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The effect of discharge training and telephone counseling service on patients' functional status and caregiver burden after stroke: A randomized controlled trial

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Abstract

Objective: This study aimed to determine the effect of discharge training and telephone counseling service on patients' functional status and caregiver burden after stroke. *Methods:* This study was conducted as a randomized controlled trial in 69 stroke patients and their caregivers. Discharge training and telephone counseling were given to the caregivers in the intervention group. Caregivers also received telephone counseling by calling researcher when needed. Information form for participants, Modified Rankin Scale, Barthel Index and The Zarit Caregiver Burden Scale were used for data collection. Pre-tests were applied to the intervention and control groups before discharge. Three months after discharge post-tests were performed for the two groups. *Results:* Three months after discharge, caregivers' burden was significantly lower in the intervention group compared to the control group. The mean Modified Rankin Scale score of the patients in the intervention group was significantly lower than the control group three months after discharge. Although the mean Barthel Index score of the patients in the intervention group was statistically significant higher than before discharge, but the difference between the groups was not statistically significant.
Conclusion: Discharge training and telephone counseling provided to the caregivers of stroke patients reduced the caregiver burden and had a positive effect on the improvement of the functional status of the patients.

Keywords: Stroke, caregiver burden, functional status, discharge training, telephone counseling

INTRODUCTION

Stroke caused by the impaired blood flow to the brain due to bleeding or blockage of the cerebral vessels is a disease that leads to various functional losses in patients.[1] Stroke is the second leading cause of death after ischemic heart diseases in Turkey and worldwide.[2,3] It is also one of the leading causes of long-term disability.[4] Cognitive and physical disorders, sensory problems, communication disorders, and emotional problems are observed after stroke.[5-7] This situation causes individuals to become dependent on others while performing daily life activities.[5] Caring for such patients causes psychological and emotional problems in caregivers. This problem is defined as "burden".[6] Burden is a multidimensional concept used to describe the physical, emotional, social and economic problems that develop in caregivers due to being responsible for the care of patients.[8,9] Stroke, which causes significant changes in individuals' daily lives, creates a burden depending on the caregiver role they play, especially in people who are responsible for the patient's care.[1] It is estimated that the caregiver burden increases due to the insufficient support given to the caregivers of stroke patients worldwide.[6]

Stroke, which is one of the leading diseases that increase caregiver burden[10], physical and emotional problems experienced by caregivers affect the patient's care and medical outcomes of the patient negatively[11] and can cause serious consequences such as the caregiver giving up the his/her caregiver role.[12] Caregivers, who have very important roles in the recovery process after stroke, do not have enough time to prepare for

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this role during hospitalization.[13] The caregivers who undertake the care of the stroke patient should be supported with training and counseling programs in order to improve their competence to cope with the difficulties associated with the care process and to improve patient outcomes.[14] It is stated that training should be given in the hospital environment before the patient is discharged, and after discharge, it should be continued as nurse telephone counseling or home visits.[15] Although face-to-face counseling is specified as an effective intervention method, it usually requires a lot of time and cost. Telephone counseling, on the other hand, is highly recommended since it can be carried out without space and time limitation.[16] The literature emphasizes the importance of nurse telephone counseling in meeting the needs of patients and caregivers, using resources appropriately, reducing costs, providing safe care, managing the disease, strengthening the patient and nurse relationship, and reducing recurrent hospitalization.[17-19] In the studies conducted, it is stated that caregivers who are given training and counseling play a more effective role in patient care as a result of the increase in their knowledge level about care and the decrease in their caregiver burden, and also the increase of independence in the daily life activities of patients.[5,13,14,20] The purpose of this study was to determine the effect of discharge training and telephone counseling service on patients' functional status and caregiver burden after stroke.

We hypothesized that discharge training and telephone counseling provided to the caregivers of stroke patients could reduce the caregiver burden and had a positive effect on the improvement of the functional status of the patients.

