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The Effect of Education Based on the Family-Centered Empowerment Model on Perceived Social Support in Women with Endometriosis: A Randomized Clinical Trial

Maryam Armaghan (MSc)[1], Hamidreza Zendehtalab (PhD)[2], Vahid Qavami (PhD)[3], Seyedah Azam Pourhosseini (PhD)[4], Nahid Jahani Shoorab (PhD)[5,6], Kobra Mirzakhani (PhD) [6,7]*

[1] MSc in Midwifery, Student Research Committee, Mashhad University of Medical Sciences, Mashhad, Iran
[2] Assistant Professor, Department of Community Health of Nursing, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran
[3] Associate Professor, Department of Biostatistics and Epidemiology, School of Health, Mashhad University of Medical Sciences, Mashhad, Iran
[4] Assistant Professor, Department of Obstetrics and Gynecology, School of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran
[5] Associate Professor, Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran
[6] Department of Midwifery, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran
[7] Assistant Professor, Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran

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ABSTRACT

Background & aim: Endometriosis affects different aspects of women's life. Many women with endometriosis do not have social support. Family-centered empowerment model is one of the care models which its effect on perceived social support among women suffering from chronic diseases have been investigated less. Therefore, this study aimed to determine the effect of education based on family-centered empowerment model on perceived social support in women with endometriosis.

Methods: This is a randomized clinical trial, which was conducted on 64 women with endometriosis reffered to the endometriosis clinic of a training Hospital in Mashhad, Iran between March 2022 and September 2023. Sampling was done using the random allocation block method. The intervention group received five 45–60-minute education sessions based on the family-centered empowerment model and a final assessment session over two weeks. Before, immediately and 6 weeks after the intervention, the Sherbon Stewart Social Support Questionnaire (MOS-SSS) was completed. Data analysis was done using independent t-test, paired t-test, Mann-Whitney and Wilcoxon with SPSS software (version27).

Results: Before the intervention, the mean of the total score of perceived social support in the intervention and control group was not significantly different (P = 0.684). After the intervention, the total perceived social support score was 67.1 ± 11.08 in the intervention and 57.63 ± 16.31 in the control group, which showed a significant difference between the two groups (P = 0.008).

Conclusion: Education based on the family-centered empowerment model could be effective on perceived social support enhancement among women with endometriosis.

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Introduction

Endometriosis is one of the most common inflammatory disorders of women, which is defined as the existence of endometrial tissue outside of the cavity of uterine (1). The overall

* *Corresponding author*: Kobra Mirzakhani, Assistant Professor, Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran Tel: 00989151203606, Email: mirzakhanik@mums.ac.ir

prevalence of endometriosis in the world is between 8-10% of women of reproductive age, and in Iran, the prevalence of endometriosis among infertile women is reported to be about 29% (2). The peak prevalence of this disease is at the age of 25-35, but it has been reported in girls before menarche (3) and 2-5% of women in the post-menopausal period (4). The average time from the first onset of symptoms to diagnosis of this disease is about 5-10 years (5).

Endometriosis pathogenesis is multifactorial. The definite diagnostic method of endometriosis is laparoscopy, and it would have been confirmed through histological and pathological examinations (2, 6). The cause of endometriosis is unknown, but menstrual blood return, cellular metaplasia, or both of them can be the causative factors (7). The endometriosis symptoms include pelvic pain, infertility, menstrual pain, irregular uterine bleeding, and pain during intercourse, and burning in urination (8, 9). Endometriosis pain is related to intraperitoneal bleeding and inflammation caused by inflammatory cytokine activity (10). Nowadays, there is no definitive treatment for endometriosis, and it is mainly Symptomatic and supportive treatment, that by stopping them, the symptoms will return (11).

