

Evaluation of stroke patients caregivers burnout and stress coping style situations

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ABSTRACT

Aim: It is a descriptive study aimed at assessing burnout and stress coping styles of stroke patient caregivers.

Materials and Methods: The universe of this study constitute the 150 stroke patients who hospitalized in Neurology and Palliative Service from March to August 2016 and their caregivers. The data were obtained from questionnaires "Patient and Caregiver Promoter Form", "Functional Independence Measure (FIM)", "Caregiver Strain Index (CSI1)", "Maslach Burnout Inventory (MBI)" and "Coping Styles Inventory (CSI2)" that were applied to patients and their caregivers. Data were evaluated in Statistical Package for the Social Sciences 21 (SPSS) package program using arithmetic mean, percentile calculation, T Test, Anova, Mann Whitney U Test, Kruskal Wallis Post Hoc, Correlation Analysis methods.

Results: 71.3% of caregivers are women and 57.3% are children of the patients. It was identified that caregivers' mean emotional exhaustion score was 29.31 ± 8.21 , depersonalization was 12.2 ± 4.5 , and personal

achievement was 18.68 ± 4.03 . It has been determined that caregivers use the most; self-confident approach (13.93 ± 3.45), helpless approach (13.46 ± 4.26) and optimistic approach (11.16 ± 2.36) sub-dimensions to cope with stress. There was a negative relationship between emotional exhaustion and self-confident approach, optimistic approach and applying for social support, a positive relationship between desensitization and helpless approach, and a negative relationship between personal success and a self-confident and optimistic approach.

Conclusions: It was determined that as the levels of emotional exhaustion of caregivers increased, the rates of using effective coping methods with stress decreased, as the level of desensitization increased, the rates of using desperate approach increased and as the level of personal success increased, the rates of using safe and optimistic approach sub-dimensions significantly decreased.

Key words: Stroke, Caregiver, Burnout, Stress Coping Inventory

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INTRODUCTION

Stroke has always been a major health problem worldwide and is the third most common cause of death after coronary artery diseases and cancer worldwide [1]. It is one of the most common causes of adult disability in developed countries [2].

Many functional health problems are seen in patients who continue their lives after stroke, making the need for a care provider necessary. Research has shown that the majority of patients after stroke continue their lives by needing the support of someone else [3,4] and revealed that this support was mostly given by family members. Caregivers for stroke patients are required to assume the caregiving role immediately. This is because stroke is a sudden onset condition and the multidimensional functional impairments in the patient necessitate the need for a caregiver. Difficulties experienced by caregivers in this process include their unpreparedness for the caregiving journey, initially expecting the patient to fully recover, coming to terms with the fact that symptoms may persist for months or a lifetime, and the physical burden that caregiving places on them. Research indicates that caregivers face physical, psychological, and social problems during this process [5-8]. As a result of these problems, caregivers often experience a state of burnout. The concept of burnout has been widely accepted and defined by Maslach. According to Maslach, burnout is "a syndrome that results from chronic workplace stress that has not been successfully managed. It is characterized by three dimensions: feelings of exhaustion, cynicism (less identification with the job), and professional inefficacy (reduced personal accomplishment)." In the context of caregiving for stroke patients, burnout refers to the physical exhaustion, prolonged fatigue, feelings of helplessness and hopelessness, and negative attitudes towards the job, life, and others [9].

As a result of these problems, caregivers may face a burnout table. The fact that caregivers do not have enough time for themselves during the care process, the fact that they experience negative social life-work life and lack of adequate support in the process leads them to burnout. Studies have shown that those who care for patients with chronic disease have high rates of experiencing burnout [10].

In the study conducted by Tuna et al., it was determined that caregivers of stroke patients experienced emotional exhaustion and depersonalization during the caregiving process [11]. Studies have identified that one of the significant problems faced by caregivers experiencing burnout in the caregiving process is stress, and it has been found that caregivers experiencing burnout do not employ effective coping mechanisms to deal with stress [12].

Stress is a common concept encountered in our daily lives, and it has various definitions in the literature. Cüceloğlu defined stress as "the effort exerted by an individual beyond their physical and psychological limits due to maladaptive conditions in the physical and social environment" [13].

An individual under stress responds to the current situation by using coping mechanisms. When

examining the coping mechanisms of caregivers in dealing with stress, it is observed that the methods they use vary [14,15]. Studies have shown that caregivers experiencing burnout use ineffective coping strategies to deal with stress [10,12]. However, it is believed that caregivers who can effectively cope with stress will also experience a decrease in burnout, thus making the caregiving process more beneficial for both the caregiver and the patient.

