

# Caregiver Burden in Caregivers of Acute Stroke Patients: From a Biopsychosocial Perspective in a Turkey Sample

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**Received:** 20.02.2020

**Accepted:** 05.06.2021

## ABSTRACT

**Objective:** This study aimed to evaluate caregiver burden among caregivers of acute stroke patients with a biopsychosocial perspective in a Turkey sample.

**Methods:** 72 stroke patients and 72 their caregivers were included the study. The mean age of the stroke patients included in the study was 65±12.39. The mean age of caregivers was 44.5±14 and 66.7% of them were females. Modified Motor Assessment Scale (MMAS), Standardized Mini Mental State Examination (SMMSE) and The Barthel Index (BI) were used to assess the patients with stroke. The caregivers were evaluated by using the Bakas Caregiving Outcomes Scale, Family Sense of Coherence Scale-Short Form (FSOC-S), Hospital Anxiety and Depression Scale (HADS), WHOQOL-Bref-Short Form and Multidimensional Scale of Perceived Social Support (MSPSS).

**Results:** There were significant positive correlation between the BCOS score and the SMMSE ( $r=0.36$ ;  $p=0.002$ ) and BI ( $r=0.22$ ;  $p=0.05$ ) scores. A significant positive correlation was found between the BCOS score and MSPSS's family ( $r=0.31$ ;  $p=0.007$ ), friend ( $r=0.41$ ;  $p<0.01$ ) and special human ( $r=0.46$ ;  $p<0.01$ ) sub-parameters. In addition, there were significant positive correlations between BCOS score and the physical ( $r=0.35$ ;  $p=0.02$ ) and environmental ( $r=0.42$ ;  $p<0.01$ ) sub-dimensions of the WHOQOL-BREF, also HADS Depression sub-score ( $r=0.93$ ;  $p=0.01$ ). Correlations between BCOS score and patients' age, MMAS, FSOC-S, scores and HAD Anxiety sub-score were not statistically significant ( $p>0.05$ ).

**Conclusion:** The cognitive function and independence level of the patients is associated with care burden. Furthermore, psychosocial features such as poor social functioning, quality of life and emotional health of caregiver have adverse effects on caregiver burden.

**Keywords:** Acute stroke, Biopsychosocial model, Caregiver burden, Quality of life

## 1. INTRODUCTION

Stroke is globally the second most common cause of death and a major cause of disability (1). Post-stroke rehabilitation and care have become the most important building blocks in terms of survival and independence of stroke survivors (2). In most cases of stroke, patients generally receive care from their relatives in hospital and at home. Due to the severe disorders and disabilities after stroke, not only the patients but also their caregivers have to struggle with challenging conditions in this process (3).

Caregivers generally deal with a range of care needs and demands such as mobility, self-care, cognitive and mood changes (4). This process causes caregiver burden which is known as the experience of physical, psychological, emotional or social problems due to caring responsibility for ill person (5). Caregiving to a person with disability restricts the work and leisure activities, and negatively affects the

family relationship and quality of life of the caregivers. This situation creates a physical and psychological burden on individuals (6). Caregivers also have to cope with chronic stress, especially if there are serious problems about physical / psychological conditions and financial resources (7).

According to current interdisciplinary rehabilitation care of stroke patients suggestions', well-being of caregiver is as important as well-being of the stroke patient in the disease period (8). Also providing support and intervention to caregivers has been emphasized (9). To develop appropriate and effective interventions to meet the specific needs of caregivers, the caregiver burden should be assessed with a broad perspective (10).

Many studies have examined potential factors associated with caregiving burden after stroke, such as the caregivers'

quality of life, income level, and family integrity. Also, it is known that the patients' age, sex and independence level affects caregiver burden (11-16). However, caregiving burden is related to the combination of multiple and simultaneous factors and the number of studies evaluating these factors as multidimensional (including all bio-psycho-social factors) are limited (17). Moreover, although caregiving burden is known as a chronic period problem, it is also highly prevalent in acute stroke and there are very few studies about caregiving burden in an acute phase of stroke (18). Furthermore, the studies that mention both patient and caregiver features and evaluating biopsychosocial aspects of caregiving in acute period are insufficient in Turkey.