In a study (2017), it was shown that the symptoms of endometriosis can have a significant relationship with the personal, social, and economic aspects of endometriosis patients, their partners, and families (12). In other words, endometriosis will also affect the social aspect of the person's life. In this regard, a qualitative study was conducted to explain the experiences of 15 endometriosis patients, and the results showed that in addition to the pain, which is often described as intense and excruciating, the patients also complained about the impact of the disease on work, social-family relationships, and sexual life (13). However, a cross-sectional study on 163 women showed that 13% of women with endometriosis were absent from work due to the symptoms of endometriosis, 65% were impaired at work, 64% had decreased efficiency, and 60% experienced activity with anxiety (deficiency in daily activity) (14). As with other chronic diseases, endometriosis has a high economic cost (15). The economic burden of this disease, which is imposed on society annually for health care and infertility treatment, is estimated to be 2801 and 1023 dollars per patient, respectively (16).

Whitney et al. (1995) showed that women with endometriosis are dissatisfied with the lack of social support from family and friends, and they want to be accepted, understood, and supported by them (17). Considering the chronic nature of endometriosis and due to the effectiveness of family support in the control of chronic diseases, adapting to the disease and maintaining the patient's quality of life, social support is necessary for endometriosis patients as well (18).

Social support emphasizes the availability and quality of relationships with people who provide support resources when needed. Friends, acquaintances, and family members provide objective services and information that make a person feel cared for, loved, self-respected, and valuable, and consider themselves a part of the communication network. Studies show that social support has a positive role in treating chronic diseases (19). Also, a study showed that there is a relationship between self-care behaviors and perceived social support (20). Increasing social support is associated with better treatment acceptance in chronic diseases (21). Badrizadeh et al. (2021) in their study investigated the role of social support in the adherence to medical treatment of type 2 diabetic patients. The results showed that social support (dimensions of friends and family) has a positive and significant relationship with adherence to drug treatment. Also, the total dimensions of social support can explain nearly 13% (12.9) of changes in adherence to drug treatment (22).

The family is considered to be the first source of support for the patient. In this way, the family unit needs to be trained and empowered so that it can be ready for its supporting role. Empowerment, either at the individual level or at the level of connection with the disease, leads to personal satisfaction, self-efficacy, positive self-concept, desire to live, improvement of life quality, and growth. Social support and family empowerment in establishing a supportive relationship are influenced by collaborative decision-making, education, and counseling. For this reason, one of the indigenous models based on the culture and structure of Iranian society,

which relies on empowering the family system (patient and family members), is the family-centered empowerment model (23). The family-centered empowerment model is based on the general theory of systems, the theory of human science, the systemic theory of the family, and the theory of power, that people gain the ability to control the situation with self-confidence through systemic interactions between themselves, their family, and the surrounding environment, with a sense of perceived power. The family-centered empowerment model is the result of a qualitative-quantitative study of the context theory, which was conducted by Al-Hani et al. (2003), and its efficiency has been measured during a semi-experimental study (24). Family-oriented care is one of the effective care methods for chronic diseases (25).

The family-centered empowerment model is based on four constructs including perceived threat, self-efficacy, self-esteem, evaluation, which follow the principles of chronic disease care. The perceived threat has a direct relationship with knowledge, awareness, and understanding of the disease's risk factors and includes two concepts: perceived intensity and perceived sensitivity. The ability to solve problems leads to self-efficacy, and it is very important in the treatment of chronic diseases. Educational participation will lead to self-confidence and self-esteem by involving the family. The evaluation shows the level of empowerment in the individual and family. In the philosophy of family-centered care, the family is recognized as the primary focus point in all health care, and because the family is the main unit of society, considering its influences on the members of the family, is very important and effective in the control and treatment of diseases (26-27). Since endometriosis affects all aspects of life, especially social, marital, and sexual aspects of womens life, studies in this field, particularly with focus on family-centered empowerment model, are limited. Therefore, the present study was conducted to investigate the effect of education based on the family-centered empowerment model on perceived social support in women with endometriosis.

Materials and Methods

This study is a randomized clinical trial with a pre-test and post-test desigh which was registered in the Iranian registry of clinical trials with registration number of IRCT20220720055505N1), and was conducted on women with endometriosis reffered to the endometriosis clinic of a training Hospital in Mashhad, Iran between March 2022 and September 2023.

