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Research Article

Effects of a Supportive Training on Caregiving Burden of Stroke Patients' Caregivers after Discharge from an Intensive Care Unit (ICU)

Mahla Dahmardeh[1], Hanie Dahmardeh[1*], Narjes Khatoon Sadeghi[2], Alireza Ansari Moghaddam[3]

[1]*Department of Medical-Surgical Nursing, Faculty of Nursing, Zahedan University of Medical Sciences, Zahedan, Iran.*

[2]*Department of Nursing, Zahedan University of Medical Sciences, Zahedan, Iran.*

[3]*Health Promotion Research Center, Zahedan University of Medical Sciences, Zahedan, Iran.*

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ABSTRACT

Background: The caregivers of stroke patients experience a sense of confusion and stress after the patients are discharged from the hospital. Such that after a while, they experience a sense of inability to provide care and an increased caregiving burden. Therefore, this research aims to study the effects of a supportive training program on the caregiving burden of stroke patients' caregivers after discharge from the Intensive Care Unit (ICU).
Methods: In this randomized clinical trial, the study population consisted of 60 caregivers of stroke patients. The sampling method was purposive based on the inclusion criteria. The intervention was performed in 6 supportive training program sessions. Data were collected using demographic questionnaires and the Novak and Guest Caregiver Burden Inventory. Data were analyzed using the paired t-test, independent t-test, and ANCOVA.
Results: There was no significant difference in the caregiving burden before the intervention between the two groups (intervention: 81.13 ± 13.99, control: 70.66 ± 14.61, P value= 0.030). After the post-test, the caregiving burden reduced significantly in the intervention group compared to before the intervention (56.46 ± 10.52) and compared with the control group (72.33 ± 15.86, (P value< 0.001).
Conclusion: According to the findings, the caregiving burden of stroke patients' caregivers can be alleviated through the intervention of supportive training, which is an effective and cost-effective method. As nurses play a key role in training and supporting these patients as primary caregivers, they should take this program seriously.

Introduction

Stroke is a type of sudden neurological disorder. In this condition, the blood supply to the affected area is disrupted, preventing it from functioning properly [1]. Generally, this disorder can be caused by the blockade or the rupture of a brain blood vessel (ischemic stroke) or the termination of blood supply following the rupture of a blood vessel in the brain (hemorrhagic stroke) [1].

This disorder is the most common cerebrovascular condition and the third leading cause of mortality worldwide, after cardiovascular diseases and cancer. The annual risk of stroke fluctuates between 2.7 to 4.7 cases per 1000 people. In the United States, 500,000 people

The authors declare no conflicts of interest.
*Corresponding author.
E-mail address: haniedahmardeh@gmail.com

experience a first stroke annually, with 100,000 experiencing recurrent strokes, and approximately 160,000 lives lost annually due to stroke [2]. Its incidence in Western countries ranges between 100 to 300 per 100,000 of the population annually [3]. In Iran, it is stated at 283 per 100,000 of the population [2]. As, every 40s, someone experiences a stroke, and every 5.3min, one person dies from a stroke [4].

Annually, more than 400,000 patients are discharged from the hospital after experiencing acute strokes, often accompanied by different levels of physical disabilities and impairments resulting from this disorder [5]. They require continuous care at home for at least 6 months following discharge. These patients are disabled in performing daily activities and implementing their care plans due to the progression of the disease and its resulting complications [6]. As unofficial or home caregivers are considered the main pillar of the long-term care system, the responsibility of caring for these patients at home will fall on the patient's family [7].

Home caregivers offer free care for people with any form of disabilities in their homes and with no formal training [7]. Hence, caring for a stroke patient, similar to caring for other chronic disabling conditions, creates significant stress and strain for both the caregiver and the patient's family [8]. Due to the increased physical disabilitiesand cognitive impairment caused by stroke, it need for physical assistance and intervention to assist in daily activities of patients escalates, thus amplifying the caregiving burden on them [9]. This can lead to various consequences such as inadequate patient care, patient abandonment, family isolation, and disruptions in family relationships for caregivers [8,10].

Therefore, attention to the need for care and support from the family members, especially family caregivers, is of particular importance, and training is one of the most effective methods to support families and reduce their caregiving demands [11]. Many nurses are often involved in developing such training programs, serving not only as educators but also as leaders. An essential nursing care approach involves the implementation of nurse-led training-supportive interventions, which extend from the hospital to the home setting. Through this approach, nurses can identify and address health issues that arise post-hospital discharge [12]. In training-supportive interventions, a set of systematic interventions is structured based on train, support, and cognitive-behavioral therapeutic approaches, emphasizing the needs of the patient and family. These interventions focus on increasing the knowledge of the patient and family about the disease, their adaptation to it, and the utilization of communication, coping, and problem-solving skills [13].

