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THE LEVEL OF DEPRESSION AND QUALITY OF LIFE OF CAREGIVERS TO STROKE SURVIVORS

İnmeli Hastaların Bakıcılarında Depresyon Düzeyi ve Yaşam Kalitesi

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ABSTRACT

This study aimed at determining the level of depression and quality of life and investigating their correlations with certain concurrent problems in caregivers to stroke patients and comparing these results to those obtained in healthy volunteers.

84 caregivers to stroke patients were included in the patient group while the control group included 77 healthy volunteers who were not responsible for caregiving to any chronic patient. The Modified Rankin Scale was used to determine the disability level of stroke survivors and the National Institute of Health Stroke Scale (NIHSS) was used to determine the severity of stroke; the Functional Independence Measure (FIM) was used to determine the functional level of stroke survivors. The Beck Depression Inventory (BDI) was used to determine the level of depression and Visual Analogue Scale (VAS) was used to determine the level of pain. The level of depression in the caregiver and control groups was assessed by using the BDI, their quality of life was assessed by using the Short Form-36 (SF-36) and their level of pain was assessed by using the VAS. In addition, the level of fatigue of caregivers and controls was assessed by using a 0 to 10 scale (no fatigue at all and extreme fatigue).

Intergroup comparisons revealed that the level of depression, the level of fatigue and the level of pain were statistically significantly higher while mental quality of life was lower in the caregiver group ($p<0.05$), and no significant difference was found between two groups in the physical component of the quality of life ($p>0.05$).

The level of depression, the level of pain and the level of fatigue in caregiver group revealed a negative impact associated with caregiving to a stroke survivor. Therefore, these parameters should be assessed in people who are responsible for caregiving to stroke survivors and especially mental and psychological influences of caregiving should be taken in consideration.

Key words: stroke, caregivers, level of depression, quality of life

ÖZET

Bu çalışmada inmeli hastalara bakım veren bireylerde depresyon ve yaşam kalitesi düzeyinin tespit edilmesi, eşlik eden bazı problemler arasındaki ilişkinin araştırılması ve bu sonuçların sağlıklı gönüllülerle karşılaştırılması amaçlandı.

Hasta grubuna inmeli hastaların bakımını üstlenen 84 bakıcı, kontrol grubuna ise kronik hastaya bakıcılık yapmayan sağlıklı gönüllü 77 kişi dahil edildi. İnmeli hastaların özürlülük düzeyini değerlendirmek için Modifiye Rankin Skalası, inme şiddetini belirlemek için National Institute of Health Stroke Scale, fonksiyonel düzeyini belirlemek için Fonksiyonel Bağımsızlık Ölçeği, depresyon düzeyini belirlemek için Beck Depresyon ölçeği (BDİ) ve ağrı düzeyini değerlendirmek için visual analog skala (VAS) kullanıldı. Bakıcıların ve kontrol grubunun depresyon düzeyi BDİ ile, yaşam kalitesi düzeyleri Short Form-36 (SF-36) ve ağrı düzeyi VAS ile değerlendirildi. Ayrıca inmeli hastaların, bakıcılarının ve kontrol grubunun yorgunluk düzeyi 0-10 puanlık (hiç yorgunluk yok-dayanılmaz yorgunluk) bir skala ile değerlendirildi.

Bakım veren kişilerin depresyon, mental yaşam kaliteleri, yorgunluk ve ağrı düzeyleri kontrol grubuna göre istatistiksel olarak anlamlı derecede daha kötü bulunurken ($p<0.05$), fiziksel yaşam kalitesi skorları arasında fark saptanmadı ($p>0.05$).

İnme geçirmiş hastalara bakım veren bireylerin depresyon düzeyi, yaşam kalitesi, ağrı ve yorgunluk düzeyi olumsuz yönde etkilenmektedir. Bu nedenle bakım veren kişiler bu parametreler yönünden değerlendirilmeli özellikle de mental ve psikolojik etkilenimler göz önünde bulundurulmalıdır.

Anahtar kelimeler: inme, bakımveren, depresyon düzeyi, yaşam kalitesi

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INTRODUCTION

Stroke is one of the main causes of a serious, long-term disability. Approximately 500.000 people develop stroke annually and the majority of survivors become dependent on care (1). Severe disability occurs in 35% of stroke survivors and these people require the assistance of a caregiver to carry out their activities of daily living (2). With advances in stroke rehabilitation, the rate of severe disability has reduced, and the number of stroke survivors being supported by informal caregivers has increased (3).