It may be possible for care to be effective and quality with the evaluation of patients and those who care for them together. While we have access to a large number of studies on stroke cases in our country, it is seen that there are very few studies evaluating the problems of those who care for stroke patients. In the light of a holistic approach, it is important to identify the problems experienced by caregivers. The effective solution proposals will make the caregiver more effective and positive in the role of care, and that the quality of care will also increase.

The purpose of research

This study was conducted in a descriptive manner to assess burnout and stress coping situations of relatives who care for stroke patients.

Research questions

Does the socio-demographic characteristics of caregivers affect the burnout and stress coping situations that caregivers experience?

Is there a relationship between caregivers' burnout status and their coping with stress?

MATERIALS AND METHODS

Form of the research: The study was conducted in a descriptive manner to evaluate the situation of relatives who care for stroke patients coping with burnout and stress.

Sample and Universe of the Research: March - August 2016 in Neurology and Palliative Care Services in a public hospital, stroke patients and caregivers formed the universe of the research. The sample size of the study was selected in 95% confidence range by power analysis with minitap 15 program. It is determined to have a minimum of 125 persons for the standard deviation of 8 points, with a minimum of 80% test strength [11,16]. The sample included 150 patients and their relatives who cared for the patient; the sample strength was 84.8%.

Criteria for participation in the research: the selection criteria for participation in the research were determined as follows:

- The patient and the relatives who care for the patient should volunteer to participate in the research after being informed about the research
- Caregivers must be over 18 years old
- Caregivers need to know how to read and write
- Caregivers should not have mental and communication problems
- Patients must have been diagnosed with stroke for at least 1 month

Data collection tools

The data of the study was obtained by applying ‘Patient and Caregiver Promoter Form’, ‘Caregiver Strain Index (CSI1)’, ‘Maslach Burnout Scale (MBS)’, ‘Coping Styles Inventory (CSI2)’ to caregivers and by applying ‘Patient Introduction Form’ and ‘Functional Independence Measure (FIM)’ to stroke patients.

Patient Introduction Form

There are 7 questions describing the socio-demographic characteristics of the patients and 1 question evaluating the patient's relationship with the caregivers.

Functional Independence Measure

The functional independence measure indicates a person's level of dependence and independence when performing physical and cognitive activities in daily life. Turkish adaptation made by Yavuzer [17]. FIM consists of two parts: Motor- FIM (13 items) and cognitive- FIM (5 items). In Yavuzer's study, Cronbach's Alpha coefficient of the FIM was

determined as 0.81 [17]. and in this study, Cronbach's Alpha coefficient of the FIM was determined as 0.982.

Care Giving Promotion Form

It contains 23 questions created by the researcher by reviewing the literature. It includes questions related to socio-demographic characteristics of relatives who care for stroke patients and descriptive questions related to care.

Maslach Burnout Inventory (MBI)

It was developed by Maslach and Jackson [9]. Turkish adaptation; validity and reliability study conducted by Çapri [18]. It consists of 22 substances in total and burnout is assessed in three sub-dimensions. Emotional exhaustion dimension 9 item (1., 2., 3., 6., 8., 13., 14., 16., and 20. substances), desensitization dimension 5 substance (5., 10., 11., 15., 22. items) and personal achievement is the lower dimension of 8 items (4., 7., 9., 12., 17., 18., 19., Composed of 21 ingredients). The dimensions of emotional exhaustion and desensitization are negative, while the dimension of personal success includes positive statements unlike others. Insert Table 1.

Table 1. Interpretation of average scores from lower dimensions of burnout scale 18

Burnout Levels			
	Low	Normal	High
Emotional Exhaustion – EE	0-16	17-26	27 and more
Desensitization – DY	0-6	7-12	13 and more
Personal Succes – PS	39 and more	32-38	0-31

Care Giver Stress Index (CSI1)

The caregiver's Stress Index is a scale used to identify families with concerns about care as soon as possible and consists of 13 items. Participants answer questions in the form of Yes (1) or No (0) [19].

The highest score that can be taken from the scale is 13 and the lowest is 0 [19].

The positive response to 7 or more items on the scale indicates a greater level of stress and therefore the burden of care [19].

Coping Styles Inventory (CSI2)

The stress coping styles scale was adapted to Turkish by Folkman and Lazarus by simplification of the Ways of Coping Inventory (Ways of Coping) developed by individuals to determine their stress coping status by Şahin and Durak. Validity and reliability were checked by Şahin and Durak [20].