Ultimately, it should be stated that given the unique role of nurses in interacting with patients and their family members, attention to the problems of caregivers alongside patients with stroke and the preparation of training-supportive programs to reduce the caregiving burden of caregivers in nursing planning seem necessary and essential [14]. At present, there is no codified and mandatory guideline in the direction of supportive care for patients and their families in Iran [11]. This study aims to assess the effect of a training-supportive program on the burden of care for the caregivers of stroke patients who were discharged from ICUs in Zahedan.

Methods

The present study is a clinical trial. All Zahedan stroke patients during 2023-2024 Bani Ardalan et al. (2022) [8] were enrolled in this clinical trial. Sample size was calculated by the formula of comparing means according to $\alpha = 0.05$, $\beta = 0.02$, and the results of a former study. The difference in the changes created in the two groups is 10, and the standard deviation is 12. The needed sample size was obtained to be 23 patients in each group. Considering the number of probable dropouts and to have a good number of patients for statistical analysis, 30 patients in each group, a total of 60 patients, were included in the study.

The research locale included the patients' home or any other place where there was access to the patients' caregivers after the discharge of the patient from the ICU. The inclusion criteria for patients included: confirmation of stroke diagnosis by the treating physician, the level of consciousness GCS ≥ 11 at the time of discharge from ICU, the need for care after discharge, the inability to self-care (for the activities of daily living including bathing, feeding, moving), and age ≥ 20 years. Exclusion criteria included: the death of the patients, re-hospitalization for any reason during the study.

Inclusion criteria for caregivers included: willingness to be included in the study, lack of prior experience of working in a care team, age between 20 and 70 years, lack of defects in speech, hearing, and eyes and the ability to read and write, having the ability to care for a patient, having direct responsibility for caring at least 8 hours a day, having a familial relationship (e.g., spouse, child, sibling) with the patient, and and providing care without receiving compensation. Exclusion criteria: ' inability to communicate with the patient, unwillingness to cooperate with this approach, loss of contact for two continuous weeks during the first month of the intervention, and use of the nursing service offices or home nursing.

The data collection tools in this research include a demographic and disease information form Novak and Guest Caregiver Burden Inventory, and a patient problem needs assessment. These forms were completed by the patients' caregivers during in-person meetings before and three months after the intervention.

Caregiver Burden Questionnaire: This questionnaire has 24 items in five sub-dimensions: time-dependent burden, developmental burden, physical burden, social burden, and emotional burden. It is measured using a 5-point Likert scale from "completely incorrect" to "completely correct," ranging from 24 to 120. Scores from 24 to 39 indicate a mild burden, from 40 to 71 indicate a moderate burden, and from 72 to 120 indicate a severe burden.

Patient Problem Needs Assessment Form: Designed by the researcher to evaluate patient problems, this form consists of a list of common patient problems such as bathing, hygiene, dressing, physical activities, diet and medication, weight and blood pressure control, drain care, constipation, urinary and fecal incontinence, memory loss, muscle weakness, adaptation problems, anxiety, stress, and blank spaces to write other problems. Caregivers indicated their patient's issues using a list and a blank paper for additional problems. Apart from the general training given to all intervention group members, specific problem-focused and comprehensive training was provided.

For sampling, the records of patients who had been hospitalized with a stroke in the past six months at medical centers affiliated with Zahedan University of Medical Sciences (Khatam, Ali Ibn Abi Talib, and Bu Ali Hospitals) were reviewed. Caregivers meeting the inclusion criteria were contacted, and after explaining the study objectives and methods, those willing to participate were scheduled for face-to-face meetings at the patient's home, doctor's office, or rehabilitation centers to complete the questionnaires. The sampling method applied in this study was a combination of convenient and judgmental sampling.

In the intervention group, caregivers were first given the needs assessment, demographic information, disease information, and caregiver burden questionnaires to complete. Then, the designed training program was taught to the caregivers. The training was one-on-one and face-to-face with each caregiver. The format included initial instruction, practical exercises with the caregiver, independent practice by the caregiver, and confirmation of learning by the researcher before moving to the next topic. The training program was conducted in six sessions at a location chosen by the caregiver (Table 1).