To calculate the sample size, we used the study by Kava (2014) regarding the social support of endometriosis patients (35 ± 7.6) to detect an increase in the social support score by 30% in the education group compared to the control group (with a standard effect size of 1.3) and at the error level of 0.05, and the test power was 80%, the final sample size in each group was determined based on the following ratio 29 people in each group. Considering 20% sample dropout, 32 people were estimated for each group (28).

Sampling was done by using the convenience method among women with endometriosis who were referred to the Women's Clinic of one of the training Hospitals in Mashhad, Iran.

In this study, patients were randomly assigned to two control and intervention groups by using the random allocation block method with blocks of size 4. For this purpose, 16 blocks were randomly generated from the website https://www.sealedenvelope.com. To prevent information contamination, Saturdays and Mondays were selected for the intervention group and Wednesdays for the control group through a simple sortation (Figure 1).

Inclusion criteria include age between 18-50 years, elementary literacy at least, diagnosis of endometriosis by a gynecologist using ultrasound, candidate for medical treatment, the onset of endometriosis symptoms at least in the last 6 months , no consumption of antidepressants and sedatives in the last three months , satisfaction of the patient and her husband, no history of malignant diseases , not having unpleasant events such as the death of relatives in the last three months, living with her husband. The exclusion criteria included the patient's unwillingness to continue the study, unfortunate events during the study, such as the death of relatives or divorce, which disturb the mental health of the person. Pregnancy,

diagnosis of malignant diseases during intervention, failure to participate in more than one training session, patients who were candidates for surgery during the treatment period. - Suffering from other chronic diseases such as asthma, anemia, hypertension, diabetes, and multiple sclerosis.