The biopsychosocial approach systematically considers biological (age, gender, acute illness, disability etc.), psychological (mood, personality, behavior, etc.), and social factors (cultural, familial, socioeconomic, medical, etc.) and their complex interactions in understanding health, illness, and health care delivery (19). In health care delivery of stroke patients, caregivers play important role. As caregiving burden can be caused by many factors, assessing caregiver burden with the frame of biopsychosocial model may guide in understanding the caregiving burden of stroke patients and creating strategies on problem-solving interventions of caregivers (10). In this case, while biological factors could belong to both patients' disease characteristics and caregiver demographic characteristics, psychosocial factors could be related to caregivers' features.

Therefore, the aim of our study was to evaluate caregiver burden among caregivers of acute stroke patients with biopsychosocial perspective in a Turkey sample.

## 2. METHODS

### 2.1. Recruitment and inclusion of participants

Our descriptive cross-sectional study included individuals with stroke who were being treated at the Neurology Clinic of a Training and Research Hospital and their caregivers between December 2015-July 2017. The study diagram with the individuals included in the study and the evaluation methods are shown in Figure 1.

G Power was used to calculate the sample size of the present study. The sample size was based on the estimates obtained by using Barthel Index scores as a criterion. In order to determine the sample size 0.40 points of effect size, 0.05 type I error and 90% power were accepted. The minimum sample size was estimated at 54 participants (20).

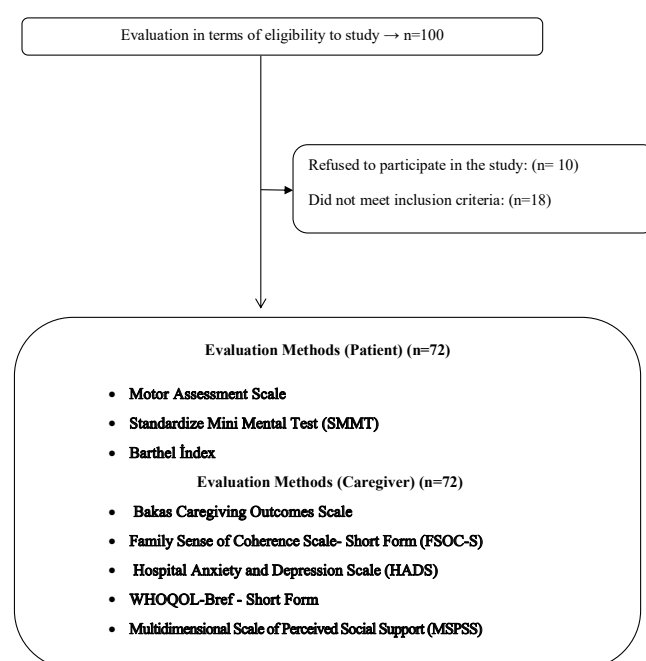
The study was approved by the Clinical Research Ethics Committee. All the subjects were informed about the purpose, duration and evaluations of the study and were included in the study after they approved the Voluntary Informed Consent Form.

Inclusion criteria for patients:

- to have a clinical diagnosis of stroke by computed tomography (CT) or magnetic resonance imaging (MRI),
  - to have a Glaskow Score of 9 or higher
  - to be 18 years or older,
- Inclusion criteria for caregivers:
- to be 18 years or older,
  - to be the main caregiver of the patient

Patients with any other neurological problem and mentally disabled caregivers were excluded from the study.

Figure 1: Study Diagram



### 2.2. Evaluation Methods of Stroke Patients

Demographic and clinical data such as age, gender, affected body part and history of the stroke attack were collected by using the "Case Follow-up Form". "The modified Motor Assessment Scale" was used to evaluate the motor status of the patients. The cognitive levels of the patients were evaluated using "the Standardized Mini Mental Test". Barthel Index was used to evaluate the independence levels of the patients in daily living activities.

#### 2.2.1. The modified Motor Assessment Scale (MMAS)

MMAS is a performance-based scale developed to evaluate daily motor functions in stroke patients. It is a short and practical assessment tool that evaluates eight different motor functions and muscle tone. Each item is scored between 0 and 6. MDS was found to be highly reliable with a mean

correlation of 0.95 and an average test-retest correlation of 0.98 according to a study by Carr JH et al. (21).

### 2.2.2. Standardised Mini-Mental State Test (SMMSE)

SMMSE is a short screening tool used to quantify the cognitive impairment of the individual and to record the cognitive changes over time. The scale consists of orientation, memory, attention and calculation, recall and language subtitles. The maximum score taken from the scale is 30, and a higher score means better cognitive function (22).

### 2.2.3. Barthel Index (BI)

The Barthel Index is a short and widely used scale consisting of 10 items, evaluating the level of independence and improvement of the individual's daily living activities. The highest score from the scale is 100, and the highest score is the indicator of best independence level (23).