Stroke greatly changes the life for both patients and their caregivers. This change, if it occurs, may be negative, and therefore, both the stroke survivor and the caregiver themselves may need to proactively cope with the emotional, physical, and sociological problems created by these new events in their own lives (3). Stroke survivors may have sensorial, motor, visual, cognitive, and emotional and speech impairments and caring for such a patient may lead to emotional and physical problems (4, 5). Depression is the leading emotional problem. The prevalence of depression among the caregivers of stroke survivors has been estimated as high as 52% (6, 7), in certain studies. Depression further increases the physical fatigue of caregivers, restricts their social life and eventually may negatively impact the quality of life of the caregiver (8-10). Unfortunately, too little attention is paid to this condition and quality of life and mental health of spousal caregivers is often neglected or takes lower priority than that of stroke survivors (8, 11). For that reason, the aim of this study was to detect the level of depression and quality of life and investigating their correlations with certain concurrent problems in caregivers to stroke patients and to compare these results to those obtained in healthy volunteers.

METHODS

This study was conducted in the Physical Therapy and Rehabilitation Clinic of Konya Education and Research Hospital between 2014 and 2015. 84 consecutive caregivers who had undertaken to care for stroke survivors, were included in the patient group and 75 subjects who were not responsible for caregiving to any chronic patient, were included in the control group. Stroke was diagnosed by the attending neurologists according to the World Health Organization definition (12). The approval to conduct of the study was obtained from the Institutional Ethics Committee of the Medical School of Selçuk University. Subjects who accepted to participate in the study were informed and a signed consent form was obtained from each participant.

The criteria to be icluded in the patient group consisted of being aged between 18 and 65 years and caregiving to a stroke survivor for at least one month, while the exclusion criteria were chronic diseases, pregnancy, a history of psychological disorders, a recent(last two months) use of antidepressant and anxiolytic medication use, any pathological condition that may cause musculoskeletal pain (strain, sprain, fracture etc.). Participants should be aged between 18 and 65 years to be included in the control group, while while the exclusion criteria consisted of having a disabled or sick individual in the household, any medical treatment during the previous 3 months, a history of psychological disorders, a history of antidepressant and anxiolytic medication use, chronic diseases, pregnancy.

Demographic data (age, gender, body mass index, level of educational attainment, marital status) concurrent chronic diseases, time elapsed after the stroke, use of assistive devices, stroke-associated complications (speech disorders, urinary and fecal incontinence) of stroke survivors were recorded. Demographic data of the patients and controls (age, gender, body mass index, level of educational attainment, marital status) were also recorded.

The Modified Rankin Scale (MRS) was used to determine the disability level of stroke survivor and the National Institute of Health Stroke Scale (NIHSS) was used to determine the severity of stroke; the Functional Independence Measure (FIM) was used to determine the functional level of the stroke survivor. Beck Depression Inventory (BDI) was used to determine the level of depression and Visual Analogue Scale (VAS) was used to determine the level of pain. The depression level in the caregiver and control group was assessed by using the BDI, their quality of life was assessed by using the Short Form-36 (SF-36) and their level of pain was assessed by using the VAS. In addition, the level of fatigue of caregivers and controls was assessed by using a 0 to 10 scale (no fatigue at all and extreme fatigue). These instruments were recorded by a researcher. MRS is a tool, used to assess the functional status of the patient and consists of 6 grades, from 0 to 5: 0: no symptom; 1: No significant disability. Able to carry out all usual activities, despite some symptoms; 2: Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities; 3: Moderate disability. Requires some help, but able to walk unassisted; 4: Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted; 5: Severe disability. Requires constant nursing care and attention, bedridden, incontinent (13).

NIHSS is a clinical measure used to monitor stroke survivors and to assess the severity of stroke. This measure is composed of 11 items, one of which includes 3 subitems and assesses the level of consciousness, LOC responsiveness, LOC commands, extraocular muscle movements, visual field, arm and leg motor drift Limb ataxia, sensory loss, aphasia, dysarthria and neurologic neglect syndrome and other potential problems. The maximum possible score is 36. Lower NIHSS scores indicate less clinical impairment (14).

The FIM was used to determine the functional level of stroke survivors. The FIM assesses self-care, sphincter control, mobility, transfers, communication and social perception functions. These six basic divisions include 18 activities and each activity is rated on a 7-point scale. Total scores range from 18 to 126 (total assistance- complete independence) (15).