The CSI2 consists of five sub-dimensions. The “self-confident approach”, “optimistic approach”, “applying for social support” are the lower dimensions that are effective in coping with stress, while the “helpless approach” and the “subservient approach” are the lower dimensions that are ineffective. CSI2 coping methods used by the individual in the presence of stress, it measures with a rating of between 0-3 with Type 4 likert (0=%0, 1=%30, 2=%70, 3=%100). The scale consists of 30 items [20,21].

Ethical Dimension of Research

In order to evaluate the ethical relevance of the research, Ondokuz Mayıs University Clinical Research Ethics Committee was applied and approved by the Ethics Commission. Written permission has been obtained from the administration of Tokat State Hospital where the research will be carried out and from the General Secretariat of Public Hospitals Association of Tokat province. After the individuals agreed to participate in the research, data was collected by face-to-face interview method in accordance with the principle of “Informed Consent”.

Statistical Analysis

The data were evaluated in SPSS 21 package program using arithmetic mean, percentile calculation, T Test, Anova, Mann Whitney U test, Kruskal Wallis Post Hoc, Correlation Analysis methods.

RESULTS

When the distribution of caregivers according to their descriptive characteristics was examined, 57.3% stated that the patient had a daughter or son, 76% had no other person to care for except the patient, 58% had someone to help care for, 65.3% had cared for the patient for 1-6 months, 51.3% had 12 hours of day care, 97.3% did not agree to be cared for by CGSI total score average was found to be 8.82±3.91.

When the distribution of problems faced by caregivers in the care process is examined; 54.7% of caregivers stated that giving care negatively affects their private life and their roles, 73.2% said that their work life is affected, 48.3% said that care negatively affects their social life; 54.1% of those experiencing negative

social life defined this negative as not having time to do their social activities. 79.3% of caregivers stated that they had no time for themselves, 84.7% stated that they had experienced a psychological problem after starting to give care, and 52.3% described this psychological problem as despair. Insert Table 2.

Table 2. Score distribution of MBI and lower dimensions of caregivers

Scal	Lower Dimensions	Averaget± SS	Median	Min-Max
MBI	Emotional Exhaustion	29,31±8,21	30	9,0-45,0
	Desensitization	12,21±4,5	12	5,0-23,0
	Personal Succes	18,68±4,03	19	8,0-37,0
	Total Score	60,2±12,21	62	30,0-85,0

Table 2 shows the distribution of the scores that caregivers receive from the lower dimensions of MBI. Accordingly, the average MBI score of the caregivers was determined as 60.2±12.21.

As a result of research with gender; examined the relationship between MBI and CSI2: Female emotional exhaustion and burnout of caregivers an average of total score is higher, and the relationship between them was statistically significant (p<0.05); women helpless in coping with stress sub the size of the approach; the approach of male caregivers significantly more confident in coping with job stress were determined by using the size of sub (p<0.05).

The study found a statistically significant relationship between the status of caregivers having a

psychological problem after starting care and the emotional depletion, desensitization and total burnout scores of MBI (p<0.05).

In the study, a statistically significant correlation was found between the caregivers ' lack of time and emotional exhaustion, desensitization sub dimension of MBI and total burnout score averages (p<0.05).

The study found a statistically significant relationship between emotional exhaustion and total burnout score with whether caregivers wanted their patients to be cared for by someone other than themselves or by an institution (p<0.05). Insert Table 3.

Table 3. Score average distribution of CSI2 and lower dimensions of caregivers

Scale	Lower Dimensions	Average±SS	Median	Min-Maks
CSI2	Self-Confident Approach	13,93±3,45	14	5,0-21,0
	Optimistic Approach	11,16±2,36	11	6,0-15,0
	Desperate Approach	13,46±4,26	13	3,0-22,0
	Subjugation Approach	10,47±2,36	11	2,0-18,0
	Applying for Social Support	7,27±3,04	7	0,0-12,0
	Total Score	56,14±8,19	57	27,0-78,0

Table 3 shows the averages of the scores that caregivers receive from the lower dimensions of CSI2 . It is observed that caregivers received the highest score

in coping with stress from the lower dimension of “Self-Confident Approach” (13.93±3.45). Insert Table 4.