## 2.3. Evaluation Methods of Caregivers

Information about caregivers such as age, gender, previous patient care experience was collected by the "Caregiver Follow-up Form". The Bakas Caregiving Outcomes Scale was used to evaluate caregiving burden. The condition of the family relations of participants was measured by the "Family Sense of Coherence Scale – Short Form (FSOC-S)". The anxiety and depression levels of participants were measured by the Hospital Anxiety and Depression Scale (HADS). WHOQOL-Bref – Short Form was used to evaluate the quality of life and the Multidimensional Scale of Perceived Social Support (MSPSS) for social support.

### 2.3.1. Bakas Caregiving Outcomes Scale (BCOS)

BCOS is a self-report scale that evaluates the care-giving process developed by Bakas et al. The items of the scale are rated on a 7-point scale ranging from -3 (Changed for the worst) to +3 (Changed for the best). The ratings are performed between 1 and 7. The maximum score from the scale is 105 and high scores from the scale indicate better caregiver outcomes (24).

### 2.3.2 Family Sense of Coherence Scale – Short Form (FSOC-S)

FSOC-S is a 7-point likert scale that was developed by Antonovsky and Sourani. The scale is composed of 12 items and scored from 1 to 7. High scores from the scale indicate high family integrity (25).

### 2.3.3. Hospital Anxiety and Depression Scale (HADS)

The HAD scale was developed by Zigmond and Snaith to evaluate the level of anxiety and depression. 7 out of 14 questions evaluate anxiety and 7 evaluate depression. Each

item is scored between 0 and 3. High scores from the scale indicate high anxiety and depression levels (26).

### 2.3.4. WHOQOL-BREF

WHOQOL-BREF is a scale developed by the World Health Organization consisting of 4 subscales (Physical Health, Psychological, Social Relations, Environmental). High scores from the scale indicate high quality of life (27). In our study, physical and environmental subscales of the scale were used.

### 2.3.5. Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS is a short, easy-to-use scale that assesses the level of support from family, friends and a special person subjectively. Each subscale consists of 4 questions (3 subscales total= 12 questions). High scores from the scale indicate high level of social support (28).

## 2.4. Data Analysis

All statistical analysis were accomplished by the Statistical Package for the Social Sciences (SPSS) 21.0 (SPSS Inc, Chicago, IL, USA). Descriptive statistics included nominal variables, which were expressed as percentages, and continuous variables, which were expressed as mean and standard deviation. The Kolmogorov-Smirnov test was used to determine for normal distribution of data before the statistical analysis. The distribution of data was found abnormal. Kruskal-Wallis test was used to compare the BCOS score according to demographic and clinical baseline variables. Correlation levels between variables were computed through Spearman's correlation analysis. The strength of correlations was interpreted as: 0.00-0.19 very weak, 0.20-0.39 weak, 0.40-0.59 moderate, 0.60-0.79 strong, 0.80-1.0 very strong (29).

## 3. RESULTS

A total of 72 stroke patients and their caregivers (n=72) were included in the present study. 34.7% of the caregivers participating in the study were found to be in the 45-54 age group, 66.7% were females, 52.8% had a moderate income and 56.9% of caregivers were children of stroke patients. 52.8% of the caregivers participating in the study were living with the patient, 51.4% had not given care to a patient before, 41.7% had been given care for 1-5 years, 61.1% had received help from their family members in the care, and 51.4% were found to have difficulty in positioning or moving patients (Table 1). The mean score of caregivers was 59.33±15.95, the mean score of the Social Support Scale was 44.12±11.96, the mean score of the WHOQOL-Bref scale physical sub parameter was 23.75±4.08, and the mean score of the environmental parameter was 25.4 ± 5.05, and HAD Scale Anxiety score was 12.00±5.82, the HAD Scale Depression score was found to be 10.86±5.17.

