicians. Postgraduate Medicine 108(7): 119-123.
- Kaufman AV., Kosberg JI., Leeper JD. & Tang M. (2010) Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. Journal of Gerontological Work 53(3): 251-269.
- Kim Y., Carver CS., Rocha-Lima C. & Shaffer KM. (2013) Depressive symptoms among caregivers of colorectal cancer patients during the first year since diagnosis: longitudinal investigation. Psycho-Oncology 22(2):362-367.
- Kucukguclu O., Esen A. & Yener G. (2009) The reliability and validity of the Caregiver Burden Inventory in Turkey. Journal of Neurological Sciences 26: 60-73.

- Leggett AN., Zarit S., Taylor A. & Galvin JE. (2010) Stress and burden among caregivers of patients with Lewy body dementia. The Gerontologist 51(1): 76-85.
- Lutz BJ. & Young ME. (2010) Rethinking intervention strategies in stroke caregiving. Rehabilitation Nursing 35(4): 152-160.
- Mollaoglu M., Ozkan Tuncay F. & Kars Fertelli T. (2011) Care Burden Of Care Givers Of Stroke Patients And Related Factors. DEUHYO ED 4 (3):125-130.
- Orak OS. & Sezgin S. (2015) Caregiver Burden in Family Members of Cancer Patients. Journal of Psychiatric Nursing 6(1):10-15.
- Oshodi YO., Adeyemi JD., Aina OF., Suleiman TF., Erinfolami AR. & Umeh C. (2012) Burden and psychological effects: caregiver experiences in a psychiatric outpatient unit Nigeria. African journal of psychiatry 15(2): 99-
- Ozyesil Z., Oluk A. & Cakmak D. (2014) The prediction level of caregiver burden on caregivers' state-trait anxiety levels. Anatolian Journal of Psychiatry 15:39-44.
- Palos GR., Mendoza TR., Liao K P., Anderson KO., Garcia-Gonzalez A., Hahn K., Jibaja-Weiss ML. (2011) Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. Cancer 117(5): 1070-1079.
- Powers Daniel A. & Xie Yu. (2000) Statistical Methods for Categorical Data Analysis, Academic Press, ABD.
- Robinson BC. (1983) Validation of a caregiver strain index. Journal of gerontology 38(3): 344-348.
- Rodakowski J., Skidmore ER., Rogers, JC. & Schulz R. (2012) Role of social support in predicting caregiver burden. Archives of physical medicine and rehabilitation 93(12): 2229-2236.
- Salama R. (2012) Caregiver burden from caring for impaired elderly: A cross-sectional study in rural lower Egypt. Italian Journal of Public Health 9(4):11-17.
- Schreiner AS., Morimoto T., Arai Y. & Zarit S. (2006). Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. Aging and Mental Health 10(2): 107-111.
- Schulze B. & Rossler W. (2005) Caregiver burden in mental illness: review of measurement, findings and interventions in 2004-2005. Current Opinion in Psychiatry 18(6): 684-691.
- Selen F. & Kav S. (2014) Determining the needs, caregiving burden and associated factors in primary caregivers of patients with chronic obstructive pulmonary diseases. Association for Research and Development in Nursing-HEMAR-G 16(1): 12-22.
- Shieh SC., Tung HS. & Liang SY. (2012) Social support as influencing primary family caregiver burden in Taiwanese patients with colorectal

- cancer. Journal of nursing scholarship 44(3): 223-
- Sirzai H., Unsal Delialioglu S., Sarı İF. & Ozel S. (2015) Stroke and Caregiver Burden. JPMR 18(3): 162-169.
- Stetz KM. & Brown MA. (1997) Taking care: Caregiving to persons with cancer AIDS. Cancer Nursing 20(1): 12-22.
- Subgranon R. & Lund DA. (2000) Maintaining caregiving at home: A culturally sensitive theory of providing care grounded Thailand. Journal of Transcultural Nursing 11(3): 166-173.
- Tasdelen P. & Ates M. (2012) The Needs of Home Care Patients and the Burdens of their Caregivers. Association for Research Development in Nursing-HEMAR-G 9(3): 22-29.
- Teel CS., Duncan P. & Lai SM. (2001) Caregiving experiences after stroke. Nursing Research 50(1): 53-60.
- Tehee E., Honan R. & Hevey D. (2009) Factors contributing to stress in parents of individuals with autistic spectrum disorders. Journal of Applied Research in Intellectual Disabilities 22(1): 34-42.
- Tel H., Demirkol D., Kara S. & Aydın D. (2012) Care burden and quality of life among the caregivers of patients with COPD. Turkish Thoracic Journal 13(3): 87-92.
- Toseland RW., Smith G., Mccallion P. (2001) Handbook of social work practice with vulnerable and resilient populations. In A Gitterman (Eds.), Family caregivers of the frail elderly, Columbia University Pres, US.
- Tuncay FO., Mollaoglu M. & Fertelli TK. (2015) Care burden and social support of caregivers caring for patients with chronic diseases. Literature Symposium 1(8): 5-10.
- Turkish Statistical Institute Turkish Family Structure Survey (TUIK) 2006. www.tuik.gov.tr, (30/07/2016)
- Ugur O. & Fadiloglu C. (2010) Caregiver Strain Index validity and reliability in Turkish society. Asian Pacific Journal of Cancer Prevention 11: 1669-1675.
- Varona R., Sait, T., Takahashi M. & Kai I. (2007) Caregiving in the Philippines: A quantitative survey on adult-child caregivers' perceptions of burden, stressors, and social support. Archives of Gerontology and Geriatrics 45(1): 27-41.
- Wang LJ., Zhong WX., Ji XD. & Chen J. (2016) Depression, caregiver burden and social support among caregivers of retinoblastoma patients in China. International Journal of Nursing Practice 22(5): 478-485.
- World Health Organization (WHO- September 2011), Noncommunicable Diseases Country Profiles 2011. Erisim: 26.07.2017. http://whqlibdoc.who.int/publications/2011/97892 41502283 eng.pdf/

- Yildirim S., Engin E. & Baskaya VA. (2012) The burden of caregivers of stroke patients and the factors affecting the burden. Archives of Neuropsychiatry 50: 169-174
- Zarit SH., Reever KE. & Bach-Peterson J. (1980) Relatives of the impaired elderly: correlates of
- feelings of burden. The gerontologist 20(6): 649-655.
- Zimet GD., Dahlem NW., Zimet SG. & Farley GK. (1988) The multidimensional scale of perceived social support. Journal of personality assessment 52(1): 30-41.