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Anxiety, Depression, and Burnout Levels in Stroke Patient Caregivers at a Rehabilitation Hospital

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ABSTRACT

Objective: The rehabilitation of stroke patients is work that requires a multi-faceted team, which includes the patients, physicians, nurses, psychologists, and caregivers. In this study, the purpose was to determine the level of anxiety, depression, and burnout in caregivers of stroke inpatients.

Methods: In all, 72 caregivers who each care for 1 stroke patient were included in the study. The Beck Anxiety Inventory, the Beck Depression Inventory, and the Maslach Burnout Inventory were used to assess the level of anxiety, depression, and burnout in the study group.

Results: The caregivers of stroke patients were found to have scores reflecting mild depression and mild anxiety. The burnout level evaluated in subdimensions of emotional exhaustion, desensitization, and personal accomplishment was at a normal level.

Conclusion: The psychiatric component of stroke therapy and rehabilitation should not only be patient-oriented. Patient relatives, and particularly their caregivers, may need training and psychiatric support. A rehabilitation program that includes education and interactive group therapies could be very useful.

INTRODUCTION

Stroke ranks first among causes of dependency/semi-dependency among adults, but third among causes of death.[1]

Following a stroke, the patient is affected in physiological, psychological, sociocultural, and economic aspects, and often becomes dependent on others for assistance with their daily activities.[2] In this country and some others, professional care, and supportive practices concerning individual care and rehabilitation are very limited, and responsibility for the patient's care is frequently assumed by relatives and family members at home.[3] Since stroke patients require long-term care, patient relatives may experience difficulties in adapting to their new caregiving roles. Stroke creates a crisis, especially for family members who provide primary care for the patient, and anxiety, depression, and burnout syndrome can frequently be observed in these caregivers if there is no intervention.[3,4]

This study was an evaluation of the level of anxiety, depression, and burnout in caregivers of stroke patients.

MATERIAL AND METHODS

This study was a qualitative, observational, and comparative trial to determine the level of anxiety, depression, and burnout in individuals who were responsible for the primary care of a stroke patient.

From a total of 178 stroke patients hospitalized between October 2014 and March 2017 and the individuals primarily responsible for patient care, 72 patients and 72 relatives selected using a simple randomization method were included in the study. Approval to conduct the study was received from the Ethics Committee.

Patients who were fully conscious, cooperative, and well oriented who were enrolled in a rehabilitation program following a stroke and who had a National Institutes of Health Stroke Scale (NIHSS) score of fewer than 16 points were included in the study. Among the individuals who were primarily responsible for the care of the patients, those aged ≥18 years with the physical and emotional competency required for caregiving and without past or present history of a psychiatric disorder were included in the study.

The study data were gathered using the NIHSS scores, patient/patient relative information forms, Barthel Index (BI), Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), and the Maslach Burnout Inventory (MBI).

National Institutes of Health Stroke Scale

The NIHSS is used to evaluate the neurological function of ischemic stroke patients at admission, and gives an idea about their long-term prognosis. An NIHSS score of greater than 16 points is an indicator of severe insufficiency and a greater probability of death, while an NIHSS score of fewer than 6 points indicates a probability of a good recovery.[5]

Barthel Index

This scale evaluates physical independency in performing daily living activities. It consists of 10 items (mobility, transfer, ascending/descending stairs, dressing, grooming, bathing, toilet use, feeding, and control of defecation and urination). Each item is individually scored 0 to 3, and a total score (0–100) is calculated. A total score of 0 indicates complete dependency, and 100 signifies complete independence. A maximum score per item of 5 was implemented in a modified BI to increase the sensitivity of the index. Patients who score between 5 and 55 points need assistance in their daily lives, while patients with a score between 55 and 100 points can live independently.[6]