**Table 1.** The demographic and clinical features of caregivers (n=72)

		Mean ± SD	n	%
<b>Age</b>		44.5±14.8		
<b>Sex</b>	Female		48	66.7
	Male		24	33.3
<b>BCOS Score</b>		59.33 ± 1.95		
<b>MSPSS</b>	Family Support Dimension	15.87± 5.22		
	Friend Support Dimension	14.18± 4.88		
	Special Human Support Dimension	14.06± 5.7		
	Total	44.12 ± 11.96		
<b>WHOQOL-Bref</b>	Physical	23.75 ± 4.08		
	Environmental	25.4 ± 5.05		
<b>HADS Score</b>	Anxiety	12.00 ± 5.82		
	Depression	10.86 ± 5.17		
<b>Income level</b>	Poor		31	43.1
	Moderate		38	52.8
	Good		3	4.2
<b>Relationship with the patient</b>	Partner		18	25.0
	Children		41	56.9
	Relative/ Other		13	18.1
<b>Living together with patient</b>	Yes		38	52.8
	No		34	47.2
<b>Previous Caregiving Experience</b>	Yes		35	48.6
	No		37	51.4
<b>Previous Caregiving Time</b>	Below a year		30	41.7
	1-5 years		30	41.7
	6-11 years and above		12	16.7
<b>Help Status during caregiving</b>	No		25	34.7
	Family/ Relative		47	65.3
<b>Type of received help during caregiving</b>	No		14	19.4
	Information Support		6	8.3
	Care Support		12	16.7
	Financial support		37	51.4
<b>Difficulties during caregiving</b>	No		2	2.8
	Nutrition / Dressing		13	18
	Move / Position Change		37	51.3
	Communication / Other		20	27.8

Mean±SD: Mean±Standart Deviation; n:number; %:percentage BCOS: Bakas Caregiving Outcomes Scale, MSPSS: Multidimensional Scale of Perceived Social Support; WHOQOL-Bref: World Health Organization Quality of Life Bref; HADS: Hospital Anxiety and Depression Scale Anxiety and Depression

The mean age of the stroke patients included in the study was 65±12.39, the mean score of the Mini-Mental State was 15.9±10, the Barthel Index average score was 41.45±38.2 and the mean score of the Motor Rating Scale was 17.95±13.52 (Table 2). According to the BCOS, caregiver burden mean score of caregivers with poor income levels was significantly lower than the other groups (p<0.01). The mean score of the care burden of the caregivers who received information

and care support was significantly higher than the other groups (p<0.01) (Table 3).

**Table 2.** The demographic and clinical characteristics of stroke patients (n = 72)

	Mean± SD
<b>Age (years)</b>	65±12.39
<b>Time since stroke (days)</b>	11.4±6.2
<b>SMMT</b>	15.9±10.1
<b>BI</b>	41.45±38.2
<b>MAS</b>	17.95±13.52

Mean±SD: Mean±Standart Deviation; WHOQOL-Bref: World Health Organization Quality of Life Bref; SMMT:Standardized Mini Mental Test; BI:Barthel Index; MMAS: Modified Motor Assessment Scale MAS: Motor Assessment Scale.

**Table 3.** Distribution of BCOS Scores according to demographic and clinical characteristics of caregivers of stroke patients

		Median (min-max)	p
<b>Age Group</b>	Below 18 age	46.5 (45-48)	0.05
	18-24 age	60.0 (45-80)	
	25-34 age	67.5 (51-80)	
	35-44 age	65.0 (48-99)	
	45-54 age	50.0 (32-92)	
	Above 55 age	54.5 (32-91)	
<b>Sex</b>	Female	55.5 (32-92)	0.08
	Male	64.5 (36-99)	
<b>Income Level</b>	Poor	50.0 (32-75)	<b>0.003</b>
	Moderate	65.0 (35-99)	
	Good	60.0 (55-92)	
<b>Relationship with the patient</b>	Partner	54.5 (32-92)	0.34
	Children	59.0 (35-99)	
	Relative/ Other	50 (32-92)	
<b>Living together with the patient</b>	Yes	55.0 (32-99)	0.68
	No	58.0 (35-92)	
<b>Previous Caregiving Experience</b>	Yes	57 (35-99)	0.60
	No	58 (32-92)	
<b>Previous Caregiving Time</b>	Below a year	58.5 (35-99)	0.09
	1-5 years	53.5 (33-80)	
	6-11 years and above	85 (82-88)	
<b>Help Status during caregiving</b>	No	65.0 (32-92)	0.22
	Family/ Relative	55.0 (32-99)	
<b>Type of received help during caregiving</b>	No	67.0 (32-92)	<b>&lt;0.001</b>
	Information Support	66.0 (45-99)	
	Care Support	76.5 (55-92)	
	Financial support	50 (32-76)	
<b>Difficulty during caregiving</b>	No	63.0 (46-80)	0.10
	Nutrition / Dressing	62.0 (32-78)	
	Move / Position Change	51.0 (32-99)	
	Communication /	68.0 (44-92)	
	Other		

Mean±SD: Mean±Standart Deviation; WHOQOL Bref: World Health Organization Quality of life Bref ,Min max: Minimum-maksimum; p<0,05 significance.

