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The effect of educational intervention on the quality of life of family caregivers of hemodialysis patients: A randomized controlled trial

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Abstract:

BACKGROUND: Family caregivers of hemodialysis patients experience various physical, psychological, social, economic, and spiritual problems that reduce their quality of life. The present study aimed to determine the effect of a family-centered education program on the quality of life of family caregivers of patients undergoing hemodialysis.

MATERIALS AND METHODS: This was a randomized controlled trial that was performed on 70 caregivers of patients undergoing hemodialysis in the medical centers of Hazrate Ali Asghar and Hazrate Zahraye Marzieh in Isfahan. Caregivers were randomly divided into experimental and control groups, and the experimental group received an eight-session family-centered education program. Data were collected using the Quality of Life Scale (QOLS)-short form immediately after and 1 month after the intervention. Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) software version 18 and analysis of variance and covariance.

RESULTS: The results showed that both experimental and control groups were homogeneous in terms of demographic information and there was no significant difference between them in this regard. Analysis of data on quality of life and its four domains showed that the mean scores of quality of life ($P = 0.089$) and its four domains including physical health ($P = 0.367$), mental health ($P = 0.429$), community relations ($P = 0.132$), and environmental health ($P = 0.232$) increased significantly immediately after and 1 month after the intervention ($P < 0.001$ in all cases).

CONCLUSION: Educational programs can improve the quality of life of family caregivers of hemodialysis patients. Therefore, it is recommended that programs be developed and evaluated in various studies in the future.

Keywords:

Caregivers, education, quality of life, renal dialysis

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Introduction

Chronic diseases are one of the general crises in the health field that reduce the quality of life (QOL) of patients on the one hand and increase the mortality rate on the other hand.^[1] Chronic kidney disease (CKD) is one of the chronic diseases that cause many problems not only for patients and their families, but also for the health system and even the economic system.^[2] The global

prevalence of CKD disease is about 10% and affects about 500 million people.^[3] CKD is also highly prevalent in Iran; there are about 39,000 CKD patients in this country^[4] and approximately 1400 new patients are added to this figure annually.^[5]

Kidney transplantation and hemodialysis are among the treatments used for patients who have reached the end stages of the disease. However, the shortage of kidneys for transplantation has led to dialysis

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being used as an alternative treatment for these patients.^[6] Accordingly, hemodialysis is the most common treatment for CKD in many countries, including the USA and Iran.^[7] CKD and hemodialysis reduce the living standards, increase physical and psychological problems, limit recreational, social, and occupational activities for patients, and require family care and support.^[8] This also affects the QOL of the families of these patients.^[9] Because of the nature of this disease and the long treatment duration, families are required to devote a lot of time and energy to care for these patients at home. Also, families and family caregivers undergo further burden of care due to a lack of support from the health system.^[10-13]

Previous relevant studies also show that family caregivers play an important role in caring for patients undergoing hemodialysis, which reduces their QOL^[11,14] because caring for disabled patients creates many physical and mental problems for the caregiver and even disrupts family relationships. The study of Farzi *et al.*^[15] also showed that family caregivers who experienced more caring burden had a low QOL. The study of Farzi *et al.*^[15] is a descriptive-analytical study and differs in terms of the method from the present study, which is a clinical trial study that evaluates the effectiveness of the training program. Consequently, family caregivers also sometimes lose control of their lives.^[16] Therefore, the health-care personnel need to be aware of the role of families in the care of CKD patients and the importance of this role, and while communicating with them, provide the necessary support for them when needed.^[17] In the meantime, considering their frequent contacts with patients and their companions, nurses play an important role in interacting with family members and can increase the knowledge and skills of caregivers by teaching the necessary skills to care for patients and support family caregivers, and thus improve the quality of care at home.^[18-20]

Therefore, educating caregivers and family members of hemodialysis patients has a great effect on increasing the quality of patient care at home.^[5,21] Education can increase awareness and change the attitude of families toward the nature of the problem and increase their communication and problem-solving skills.^[18,22] On the other hand, education increases the knowledge and skills of patients and their families and helps them better understand the disease, control the disease-related anger and stress and patient care, and ultimately improve their QOL.^[23-25] Various studies have shown the effectiveness of family-centered education programs in improving the QOL of caregivers of chronic cancer patients and patients with mood and mental disorders and cardiovascular disease.^[12,26-28] However, the majority of studies have focused solely on the patient, while the patient-family

interaction has been neglected.^[7,29] Therefore, the present study aims to implement a family-centered education program to improve the QOL of family caregivers of hemodialysis patients and to evaluate its effectiveness.