Beck Depression Inventory

This scale consists of 21 items, and measures emotional, somatic, cognitive, and motivational signs seen in depression. Each item is scored between 0 and 3, and the total score ranges between 0 and 63 points. A total BDI score between 1 and 10 points indicates a normal emotional mood, while 11 to 16 points reflects mild emotional distress, 17 to 20 points suggests a borderline case, 21 to 30 points indicate moderate depression, 31 to 40 points reveals severe depression, and ≥40 points warns of very severe depression.[7]

Beck Anxiety Inventory

This anxiety scale consists of a total of 21 questions. Each item is scored between 0 and 3, yielding a total score of between 0 and 63 points. Minimal anxiety is seen in a score of up to 7 points, mild anxiety in a score of 8 to15, moderate anxiety in a score of 18 to 25, and a severe level of anxiety in a score >26.[8]

Maslach Burnout Inventory

The MBI consists of 22 items divided into 3 subscales. A Likert-type scale is used to measure responses in each subscale: emotional exhaustion (0–32 points), desensitization (0–24 points), and personal accomplishment (0–32 points). Individuals experiencing burnout are expected to have higher emotional exhaustion and desensitization scores with a lower personal accomplishment score.[9]

Collection of data

Questionnaire forms and scales were used to collect the study data.

Analysis of data

The data were analyzed using SPSS Statistics for Windows, Version 17.0 (SPSS, Inc., Chicago, IL, USA). For descriptive analyses, means, percentages, and frequencies were used. Non-parametric Kruskal-Wallis and Mann-Whitney U tests were used in comparisons of the level of depression, anxiety, and burnout as the sample size was small and there was a non-normal distribution of variables. $P<0.05$ was accepted as the level of statistical significance.

RESULTS

The mean age of the patients was 61.86±15.20 years. Sixty percent of the study population was male. The majority (86.7%) of the participants were married, and 51.7% of them were primary school graduates, 31.7% of them were housewives, and 28.3% of them were self-employed. Financially, 46.7% of them indicated that they had balanced income and expenditures. An analysis of the health of the patients revealed that 72.6% of them had a hemorrhagic stroke, and it involved the right side in 65.7% of the patients. In all, 87.5% of them had chronic diseases; the most frequently seen was hypertension (70.8%), followed by diabetes (34.7%). In addition, 30.6% of the patients were smokers, and 1.4% of them consumed alcohol. The mean BI score of the patients was 50.90±10.29 points (Table 1).

The mean age of the caregivers was 45.58±13.55 years. Most of the caregivers were female (86.7%), married (78.3%), primary education graduates (53.3%), and housewives (51.7%) with balanced household finances. Sixty percent of the caregivers were not the spouse or child of the patient. Among the caregivers, 38.6% had a chronic disease, mainly hypertension (28.3%).

In all, 36.7% of the caregivers reported discontinuing activities other than education in order to provide care. Adverse effects on sleeping pattern were acknowledged by 61.7%. The mean number of hours per day spent on caregiving was 22.62±1.27 hours, and they had been providing care for a mean of 7.80±13.13 months (Table 2).

Depressive symptoms were found in 64% of the caregivers. The BDI score indicated mild depression in 20.8%, a borderline case in 16.6%, moderate depression in 19.4%, and severe depression in 0.69% (Fig. 1).

