

The Effect of Education Given to the Caregivers of Patients with Stroke on Anxiety and Depression: An Example from Eastern Turkey

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Abstract

Background: As one of the chronic conditions, stroke brings about important problems for the individual, their family and the society.

Aim: This research was made in order to determine the effect of training given to stroke patient caregivers on their anxiety and depression levels.

Methods: This experimental research with pretest-posttest control group was conducted in Neurology Clinic between July 2011 and July 2012. The experiment group of the research consisted of 31 stroke patient lying for the first time in the clinic and control group consisted of 33 stroke patients who lied in the clinic before and also care givers. The pretest data was collected by the patient and care giver introduction form prepared by the researchers starting from the week the patient was accepted to the clinic, Barthel Index and Hospital Anxiety and Depression Scale. Posttest data was collected by using all scales after discharge of patient (except introduction form). In the evaluation of the data percentage, average, chi-square was used and also t test was used in independent groups.

Results: According to research results a significant difference could not be found between anxiety and depression points of experiment and control groups before training ($p>0.05$). In the evaluation made after the training it was determined that the anxiety and depression points of the caregivers decreased and the decreases were significant ($p<0.001$).

Conclusions: As a result it was determined that the training given to care givers in the experiment group decreased their anxiety and depression levels. We can recommend that nurses participate in educations on the care of patients with stroke, provide education to caregivers and arrange workshops to increase their awareness on this issue.

Keywords: Patients with stroke, Caregiver, Anxiety, Depression, Nursing, Educational program.

Introduction

As one of the chronic conditions, stroke brings about important problems for the individual, their family and the society. Stroke is a suddenly occurring traumatic disease that catches the patient and their family/caregivers unprepared to cope with the disease; for this reason, changes occur in the lives of both the patient who had a stroke and their family and the family members have to face complex problems after the stroke [1, 2].

As one of the major reasons for morbidity and mortality, stroke is the second cause of death in the world and takes the first place in causing sequelae; it is a disease that holds an important place in hospital visits and health expenditures in industrialized societies

[3-5]. Every year, about 12 million people throughout the world die of a heart attack or a stroke. Even when stroke patients have access to modern, advanced treatment, 60% die or become disabled [6]. From the 10 diseases that comprise the Number of Years Lost Healthy in Turkey, cerebrovascular diseases comes in the third place with 5.9% and in the second place as a cause of death with 15% [7].

The social burden of stroke is very heavy and the publications in 2002 reported that more than 3000 million people are living with stroke. 30% of patients with stroke die within a year, 20% of them at an early stage and one third of the patients who survive lead a life dependent on others in their daily routines. Stroke also leads to partial or total dependence in daily life activities at a rate of 25-50% [3, 8, 9]. The caregiver looking after the ill person who is totally or partially bedridden may experience anxiety and depression while giving care. All people may experience anxiety at different degrees

throughout their lives. Anxiety is a universal emotion; it is a natural reaction developed by an individual against situations in which they feel insecure. Anxiety is within normal limits for many people; it is situational and short-term in some, but experienced for a long time in others [10]. Although depression has very important effects on social and vocational functioning, they are emphasized less than necessary. According to the World Health Organization, depression takes the fourth place among diseases that lead to physical, emotional, social and economic problems [11]. Giving care to one of the family members with a chronic illness for a long time has important effects on the health and well-being of the caregivers. Long lasting care affects the physical and emotional health of caregivers negatively and causes an increase in depressive symptoms [2]. It has been found in studies made with those giving care to patients with stroke that they experienced mostly anxiety and depression [2, 12-18], and in education-based studies that there was a decrease in the anxiety and depression levels of caregivers after the education and the education programs generally produced positive results [19-23]. It was also found in a meta-analysis that education and support programs improved the mental health issues of caregivers [24].