Table 1- Educational content program

Session	**The purpose of the meeting**	**Program content provided**
First session	Introduction to the patients' caregivers, presentation of the purpose of the research, explanation of the disease	After introducing himself, the researcher explained the purpose of the intervention and the importance of their cooperation to the caregivers, and they were also given explanations about the disease, signs and symptoms of the disease, etiology, types of treatment, and the importance of caring for patients.
Second session	How to care for the patient by the caregiver at home	To the caregiver, training on home care of the patient including: how to perform and control specific activities such as transferring the patient, providing personal care for the patient (bathing, taking care of hygiene, dressing, physical activities, diet and medication, weight and blood pressure control, taking care of the drain, etc.) and organizing physiotherapy sessions and monitoring the condition, conditions and symptoms of the patient before and after the physiotherapy sessions. Also, the problems and experiences of caregivers while caring for patients at home were investigated and discussed, and practical solutions were expressed.
Third session	Providing methods of adapting to problems for caregivers	The importance of the caring role of caregivers and their adaptation to this role were stated and the problems of adaptation created for caregivers were discussed
Fourth Session	Providing problem-oriented coping skills to caregivers	Issues related to problem-oriented coping skills to establish proper communication, identifying communication barriers were discussed and communication skills were taught.
Fifth meeting	Providing methods to control mental symptoms such as anger control for caregivers	The warning signs of anger, situation of creation and aggravation, how to control anger and anger were discussed and then how to control anger and deep breathing exercises were implemented in the form of role play and practical training.
The sixth session	Conclusion and summary	Reviewing and summarizing the taught materials and solving caregivers' problems

Three months after completing the training, the questionnaires were again given to the caregivers to complete. In the control group, the questionnaires were initially given to the caregivers, but no additional training was provided beyond the routine hospital instructions. Three months later, the caregivers in the control group were given the questionnaires again to complete. Throughout the study, the researcher continuously followed up with the patients, who addressed any questions and concerns raised by the caregivers. At the end of the study, training materials were provided to the control group to adhere to ethical principles.

The collected data was entered into SPSS software version 26. Initially, the normality of the data was assessed using the Shapiro-Wilk test. Given the normal distribution of the data, independent and paired t-tests were used to compare means between the two groups. Additionally, the Chi-square test and independent t-test were used to analyze the patients' demographic data.

Results

The average age in the intervention group was 22.12 ± 0.85 years, and in the control group was 21.89 ± 0.87 years. According to the findings, there was no statistically significant difference in the variables of age, education level, and marital status between the intervention and control groups before the intervention (P value>0.05) (Tables 2,3).

The independent t-test showed no significant difference in caregivers' average total caregiving burden score before the training intervention between the control and intervention groups. However, two months after the training intervention, there was a significant difference in the average caregiving burden score between the control and intervention groups (P value=0.001). The paired t-test showed a significant increase in the average total caregiving burden score three months after the completion of the training intervention in the intervention group (P value=0.001). In the control group, no significant difference was observed in the mean total caregiving burden score three months after the completion of the training intervention (Table 4).

Table 2- Individual characteristics of participating patients

Variable	Group	Intervention Number (percentage)	Control Number (percentage)	P value×
Gender	Men	15(50/0)	11(36/7)	0/435
	Female	15(50/0)	19(63/3)	
Marital status	Single	3(10/0)	6(20/0)	0/31
	Married	19(63/3)	17(56/7)	
	Divorced	0(0/0)	1(3/3)	
	the widow	8(26/7)	6(20/0)	
Underlying disease	Diabet	5(16/7)	5(16/7)	0/870
	HTN	8(26/7)	7(23/3)	
	HTN & Diabet	10(33/3)	12(40/0)	
	Other	1(3/3)	0(0/0)	
	absence of disease	6(20/0)	6(20/0)	
stroke time	6 months - 1 year	18(60/0)	9(30/0)	0/002
	1-3 years	8(26/7)	10(33/3)	
	3-5 years	1(3/3)	11(36/7)	
	5-7 years	3(10/0)	0(0/0)	
	7-9 years	0(0/0)	0(0/0)	
	More than 9 years	0(0/0)	0(0/0)	