Table 4. Relationship between Sub Dimensions of MBI and CSI2

	Emotional Exhaustion	Desensitization	Personal Succes
Self-Confident Approach	r= -0,309 **	r= -0,165*	r= -0,334**
Optimistic Approach	r= -0,332**	r= -0,352**	r= -0,192*
Desperate Approach	r= 0,532**	r= 0,305**	r= 0,071
Subjugation Approach	r= 0,169*	r= -0,003	r= 0,128
Applying For Social Support	r= -0,175*	r= -0,067	r= -0,115
Total Stress	r= 0,050	r= -0,026	r= -0,153

* r: Pearson Correlation Coefficient

p< 0,05*

p< 0,001**

Table 4 shows the relationship between MBI sub-dimensions and CSI2 sub-dimensions. Accordingly,

the MBI- safe approach and an optimistic approach there was a significant relationship between the size of weak

sub in the negative direction ($p < 0.001$), a significant relationship between social support and very weak in the negative direction ($p < 0.05$), a significant positive moderate relationship between the size of the sub helpless approach ($p < 0.001$) and submissive approach was a significant relationship between the size of the sub is very weak in the positive direction detected ($p < 0.05$), (Table 4).

There was a very weak relation in the negative direction between the MBI-desensitization sub dimension and the safe approach sub dimension of CSI2 ($p < 0.05$), a weak relation in the negative direction between the optimistic approach sub dimension ($p < 0.001$), and a weak relation in the positive direction between the helpless approach sub dimension ($p < 0.001$) (Table 4).

When the relationship between the sub dimension of MBI-personal achievement and the sub dimension of CSI2 was examined, a weak relation in negative direction ($p < 0.001$) and a very weak relation in negative direction between the sub dimension of optimistic approach were determined ($p < 0.05$) (Table 4).

DISCUSSION

Those who care for stroke patients experience stress due to the difficulties they experience in the care process, not being ready for the care process, and this stress leaves them facing a burnout table. However, determining the problems experienced by caregivers in the care process in advance and finding effective solutions to the problems can eliminate the stress and burnout situations experienced and improve the quality of care. To this end, the findings from the research will be discussed.

In this study, score averages from the lower dimensions of MBI indicate that caregivers experience high levels of emotional exhaustion, levels of desensitization are normal and their personal success is low. This suggests that caregivers experience emotional exhaustion due to decreased emotional and physical resources, but that they are not insensitive to the care process and the patient, and that their personal success is low due to feeling inadequate about care. In another study with stroke patient relatives, it was determined that the patient relatives experienced emotional exhaustion and desensitization, but their personal achievements were not low [11].

In the study, emotional depletion score averages of female caregivers were significantly higher than male caregivers ($p < 0.05$). In other studies that examined the burnout status of caregiver relatives, it was observed that the burnout levels of female caregivers were higher than those of male caregivers [22-24].

This may be due to women having a more emotional structure, as well as being isolated from social life as a result of not having time for themselves. In the study, it was determined that caregivers who experienced a psychological problem during the care delivery process experienced significant emotional exhaustion and desensitization ($p < 0.05$). In their study,

Truzzi and colleagues also found that caregivers who experienced any psychological symptoms, sadness, anxiety, insomnia, irritability, fatigue had a statistically significant relationship with the mean score of the lower dimension of emotional exhaustion ($p < 0.05$) [22]. A loved one is facing a life-threatening illness at an unexpected time; the reasons such as physical inadequacies in survival, long duration of treatment and care process may cause the caregivers to experience various psychological problems, to run out of emotional and physical resources depending on these problems and to become desensitized to the environment.

The study found that caregivers who did not have time for themselves were significantly higher than those who did not have emotional exhaustion, desensitization and total burnout scores ($p < 0.05$). During the care process, caregivers continue their role of care by sacrificing their social activities and personal time to rest themselves physically and spiritually. It is thought that care givers who cannot receive outside support in this process, who are left with care rolls and who do not have the time to devote to their personal needs, may experience burnout due to these factors.

The study found that caregivers who wanted their patients to be cared for by someone else or a nursing home were significantly higher than those who did not want an average of emotional exhaustion and total burnout score ($p < 0.05$). In his study, Dileköz found that emotional burnout scores of care givers who wanted their patients to be cared for at home were significantly higher than those who preferred to be cared for at home [12].

Given that the majority of the caregivers are the children of the patient, the debt of loyalty to the parents and the perception that the parents should be crowned the head of the Turkish society, serve as a basis for seeing care as a duty. Therefore, it is thought that the patient's relatives only experience emotional exhaustion from the lower dimensions of burnout. Research shows that those who care for stroke patients are most likely to use the 'self-confident approach,' 'desperate approach' and 'optimistic approach' sub-dimensions in dealing with stress. The least used lower dimension is 'social support search'. The fact that caregivers get the highest score from the self-assured approach sub-dimension shows that they are able to cope effectively with stress. The results are similar to and supported by this research [15,25,26].