Nurses should find out about the different needs of caregivers in rehabilitation of a patient with stroke. Before anything else, they should perform a comprehensive assessment of the caregiver and the patient. In this way, the needs of caregivers will have been identified when planning for the patient's treatment [2]. Caregivers should also be provided with education on anxiety, depression and participation in patient care.

Objective

This study was carried out to assess the effect of education provided to the caregivers of patients with stroke who were hospitalized in the Neurology Clinic of Erzincan State Hospital on their anxiety and depression levels.

Materials and methods

Design

The study was performed as a pretest–post-test randomized controlled model. This pretest-posttest semi-experimental study with a control group was conducted at the Neurology Clinic of Erzincan State Hospital. The study data were collected between July 2011 and July 2012.

The hypotheses of the study include 1- The education given to the caregivers of patients with stroke reduces the level of anxiety and 2- The education given to the caregivers of patients with stroke reduces the level of depression.

The caregivers' anxiety and depression levels were the dependent variables, the education provided to the caregivers in the experimental group was the independent variable and the fact that the caregivers in the experimental and control groups were similar in terms of age, gender, education status and socioeconomic level was the control variable.

The study population included all the patients with stroke who are bedded in the Neurology Clinic of Erzincan State Hospital and the patient caregivers who are primarily responsible for looking after these individuals (N=267).

The study sample consisted of 80 patients and caregivers, 40 being in the experimental group and 40 in the control group, who were hospitalized in the Neurology Clinic between the abovementioned dates and who met the sample selection criteria mentioned below. Six of the caregivers in the experimental group were excluded from the study for failing to attend the education due to reasons such as their health problems getting serious and their children becoming ill in time, one of them for being unwilling later to take part in the study and two of them for their patients to whom they gave care having deceased. Two of the caregivers in the control group were excluded from the study for failing to attend the education due to reasons such as their health problems getting serious and their children becoming ill in time, three of them for wishing to withdraw from the study and two of them for their patients to whom they gave care having deceased. The study was completed with 64 patients and caregivers, 31 from the experimental group and 33 from the control group. The data of the control group was collected first to prevent contamination.

The following criteria were considered for the individuals with stroke who would be included in the study group:

- Having been hospitalized within the first week,
- Not having any psychiatric history,
- For the experimental group, having been hospitalized for the first time with a diagnosis of stroke; for the control group, having been hospitalized more than once with a diagnosis of stroke.

The following criteria were considered for the caregivers who would be included in the study group:

- Being an individual who is primarily responsible for looking after the patient,
- Having the physical and emotional qualification to be able to give care to the patient,
- Being 18 years of age and older,
- Not having any psychiatric history,
- Willingness to communication,
- Being willing and volunteering to take part in the study.

Ethical considerations

Official permission was obtained from the Provincial Health Directorate of Erzincan to be able to conduct the study. The caregivers of the patients who were included in the study were explained that their and their patients' information would be kept confidential and they would be able to leave the study whenever they wished and then those who volunteered were included in the study.

Data collection tools

The study data were collected using a patient and caregiver description form which was prepared by the investigators, the Barthel Index (BI) and the Hospital Anxiety and Depression Scale (HADS).

Patient and caregiver description form

This form consisted of twelve questions, five for the descriptive characteristics of the patient (age, gender, marital status, occupation and economic status) and seven for the descriptive characteristics of the caregiver (age, gender, marital status, education, occupation, economic status and their kinship with the patient).

Barthel Index (BI)

The Barthel Index, whose validity and reliability have been proved in various patient groups and various countries, is a scale that basically assesses mobility and self-care activities. It includes 10 items that measure physical independence in activities of daily living (motion: transferring from wheelchair, walking on a level surface and going up and down stairs; personal cleanness and dressing: bathing, meeting toilet needs and eating; excretion: urinary control and fecal control). BI was modified by Shah (1989) introducing a five-step scoring system to increase the sensitivity of the index. BI was also adapted for the Turkish people and the index was shown to be valid and reliable for patient groups with stroke and spinal cord injury [25].