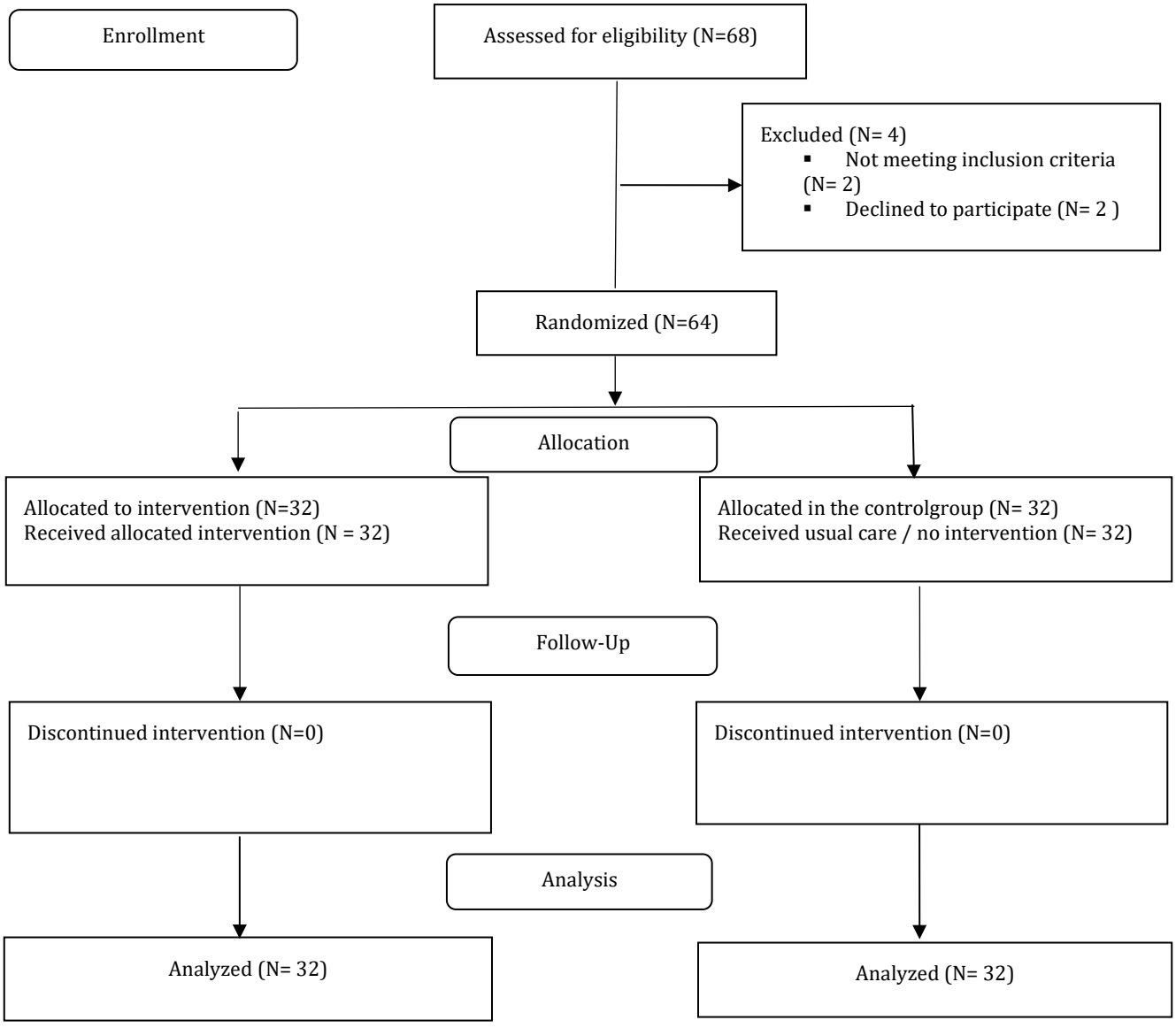

Figure 1. CONSORT Flowchart of the study

The tools of this study included the demographic and Sherbon Stewart Social

Support questionnaire. The demographic questionnaire was designed to measure the background variables and developed through consultation with the supervisor and academicsin the relevant fields. The Sherbon Stewart Social Support Questionnaire (MOS-SSS), which was created by Sherbon and Stewart in 1991 and has been translated into different languages. Arabshahi et al. (2020), in their study, confirmed its validity by using the opinions of narrative psychology experts, and its reliability was evaluated by using Cronbach's alpha coefficient of 0.97 (29). MOS-SSS measures the level of social support received with 19 items and 4 subscales. The emotional informational support section includes questions 1 to 8 that assess guidance, information, positive affect, sympathy, and encouragement to express emotions. The concrete support section includes questions 9 to 12 that measure material and behavioral support. The kindness section that measures the expression of love and affection includes questions 13 to 15. The positive social interaction section that evaluates engaging in recreational activities includes questions 16 to 19. Scoring of this questionnaire is on a 5-point Likert scale (never: 1, rarely: 2, sometimes: 3, often, always: 5). The minimum possible score will be 19, and the maximum will be 95. A score between 19 to 38 indicates a low level of family support. A score between 38 to 57 indicates a medium level of family support. A score higher than 57 indicates a high level of family support. In Iran, the psychometric properties of this questionnaire have been investigated in various studies (29). Content validity was used to determine validity in this study. The present study's tool was provided to 7 faculty members of the Mashhad Nursing and Midwifery School to confirm the application of this tool with the objectives of the present research. The reliability of this tool was also evaluated in the present research. Considering that this tool has four subscales, each subscale has multiple items, and each item in turn has grading options; therefore, the reliability of the social support tool in the present study was evaluated by the internal consistency method. Therefore, the reliability of the social support tool in the present study was evaluated by the internal consistency method, so that the social support score of patients with endometriosis was measured at one time. Cronbach's alpha was 0.78, 0.90, 0.83, and 0.86 for the dimensions of kindness, concreteness, emotional information, and social interaction, respectively. Cronbach's alpha was 0.88 for the overall score of social support. Time was 20 minutes to complete the questionnaire for each patient.

To collect data, following completing the questionnaires, the participants were divided into two groups randomly: intervention and control. The intervention group received 5 educational sessions based on the family-centered empowerment model for two weeks (every other day) on Saturdays and Mondays in the women's clinic by the first author. Consulting certificate was offered by passing special rounds. Each session was held for 45 to 60 minutes. The educational sessions were held in groups of 6 to 7 people.