The BDI, which was used to assess the psychological state of the participants, consists of 21 questions. In the BDI, patients are asked to select the most appropriate statement relevant to their condition. Each item includes four statements. These statements are graded in an increasing order of severity from neutral (0 points) to very severe condition (3 points). The highest possible score is 63 points (16). A score greater than 17 denotes the presence of depression symptoms

SF-36, which was used to evaluate the QoL, consists of 36 questions, which are employed to obtain scores for eight subscales, including physical function, role physical, role emotional, social functioning, general health, mental health, vitality and bodily pain. Total scores are also obtained for two main domains: a physical component summary (consisting of physical function, role physical, bodily pain and general health subscales) and a mental component summary (consisting of role emotional, social functioning, mental health and vitality). Scores range from 0 (maximum physical limitations) to 100 (optimal physical functioning) points (17).

VAS rates the pain of the individual on a 0-10 scale (18). Pain with movement during the previous week was assessed in the present study.

STATISTICAL ANALYSIS

Statistical analyses were made by using SPSS for Windows version 21. Data were expressed as mean ± standard deviation. Parametric data were compared by using the Student's t test, while non-parametric data were compared by the Mann Whitney U test, categorical data were analysed by the chi-square test. Skewed data were analysed by using the Mann Whitney U test. A p value less than 0.05 was considered as statistically significant. The Pearson's correlation analysis was used to investigate potential correlations and the confidence interval was 95%. Correlation coefficients were interpreted as 0 to 0.25, no correlation; 0.25 to 0.50, weak or moderate correlation; 0.50 to 0.75, good correlation; and, 0.75 to 1.00, very good correlation.

RESULTS

A total of 120 stroke survivors were evaluated in this study. 22 stroke survivors were excluded from the study, since they did not require assistance in their activities of daily living, 8 patients were excluded since the caregivers did not complete the questionnaires and 6 were excluded due to the unwillingness of the caregivers to complete the questionnaires. Eventually, the study was conducted in 84 caregivers of stroke survivors and 77 healthy volunteers (control group) who were not responsible for caregiving to any chronic patient.

Demographic and clinical data of the stroke survivors were presented in Table 1.

Table 1. Demographic and clinical data of stroke survivors

			Percent
Gender	Female	42	50.0
	Male	42	50.0
Marital status	Married	60	71.4
	Widow/widower	24	28.6
Ambulation level	TS level	19	22.6
	Ambulant dependent	11	13.1
	Independent, ambulant with assistance and orthosis	7	8.3
	Independent, ambulant with assistance	32	38.1
	Independent ambulant	15	17.9
Speech disorder	Aphasia (+)	30	35.7
	Aphasia (-)	54	64.3
Speech	Normal	54	64.3
	1-2 words	12	14.3
	Dysarthria	12	14.3
	No words	4	4.8
	Speech is not expected	2	2.4
Urinary incontinence	(+)	33	39.3
	(-)	51	60.7
Fecal incontinence	(+)	15	17.9
	(-)	69	82.1
Depression	(+)	17	20.5
	(-)	66	79.5

In this study, no statistically significant difference was found between the caregiver group and control group in age, BMI; monthly income, the length of marriage. The level of depression, mental quality of life , fatigue and pain levels were statistically significantly worse in the caregiver group, while no significant difference was found between the two groups in physical quality of life (table-2).

Positive correlations were found between the caregiver depression and their age, BMI, fatigue, pain scores along with the disease duration, depression level of the stroke survivor, severity of stroke. Negative correlations were found between the quality of life of the caregiver and the RANKIN score, FIM score, ambulation level, urinary incontinence, fecal continence, speech disorder of the stroke survivor while no correlation was found between the caregiver depression and the monthly income of the caregiver, number of children, monthly income, educational attainment of the stroke survivor (table-3)

Table-2

	Patient	Caregivers	Control group	
Age	65.69 ±11.48	52.53±12.00	52.28±8.65	0.645
BMI	29.83±4.79	29.71±3.76	28.85±3.86	0.208
Monthly income	1035.71±342.61	1158.92±298.10	1243.37±552.00	0.954
Length of marriage	43.54±10.91	32.21±12.76	29.15±9.31	0.061
BDI	30.22±15.51	20.86±11.40	6.55±5.99	0.000
SF-36 (mental component)		47.66±26.28	67.26±20.67	0.000
SF-36 (physical component)		64.05±19.73	65.82±21.48	0.348
Time elapsed after the stroke (month)	53.75±65.64			
MRS	2.82±1.37			
FIM	4.14±2.31			
NIHSS	3.54±3.31			
VAS(Pain)	6.95 ± 1.84	6.35 ± 2.46	3.02 ± 1.92	0.000
VAS(fatigue)	7.57 ±1.79	7.08 ± 2.32	3.27 ±1.89	0.000