Hospital Anxiety and Depression Scale (HADS)

Anxiety and depression were measured using HADS. The HADS was developed by Zigmond and Snaith. The HADS consists of 14 items, seven of which score for anxiety (HADS-A) and seven of which score for depression (HADS-D). The HADS is designed to measure levels of either anxiety or depression independently from each other. Each question has a 4-point scale. Scores range from 0 to 21, with higher scores indicating the presence of anxiety and depression. Each item is rated on a four-point scale; item scores are summed to yield subscores for anxiety and depression. The scores range from 0 to 21 for each subscale, with a score of 0–7 denoting a noncase, 8–10 a possible case, and 11 or higher a probable case [26]. Aydemir conducted work on its validity and reliability in Turkey. Cut-off points on each of the subscales of 7/8 for possible and 10/11 for probable diagnosis of anxiety and depression has been recommended [27, 28].

Data collection

The data of the control group were collected first in the study. The control group data were collected between July 2011 and January 2012. Within the first week of hospitalization of a patient, BI was administered to the patient by their caregivers under the supervision of the investigators and the caregivers were administered the description form, HADS and pretests. Such patients and caregivers received the routine nursing care of the clinic. The posttests were administered a month after the discharge of a patient by giving an appointment at the Neurology Policlinic by the patient's doctor. The data of the experimental group were collected between January and July 2012. After providing information about the study to the caregivers in the experimental group, BI was administered to the patients by their caregivers under the supervision of the investigators and the description form, HADS and pretests were administered to the caregivers within the first week of hospitalization of the patients. Nursing care was provided according to the scale results and the patient's needs. Education/consultancy was also provided to the caregivers. The posttests were administered a month after the discharge of a patient by giving an appointment at the Neurology Policlinic by the patient's doctor.

The Conduct of the study Caregiver education program

Giving care is one of the fundamental duties of the nursing profession. When a long-term care is needed, this duty is fulfilled by the family of the ill person. However, most of the family members are not

equipped with the knowledge and skill necessary for providing long-term care. Nurses, who are members of a professional healthcare team, should train caregivers for home care from the stage of diagnosing the disease until the discharge of the patient. During this process, nurses should fulfill their roles of education, care giving, consultancy, work organization and guidance. Nurses should observe the caregiver's communication with the patient and their knowledge, attitudes and behaviors with respect to the disease and care giving and should help the caregivers develop positive attitudes by focusing on their abilities [29].

The contents of the caregiver education were determined with the guidance of the studies made on the subject and the literature by also taking into consideration the needs of patients. The education material contained information on stroke, information on the identification and fulfillment of the needs of patients with stroke and their caregivers with respect to the activities of daily living (ensuring a safe environment, infection control, appropriate positioning, pain, complications related to the disease, effects and side-effects of medications used, coping with anxiety and depression, recommendation on speech problems, social support, principles of body mechanics, exercises for patients and bringing the patient to a standing position, recommendations on personal hygiene and dressing, urinary and digestive system problems, sleep and rest, sexuality, recommendations on work and leisure, etc.) as well as the symptoms of anxiety and depression and methods for coping with them [30, 31].

The education program was administered to the caregivers in the experimental group from the first week when the patient was hospitalized until he/she was discharged or after the patient's condition became stable or after the caregiver who was able to give long-term care was identified. The caregivers were given information on problem solving, symptoms of anxiety and depression and methods for coping with them and the importance of patients' fulfilling of their needs independently.

Composite education methods such as plain narration, question and answer, and demonstration were employed and feed-backs were obtained.