Symptoms of anxiety were observed in 68% of the caregiv-

Table 1. Sociodemographic and health status characteristics of the patients

Characteristics	n	%	Characteristics	n	%
Age, years (mean±SD)	63.18±14.31		Bilateral	–	–
	(range: 24–89)		Etiological classification		
Gender			Atherosclerosis of greater vessels	13	20.6
Female	27	37.5	Cardioembolism	1	1.6
Male	45	62.5	Occlusion of smaller vessels	2	3.2
Marital status			Ischemic stroke of unknown etiology	11	17.5
Single	6	6.9			
Married	62	86.1	Stroke known to be related to other causes	20	31.7
Widower//Divorced	5	6.9	More than one explanatory cause	16	25.4
Educational status			Presence of chronic disease		
Illiterate	4	5.6	Yes	63	87.5
Literate	15	20.8	No	9	12.5
Primary education	37	51.4	Chronic diseases present		
Secondary school	12	16.7	Hypertension	51	70.8
Higher education	4	5.6	Diabetes	25	34.7
Occupation/Profession			Epilepsy	4	5.6
Housewife	21	29.2	Depression	3	4.2
Laborer	6	8.3	Parkinson	2	2.8
White-collar employment	2	2.8	Chronic obstructive pulmonary disease	4	5.6
Self-employed	19	26.4	Bronchitis	3	4.2
Unemployed	2	2.8	Coronary artery disease	3	4.2
Retired	22	30.6	Heart failure	7	9.7
Financial status			Smoking		
Income less than expenditures	27	37.5	Yes	22	30.6
Income greater than expenditures	8	11.1	No	50	69.4
Balance between income and expenditures	37	51.4	Alcohol use		
Type of stroke			Yes	1	1.4
Hemorrhagic	19	26.4	No	71	98.6
Ischemic	53	73.6	Barthel Index score (mean+SD)	50.90±10.29	
Laterality of stroke				(range: 20–70)	
Right	47	65.3			
Left	25	34.7	National Institutes of Health Stroke Scale Score (mean±SD)	7.33±1.00	

ers. Mild anxiety was reflected in the BAI score of 30%, moderate anxiety in 25%, and severe anxiety was reported by 13% of the caregivers (Fig. 2).

The mean depression score of the caregivers was 15.76±9.38 points (mild depression: 0–16 points). The mean anxiety score of the group was 14.53±12.06 points (mild anxiety: 8–15 points). The mean levels of emotional exhaustion, desensitization, and personal accomplishment on the burnout scale were within the normal ranges (25.13±8.38;10.24±4.56; and 31.36±6.19 points, respectively) (Table 3).

Significantly higher levels of depression were found among caregivers of patients with a chronic illness and those tending their patients for ≥4 months (Table 4).

In addition, the evaluation of sociodemographic characteristics and burnout level revealed that the emotional exhaustion and desensitization scores of the caregivers whose patients had a right-sided stroke were significantly higher. The emotional exhaustion scores were also higher among caregivers providing healthcare services for male patients (Table 5).

The anxiety level of the caregivers of patients with a

Table 2. Distribution of sociodemographic characteristics of the caregivers

Characteristics	n	%
Age, years (mean±SD)	46.87±13.17 (range: 17–79)	
Gender		
Female	63	87.5
Male	9	12.5
Marital status		
Single	10	13.9
Married	56	77.8
Widower/Divorced	6	8.3
Educational level		
Illiterate	7	9.7
Literate	5	6.9
Primary education	38	52.8
Secondary education	14	19.4
Higher education	8	11.1
Occupation/Profession		
Housewife	39	54.2
Laborer	3	4.2
White-collar employment	3	4.2
Self-employed	15	20.8
Unemployed	1	1.4
Retiree	8	11.1
Other	3	4.2
Financial status		
Income less than expenditures	28	38.9
Income greater than expenditures	8	11.1
Balance between income and expenditures	36	50.0
Relationship to the patient		
Spouse	27	37.5
Adult child	6	8.3
Other	39	54.2
Presence of chronic disease		
Yes	29	40.3
No	43	59.7
Chronic diseases present		
Hypertension	21	29.2
Diabetes	8	11.1
Bronchitis	2	2.8
Migraine	1	1.4
Asthma	4	5.6
Heart failure	4	5.6
Abandonment of other activities because of caregiving duties		
Yes	31	43.1
No	41	56.9
Effect on sleeping pattern		
Yes	48	66.7
No	24	33.3
Daily hours caring for the patient (mean±SD)	21.49±5.41 (range: 4–24)	
Total number of months caring for the patient (mean±SD)	8.32±12.54 (range: 1–72)	

chronic illness was significantly higher, and furthermore, the anxiety level of female caregivers were significantly higher relative to male caregivers. The anxiety of caregivers of married patients was also significantly higher. A significant difference was not found with regard to the other sociodemographic variables assessed (Table 6). Finally, a positive correlation was found between the overall anxiety and depression level of the caregivers and the daily duration of caregiving (Table 7).