MRS: Modified Rankin Scale, NIHSS: National Institute of Health Stroke Scale, FIM: Functional Independence Measure, BDI: Beck Depression Index, VAS: Visual Analogue Scale, SF-36: Short Form-36, BMI: Body Mass Index

Table-3: Items investigated for possible correlations with caregiver depression

	R	P
Age	0.245	0.025
BMI	0.266	0.014
Monthly income of the caregiver	0.055	0.621
The number of the caregiver's children	0.068	0.538
Monthly income of the patient	0.024	0.830
Age of the patient	0.135	0.221
Educational attainment of the patient	0.152	0.168
Patient depression	0.724	0.000
SF-36 (mental component)	-0.817	0.000
SF-36 (physical component)	-0.565	0.000
Time elapsed after the stroke	0.259	0.017
MRS	-0.682	0.000
FIM	-0.723	0.000
NIHSS	0.722	0.000
Patient's speech disorder	-0.370	0.001
Ambulation level	-0.630	0.000
Urinary incontinence	-0.509	0.000
Fecal incontinence	-0.393	0.000
VAS(Pain)	0.553	0.000
VAS(fatigue)	0.704	0.000

MRS: Modified Rankin Scale, NIHSS: National Institute of Health Stroke Scale, FIM: Functional Independence Measure, BDI: Beck Depression Index, VAS: Visual Analogue Scale, SF-36: Short Form-36, BMI: Body Mass Index

Positive correlations were found between the mental quality of life of the caregiver and fatigue score, pain score of the caregiver along with FIM score, stroke severity, urinary incontinence, speech disorder, level of ambulation of the patient. Negative correlations were found between caregiver depression and the level of depression, RANKIN score, FIM score, fecal incontinence of the patient, while the level of caregiver depression did not correlate with age, BMI, number of children, monthly income of the caregiver and monthly income, disease duration, age, educational attainment of the patient (table-4)

Table-4: Items investigated for possible correlations with the mental quality of life of the caregiver

	R	P
Age of the caregiver	0.112	0.312
BMI of the caregiver	0.160	0.147
BDI score of the caregiver	-0.817	0.000
Monthly income of the caregiver	0.035	0.749
Educational attainment of the caregiver	-0.096	0.387
Number of children of the caregiver	0.144	0.191
Monthly income of the patient	0.081	0.463
Age of the patient	0.135	0.221
Educational attainment of the patient	0.125	0.258
BDI score of the patient	-0.667	0.000
SF-36 (physical component)	0.667	0.000
Time elapsed from the stroke	-0.157	0.153
MRS	-0.715	0.000
FIM	0.738	0.000
NIHSS	-0.670	0.000
Speech disorder of the patient	0.412	0.000
Level of ambulation	0.615	0.000
Urinary incontinence	0,507	0.000
Fecal incontinence	-0.344	0.001
VAS(Pain)	0.558	0.000
VAS(fatigue)	0.682	0.000

MRS: Modified Rankin Scale, NIHSS: National Institute of Health Stroke Scale, FIM: Functional Independence Measure, BDI: Beck Depression Index, VAS: Visual Analogue Scale, SF-36: Short Form-36, BMI: Body Mass Index

Positive correlations were found between the patient depression and fatigue score, pain score, level of depression of the caregiver along with time elapsed from stroke, RANKIN score, and NIH score of the patient. Negative correlations were found between the patient's depression and the quality of life of the caregiver, stroke severity, FIM score, urinary incontinence, speech disorder, level of ambulation, fecal incontinence of the patient, while the level of the patient's depression did not correlate with the age, monthly income, educational attainment of the caregiver and the monthly income and educational attainment of the patient (table-5).

Table-5: Items investigated for possible correlations with patient's depression

	R	P
Age	0.080	0.468
BDI score of the caregiver	0.724	0.000
Monthly income of the caregiver	-0.063	0.570
Educational attainment of the caregiver	0.132	0.230
Monthly income of the caregiver	-0.133	0.229
Age of the patient	0.093	0.401
Educational attainment of patient	-0.079	0.474
SF-36 (mental component)	-0.667	0.000
SF-36 (physical component)	-0.326	0.003
Time elapsed from the stroke	0.245	0.025
MRS	0.859	0.000
FIM	-0.881	0.000
NIHSS	0.865	0.000
Speech disorder of the patient	-0.448	0.000
Level of ambulation	-0.792	0.000
Urinary incontinence	-0.566	0.000
Fecal incontinence	-0.596	0.000
VAS(fatigue)	0.691	0.000

MRS: Modified Rankin Scale, NIHSS: National Institute of Health Stroke Scale, FIM: Functional Independence Measure, BDI: Beck Depression Index, VAS: Visual Analogue Scale, SF-36: Short Form-36, BMI: Body Mass Index

DISCUSSION

In this study, when compared to the control group, pain scores and the level of depression were found to be higher and the mental quality of life was negatively impacted in the caregivers to stroke survivors, in connection with the depression level, functional state, stroke severity, speech disorder, urinary and fecal incontinence and the level of ambulation of the stroke survivor.