In addition to the routine care in the hospital, the caregivers in the experimental group were administered an education program consisting of 3-5 sessions each lasting 25-30 minutes on the average. The investigators showed the caregivers demonstratively personal hygiene practices, appropriate positioning, techniques to lift a patient, helping a patient dress and deep-breathing exercises that are included in patient care until the patient was discharged. The caregivers were also given education on basic care skills such as getting support and help for activities of daily living, and management and prevention of stroke-related problems. In order to assess the effectiveness of the education, the patient and caregiver were given an appointment one month after the patient was discharged to administer the posttests. BI was used to assess the patient's activities of daily living and HADS to measure the anxiety and depression levels of the caregiver [2, 31-34].

Data collection tools	Patient during admission (first week)	Patient (one month after discharge)	Relative during admission (first week – Session 1)	Relative (Session 2)	Relative (Session 3)	Relative (one month after discharge)
BI	+	+	-	-	-	-
HADS-A	-	-	+	-	-	+
HADS-D	-	-	+	-	-	+
Education Program	-	-	+	+	+	-

Figure 1: Investigation application plan

Statistical analysis

Chi-square test and independent t-test were used in evaluating the differences between the groups according to their descriptive characteristics. Independent t-test was used to compare theme an change scores of the groups for pre-education and post-education. The level of significance was assumed to be $p < 0.05$ in the study.

Results

The mean age of the patients in the experimental group was 67.00 ± 12.86 , the majority of them were women (51.6%, $n=16$), married (64.5%, $n=20$), did not work (58.1%, $n=18$) and had income equal to their expenses (48.4%, $n=15$). The mean age of caregivers was 46.45 ± 15.65 , the majority of them were women (64.5%, $n=20$), married (61.3%, $n=19$), literate and graduates of primary school (51.6%, $n=16$), did not work (64.5%, $n=20$), had income equal to

their expenses (45.2%, $n=14$) and were spouses/sons/daughters of the patient (38.7%, $n=12$). The mean age of the patients in the control group was 65.42 ± 12.32 , the majority of them were women (57.6%, $n=19$), married (57.6%, $n=19$), did not work (63.6%, $n=21$) and had income equal to their expenses (39.4%, $n=13$). The mean age of caregivers was 46.00 ± 12.27 , the majority of them were women (54.56%, $n=18$), married (60.6%, $n=20$), literate and graduates of primary school (42.5%, $n=14$), did not work (51.5%, $n=17$), had income equal to their expenses (39.4%, $n=13$) and were spouses/sons/daughters of the patient (39.4%, $n=13$) (Table 1).

There was no difference with respect to their descriptive characteristics in the pretests administered to the patients and caregivers in the interventional and control groups ($p > 0.05$) (Table 1).
Insert Table 1

Table 1: Descriptive characteristics of patients and caregivers

	Experimental group (n=31)	Control group (n=33)	Test value, SD Statistical significance
Patient gender			
Female	16 (51.6)	19 (57.6)	$\chi^2=0.563$, $sd=1$
Male	15 (48.4)	14 (42.4)	$p=0.453$
Marital Status			
Married	20 (64.5)	19 (57.6)	$\chi^2=3.063$, $sd=1$
Divorced/widowed	11 (35.5)	14 (42.4)	$p=0.080$
Patient Occupation			
Working	13 (41.9)	12 (36.4)	$\chi^2=3.063$, $sd=1$
Not working	18 (58.1)	21 (63.6)	$p=0.080$
Patient economic status			
Less income than expenses	11 (35.5)	10 (30.3)	$\chi^2=3.969$, $sd=2$
Equal income and expenses	15 (48.4)	13 (39.4)	$p=0.137$
More income than expenses	5 (16.1)	10 (30.3)	
Caregiver gender			
Female	20 (64.5)	18 (54.5)	$\chi^2=2.250$, $sd=1$
Male	11 (35.5)	15 (45.5)	$p=0.134$
Caregiver marital status			
Married	19 (61.3)	20 (60.6)	$\chi^2=3.063$, $sd=1$
Single	12 (38.7)	13 (39.4)	$p=0.080$
Caregiver Education			
Illiterate	3 (9.7)	8 (24.2)	
Literate-Primary School	16 (51.6)	14 (42.5)	$\chi^2=5.219$, $sd=4$
Secondary School	7 (22.6)	4 (12.1)	$p=0.266$

