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Mental Health and Quality of Life Differences Between the Family Members and Paid Caregivers in Brain Injury

Beyin Hasarlı Hasta Bakımında, Hastaya Yakınlık Derecesinin Bakıcının Anksiyete, Depresyon, Yaşam Kalitesi Düzeyleri ile İlişkisi

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ABSTRACT Objective: In this study, physical, psychological effects and quality of life of caregivers of patients with brain injury due to stroke or trauma were evaluated; and the difference between the family members as caregivers and the paid caregivers were highlighted. **Material and Methods:** Fifty-four caregivers of patients were included in this cross-sectional study. Caregivers were grouped as relative group (n=43) and self-employed/employed group (n=11). Main characteristics of caregivers and patients were recorded. All caregivers completed Hospital Anxiety and Depression Scale (HADS) and Short Form-36 (SF-36) questionnaires. **Results:** There was a statistically significant difference between the groups with regard to caregiving duration. In self-employed/employed group, patients were significantly older than another group (p<0.001). Gender distribution was significantly different between groups (p=0.001). Etiology, disease duration, presence of aphasia, dysphagia, feeding type, urinary incontinence, urination type and ambulation levels were similar in groups. Both anxiety and depression scores of HADS questionnaire were significantly higher in relative group. Social functioning, physical role limitation, emotional role limitation, energy, pain, and general health domains of SF-36 questionnaire were significantly lower in relative group. **Conclusion:** In this study, the difference between the family members as caregivers and the paid caregivers were highlighted. The affection is more, if the caregiver is a family member, and it increases in proportion to the degree of disability of the patient. It should be noted that the caregivers are an important part of rehabilitation in order not to adversely affect the rehabilitation process.

Keywords: Brain injuries; caregivers; quality of life; depression; anxiety

ÖZET Amaç: Bu çalışmada inme veya travmaya bağlı beyin hasarlı hastaların bakıcılarının fiziksel, psikolojik etkilenimleri ve yaşam kalitesi düzeyleri değerlendirilerek; etkilenim düzeyinde aileden biri olan bakıcılarla ücret karşılığı bakıcılık yapanlar arasındaki fark vurgulanmıştır. **Gereç ve Yöntemler:** Kesitsel olarak planlanan bu çalışmaya 54 hasta bakıcısı dahil edildi. Bakıcılar, akraba grubu (n=43) ve paralı bakıcılar (n=11) olarak iki gruba ayrıldı. Bakıcı ve hastaların temel karakteristik özellikleri kaydedildi. Tüm bakıcılar Hastane Anksiyete ve Depresyon Ölçeği (HADS) ile Kısa Form-36 (SF-36) anketini doldurdu. **Bulgular:** Bakım süresi açısından gruplar arasında istatistiksel olarak anlamlı fark vardı. Paralı bakıcı grubunda, hasta yaşı diğer gruptaki hasta yaşından anlamlı olarak daha fazlaydı (p<0,001). Gruplar arasında cinsiyet açısından farklılık saptandı (p=0,001). Etiyoloji, hastalık süresi, afazi varlığı, disfaji, beslenme tipi, üriner inkontinans, işeme tipi, ambulasyon seviyesi açısından gruplar arasında farklılık saptanmadı. HADS anketinin hem anksiyete hem de depresyon puanları, aileden olan bakıcı grubunda anlamlı olarak yüksekti. SF-36 anketinin sosyal fonksiyon, fiziksel problemler nedeniyle olan kısıtlanma, emosyonel problemler nedeniyle olan kısıtlanma, enerji, vücut ağrısı ve genel sağlık algısı alt parametreleri, aileden olan bakıcı grubunda anlamlı olarak düşüktü. **Sonuç:** Bu çalışmada, aileden biri olan bakıcılarla ücret karşılığı bakıcılık yapanlar arasındaki fark vurgulanmıştır. Bakıcı aileden birisi ise etkilenim daha fazla olmaktadır ve hastanın özürlülük derecesi ile orantılı şekilde artmaktadır. Rehabilitasyon sürecinin olumsuz etkilenmemesi için, bakıcıların rehabilitasyonun önemli bir parçası olduğu unutulmamalıdır.