METHODS

Study design and sample

This study, which was planned as a randomized controlled trial, was conducted in the neurology clinic of a university hospital in Turkey between March 2017 and April 2018. Power analysis was used to determine the sample size of the study. The sample size was calculated as 72 patients and caregivers. Considering the possibility of losing cases in the research process, 40 stroke patients and their caregivers were included in each group, with a sample size of 80. Randomization was determined with a simple randomization calculator using the Researcher Randomizer website (https://www.randomizer.org). Patients and their caregivers who met the inclusion criteria were included in the intervention and control groups according to the order of hospitalization of the patients in the neurology clinic. The inclusion criteria for patients were that being at the age of 18 and over, having a hemorrhagic or ischemic stroke, and Rankin Scale score of 4 or less. The patients who participated in the study had a first stroke. The inclusion criteria for caregivers were that being at the age of 18 and over, being literate, primary responsibility for the care of the stroke patient during hospitalization and after discharge, using a telephone (mobile or home phone), being open to communication and collaboration, and having no problem in terms of hearing and understanding. Caregivers in the intervention and control group actively involved in the patient care during hospitalization. Patients were cared for by their caregivers at home after discharge and did not receive any institutional care.

Six patients and caregivers from the intervention group and five patients and caregivers from the control group were excluded from the study due to reasons such as change of the caregiver, the inability to reach the caregiver by telephone, or death of the stroke patient. The data collection process was completed with 69 patient and caregiver dyads (34 dyads in the intervention group and 35 in the control group) (Figure 1).

Data collection

In this study, patient information form prepared by the researchers (included socio-demographic and disease related characteristics), Modified Rankin Scale (mRS) and Barthel Index (BI) were used to collect data about patients, while caregiver information form prepared by the researchers (included socio-demographic characteristics of the caregivers and the care giving process) and The Zarit Caregiver Burden Scale (ZCBS) were used to collect data about caregivers. Data collection tools were collected by the researcher and applied to patients in the wards and caregivers in a separate room in the ward.

The ZCBS, developed by Zarit *et al.* in 1980 measures caregiving burden. This scale includes 22 questions that determine the impact of caregiving on the individual's life. The score obtained from the five-point Likert scale is minimum 0 and maximum 88.[9,21] A high score on the scale indicates that the problem experienced by the caregiver is high. The Cronbach alpha value of the Turkish version was found to be 0.95.[22] In this study, the Cronbach alpha value was found 0.91 in the pre-test and 0.94 in the post-test.

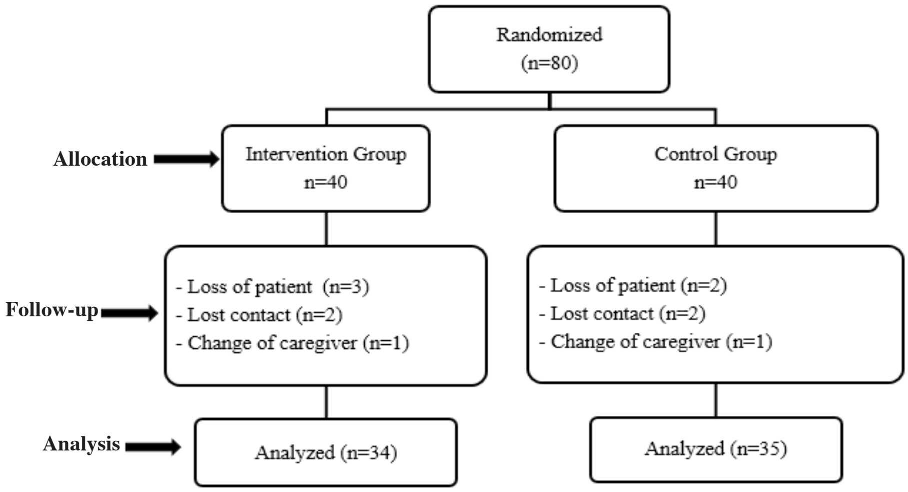

Figure 1. Flow diagram of the study

The BI developed by Mahoney and Barthel in 1965 was used to determine the independence levels of individuals in activities of daily living. Turkish validity was made by Küçükdeveci *et al.* (2000).[23] The index consists of 10 items including activities of daily living such as eating, bathing, self-care, dressing, bladder control, bowel control, toilet use, chair/bed transfer, mobility, stair use and is used to evaluate the level of functional independence. The score ranges from 0 to 100 (0-20 points: Completely dependent, 21-61 points: Highly dependent, 62-90 points: Moderately dependent, 91-99 points: Slightly dependent, 100 points: Completely independent).[24]