The intervention group was divided into 5 groups. Two groups had 7 member, and the rest of the groups had 6 member. The first and the fifth sessions of education were held face-to-face, and other sessions were held online due to the epidemic of the Coronavirus and the difficulty of transportation for patients. A quiet and private place was considered for education. The content of the empowerment educational program was designed based on the family-centered model. The intervention lasted for eight weeks (2 weeks of educational sessions, and an assessment session, after 6 weeks of practice) (Table 1). The control group only received the routine care of the endometriosis clinic.

The intervention was designed based on the family-centered empowerment model structures and included the first step (focused on perceived threat), the second step (concentrated on self-efficacy), and the third step (focused on self-belief and self-esteem). In this step, the researcher followed the implementation of the programs through a telephone call as well as the fourth step (assessment). According to the research ethical codes, educational pamphlets were given to the patients and their husbands in the control group.

The tools of this study included the demographic and Sherbon Stewart Social Support questionnaire. The demographic questionnaire was designed to measure the background

variables and developed through consultation with the supervisor and academicsin the relevant fields.

Table 1. The content of educational sessions

Step	Construct	Method	Comments	Duration
1	Perceived threat	Group discussion with question and response	Discussion about risk factors, symptoms, treatment , complications and consequences of disease on different aspects of life	Two 45 - 60 minutes sessions
2	Self efficacy	Problem-solving group discussion		Two 45 - 60 minutes sessions
3	Self esteem	Educational participation		One45 - 60 minutes session
4	Process and outcome evaluation	Question and response in each session and following up questionnaire completion		During the study and 6 week after intervention

Data analysis of 64 samples was done by using SPSS statistical software (version 27), and independent t-test, Mann-Whitney, paired t-test, and Wilcoxon were used. P value less than 0.05 was considered significant.

In order to compare the main variables between the intervention and control groups, first the normality of quantitative variables was determined by Shapiro - Wilk test, which means the significance level was 0 / 05. Then, based on normal or abnormal distribution of variables, parametric and non - parametric tests were used for analysis. For comparison of the two groups, the independent t-test and for quantitative variables, Mann - Whitney test was used. Paired t-test and Wilcoxon was used to compare the preand post -intervention social support scores.

Results

Based on the results of the study, there was no significant difference between the demographic and obstetric characteristics including age, occupation, education, husband's occupation, family income, state of residence, history of infertility, duration of endometriosis diagnosis, medical treatment, and post-treatment condition in women in the intervention and control group (P<0.05) (Table 2).

The difference in the mean score of the total social support after the intervention compared to before, in the intervention group, there was an increase of 9.2 ± 10 points, and in the control group, there was a decrease of 12.4 ± 1.34 points. (Table 3). The Mann-Whitney test showed this difference to be significant (P>0.001). Also, the difference in the mean score of the emotional information construct in social support after the intervention compared to before showed an increase of 4.09 ± 4 points in the intervention group and a decrease of 0 ± 5.01 points in the control group (Table 4). The difference in the mean score of the concrete support dimension in social support after the intervention compared to before increased by 2.90 ± 2 points in the intervention group and decreased by 0.96 ± 2 points in the control group. The Mann-Whitney test showed these differences to be significant (P>0.001)(Table 5). The difference in the mean score of kindness dimension in social support after the intervention compared to before increased by 2.68 ± 1 points in the intervention group and decreased by 0 ± 2.18 points in the control group (P=0.004) (Table 6). The difference in the mean score of the positive social interaction dimension in social support after the intervention compared to before, increased by

2.84 ± 2 points in the intervention group and decreased by 09 ± 3.45 points in the control group, as the Mann-Whitney test showed these differences to be significant (P>0.001).