Anahtar Kelimeler: Beyin hasarı; bakıcı; yaşam kalitesi; depresyon; anksiyete

Brain injury due to stroke and trauma are clinical conditions that have high mortality and may cause disability at various levels in survivors. Motor and sensory deficits, balance disorder, speech and swallowing disorders, cognitive problems, vision problems, bowel and bladder dysfunctions can be seen in both patient groups.[1,2] For this reason, patients need different levels of assistance at all stages in the course following the brain injury, such as personal care, daily life activities, exercise, social activities, depending on the severity of the disease. A family member or a paid caregiver undertakes this responsibility from the early stages of the disease. It has been reported that physical and psychological problems, decrease in quality of life and in social functions can be seen in the caregivers of patients with brain injury as well.[3,4] Such impairments in caregivers increase the burden of care and adversely affect the rehabilitation process.[5] In previous studies, parameters related to psychological, physical, and quality of life in the caregivers of patients with brain injury due to stroke or trauma, were compared with the normal population. In this study, the physical and psychological effects on the caregivers of patients with brain injury due to stroke or trauma and their quality of life were assessed by a variety of tests with proven validity and reliability, and evaluation was made on whether there is a difference between a family member and a paid caregiver.

MATERIALS AND METHODS

STUDY DESIGN AND PARTICIPANTS

Fifty-four caregivers of patients who were admitted to the brain injury unit of a national rehabilitation hospital for inpatient rehabilitation were included for this cross-sectional study. Caregivers were grouped as relative group (n=43) and self-employed/employed group (n=11). Inclusion criteria were as follows 1) providing care for a patient diagnosed with stroke or brain injury as patient's relative or self-employed or employed as caregiver 2) age older than 18 years; 3) able to read or understand the questionnaire 4) providing care for at least one month. The caregivers with psychiatric history were excluded. Main characteristics of caregivers and patients were recorded. Data including aphasia, dysphagia, feeding type, urination and defecation regime, prevalence of pressure ulcer, spasticity, severity of spasticity (according to Modified Ashworth Scale), mobilization (according to Functional Ambulation Scale) were obtained from patient records. All caregivers completed Hospital Anxiety and Depression Scale (HADS) and Short Form-36 (SF-36) questionnaires. The study design was approved by Local Ethics Committee. All patients and caregivers provided a signed written informed consent form before inclusion.

OUTCOME MEASURES

Short Form 36

Short Form-36 is a scale including 8 scales and 2 summary scales. These scales are physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, emotional problems, mental health and a physical and mental component summary. The reliability of this scale has been reported as 0.88-0.92.[6]

Hospital Anxiety and Depression Scale

This is a scale that measures anxiety and depression.[7] It is a 14-item questionnaire and used in hospital and general practices.[8] Seven items evaluate dep ression and the other seven items evaluate anxiety.

STATISTICAL ANALYSIS

Statistical analyses were made with the Statistical Package for Social Sciences (SPSS) version 22.0 for Mac software (SPSS Inc., Chicago, IL). Continuous variables were presented as mean ± standard deviation. Qualitative variables were presented with number and percentages. Kolmogorov-Smirnov test was used to determine the normality of data distribution. Chi-Square test was used to compare categorical data between groups. Mann Whitney-U test was used to compare nominal data between groups. A value of $p<0.05$ was considered statistically significant.

RESULTS

Main characteristics of caregivers are given in Table 1. Age and gender of caregivers were not different between groups. Caregiving duration was more than 12 months in most of the patients in relative group and in self-employed/employed group, it was 1-3 months in most of the patients. There was a statistically significant difference between groups with regard to caregiving duration (Table 1).

Main characteristics of the patients were given in Table 2. In self-employed/employed group, patients were significantly older than other group ($p<0.001$). Gender distribution was significantly different between groups ($p=0.001$). Etiology, disease duration, presence of aphasia, dysphagia, feeding type, urinary incontinence, and urination type were similar in groups (Table 2).

Ambulation levels of the patients were shown in Table 3. In both groups, most of the patients were non-functional ambulators. There was no significant difference between groups (Table 3).

In Table 4, HADS and SF-36 scores of the caregivers were shown. Both anxiety and depression scores of HADS questionnaire were significantly higher in relative group. Social functioning, physical role limitation, emotional role limitation, energy, pain, and general health domains of SF-36 questionnaire were significantly lower in relative group (Table 4).

DISCUSSION

In this study, physical, psychological effects and quality of life of caregivers of patients with brain injury due to stroke or trauma were evaluated; and the difference between the family members as caregivers and the paid caregivers were highlighted. In addition, the relationship between the level of affection and the complications associated with stroke and brain injury was investigated.