In the study, it was determined that female caregivers used a desperate and submissive approach to dealing with stress, while male caregivers used a more self-confident approach ($p < 0.05$). This suggests that female caregivers use ineffective methods to deal with stress, fail more to express themselves and the problems they experience than men, and are helplessly subservient and accepting of the current situation. In her study, Erkuran also determined that caring women used the helpless approach lower dimensions while men used the self-confident approach and optimistic approach lower dimensions [15].

In the study, caregivers who wanted to be looked after by someone other than their patients or by an institution were significantly higher than those who

did not want to have a score average ($p < 0.05$). The long and arduous process of care may have led the caregiver to ask that the role of care be provided by someone else or an institution. In this case, the caregivers may have taken a submissive approach to fate and the present situation under the influence of religious sentiments. In his study, Dileköz found that the individuals who wanted their patient to be looked at in a nursing home had lower SCSS— safe approaches than those who wanted them to be looked at at home, and did not find any significant relationship between the other lower dimensions [12]. In the study, as emotional exhaustion increased in caregivers, the use of self-confident approach, optimistic approach and seeking social support, which are sub-dimensions of the scale of coping with stress, decreased significantly; However, it was determined that the use of the helpless approach and the submissive approach, which are ineffective coping methods with stress, increased significantly. The lower dimension of emotional exhaustion in Dileköz's work; there was a positive correlation between the safe approach and the optimistic approach sub-dimensions and the helpless approach and the sub-dimensions of the subjunctive approach. No relation between applying for social support has been determined [12].

These results of emotional exhaustion emotional and physical resources of caregivers living in the decline due to a decrease in confidence in themselves, the current situation of psychological, social and physical challenges were insufficient to cope with that, they have an optimistic approach to the situation, suggests that they did not get outside help to overcome the difficulties. It is thought that care givers who do not use effective coping methods, who are not supported from outside, who are left alone in the process, succumb to the situation and accept it helplessly.

The study determined a negative correlation between the desensitization levels of caregivers and their use of the safe and optimistic approach, which are effective methods of coping with stress. In his study, Dileköz determined that the relationship between the MBI-desensitization sub dimension and the optimistic approach sub dimension was negatively significant [12].

In the study, a positive correlation between the MBI- desensitization sub dimension and the CSI2-helpless approach sub dimension was determined. These results suggest that caregivers are unable to overcome the problems they face in the process, are unable to approach the problems optimistically, their self-confidence is reduced, they are helplessly desensitized to the situation. The study found that those who used the self-confident approach had low personal success, but this relationship was weak. At the same time, it was determined that those using the optimistic approach sub-dimension had low personal success but that this relationship was very weak. In a sense, in contrast to the results of this study, the MBI- size of the lower personal accomplishment CSI2- safe approach that is positive and significant between social support and the size of the search sub, MBS and helpless approach submissive approach with lower personal accomplishment sub-dimension has determined that the relationship between the size is significantly negative [10].

This difference between studies may be due to the lack of proper understanding of the questions of caregivers, as well as cultural differences in social life may be a cause of this conclusion. In addition, even if their personal success is high, their inability to trust themselves during the care process, lack of knowledge about the care, and being left alone in the process may have led to a decrease in self-confidence and a lack of optimism.

CONCLUSIONS

When the stress levels of caregivers are high as a result of this research, the experiences of high levels of emotional exhaustion, depersonalization and personal level is normal for their success is low; coping with stress in the most 'self-confident Approach', the 'desperate Approach' and the 'Optimistic Approach' sub-dimensions shows that use.

It was determined that as their emotional exhaustion increased, their use of effective methods of coping with stress decreased, and their use of the subjugative approach, which is an ineffective way of coping with stress, increased.

It was determined that as the level of desensitization of caregivers increased, the use of safe approach and optimistic approach sub-dimensions, which are effective methods of coping with stress, decreased, and the use of helpless approach, which is ineffective, increased.

It was determined that caregivers ' use of the safe and optimistic approach, the effective method of coping with stress, decreased as their personal success increased.

In line with these results, the following recommendations have been developed;

To identify those who need support for care during the visit, who cannot bear the burden of the care process, who are physically and psychologically challenged and who are experiencing burnout by public health nurses,

To provide training and counseling services with the support of the institution on issues such as effective coping with stress, preventing burnout, and to manage this process and its results effectively by using the role of nurses,

In order to prevent care givers experiencing burnout because they can not take time to themselves, institution-supported health centers to be implemented where care givers can leave their patients for short periods of time,

It is recommended that researchers enrich the literature with new studies in order to identify the physiological, psychological and social problems experienced by caregivers with stroke and to provide effective solution suggestions by taking an example of the results of this study.

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Disclosure

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Conflicts of interest

There are no conflicts of interest to declare.

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