Table 2. Demographic characteristics of participants in the intervention and control groups

Variable	Groups		Test result
	Control group N (%)	Intervention group N (%t)	
Age			
18-30	6(19)	13(41)	X^2=3.67
31-40	19(59)	14(44)	P=0.160
50-41	7(22)	5(15)	
Job			
Housewife	20(63)	24(75)	X^2=1.164
Employed	12(37)	8(25)	P=0.281
Education			
Elementary	5(16)	5(16)	X^2=2.802
High school	5(16)	8(25)	P=0.423
Diploma	8(25)	11(34)	
University	14(43)	8(25)	
Husband's job			
Unemployed	1(3)	1(3)	
Labourer	4(12)	10(31)	F**=6.580
Employee	9(28)	8(25)	P=0.135
Freelance job	14(44)	13(41)	
Other	4(13)	0(0)	
Family income			
Enough	13(41)	7(22)	X^2=2.663
Not enough	7(22)	10(31)	P=0.264
Relatively enough	12(37)	15(47)	
Residence			
Personal	12(38)	13(41)	F=0.476
Rental	18(56)	18(56)	P=1
Organizational	2(6)	1(3)	
History of infertility			
No	9(28)	15(47)	X^2=2.743
Less than 2 years	10(31)	9(28)	P=0.254
More than 2 years	13(41)	8(25)	
Duration of diagnosis			
1 year	8(25)	12(38)	X^2=1.853
2 years	9(28)	10(31)	P=0.396
3 and more years or more	15(47)	10(31)	
Type of medical treatment			
Progesterone pill	16(50)	21(66)	F=3.225
Oral contraceptive pill	11(34)	10(31)	P=0.209
Progesterone ampule	5(16)	1(3)	
Post treatment status			
Improved	19(59)	15(47)	X^2=1.004
Relapsed	13(48)	17(53)	P=0.316

Table 3. Intra- and inter-group comparison of the total social support score

Variable	groups		Intergroup test	
	Control M±SD	Intervention M±SD		
Total score of Social support before intervention	58.97 ± 19.01	57.16 ±16.33	T=0.409	P=0.684
Total score of Social support after intervention	57.63 ±16.31	67.16 ±11.08	T=-2.73	P=0.008
Changes in the total score of support after compared to before the intervention	-1.34 ± 12.48	10 ±9.28	P<0.001	z= -4.40
In-group test	T=0.609 P=0.547	T= -6.09 P<0.01		

Table 4. Intra and inter-group comparison of the "Emotional information" dimension score

Variable	group		Intergroup test	
	Control M±SD	Intervention M±SD		
Emotional information score before the intervention	23.47 ±8.21	23.38 ±6.12	P=0.662	z= -0.437
Emotional information score after the intervention	22,81 ±7.14	27.28 ±4.34	P=0.004	t= -3.02
Changes in the emotional information score after compared to before	-0.65 ±5.01	3.90 ±4.09	P<0.001	z= -3.814
In-group test	Z= -0.597 P=0.55	T= -5.40 P<0.001		

Table 5. Examination of intra and inter-group distribution of the "Concrete Support" dimension score

Variable	group		Intergroup test	
	Control± M±SD	Intervention M±SD		
Tangible support score before the intervention	13.31 ±4.13	12.09 ±4.08	P=0.240	t=1.187
Tangible support score after the intervention	12.87 ±3.76	14.34 ±3.4	P=0.111	t= -1.61
Changes in tangible support score after compared to before	-0.43 ±2.96	2.25 ±2.90	P<0.001	z= -3.69
In-group test	T=0.836 P=0.410	T= -4.378 P<0.001		

Table 6. Examination of intra and inter-group distribution of the "kindness support" dimension score

variable	group		Intergroup test	
	Control M±SD	Intervention M±SD		
Kindness score before intervention	9.63 ±3.22	9.62 ±3.50	P=0.806	z= -0.246
Kindness score after intervention	9.46 ±2.74	11.09 ±2.41	P=0.15	t= -2.513
Changes in the kindness score after the intervention compared to before	-0.15 ±2.18	1.46 ±2.68	P=0.004	z= -2.86
In-group test	T=0.404 P=0.689	Z= -2.70 P=0.007		

Discussion

This study aimed to determine the effect of education based on the family-centered empowerment model on perceived social support in women with endometriosis. The

groups were compared in terms of social-individual variables, and they were homogeneous in all variables; there was no statistically significant difference between the groups. The results showed that the intervention based on the family-centered empowerment model in this study was able to influence the social support of endometriosis patients.