The mRS evaluating the functional limitation and degree of addiction occurring in the patient after stroke was evaluated in seven categories (0: No symptoms, 1: No obvious deficits, 2: Mild deficits, 3: Moderate deficits, 4: Severe deficits, 5: Very severe deficit and 6: Death).[25] According to this scale, those who scored 1-2 points continue to live independently, and those who score 3 or more depended on. This scale is also used clinically to distinguish post-stroke disability and recovery levels.[26]

Interventions

Before the intervention data collection tools were applied to the patients and their caregivers. An information form, mRS, BI and ZCBS were given to the participants. After completing the questionnaires, the intervention group received face-to-face discharge training for an average of 40-60 minutes in the hospital and training booklets were delivered to the caregivers. The booklet, which is a training material, was prepared by the researchers based on the literature. The content of the booklet included stroke disease (causes, risk factors, symptoms, treatment, secondary stroke prevention), daily needs and care of the patient after stroke, position change and movement, transport techniques, pain management, drug use, safety and communication issues. In the discharge training, besides the topics in the booklet, the topics needed by the caregivers were also included.

The telephone number of the caregivers in the intervention group for telephone counseling was obtained, and the telephone number of the researcher was given to the caregivers. The caregivers were also provided with counseling by calling the researcher when they needed it. The topics that the caregivers received the most counseling after discharge by calling the researcher are information about related institutions, drugs used by the patient, feeding problems, medical report, health services, care of pressure ulcer, physical activity and coping with stress. Consultation service was given to the caregivers one week after discharge and once a month for three months by telephone call. A total of 136 counseling was given to the intervention group after discharge. At the end of the third month, both the intervention and control groups were interviewed by telephone and the caregivers were administered the questionnaires applied before discharge (Figure 2).

No intervention was applied to the participants in the control group. Standard, routine patient care and discharge procedures were applied by clinic nurses. After the study and data collection, a training booklet was also given to all caregivers in the control group.

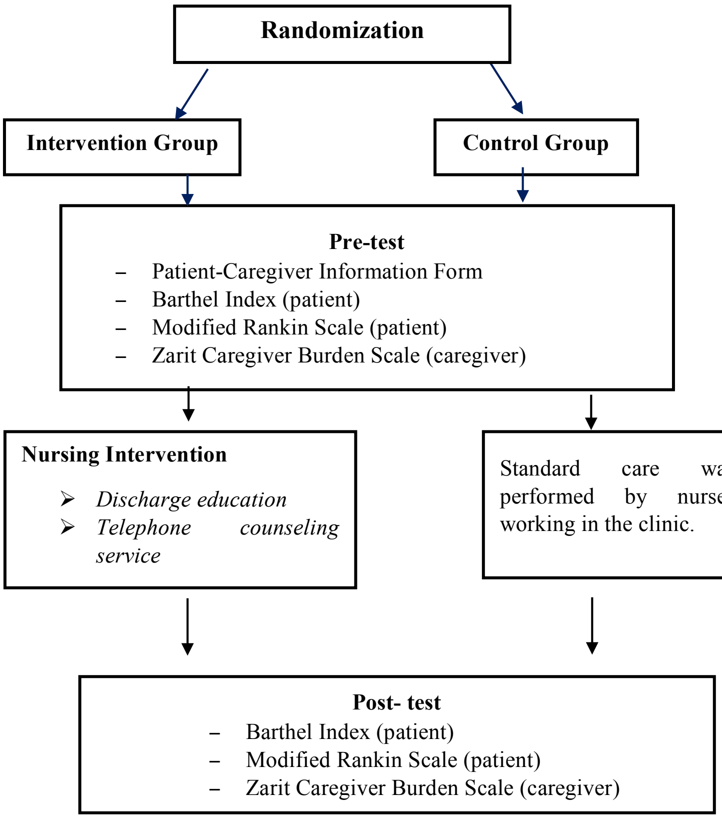

Figure 2. Workflow diagram

Statistical analysis

Descriptive (average, number, percent) and comparative (t-test, chi-square test, Mann-Whitney U test and the Wilcoxon signed rank test) statistics were used to assesed demographic, disease and care characteristics of the participants. The chi-square test was used to compare the characteristics between the groups. Mann-Whitney U test was used to compare differences between two groups. Wilcoxon Signed Rank Test was used to compare the pre-test and post-test mean scores within the groups. A p value < .05 was considered statistically significant. The data was analysed by SPSS (Statistical Package for Social Sciences) version 21.