High School	5 (16.1)	7 (21.2)	
Caregiver occupation			
Working	11 (35.5)	16 (48.5)	X ² =1.563, sd=1
Not working	20 (64.5)	17 (51.5)	p= 0.211
Caregiver economic status			
Less income than expenses	11 (35.5)	12 (36.4)	X ² =4.156, sd=2
Equal income and expenses	14 (45.2)	13 (39.4)	p= 0.125
More income than expenses	6 (19.4)	8 (24.2)	
Kinship with the patient			
Spouse	12 (38.7)	13 (39.4)	X ² =3.781, sd=2
Son/daughter	12 (38.7)	13 (39.4)	p= 0.151
Relative	7 (22.6)	7 (21.2)	
Mean age of patients	67.00±12.86	65.42±12.32	t=0.501, sd=62 p= 0.618
Mean age of caregivers	46.45±15.65	46.00±12.27	t= 0.129, sd=62 p= 0.898

There was no significant difference between the pre-education mean anxiety scores of the caregivers in the experimental and control groups ($p>0.05$); after the education, however, the mean anxiety scores of the caregivers in the experimental group significantly decreased as compared to the control group ($p<0.001$) (Table 2).

Table 2: Distribution of pre- and post-education mean anxiety scores of caregivers in experimental and control groups

Anxiety Scores	Experimental Group Mean (SD)	Control Group Mean (SD)	Mean difference (95% CI)	p value
Before Education	14.52±2.85	14.42±2.25	0.144 (-1.19to1.37)	0.886
After Education	11.61±3.77	14.55±2.24	-3.815 (-4.47to -1.40)	0.000

There was no significant difference between the pre-education mean depression scores of the caregivers in the experimental and control groups ($p>0.05$); after the education, however, the mean depression scores of the caregivers in the experimental group significantly decreased as compared to the control group ($p<0.001$) (Table 3).

Table 3: Distribution of pre- and post-education mean depression scores of caregivers in experimental and control groups

Anxiety Scores	Experimental Group Mean (SD)	Control Group Mean (SD)	Mean difference (95% CI)	p value
Before Education	13.81±2.90	14.79±1.88	-1.614 (-2.20to0.23)	0.112
After Education	11.61±4.33	14.76±2.03	-3.759 (-4.82to -1.47)	0.000

Looking at the dependency level as per BI of the ill individuals who were given care in the experimental and control groups before education, no significant difference was found between the mean BI scores ($p>0.05$). However, after education, a significant difference can be seen between the mean BI scores of ill individuals in the experimental and control groups in terms of dependency level as per BI ($p<0.001$) (Table 4).

Table 4: Distribution of pre- and post-education mean barthel index scores of caregivers in experimental and control groups

Anxiety Scores	Experimental Group Mean (SD)	Control Group Mean (SD)	Mean difference (95% CI)	p value
Before education	56.13±26.13	52.73±21.29	0.572 (-8.48 to15.28)	0.569
After education	60.81±13.85	53.18±08.37	2.684 (-8.57to15.37)	0.009

Discussion

Being one of the chronic diseases in our society, stroke brings about important problems for the individual, family and community. In this disease, patients and their families experience intense problems from time to time [1]. Stroke has a major effect not only on the life of patient but also on the life of caregiver [35]. Caregivers should certainly be provided with physical and emotional support [32].