A statistically significant positive correlation was found between the BCOS scores and family ( $r=0.31$ ;  $p=0.007$ ), friend ( $r=0.41$ ;  $p<0.01$ ) and special human ( $r=0.46$ ;  $p<0.01$ ) sub-parameters of the MSPSS Social Support Scale, and the physical ( $r=0.35$ ;  $p=0.02$ ) and environmental ( $r=0.42$ ;  $p<0.01$ )

sub-dimensions of the WHOQOL-BREF. In addition, there was a statistically significant relationship between the BCOS score and HADS Depression sub-score ( $r=0.93$ ;  $p=0.01$ ). Correlations between BCOS score and patients' age and MMAS were not statistically significant ( $p>0.05$ ) (Table 4).

**Table 4.** The relationship between caregiver burden and caregiver characteristics

	Age	MSPSS Total	MSPSS Family	MSPSS Friend	MSPSS Special Human	WHOQOL-Bref Physical	WHOQOL-Bref Environ.	FSOC-S Score	HADS Anxiety	HADS Depression	
BCOS Score	r	0.26	0.53	0.31	0.41	0.46	0.35	0.42	0.01	0.13	0.93
	p*	0.02	0.001	0.007	<0.001	<0.001	0.002	<0.001	0.91	0.26	0.01

\*: Spearman Correlation Test; r: Correlation Coefficient;  $p<0.05$  significance, BCOS: Bakas Caregiving Outcomes Scale; MSPSS: Multidimensional Scale of Perceived Social Support;

WHOQOL-Bref: World Health Organization Quality of Life Bref; FSOC-S: Family Sense of Coherence Scale-Short Form Physical and Environmental; HADS: Hospital Anxiety and Depression Scale Anxiety and Depression

When the relationship between caregiving burden and patient characteristics is examined, there was a statistically significant positive correlation between BCOS and SMMSE scores ( $r=0.36$ ;  $p=0.002$ ). In addition, there was a statistically significant positive correlation between BCOS and the Barthel Scores ( $r=0.22$ ;  $p=0.05$ ). Correlations between BCOS score and FSOC-S score and HAD Anxiety sub-score were not statistically significant ( $p>0.05$ ) (Table 5).

**Table 5.** The relationship between caregiving burden and patient characteristics

	Age	SMMT	BI	MMAS	
BCOS Score	r	-0.06	0.36	0.34	0.22
	p*	0.59	0.002	0.003	0.05

\*: Spearman Correlation Test; r: Correlation Coefficient;  $p<0.05$  significance; BCOS: Bakas Caregiving Outcomes Scale; SMMT: Standardized Mini Mental Test; BI: Barthel Index; MMAS: Modified Motor Assessment Scale

#### 4. CONCLUSION

Caregiver burden in caregivers of acute phase stroke patients was investigated in terms of biopsychosocial perspective in the present study due to the lack of knowledge about caregiver burden in Turkey. When all factors that may affect the severity of caregiver burden are evaluated together, caregiver burden is found associated with poor social functioning, quality of life and emotional health of caregiver in an acute phase of stroke. In this case, it can be considered that the burden of care is most affected by psychosocial variables. Also, the patients' cognitive and independence level should be considered about the caregiver burden level.

#### 5. DISCUSSION

In a recent meta-analysis about caregiver burden in patients with stroke, it was found that caregivers under higher burden are likely to experience high anxiety and depression.

Moreover, patients with lower activity of daily living and anxiety symptoms also lead to more burden to caregivers. In this meta-analysis, the average time after stroke onset was over 6 months in the included studies (30). To our knowledge, there are not sufficient studies in the literature about caregiver burden in caregivers of acute phase stroke patients (30, 31). However, caregivers have to cope with the changes of stroke survivors in many respects such as mobility, mood or communication from the first day of the disease. It is known from previous studies that these changes contribute with increased perceived burden as well as high rate of depressive symptoms, stress and other mental problems in the later years (32). Also, it is associated with poor response to rehabilitation among stroke (31). Therefore, detecting the risk factors and early intervention to decrease the level of burden among stroke caregivers are important clinical implications in the acute stroke rehabilitation field.