Materials and Methods

Study design and setting

This was a randomized controlled clinical trial approved by the ethics committee of Isfahan University of Medical Sciences (IR.MUI.REC.1395.3.950) and was registered in the Iranian Clinical Trial Registration Center (IRCT20170812035635 N2).

Study participants and sampling

The study population included the main family caregivers of patients receiving hemodialysis in two medical centers affiliated with Isfahan University of Medical Sciences. After conducting convenient sampling, 70 caregivers of hemodialysis patients were randomly allocated to the experimental and control groups based on a random numbers table. The inclusion criteria included caregivers aged 18 and over who were assuming all the responsibilities of the patient, being interested in participating in the study, being able to communicate and read and write in Persian, absence of psychosis symptoms as well as other mental and physical disorders in them, and being not a medical staff. The exclusion criteria included noncooperation of caregivers until the end of the intervention, the existence of any physical or mental problem so that the caregiver is not able to continue to participate in the study, death of the patient under care during the research, severe stressful events during the intervention, unwillingness of caregivers to continue participating in the research project, and being absent in two training sessions.

Data collection tool and technique

Data were collected using the World Health Organization QOL (WHOQOL)-BREF along with a demographic information questionnaire. Demographic information included age, sex, marital status, education level, employment status, patient relationship, length of care, income status, place of residence, housing status, and living with the patient for caregivers and information such as age, sex, marriage, level of education, employment status, patient care needs, patient's physical ability to perform tasks, hemodialysis period, patient dependence on the caregiver, insurance coverage, and membership in support organizations for patients. The WHOQOL-BREF is a 26-item instrument consisting of four domains: physical health, psychological health, social relationships, and environmental health, as well as the QOL and general health items. Each question is assigned a score from 1 to 5, and questions 4, 3, and 26 are scored reversely. The possible score range in each

domain is 0–100, which indicates the worst and best conditions, respectively. The validity of the educational booklet and demographic information was confirmed by the opinions of 10 professors of Isfahan School of Nursing and Midwifery.

Ethical consideration

To carry out the present research, the researcher obtained a letter of ethics from the ethics committee of Isfahan University of Medical Sciences and referred to Hazrate Ali Asghar and Hazrate Zahraye Marzieh's educational and medical centers. The researcher first obtained study permission from the director of the center and the head of the hemodialysis department. The researcher then introduced himself to the eligible participants and explained the study objectives, and invited them to cooperate after obtaining their written consent. The family-centered education program included eight 90-min sessions that were performed twice a week in two shifts (morning and afternoon) in both medical centers through lectures, group discussions, practical exercises, and questions and answers using slides and educational booklets. The aim of each training session is shown in Table 1.

The control group received no intervention, and the subjects of this group only talked to each other about their problems, feelings, and experiences in two sessions under the supervision of the researcher, but at a time other than the time when the intervention was held for the experimental group. At the end of the intervention, to observe ethical considerations, the educational booklet was given to the control group. Data were collected and analyzed using Statistical Package for the Social Sciences (SPSS) ver. 18, and P value < 0.05 was considered as the significance level. The assumptions of the repeated measures analysis of variance (ANOVA)

model, such as the normality of the dependent variables, were investigated using the Kolmogorov–Smirnov test, homogeneity of variances by Levene's test, and homogeneity of covariances by Box's test.

Results

The present study was carried out on 90 caregivers of hemodialysis patients. After screening, 15 people were excluded from the study as they did not meet the inclusion criteria and five people were excluded as they did not give consent to participate in the study. Finally, 70 eligible individuals were randomly assigned to one of the two research groups. All participants remained in the study until its completion. Chart 1 shows the selection process of study participants.

The results showed that both experimental and control groups were homogeneous in terms of demographic information and there was no significant difference between them in this regard [Table 2].

Results of repeated measures analysis of covariance (ANCOVA) showed a significant increase in the mean score of QOL and its four domains in the experimental group before, immediately after, and 1 month after the intervention ($P < 0.05$) [Table 3].

Discussion

The present study aimed to determine the effect of a family-centered education program on the QOL of hemodialysis patients. The results showed a significant increase in the QOL score and its four domains of the experimental group immediately after and 1 month after the intervention ($P < 0.05$). In this regard, the results of the present study are in line with the results of Qhane^[21] and Sotoudeh's^[22] study. The results of the

Table 1: Objectives and summary of the content of family-based education sessions