Since caregivers who look after patients with stroke have to assume a number of roles and responsibilities of patients, their physical and psychosocial conditions are affected negatively [36]. It has been reported in many studies made with caregivers of patients with stroke that caregivers experienced anxiety at various levels [14, 16, 37, 38]. It was found in this study that anxiety symptoms significantly decreased after the education given to the caregivers of patients with stroke. In many educational studies carried out abroad with

caregivers of patients with stroke, a decrease has been seen in the anxiety symptoms of caregivers after education [15, 20]. It was also found in a meta-analysis where caregivers of patients with stroke were examined that educational and supportive programs improved the mental health conditions of caregivers [24]. Educational studies made with caregivers of patients with stroke are of limited number in our country. It was found in a randomized controlled study in Turkey that after the education provided to the caregivers of patients with stroke, no difference was found between the intervention and control groups in terms of mean trait anxiety scores of caregivers at the time of admission into the hospital and the mean state anxiety scores of caregivers did not change over time either between the intervention and control groups or within the groups themselves at admission into the hospital and at Month 3 and Month 6 after leaving the hospital [31]. Nurses should observe the caregiver's communication with the patient and their knowledge, attitudes and behaviors with respect to the disease and care giving and should help the caregivers develop positive attitudes by focusing on their abilities [29]. The caregivers of patients with a chronic disease in particular become obliged to assume the care of their patients after the patient is discharged. This situation hinders the responsibility of the caregiver in their activities and can result in depression [39]. Many studies made with caregivers have reported that caregivers have depression at various levels [15, 18, 36-38, 40-42]. It was found in this study that depression symptoms significantly decreased after the education given to the caregivers of patients with stroke. A decrease has been seen in the depression levels of caregivers after education also in many educational studies carried out with patients with stroke and their caregivers [19, 20]. It was found in an educational study made with caregivers of patients with stroke in our country that the mean depression score did not change significantly between the experimental and control groups at the time of admission into the hospital and at Month 3 and Month 6 after leaving the hospital nor within the experimental and control groups themselves in time [31]. Nurses should observe the caregiver's communication with the patient and their knowledge, attitudes and behaviors with respect to the disease and care giving and should help the caregivers develop positive attitudes by focusing on their abilities [29].

The caregivers of patients with a chronic disease in particular become obliged to assume the care of their patients after the patient is discharged. This situation hinders the responsibility of the caregiver in their activities and can result in depression [39]. Many studies made with caregivers have reported that caregivers have depression at various levels [15, 18, 36-38, 40-42]. It was found in this study that depression symptoms significantly decreased after the education given to the caregivers of patients with stroke. A decrease has been seen in the depression levels of caregivers after education also in many educational studies carried out with patients with stroke and their caregivers [19,20]. It was found in an educational study made with caregivers of patients with stroke in our country that the mean depression score did not change significantly between the experimental and control groups at the time of admission into the hospital and at Month 3 and Month 6 after leaving the hospital nor within the experimental and control groups themselves in time [31].

It was found that there was no significant difference in the dependency levels of the patients with stroke in the experimental and control groups with respect to their mean BI scores at the time of admission into the hospital, but after the education, the physical independence levels of the patients in the experimental and control

groups significantly increased in their activities of daily living as per the statistical analysis performed. The total score ranges between 0 and 100 in BI, "0" showing complete dependence and "100" complete independence [43]. The threshold score was determined to be 60 in studies using BI and scores above 60 indicate being able to function independently [44, 45]. It was also seen in this study that the mean BI score became 60.81 ± 13.85 after the education given to the caregivers of the patients in the experimental group. In an educational study made by Aktaş (2010) with patients with stroke and their caregivers, it was found that there was no significant difference between the experimental and control groups in terms of their mean BI scores, but the physical independence levels of both the experimental group and the control group increased significantly within themselves in time with respect to their activities of daily living [31].

Conclusion

The study revealed that a decrease was seen in the anxiety and depression levels of caregivers after the education. We think that this study will be useful in showing that education provided to the caregivers of patients with stroke bedded in the clinic will not only enable patients to have a more comfortable life in the following periods but also will relieve the difficulties and handicaps of caregivers in giving care to these patients. Therefore, we can recommend that nurses participate in educations on the care of patients with stroke, provide education to caregivers and arrange workshops to increase their awareness on this issue.

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