Ethical considerations

The conduct of the research was approved by the decision of the Trakya University Faculty of Medicine Scientific Research Ethics Committee (No. 2016/256). Written and verbal consent was taken from all patients and caregivers. The study was registered in ClinicalTrials.gov (NCT04648098).

RESULTS

Stroke patients' characteristics

When the mean age of the patients in the study group was analysed, it was found that patients in the intervention group was 68.47 ± 13.04 years, and patients in the control group was 67.91 ± 14.37 years. More than half of the patients in the intervention and control groups were male, the majority of them were married and had primary education graduation, and almost half of them were retired. More than 90% of the patients were diagnosed with ischemic stroke in both groups. The majority of the patients in both the control and intervention groups had a chronic disease. There was no statistically significant difference between the intervention and control groups in terms of demographic and clinical characteristics (p>05; Table1).

Caregivers' characteristics

The mean age of the caregivers in the intervention group was 54.61 ± 11.73 years, and the mean age of the caregivers in the control group was 51.60 ± 14.18 years. The majority of the caregivers in both

Table 1: Characteristics of stroke patients

Variable	Intervention group (n=34)		Control group (n=35)		Statistical significance	
	n	%	n	%	Test	p
Age (years), Mean ± SD	68.47±13.04		67.91±14.37		t=0.168*	0.867
Gender						
Female	12	35.3	13	37.1	χ2=0.000ǂ	1.000
Male	22	64.7	22	62.9		
Marital status						
Single	0	0.0	1	2.9	χ2=1.756‡	0.416
Married	28	82.4	25	71.4		
Widowed	6	17.6	9	25.7		
Education level						
Illiterate	1	2.9	1	2.9	χ2=3.063‡	0.547
Literate	6	17.6	7	20.0		
Primary education	24	70.6	24	68.5		
High school	3	8.8	1	2.9		
University	0	0.0	2	5.7		
Working status						
Unemployed	14	41.2	13	37.1	χ2=2.356‡	0.671
Worker	1	2.9	3	8.6		
Officer	0	0.0	1	2.9		
Self employment	2	5.9	1	2.9		
Retired	17	50.0	17	48.6		
Stroke type					–	
Ischemic	31	91.2	33	94.3		0.673§
Hemorrhagic	3	8.8	2	5.7		
Other chronic disease						
Yes	30	88.2	31	88.6	–	1.000§
No	4	11.8	4	11.4		

* Independent-samples t test, † Continuity correction, ‡ Pearson chi-square analysis, § Fisher's exact

the intervention and control groups were female, married and had primary education graduation. More than half of the caregivers did not work in any job. It was determined that the majority of the caregivers in both the intervention and control groups were the patient's spouse and lived with the patient. There was no statistically significant difference between the intervention and control groups in terms of the demographic characteristics of the caregivers (p>.05; Table 2).

The caregiver burden

Scores of the ZCBS was shown in Table 3. It was found that the mean caregiver burden scale score of the caregivers in the intervention group 3 months after discharge was statistically significantly lower than that of the period before discharge (p<.001). The difference between the groups was determined to be statistically significant (p=.012). It was determined that the caregiver burden in the intervention group decreased significantly three months after discharge compared to the control group.

Functional status of the patients

The comparison of the functional status of the patients according to the groups was presented in Table 4. It was determined that the mean mRS score of the patients in the intervention group three months after discharge was statistically significantly lower than that of the period before discharge (p=.005). Three months after discharge, it was revealed that there was a significant improvement in the functional impairment level of the patients in the intervention group compared to the control group (p=.028).