It is a well-known fact that, people taking care of patients experience physical, psychological and social problems (19, 20). Depression is one of the most commonly encountered psychological problems in caregivers of stroke survivors (21). In a study conducted by Berg et al. the prevalence of depression was found to be 33% in caregivers to stroke survivors, (6). In a study conducted by Morimoto et al, the prevalence of depressive symptoms in this population was found to be 52% (22). In this study the prevalence of depression among caregivers was similar to the previous studies and it was found as 59% in the caregiver group. Studies on the emotional state of the caregivers have indicated a negative impact on the emotional state and the level of caregiver depression directly correlated with the dependency level of the stroke survivor. (6, 23). In this study, in line with these results, a positive correlation was found between the disability level of the stroke survivor and the level of the caregiver depression. Therefore, the disability level of the stroke survivor should be taken in consideration when assessing the caregiver.

In addition to the emotional state of caregivers to stroke patients, a negative impact was also observed on their quality of life (10). The negative impact on the quality of life of caregivers was related to chronic tiredness, muscle pain, difficulty in concentrating and lack of enough time to allocate for self-care (19). Additionally, in a multicenter study of 132 stroke survivors and their caregivers, caregivers who were caring for individuals with poor motor function in combination with high memory and behavior problems changes, reported a poor mental health-related quality of life (24). In line with this study a negative impact was observed on the mental quality of life of the caregivers of stroke survivors while no effect was observed on the physical component of the quality of life. Furthermore, this study revealed a positive correlation between the mental quality of life of caregivers and the level of depression, disability of the patient as well as pain score and depression level of the caregiver. The deterioration of mental quality of life in correlation with the increasing level of depression suggests the predominance of psychological impact over physical impact. Actually, although it looks like that the physical burden is greater, mental and psychological impacts on the caregiver are greater than the physical impact. Social pressure, lack of spare time for their own activities, inadequate social support, breakdowns in family relationships, anger, and disappointment may contribute to this result. (19, 25, 26).

Other common complaints among the caregivers include fatigue and pain (27). However, the complaint of fatigue may be overlooked, if not asked particularly about it. Studies conducted in people caring for stroke survivors have reported that not only the caregivers had difficulties in performing their caring responsibilities but also they were experiencing other problems such as fatigue and sleep disorders (28, 29). In this study, the pain and fatigue scores were also found to be higher in the caregivers in comparison to that of the controls and a correlation was shown between the level of fatigue of the caregiver and the level of caregiver depression as well as the mental quality of life of the caregiver. According to these results, the level of fatigue of stroke survivors' caregivers should always be assessed and this problem should also be resolved in order to decrease the level of depression and to increase the quality of life of the caregiver.

In conclusion, increased levels of depression in people who care for stroke survivors, are associated with decreased mental quality of life, increased the complaints of pain and fatigue Moreover, these parameters interact with each other. In a study conducted by McCullagh et al. burden the burden and quality of life of the caregiver correlated with the age, dependency level and psychological status of the stoke survivor, as well as the age, sex and psychological status of the caregiver (30). Relationships were found between the quality of life of the caregiver and behavioral problems, severe disability, depressive symptoms in the stroke survivor and passive coping strategy (8). In this study, the level of depression in caregivers was correlated with the level of quality of life, pain and fatigue. These results indicate that the presence of one of these parameters may trigger other parameters leading to a vicious circle.

The present study has some limitations. First, because the study was conducted in a single center, it cannot be generalized to the whole population, and so the situation has decreased the strength of the study. Second, the present study was designed as cross sectional, not longitudinal. Therefore, further studies should address such limitations.

Physical and emotional health of the caregiver is an important issue in the management of the care for stroke survivor. Although it looks like that the physical burden of the caregiver is greater, mental and psychological impacts on the caregiver are in the forefront. Therefore, in chronic conditions that lead to functional loss, such as stoke, the level of depression, quality of life and fatigue should be taken into consideration, contributing factors should be identified and the needs and medical condition of the caregiver as well as support resources should be determined and the caregiver should be monitored periodically. This approach may also have positive effects on the rehabilitation process of the stroke survivor.

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Conflict of Interest

The authors declare no conflict of interest.