Most of the caregivers were women and the children of stroke patients in our study. The previous studies supported that giving care to the parents was an individual duty and responsibility traditionally in Turkish culture (33). A study from Nigeria had similar results about the caregivers' sex and kinship with the patients (18).

The caregivers demonstrated moderate levels of burden, considering the average of 59.33 in the Bakas Caregiving Outcomes scale (BCOS). BCOS score points were found to be lower in lower income levels compared to caregivers with higher income levels. The decrease in mean scores reflected the increment of the burden of care. Similarly, Tsai Y. H et al (2018) (34) showed the relationship between caregivers' financial situation and caregivers burden in their study of acute phase stroke patients. Moreover, Jeong, Y. G. et al. (2015) (14) emphasized that lower income negatively affected quality of life of caregivers and this relation was found to increase caregiver burden secondarily among the patients with chronic stroke. Hence, when caregiver burden is examined according to the received support type, we observed that caregiver burden increases in caregivers

who receive financial support. It was also found that the caregivers who need only information and care support from their families or relatives had decreased caregiver burden when compared to the persons who received only financial support. *Yu et al. (2013)* (35) stated that the support of caregivers are generally received from family members as well.

Considering the social component of the biopsychosocial model, our results showed that there was significant correlation between perceived family, friend or special human social support dimensions scores and caregiver burden level. As the social support increased, it was seen that caregiver burden decreased in the present study. These findings were similar with a study which was conducted by *Akosile C.O et al. (2018)* conducted a study using Cara Giver Strain Index and found similar results with our study (18).

As a point of the psychological component, *Efi, P. et al (2017)* (36) reported the strong correlation between caregiver burden and anxiety, depression and quality of life. In our study there were significant correlations between BCOS caregiver burden and the depression component of HAD scale, WHOQOL-Brief physical and environmental sub scores. It means that the anxiety and depression scores from HAD and the worse quality of life leads to more caregiver burden.

In our study we found a strong relationship between BCOS caregiver burden level and the stroke patients' cognitive status and independency level during activities daily living (ADL). It was seen that as the cognitive level and independence level in ADL increased, the burden of care decreased among caregivers of acute phase stroke patients. The literature shows similar findings. *Caro, C et al (2017)* (37) stated the significant correlation between independence level, cognitive status of stroke patients and caregiver burden.

Lastly, it has been shown that increased caregiver burden in acute stroke is associated with social functioning, quality of life, caregiver's emotional health, patients' cognitive and independence level in accordance with the literature providing information on care burden in chronic strokes (38). Caregiver burden should be considered via a biopsychosocial model and it contributes to more systematic information about health status of stroke survivors and caregivers. More importantly, it is effective in improving the provision of evidence-based recommendations for the design of solution strategies to improve health status.

The study has some strengths. Although there are studies in the literature in which biopsychosocial evaluations and treatments are applied using different assessment parameters (4, 39), to our knowledge, this is the first study which researches caregiver burden in terms of a biopsychosocial perspective among both stroke patients and their caregivers' in a Turkish population. This study has also a guiding feature as it has reflected the neurology service needs beside the clinic interventions to improve the stroke patients' care.

The study has certain limitations. Firstly, long-term findings about caregiver burden and related factors were not

collected. Secondly, as this is an observational and cross-sectional study, especially anxiety, depression level of caregivers could not be distinguished from the other reasons except caregiver burden. Lastly, as our results did not show normally distributed data, we could not do any regression analysis to decide which one of the factor has more effects on caregiver burden.

In conclusion, the findings of this study pointed out the significant association between burden and poor social functioning, quality of life and emotional health of caregiver in acute phase of stroke. The burden of care seemed most affected by psychosocial variables; therefore, thinking about the future status of patients, if necessary, caregivers should take support and training about care giving. Therefore, providing education to the caregivers in hospitals about the disease and caregiving could be beneficial. In addition, caregivers should be trained for physically support according to independency level of patient.

**Acknowledgements and Funding:** The author(s) received no financial support for the research, authorship, and/or publication of this article.

**Conflict of Interest:** The authors declare that there is no conflict of interest regarding the publication of this article.

All authors confirm that the patient/person(s) have read this manuscript and given their permission for it to be published.

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**How to cite this article:** Ersoz Huseyinsinoglu B, Zirek E, Aytutuldu Kaya G, Kucukoglu H. Caregiver Burden in Caregivers of Acute Stroke Patients: From a Biopsychosocial Perspective in a Turkey Sample. *Clin Exp Health Sci* 2021;11:667-673. DOI:10.33808/clinexphealthsci.685431