It was found that the mean BI score of the patients in the intervention group three months

Table 2: Characteristics of caregivers

Variable	Intervention group (n=34)		Control group (n=35)		Statistical significance	
	n	%	n	%	Test	p
Age (years), Mean ± SD	54.61±11.73		51.60±14.18		t=0.961*	0.340
Gender						
Female	24	70.6	25	71.4	χ2=0.000†	1.000
Male	10	29.4	10	28.6		
Marital status						
Single	2	5.9	3	8.6	χ2=1.202‡	0.548
Married	31	91.2	32	91.4		
Widowed	1	2.9	0	0.0		
Education level						
Literate	1	2.9	4	11.4	χ2=2.006‡	0.571
Primary education	25	73.5	24	68.6		
High school	5	14.7	5	14.3		
University	3	8.8	2	5.7		
Working status						
Unemployed	22	64.7	21	60.0	χ2=2.152‡	0.708
Worker	1	2.9	3	8.6		
Officer	1	2.9	0	0.0		
Self employment	3	8.8	4	11.4		
Retired	7	20.6	7	20.0		
Relationship with the patient						
Spouse	18	52.9	16	45.7	χ2=1.351‡	0.717
Child	11	32.4	10	28.6		
Relative	2	5.9	3	8.6		
Other (daughter-in-law, formal caregivers)	3	8.8	6	17.1		
Living with the patient						
Yes	29	85.3	25	71.4	χ2=1.219‡	0.270
No	5	14.7	10	28.6		
Patient care experience						
Yes	13	38.2	15	42.9	χ2=0.021‡	0.884
No	21	61.8	20	57.1		
Difficulty in Patient Care						
Yes	29	85.3	29	82.9	χ2=0.000‡	1.000
No	5	14.7	6	17.1		
Support in patient care						
Yes	19	55.9	17	48.6	χ2=0.135‡	0.714
No	15	44.1	18	51.4		
Who support in patient care						
Family members	18	94.7	15	88.2	χ2=1.165‡	0.558
Relative	1	5.3	1	5.9		
Neighbor	0	0.0	1	5.9		
Support level in patient care						
Enough	4	21.1	6	35.3	χ2=2.143‡	0.342
Partly enough	11	57.9	10	58.8		
Not enough	4	21.1	1	5.9		

* Independent-samples t test, † Continuity correction, ‡ Pearson chi-square analysis

Table 3: Comparison of the mean zarit caregiver burden scale pre-test and post-test scores between and within groups

	Intervention Group (n=34)					Control Group (n=35)					Statistical significance	
	Pre- test Mean ± SD	Post- test Mean ± SD	Change score	Statistical Test	*P*	Pre- test Mean ± SD	Post-test Mean ± SD	Change score	Statistical Test	*P*	Statistical Test	*P*
ZCBS	40.70±13.69	32.14±15.40	8.56±11.83	Z=-3.668*	**<0.001**	35.77±14.35	34.37±14.20	1.40±11.30	Z=-0.821*	0.412	Z=-2.498†	**0.012**

ZCBS: Zarit Caregiver Burden Scale.

* Wilcoxon test, † Mann Whitney U test

Table 4: Comparison of the mean modified rankin scale and barthel index pre-test and post-test scores between and within groups

	Intervention Group (n=34)					Control Group (n=35)					Statistical significance	
	Pre-test Mean ± SD	Post test Mean ± SD	Change score	Statistical Test	*P*	Pre- test Mean ± SD	Post- test Mean ± SD	Change score	Statistical Test	*P*	Statistical Test	*P*
Modified Rankin Scale	3.29±0.75	2.91±1.02	0.38±0.69	Z= -2.829*	**0.005**	3.20±0.75	3.11±0.86	0.09±0.61	Z=-0.879*	0.380	Z=-2.203†	**0.028**
Barthel Index	51.76±21.80	58.52±25.21	6.76±14.61	Z= -2.394*	**0.017**	52.71±20.12	56.14±21.42	3.43±16.30	Z=-1.104*	0.270	Z=-1.343†	0.179

* Wilcoxon test, † Mann Whitney U test

after discharge was statistically significantly higher than that of the period before discharge (p=.017). Improvement in the patients' level of independence in the daily life activities three months after discharge was found to be significant, but the difference between the groups was not statistically significant (p=.179).