In previous studies on caregivers of brain injury patients, it was reported that the majority of caregivers (70%) were a member of the family and were female.[9,10] In this study, the majority of caregivers (79.6%) were family members. It has been reported that a large proportion of patients with brain injury due to stroke or trauma need a family member caregiver support, although this varies according to social and economic structure.[11] However, in another study, a family-centered approach was reported to be more useful for the patient at each stage of rehabilitation.[12] We also attribute this result to the strong family relations in Turkey, failing to receive professional assistance due to the economic problems in our country, and the compliance of brain-injured patients in the rehabilitation to be more likely with the family member caregiver.

In the current study, in self-employed/employed group, patients were significantly older than other group. Care of the older patients would cause more caregiver burden but we did not detect

TABLE 1: Main characteristics of the caregivers.

		Self-employed/employed		Relative		
		Mean	SD	Mean	SD	p
Age (years)		49.3	7.8	46.2	12.3	0.437
		n	%	n	%	
Gender	Male	1	9.1	9	20.9	0.367
	Female	10	90.9	34	79.1	
Caregiving duration	1-3 months	9	81.8	10	23.3	0.001*
	4-12 months	2	18.2	13	30.2	
	>12 months	-	-	20	45.6	

SD: standard deviation; *Mann-Whitney U test.

TABLE 2: Main characteristics of the patients.

		Self-employed/employed		Relative		
		Mean	SD	Mean	SD	p
Age (years)		68.3	12.3	42.6	17.2	<0.001*
		n	%	n	%	
Patient	Male	4	36.4	36	83.7	<0.001**
Gender	Female	7	63.6	7	16.3	
Etiology	Hemorrhagic SVA	2	18.2	6	14.0	0.311
	Ischemic SVA	7	63.6	16	37.2	
	Traumatic brain injury	2	18.2	19	44.2	
	Anoxic brain injury	-	-	2	4.7	
Disease duration	1-3 months	2	18.2	4	9.3	0.624
	4-12 months	5	45.5	18	41.9	
	>12 months	4	36.4	21	48.8	
Aphasia	Motor	2	18.1	5	11.6	0.817
	Global	1	9.1	7	16.3	
	Dysarthria	4	36.4	12	27.9	
	None	4	36.4	19	44.2	
Dysphagia	Yes	4	36.4	11	25.6	0.476
	None	7	63.6	32	74.4	
Feeding type	Oral	10	90.9	38	88.4	0.877
	PEG	-		1	2.3	
	Oral+PEG	1	9.1	4	9.3	
Urinary incontinence	Yes	5	45.5	11	25.6	0.198
	None	6	54.5	32	74.4	
Urination type	Normal	6	54.5	33	76.8	0.280
	Indwelling catheter	1	9.1	1	2.3	
	Into diaper	4	36.4	9	20.9	
Fecal incontinence	Yes	6	54.5	8	18.6	0.015
	None	5	45.5	35	81.4	
Defecation type	Normal	5	45.5	36	83.7	0.008**
	Into diaper	6	54.5	7	16.3	
Pressure ulcer	Yes	-	-	1	2.3	0.610
	None	11	100.0	42	97.7	
Spasticity	MAS 1-2	8	72.7	20	46.5	0.092
	MAS 3-4	1	9.1	14	32.5	
	None	2	18.2	9	21.0	
Sleep disturbance	Yes	3	27.3	6	14.0	0.290
	None	8	72.7	37	86.0	

SD: standard deviation; SVA: serebrovascular accident; PEG: percutan enteral gastrostomy; MAS: modified Ashworth scale; *Mann-Whitney U test, **Chi-Square test.

such difference. In addition, the majority of caregivers were women in both groups, 79.1% of family member caregivers and 90.9% of paid caregivers were female. It is reported that this result may be related to the women to be more compassionate, giving more importance to kinship ties, having greater ability to overcome the problems related to patient care, and the role of caregiving often being imposed on women traditionally.[9]

In the current study, we found that patient care time was different in both groups. The average duration of care in the paid caregiver group was generally between 1-3 months (81.8%); while it was 23.3% in the family member group.

TABLE 3: Ambulation levels of the patients.