DISCUSSION

Since stroke often leads to disability and functional loss,

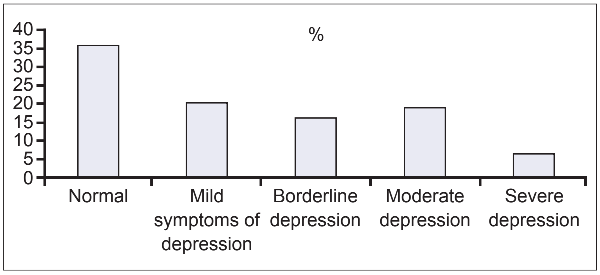

Figure 1. Distribution of Beck Depression Inventory scores of the caregivers.

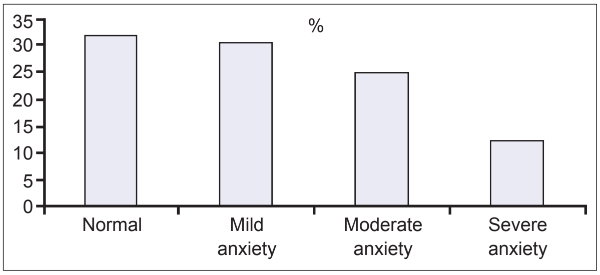

Figure 2. Distribution of Beck Anxiety Inventory scores of the caregivers.

Table 3. Mean depression, anxiety, and burnout scale scores of the caregivers

Scales	Mean	SD
Beck Depression Inventory	15.76	9.38
Beck Anxiety Inventory	14.53	12.06
Maslach Burnout Inventory		
Emotional exhaustion	25.13	8.38
Desensitization	10.24	4.56
Personal accomplishment	31.36	6.19

Table 4. Sociodemographic and health status characteristics of the patients and anxiety level

Characteristics	n	Mean±SD	p
Presence of chronic disease			
Present	63	16.73±12.23	=0.013*
Absent	9	6.33±6.65	
Marital status of the patient			
Single	6	8.80±6.30	=0.017*
Married	61	15.90±12.28	
Divorced/Widower	5	3.60±4.99	
Gender of the caregiver			
Female	63	5.96±12.19	=0.002**
Male	9	4.78±4.06	

*p<0.05, **p<0.01.

the patients frequently need substantial physical help and attention. The lives of the caregivers of these patients can be profoundly affected, including their relationships with family and friends, their career, and their physical and psychological well-being.[10] Depression, anxiety, and burnout can be the result.

The mean age of the patients and the percentage of those who were married and male in this study were consistent with the data of many related studies.[10–13] Similarly, the mean age of the caregivers and the fact that they were mostly female was also consistent with that seen in other studies, such as that of Morais. However, in our study, most of the caregivers were not the patient's spouse or child, and in this case, there was only a single caregiver for each patient.[14]

Our results Indicated that the level of depression was significantly higher in caregivers of married patients, patients with chronic diseases, and those receiving care for ≥4 months. Hung et al.[13] also reported depressive symptoms in 40%-70% of caregivers of patients requiring long-term care, and 50% of them had received a diagnosis of depression. It is acknowledged that symptoms of depression increase with the prolongation of the caregiving period. Additionally, the presence of chronic disease increases the workload and may thereby add to depression. Therefore, caregivers should be informed about the potential burdens

Table 5. Sociodemographic and health status characteristics of the participants and depression level of the caregivers

Characteristics	n	Mean±SD	p
Chronic patients			
Yes	63	16.50±9.33	=0.046*
No	9	10.67±8.49	
Duration of caregiving			
0–3 months	35	12.88±9.32	=0.007**
≥4 months	37	18.41±8.74	

*p<0.05, **p<0.01.