DISCUSSION

In this study, the caregiver burden in the intervention group was found to be significantly lower than that of the control group three months after discharge. In the literature, it was determined that the training and counseling given to caregivers for three months reduced the caregiver burden.[27-30] In another study, it was determined that caregivers had better practical skills related to patient care, lower burden, and better mental health status as a result of home visits and telephone calls after discharge.[31] In a study in which an individual telecare intervention was applied, it was found that the burden of families of stroke patients decreased.[16] It was also reported that the telenursing application provided to caregivers of stroke patients for three months facilitated the patient care for caregivers and reduced the anxiety experienced by caregivers about daily care.[32] Cheng *et al.* showed that providing the psychoeducation program (pre-discharge training and telephone-based problem-solving and coping skills training for stroke and care skills) applied to caregivers of stroke patients reduced the caregiver burden.[12] The systematic review conducted also explained the importance of the subject and emphasized the necessity of supporting family members who provide care to stroke patients after discharge by telephone counseling and training in order to improve their ability to give care to patients and their ability to cope with problems.[14] Another study conducted telenursing reduced the caregiver burden, urinary problems and the number of falls in patients with acute stroke.[33] Similar results were obtained in other studies which had similar intervention. In line with the findings obtained, discharge training and telephone counseling were found to be effective in reducing the caregiver burden.

The functional status of stroke patients was evaluated by the mRS and BI. In our study, it was determined that the mean mRS scores of patients in the intervention group decreased significantly compared to the control group at the end of the third month and had a positive effect on improvement in their functional levels. In the study conducted by Özakgül and Aştı (2018), after the training provided to caregivers of stroke patients, it was determined that there was a decrease in the mRS scores of the patients in the intervention group.[34] Another study found that nursing care strategies were successful in improving the physical and functional status of stroke patients.[35] Ramussen *et al.(*2016) found that mRS scores were better in patients undergoing early rehabilitation at home (therapeutic interventions, training) by the multidisciplinary team compared to the control group.[36] At the end of the third month after discharge, the increase in the mean BI scores of the patients in the intervention group was found to be significant, but the increase in the level of independence in the daily life activities was not statistically significant between the groups. In accordance with our results, no significant difference was found in the study of Kalra *et al*. (2004) between the training and control groups in terms of the levels of functional independence.[37] In the study of Torres-Arreola *et al*. (2009), it was determined that the training of the caregiver and the physiotherapy applied to the patient increased the BI scores of stroke patients within the scope of rehabilitation strategies.[38] In the another study as a result of individual training on patient care and telephone counseling service for three months after discharge, there was an increase in the BI scores of patients, but no significant difference was found between the groups.[39] Bernocchi *et al*. (2016) found that the home-based telephone follow-up program improved the functional capacity of stroke patients.[40] Furthermore, it was stated in the literature that the training provided to stroke patients and their caregivers had a positive effect on the recovery process after the stroke and in reducing recurrent hospitalizations.[41] The literature information supports the results of our study. In this study, it was found that after the discharge training and telephone counseling service provided to the caregivers of the patients, the functional status of the stroke patients was better in comparison with the pre-discharge level, and they could carry out their daily life activities more independently. One of the important roles of the caregiver is to help functional recovery. This will be provided with training. Training will increase the caregiver's knowledge and skills in providing care, thus impacting the patient's recovery.[42]

The facts that the number of patients and caregivers that met the inclusion criteria of the study was low, some caregivers changed in the period after discharge, some caregivers changed their telephone number while the study was continuing, and some patients died due to the development of a stroke-related complication after discharge were the limitations of the study.

In conclusion, the discharge training and telephone counseling interventions positively impacted the caregivers and stroke patients. These impacts included reducing the caregiver burden, increasing the functional capacity of stroke patients. Accordingly, it is recommended to use the discharge training in the neurology clinics of hospitals and the telephone counseling application as an effective intervention after discharge. This study will guide the training and telephone counseling programs to be planned and applied in relation to the caregivers of stroke patients and will contribute to the literature in this respect.

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DISCLOSURE

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Conflict of interest: None

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