Arabshahi et al. (2020) conducted an experimental study to investigate the effect of educational intervention based on received social support from the spouse on improving adherence to the treatment diet in patients with hypertension and the results showed that the average score of adherence to the treatment diet and social support received by the spouse after the educational intervention in the test group increased significantly which is by the results of the present study. It seems that the social support received from the spouse empowers patients in the context of family and its support, so that, according to the chronic nature of the disease and the problems caused by it, patients can reach a level of ability to manage their illness, take control, and somehow cure it (30).

Also, in a semi-experimental study, Izadi et al. (2019) investigated the effect of education based on health belief model and social support on self-care behaviors during pregnancy in 90 pregnant women, and they showed that the score of the social support constract in the test group who received education increased significantly ($P<0.001$). (31). Also, the results of study by Badrizadeh et al. (2021) showed that social support has a positive and significant relationship with adherence to drug treatment (22).

Family and its support play a very important role in controlling diseases and self-care behaviors in patients; because the family is the first source of support, and for this reason, the role of the family in endometriosis and acceptance of this disease is vital (32).

In another study by Arabshahi et al. (2020), which was conducted to observe the treatment diet and social support of the spouse in patients with hypertension, the results showed that more than half of the patients who adhered to their treatment diet benefited from a high level of social support. In addition, the results showed that there is a significant relationship between adherence to the treatment regimen and the social support of the spouse. The results have shown that the social support of the spouse should be considered as an influencing factor in the adherence to the treatment diet and blood pressure level of patients with hypertension (29).

In the present study, it was seen that accompanying spouses in education based on the family-centered empowerment model increases the social support of patients, and it led to better control of the disease by patients. Also, in study by Arabshahi (2019), the support and role of the husband is considered very important in the control of disease.

One of the strength of the present study is the randomization and the of the allocation concealment that prevented selection bias. Also, the telephone number was provided to the participants, and their questions were answered to ensure that the problems were solved. Most of the sessions were held online for the convenience of the samples.

It should be mentioned that, according to the results of the study, which show the positive effect of education, the content of the education sessions was provided to the control group as well.

The mental and psychological conditions of the participants and their difference in learning style can affect the learning content and how they answer the questionnaires, so this is one of the study's limitations, and we tried to provide the study tools to the participants to complete them at the right time and conditions for learning by observing the educational principles. The short-term follow-up of six week was another limitation of the research. Also, since the intervention was in the form of educational sessions conducted by the researcher, it is not possible to blind the researcher and the participants.

We suggest to conduct a study regarding the long-term effect of education based on family-centered empowerment model on social support of women with endometriosis.

Conclusion

Based on the results of this study, education based on the family-centered empowerment model can increase the social support of patients by accompanying the patients' spouses in the

disease process and increasing their insight and attitude regarding the disease. Due to the prevalence of endometriosis, this educational model is recommended to midwives, health care providers, and physicians to use it to change the lifestyle of patients influenced by endometriosis through improving their social support.

Declarations

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Conflicts of interest

The authors declared no conflicts of interest.

Ethical approval

The first author conducted the sampling and data collection process while introducing herself to the participants and explaining the purpose of the study. Additionally, she assured them that their data would remain confidential and that they could withdraw from the study at any time. Also, she obtained their written informed consent.

Code of Ethics

IR.MUMS.NURSE.REC.1401.032.

Use of Artificial Intelligence

No artificial intelligence tools were used in the writing or analysis of this manuscript.

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Authors' contributions

KM and HRZ supervised the study. MA participated in data collection, and data analysis. VG and NJ assisted with data analysis and data interpretation. SAP participated in data collection. All authors have read and approved the manuscript.

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