Table 6. Sociodemographic and health status characteristics of the participants and the burnout level of the caregivers

Characteristics	n	Mean±SD	p
Laterality of stroke			
Right	47	26.70±8.22	=0.048*
Left	25	22.33±8.32	(emotional)
Laterality of stroke			
Right	47	11.30±5.02	=0.018*
Left	25	8.25±2.61	(desensitization)
Gender of the patient			
Female	27	22.89±8.73	=0.042*
Male	45	26.47±7.96	(emotional)

*p<0.05

Table 7. Hours of daily care provided by caregivers and indicators of their psychosocial state

	Statistics score	Total anxiety	Total depression score
Hours of daily care provided	Pearson Correlation (r)	0.276	0.272
	Significant (p)	0.020*	0.022*
	N	71	71

*p<0.05

and the necessary precautions should be taken. Zarit[15] reported that caregivers should be included in the treatment program together with the patients, that there should be follow-up on the adaptation process of these individuals, and that psychiatric monitoring might be advisable.[15]

In our study, the anxiety level of the caregivers of patients with a chronic illness was higher than that of other caregivers. Furthermore, the anxiety level of female caregivers was higher than that of male caregivers. Previous studies have also found that depression increased as the duration of care increased, and that anxiety was greater among female caregivers.[16–21] Investigations performed related to the gender of caregivers have demonstrated that the caregiving burden is perceived differently by female caregivers.[21] In many cultures, including our culture, caregiving is considered a simple task that should be performed by a woman, an attitude that increases the caregiving burden of women and may weaken their self-confidence.[21–23]

Young caregivers receive less social support than their older counterparts, which is also associated with an increased caregiving burden.[24] Women, especially younger ones, perceive caregiving negatively compared with older men, and they report experiencing more psychological difficulties, even when factors such as the health status of the patient and the level of caregiving were under control.[25,26] As confirmed in many studies, including that performed by Marques et al.,[27] the presence of chronic disease increases symptoms of anxiety and depression in caregivers.

In our study, a significant, positive correlation was found between the patient's degree of dependency in daily living activities and the depression and burnout levels of caregivers. Jaracz[28] observed that the spouses and other relatives of stroke patients who depended on others in order to perform daily living activities experienced more frequent depressive episodes.[28] Some researchers argue that when the patients experience emotional stress, their caregivers are more prone to have depressive symptoms.[21,26]

Caregivers, and particularly family caregivers, must adjust and cope with the facts of the disability of the patient, which may be a very emotional experience, yet be able to perform the challenging role of caregiver effectively and to take care of their own needs, as well. The psychosocial state of the patients may be more deeply affected as the duration of caregiving increases.[17,19] In our study, an association between the length of the daily period of caregiving and psychosocial indicators of the caregivers was analyzed, and a significant positive correlation was found between overall anxiety level and hours spent in caregiving.

In order to understand the difficulties and problems experienced by caregivers tending to bedridden stroke patients, home visits and psychoeducational sessions were performed. As an outcome of this study, it was determined that the patient's relatives required further information about the drugs used, nutrition, and toileting difficulties of the patients. Support was provided to caregivers and patients by physiotherapists, dieticians, psychologists, psychiatrists, and speech therapists during these visits. The caregivers were provided with training and educational materials. The use of such materials has proven to be valuable in solving problems.[29]

Additional support in the form of meetings of psychoeducational groups for caregivers at certain intervals, interventions aiming at solving problems in accordance with the recommendations of the treatment team, and regular home visits by nurses and physicians may decrease the burden of the caregivers. Supportive psychotherapy other than psychoeducation can also be helpful to caregivers.[4]