Session	Objectives and content summary
Session 1	Familiarization of caregivers with the researcher, goals, and content of sessions, completion of the care burden scale, and personal social characteristics by caregivers
Session 2	Promoting knowledge and awareness about the end-stage renal disease (definition, ethology, symptoms, complications, hemodialysis treatment and complications of this treatment, etc.)
Session 3	Maintaining and promoting physical health and the importance of self-care (adequate rest and sleep, exercise, nutrition, 6-month and 12-month doctor visits)
Session 4	Improving communication skills with the patient and improving family relationships such as how to communicate with the patient and effective ways of communication and improving this process in the family and effective ways of expressing emotions
Session 5	Improving adaptation skills through familiarity with stress coping strategies such as muscle relaxation and deep breathing and problem solving
Session 6	Promoting social family relationships and strengthening the social dimension through interaction with support groups and organizations, how to fill in spare time and have healthy recreation, introducing family support resources, and how to access support services such as the hemodialysis patients' association
Session 7	Strengthening the spiritual dimension and familiarity with ways to increase life expectancy (prayer therapy)
Session 8	Overview of the issues raised, receiving member feedback on topics, questions and answers and group discussion, and completing the care burden scale

Table 2: Comparison of demographic characteristics of caregivers in experimental and control groups

Variables	Experimental	Control	P
Age (years)			
Mean (SD)	45.8±13.9	45.5±13.3	0.196
Medium (minimum-maximum)	45 (20-70)	48 (25-70)	
Duration of care (months)			
Mean (SD)	79.9±68.4	65.4±60.3	0.323
Medium (minimum-maximum)	60 (4-288)	48 (4-240)	
Sex Number (percentage)			
Male	29 (82.9)	26 (74.3)	0.382
Female	6 (17.1)	9 (25.7)	
Marital status Number (percentage)			
Single	5 (14.3)	7 (20)	0.526
Married	30 (85.7)	28 (80)	
Education Number (percentage)			
<Diploma	18 (51.5)	15 (42.9)	0.473
>Diploma	17 (48.5)	20 (57.1)	
Relationship with the patient Number (percentage)			
Spouse	17 (48.6)	18 (51.4)	0.694
Child	14 (40)	15 (42.9)	
Other	4 (11.5)	2 (5.8)	
Living with a patient Number (percentage)			
Yes	27 (77.1)	30 (85.7)	0.356
No	8 (22.9)	5 (14.3)	
Habitat Number (percentage)			
City	34 (97.1)	35 (100)	1
Village	1 (2.9)	0	
Housing situation Number (percentage)			
Private	25 (71.4)	26 (74.3)	0.788
Rental	10 (28.6)	9 (25.8)	

SD=Standard deviation

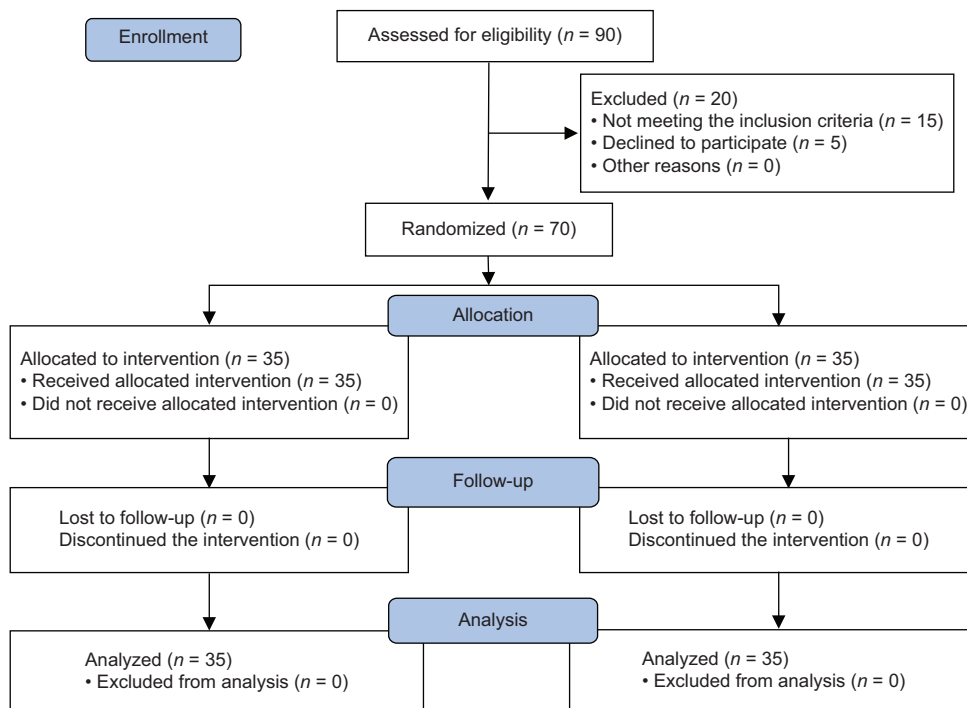


Chart 1: Consolidated Standards of Reporting Trials 2010 flow diagram

Table 3: Estimating the effect of caregivers' intervention and its follow-up immediately after and 1 month after the intervention on quality of life and its domains on caregivers (The Independent Samples t Test for the between group comparisons in three times and Repeated Measures ANCOVA Test to examine main effects controlling for the pretest scores)