×Chi-square test

The significance level is P value <0.05

Table 3- Personal characteristics of participating caregivers

Variable	Group	Intervention Number (percentage)	Control Number (percentage)	P value×
Gender	Men	6(20/0)	21(72/4)	0/676
	Female	24(80/0)	8(27/6)	
Marital status	Single	5(16/7)	3(10/0)	0/31
	Married	25(83/3)	26(86/7)	
	Divorced	0(0/0)	1(3/3)	
	the widow	0(0/0)	0(0/0)	
Education	Illiterate	1(3/3)	1(3/3)	0/418
	Primary	1(3/3)	4(13/3)	
	High school	5(16/7)	0(0/0)	
	Diploma	13(43/3)	15(50/0)	
	Bachelor's degree	9(30/0)	10(33/3)	
	Master's degree	1(3/3)	0(0/0)	
	Phd	0(0/0)	0(0/0)	

Caregiver dependency	Parents	1(3/3)	1(3/3)	0/002
	Child	20(66/7)	15(51/7)	
	Brother and sister	2(6/7)	2(3/5)	
	Partner	7(23/3)	12(41/4)	

×Chi-square test

The significance level is P value <0.05

Table 4- Comparison of the average score of the total care burden before and after the intervention in the participants of the two groups

Variable	Group	Before intervention Mean ± standard deviation	After intervention Mean ± standard deviation	P value$^{\times}$
burden of care	intervention	99/13 ± 13/81	52/10 ± 46/56	001/0=P
	Control	61/14 ± 66/70	86/15 ± 33/72	0/354=P
	P$^{\times\times}$	0/030=P	001/0	

× Paired t test

×× independent t-test

Discussion

This study intended to find out the effectiveness of a training-supportive program on caregiving burden of stroke patients' caregivers three months after ICU discharge. Based on the findings, this study indicated that the implemented program of training- supportive within the interventional group resulted in a significant reduction in the burden of caregiving at the end of three months. Indeed, the difference between the control and interventional group was significant with regard to the burden. Accordingly, the training-supportive program implemented can be effectively used in reducing the burden of caregiving of stroke patients' caregivers after ICU discharge.

The current research showed a significant decrease in the caregiver's burden score at three months after a training-supportive intervention program by the intervention group. Based on the results, a significant reduction was observed in the caregiver burden scores three months after the completion of the educational-support intervention in the intervention group. These findings are accordance with the results of the study by Poursheban et al. [15], which investigated the effect of the follow-up care model on caregiver burden in family caregivers of stroke patients. In the study, despite using thefollow-up care and similar techniques include direct and telephone training for the caregiver, all required trainings for the care of stroke patients reduce the caregiver burden effectively. Therefore, the findings are accordance with this study.

This was also in line with the findings of Bani Ardalan et al. [8] in their study, which showed that a training program and follow-up telephone support significantly reduced the care burden of elderly patients with stroke. This finding also are accordance with the results of Heidari et al. [16] in their research on the effect of self-management care on the burden of family caregivers of patients with stroke in an intervention designed using the five A's model. Another researcher, Hall et al. [17], also designed a program for evidence-based intervention that will help in reducing the stroke burden on the caregivers, who are the backbone of the patients. These studies had the intention of applying different training programs and their impact on the caregiver's burden, which brought out the perspective that the patients with stroke who remain disabled after the strike require continuous care and management. These patients become a liability for the family, since managing the patients with stroke causes a lot of stress [18]. When the family members take the role of caregivers, they are forced to balance their living with the new style. Caring for this category of patients is so demanding and exerts a lot of pressure and effort on the caregiver, as the condition is both chronic and persistent in nature [19]. Therefore, the training-supportive approach can be put to maximum use in order to reduce the burden regarding caregiving for the caregivers of these patients [15].

In a study by Faravi et al. [20], designing and providing a training program for family caregivers, follow-up training for care of stroke patients was stated as cutting down overcare burden for family caregivers. In this aspect, the training-supportive program in our research was also effective about reducing the burden of caregivers of stroke patients, which is accordance with the results of this research.

Conclusion

This study was conducted in Zahedan. However, in Zahedan, more cultural factors push a person to have strong family bonds and, therefore, feel it is his duty to care for family members, especially parents, during illness. For this, it suggested the formation of a wide research base in communities and cultures in order to explore the difficulties of applying training-supportive programs and to use them as a model of total care at home in the period following discharge.

Ethical considerations

This study was approved by the ethics committee at Zahedan University of Medical Sciences (IR.ZAUMS.REC.1402.293) And IRCT code: IRCT: IRCT20231120060120N1, Autonomy, independence, confidentiality and privacy of the participants were considered. Participants were informed about the study. The written and oral informed consent was obtained in order to take notes or record their audio. The participants were free to exit the study whenever.

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