Instilling and maintaining hope is an important issue to be included in psychotherapy sessions. Groups that would provide support to the caregivers of stroke patients could be organized, similar to groups formed for the families of Alzheimer patients and others. Caregivers are in the difficult position of facing and adapting to the loss of functionality of the patient, and at times, helping the patient to perform basic functions like a parent, in addition to ensuring that other needs and tasks the patient can no longer be responsible for are completed. Caregivers often struggle with social problems, loneliness, stress managing the burdens incurred as a result of the disease, and feelings of guilt stemming from the desire to be relieved of this burden. New ways to share and relieve feelings of stress, guilt, regret, and loneliness, as well as encouraging a positive outlook and reinforcing self-esteem should be established.[30]

In conclusion, informing caregivers early about problems they may experience is important for them to develop adequate coping strategies. Research in this area is becoming increasingly important and will guide the development of useful approaches to support the patients, their families, and their caregivers. Patient caregivers, especially when family members, should be expected to require education and training and, if necessary, psychiatric support. Rehabilitation programs that include training components and interactive group therapies are thought to be helpful. Many authors have recommended that the correlation between stroke-related characteristics and sociocultural and economic conditions and psychosocial aspects should be analyzed in larger studies. The need remains for further research of this complex topic performed in various regions so as to be able to understand differences among populations in diverse cultures and environments.

Ethics Committee Approval

Approval has been obtained from the Yeditepe University Faculty of Medicine Ethics Committee.

Peer-review

Internally peer-reviewed.

Authorship Contributions

Concept: A.S.; Design: A.S.; Data collection &/or processing: A.S.; Analysis and/or interpretation: A.S.; Literature search: A.S.; Writing: A.S.; Critical review: A.S.

Conflict of Interest

None declared.

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Bir Rehabilitasyon Hastanesinde İnmeli Hastalara Bakım Veren Bireylerde Anksiyete, Depresyon ve Tükenmişlik Düzeyleri

Amaç: İnmeli hastaların rehabilitasyonu başta hasta, hekim, hemşire, psikolog ve bakım veren olmak üzere çok yönlü bir ekip işidir. Bu çalışmada ekibin bir parçası olarak kabul edilen bakım veren bireyler ele alındı. İnme rehabilitasyonu amaçlı yatarak tedavi gören hastalara bakım veren bireylerde anksiyete, depresyon ve tükenmişlik durumlarının belirlenmesi amaçlandı.

Gereç ve Yöntem: Çalışmaya 72 inmeli hastaya bakım veren 72 gönüllü katılımcı dahil edildi. Çalışmada anksiyete düzeyinin belirlenmesinde Beck Anksiyete Ölçeği, depresyon düzeyinin belirlenmesinde Beck Depresyon Ölçeği ve tükenmişlik düzeyinin belirlenmesinde Maslach Tükenmişlik Ölçeği kullanıldı.

Bulgular: İnme hastalarına bakım veren bireylerde hafif düzeyde depresyon ve hafif düzeyde anksiyete görüldü. Tükenmişlik düzeyi yönünden değerlendirmede gerek duygusal tükenme puanı, gerek duyarsızlaştırma boyutu ve gerekse kişisel başarı boyutu normal düzeyde bulundu.

Sonuç: İnme tedavisi ve rehabilitasyonunun psikiyatrik komponenti yalnız hasta odaklı olmamalıdır. Hastaya bakım veren bireyler başta olmak üzere hasta yakınlarının öncelikli eğitimi ve gerektiğinde psikiyatrik desteğe ihtiyaç duyacağı görülmüştür. Uygulanacak rehabilitasyon programının eğitsel gruplar ve etkileşim grup terapileri şeklinde düzenlenmesinde yarar olduğu düşünülmektedir.

Anahtar Sözcükler: Anksiyete; bakım veren; depresyon; inme; tükenmişlik.