	Self-employed/employed		Relative		
FAS	**n**	**%**	**n**	**%**	**p**
0	6	54.5	11	25.6	
1	4	36.4	10	23.3	
2	-	-	7	16.3	0.216
3	-	-	5	11.6	
4	1	9.1	7	16.3	
5	-	-	3	7.0	

FAS: Functional Ambulation Scale.

We think that the reasons for this difference may be the incompatibility of patient and caregiver, dissatisfaction of the relatives and dissatisfaction of paid caregivers. We can also relate this difference to the need of family members for professional help in the early stages of the disease.

Em et al. (2017) found high anxiety and depression rates in caregivers of patients with brain injury due to stroke.[4] Same results have been reported in similar studies.[13,14] Em et al. (2017) evaluated anxiety and depression with Hospital Anxiety and Depression Scale (HADS) in their study, and reported the mean score of anxiety in the caregiver group as 9.73, and the mean score for depression as 9.81. In addition, they claimed that the cause of emotional disturbance in caregivers may be related to the degree of dependence of the patient to the caregiver.[4] Similar studies supportively showed that there is a correlation between the emotional disability of caregivers and the degree of functional disability of the patient they care for.[14-19] In contrast, some studies have reported no significant correlation between emotional impairments of caregivers and physical disability of the patient.[13,20,21] In this study, we evaluated anxiety and depression with HADS and the mean anxiety score was 5.4, and the mean depression score was 4.8 in the paid caregiver group; while the mean anxiety (8.1) and depression (8.3) scores in the family member caregiver group were higher. In this study, anxiety and depression levels were higher in the family member caregiver group than in the paid caregiver group, while the anxiety and depression scores in the paid caregiver group were better than the healthy control groups of similar studies.[4] In this study, anxiety and depression scores were better in the paid caregiver group than in the family member caregiver group, although ambulation disorder, aphasia, dysphagia, urinary incontinence, fecal incontinence, and sleep problems were more common in patients and therefore the patients had higher functional disability degrees in the paid caregiver

TABLE 4: HADS and SF-36 scores of the caregivers.

	Self-employed/employed		Relative		
	Mean	**SD**	**Mean**	**SD**	**p**
HADS					
Anxiety	5.4	2.6	8.1	3.8	0.04*
Depression	4.8	2.9	8.3	3.9	0.007*
SF-36					
Physical functioning	78.1	21.2	67.4	25.2	0.158
Social functioning	74.0	24.5	53.7	26.3	0.029
Physical role limitation	70.4	21.8	31.9	31.4	0.001*
Emotional role limitation	60.8	13.7	42.5	27.6	0.015*
Mental health	71.2	16.6	61.6	18.8	0.118
Energy	70.0	19.8	53.8	21.5	0.024*
Pain	89.2	15.7	63.4	27.3	0.003*
General health	75.0	15.1	59.7	23.3	0.036*

*Mann-Whitney U test.

group. For this reason, we think that especially the family member caregivers of brain-injured patients should be supported in terms of anxiety and depression and this will affect the rehabilitation process positively.

It has been reported in several studies that the quality of life of caregivers of patients with brain injury due to stroke and trauma has also been adversely affected.[4,22-24] However, the level of quality of life of caregivers has been reported to increase as the patient's disability improved.[25] Em et al. (2017) evaluated the level of quality of life of caregivers with SF-36 and found that the quality of life in caregivers was lower for all subtitles compared to the healthy control group. In our study, the level of quality of life of both the paid and the family member caregivers were better than the caregivers of this study. However, the quality of life of the paid caregiver group was better than that of the family member caregiver group except for the physical role limitation. This group may be associated with the conduct of care as a profession and a less emotional connection with the patient.

CONCLUSION

Brain-injured patients due to stroke and trauma need help from another person to varying degrees. This person is usually one of the family members, but a paid caregiver is also a frequently used option. Psychological and physical disorders affect the quality of life negatively in the caregivers of these patients. The affection is more, if the caregiver is a family member, and it increases in proportion to the degree of disability of the patient. It should be noted that the caregivers are an important part of rehabilitation in order not to adversely affect the rehabilitation process. Physical, psychological and social problems of the caregivers should not be ignored and they should be supported in terms of social, psychological and medical aspects if necessary.

In this study, the paid caregiver group was less in number than the family member caregiver group. We attribute this situation to families who want to take care of their own patients because of our social structure. In addition, many of the paid caregivers being the caregiver for their patients for 1-3 months is another limitation.

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