Variables	Mean (SD)		P Main between group effects
	Experimental	Control	
Quality of life			
Pre-test	40.6 (11.5)	37.2 (6.2)	<0.001
P		0.134	
After the intervention	79.1 (5.5)	35.8 (5.2)	
P		<0.001	
One month after the intervention	76.6 (6.1)	33.8 (5.3)	<0.001
P		<0.001	
Physical health			<0.001
Pre-test	39.4 (15.3)	40.1 (10.4)	<0.001
P		0.820	
After the intervention	80.2 (7.9)	38.3 (9.8)	
P		<0.001	
One month after the intervention	76.9 (9.3)	34.7 (10.1)	<0.001
P		<0.001	
Mental health			
Pre-test	40.8 (11.6)	36.7 (7.1)	<0.001
P		0.075	
After the intervention	79.8 (7.1)	35.4 (5.5)	
P		<0.001	
One month after the intervention	76.2 (7.5)	32.6 (5.6)	<0.001
P		<0.001	
Community relations			
Pre-test	34.5 (13.7)	30.7 (6.9)	<0.001
P		0.147	
After the intervention	77.4 (7.7)	27.9 (4.1)	
P		<0.001	
One month after the intervention	75.2 (7.4)	28.1 (4.6)	<0.001
P		<0.001	
Environmental health			
Pre-test	43.7 (9.6)	37.5 (4.5)	<0.001
P		0.001	
After the intervention	78.3 (5.2)	36.9 (4.7)	
P		<0.001	
One month after the intervention	77.1 (6.8)	36.2 (3.9)	<0.001
P		<0.001	

ANCOVA=analysis of covariance

present study also showed that most caregivers are married and middle-aged women. Studies conducted in other countries also showed that women are the main caregivers of their patients at home in most cases, and these caregivers are usually middle-aged and married.^[18] Considering the structure of families in Asian countries, women mostly play a key role in caring for patients undergoing hemodialysis.^[30] In this regard, Mollagheloo *et al.* stated that although women are sensitive and emotional, they are more capable than men to manage problems and establish intimate and close relationships with family members.^[31] Studies have shown that family caregivers play a unique role in caring for hemodialysis patients and their QOL is negatively

affected.^[14,30] The findings of the present study also showed that caregivers in both experimental and control groups had low QOL before the intervention, and the family education program led to a significant increase in QOL score and its domains of the experimental group immediately after and 1 month after the intervention. The results of a study on caregivers of women with breast cancer also showed that the QOL of caregivers increased significantly in physical, emotional, and environmental dimensions after the implementation of the supportive training program, but there was no change in the social dimension. The researcher believes that such a finding may be due to the type of education that has been used in this study to strengthen the social dimension. The

caregivers who participated in the present study were provided with methods of strengthening the social dimension through interaction with support groups and organizations, introducing support resources and ways to access support services such as the hemodialysis patients' association.

The results of this study shed more insight on the importance of provision of continuing education for caregivers to make the effects last longer. Farzi *et al.*^[15] also recommended the design and implementation of training programs for caregivers of hemodialysis patients. Continuing education was provided to caregivers using an educational booklet containing the content of the educational program sessions. Moreover, it is recommended that such a program be implemented collaboratively with other health professionals as a team for the family caregivers of patients.^[17] Future studies are recommended to evaluate the feasibility and effectiveness of team interventions in improving the QOL of family caregivers of hemodialysis patients. Also, the results of the present study indicated the need to encourage nurses to develop educational programs such as family-centered education programs to maintain and improve the mental health of caregivers. Future studies need to be conducted to examine the effectiveness of similar interventions in different settings.

Limitation and recommendation

The limitation of the present study was different places of data collection. This may limit the generalizability of findings. On the other hand, due to lack of facilities and limited time, it was not possible to implement a family education program in this study as a team with the presence of a specialist physician, psychologist, and nurse. Therefore, it is recommended that such an educational intervention be implemented as a team in future studies.

Conclusion

The amount of care burden is high in the caregivers of patients undergoing hemodialysis. This pressure might reduce the quality of care given to the patients and endanger the caregivers' physical and mental health. The families of these patients are the vulnerable caregivers who need long-term interventions and counseling. The role of family members should, therefore, be considered in health-care planning for this group of patients, and interventions such as patient and caregiver training, counseling, family therapy, support groups, and referral services should be provided to decrease the care burden. These measures also help improve the quality of patient care and ensure the physical and mental health of the caregivers as the hidden patients.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient (s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published, and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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