

The Impact of Family-Centered Empowerment Program on the Quality of Life of Mothers with Epileptic Children

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Abstract

Background: There is a relationship between diseases and the quality of life. Epilepsy is a disease that is unpredictable and uncontrollable and its actions are limited to scattered and brief education. Therefore, this study aimed to investigate the effect of family-centered empowerment program on the quality of life of mothers with epileptic children.

Methods: This clinical trial was undertaken on 60 mothers with epileptic children. Thirty mothers with epileptic children participated in family-centered empowerment sessions and 30 mothers with epileptic children served as the control group. Personal information form and quality of life questionnaire were administered at baseline and 75 days after intervention. In order to analyze data, chi-square test, independent t-test, paired t-test, and covariance were used accordingly.

Results: The quality of life between the two groups was not significantly different at the beginning of the study, but it was significantly different 75 days after the onset of the empowerment program. In other words, the family-centered empowerment program had a significantly positive impact on the quality of life of mothers with epileptic children ($P = 0.03$).

Conclusion: According to the results of this study, the family-centered empowerment program can be considered as a potent alternative in health care system to enhance the quality of life of families with epileptic children.

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Introduction

The World Health Organization (WHO) describes quality of life as an understanding of individuals about their status, expectations, standards and priorities that are perfectly personalized (1).

People's understanding about quality of life is influenced by the ability of individuals in different ages to carry out daily activities such as self-care, going to school and work. With regard to mental aspect, mental health is an important part of quality of life and having a positive attitude is effective in improving the quality of life. With respect to the socio-cultural dimension, the roles of each individual in the family and society and his/her social connections are factors that influence the quality of life (2).

There is a relationship between diseases and the quality of life (3). Disease has a significant impact on different dimensions of patients' lives and their families. Thus, it has a detrimental effect on their quality of life (4).

The disease of a family member changes the lifestyle of the whole family and disrupts the balance of the family (5). One of these diseases is epilepsy that is one of the most common neurological disorders causing seizures or periods of unusual behavior (6-8). Anyone can develop epilepsy irrespective of age, gender, and socioeconomic status (9). In childhood, pre-natal events, evolutionary defects, genetic factors and central nervous system degeneration are the most common causes of epilepsy disease (10). According to World Health Organization statistics, nearly 50 million people worldwide are suffering from epilepsy. In Iran, 2.4% of every 1,000 school-aged children suffer from epilepsy and 65% of patients with epilepsy are children and adolescents (11). This event reduces the quality of life of both the child and his/her family members. On the

other hand, children with epilepsy do not have the ability to control the attacks, so most of the care responsibilities are upon the parents (12). Consequently, there is a need for action beyond medical treatment since it is clear that if the level of anxiety of parents with epileptic children does not decrease, they will have a lower quality of life (13).

The family-centered empowerment model with its emphasis on the effectiveness of the family roles regarding motivation, psychology, knowledge and attitude plays a significant role in the prevention or control of behavioral or emotional problems (6). Empowerment is the promotion of a sense of trust and positive adjustment, a sense of power control and helping others achieve their goals. Empowering helps people understand their needs and how to solve them (10). The principles of empowerment include the ability to solve problems, self-reliance and self-esteem. In this regard, empowerment is the main factor in promoting community health (11,14).

Nursing strategies that are needed for empowerment should be in line with nursing and family partnerships. They should have an emphasis on reducing risk factors and promoting health (15). Evidence shows that using empowerment programs for parents with disabled children can increase self-reliance and help them to solve problems. The role of the nurse in family-centered care is to identify the concepts and provide information for the decision-making process. (12).

Epilepsy is unpredictable and uncontrollable. In addition, research findings reveal that in the course of the epilepsy disease, the family members especially the mother is affected by the child's illness in a way that she would experience a very challenging life. Therefore, educating and empowering mothers may have positive effects. In this study, we aimed to

investigate the effect of the family-centered empowerment program on the quality of life of mothers with epileptic children.

Materials and Methods

The present study is a pre-post randomized clinical trial. The study population included mothers of children with epilepsy who were admitted in Bojnurd educational hospitals. In this study, children with epilepsy were between the ages of 1 and 12 years with a history of admission to the pediatric ward of Bojnurd hospitals. In order to estimate the sample size, we used the sample size formula for interventional studies with 95% confidence level and 80% power. In this regard, 26 samples were recruited in each intervention and control groups. We considered 10% reduction for each group, thus, we estimated 30 samples in each group (a total of 60 people were assigned). In order to choose cases and controls, we used patients' recent medical files. The researchers invited the mothers to attend a meeting on a particular day convenient for them. Maternal inclusion criteria encompassed willingness to participate in the study, having an epileptic child between the ages of 1-12 years, a diagnosis period of at least 6 months of the child's illness, being Iranian, having reading and writing skills, having the most responsibility for child care, lack of having speech and hearing problems, no history of drug use and psychotropic drugs. Mothers were asked to sign an informed consent form for participation in the study. In addition, they were asked to complete personal information questionnaire and quality of life questionnaire. We divided the subjects into two groups namely intervention and control groups using random selection method. Subsequently, mothers selected as intervention group were asked to participate in the

empowerment sessions according to the schedule, while the control group did not receive any interventions.

Concerning the intervention, we used the empowerment model which included these steps: 1. Understanding the threat. 2. Problem-solving. 3. Evaluation. Group discussion was performed during 5 sessions (4 days) and each session lasted for 1 hour for the intervention group. In order to implement the first step of the empowerment model, in the first session, the nature of epilepsy disease was clarified to mothers with the help of a neurologist. From the second to the fifth session, mothers became familiar with the obstacles and the process of solving problems (for example, what mothers should do during a seizure attack and practical resuscitation procedure by using the Models, Anatomic). Also, under the supervision of the researcher, they discussed their situation and what they did to improve the problem. Besides, at this stage, mothers could identify ways to increase self-efficacy, such as preventive measures, adherence to the principles of proper nutrition and the elimination of false nutritional beliefs, drug therapy, and coping with the mental-psychological problems of the disease. At the end of each training session, a summary of the training session was explained to mothers. Concerning the evaluation, the researchers evaluated mothers based on the previous meetings. After the last empowerment session, the researcher provided the mothers with a telephone number to call if they had any questions. Then the mother was given 1.5 months opportunity to execute the learned pattern. Then, they were given 1.5 months to implement the program. Follow up was done by contacting mothers via telephone calls twice a week. This follow up was related to the process by asking some relevant questions. After a period of 2.5 months, the researchers

invited all mothers (both groups) to participate in the final session and complete the quality of life questionnaire.

The personal information form includes 14 questions. These questions are related to age, level of education, woman occupation, job status, marital status, male occupation, monthly income, the monthly cost of care, the length of care, the care experience, the hours of care, etc. The patient information includes 7 questions related to gender, age, educational status, place of residence, medical diagnosis, family history of epilepsy, etc. In order to assess quality of life, we used WHOQOL-100 questionnaire. This questionnaire includes 26 questions in four areas related to health: physical health, mental health, social relations, and living environment. Questions were answered on a 5-point Likert scale. The effectiveness range of each question was (very high, high, somewhat, low, not at all) in which the highest score for each question was 4 and the lowest score was 1(4). To analyze data, descriptive statistics, frequency, mean and standard deviations were used. For inter-group comparisons we used chi-square and independent t-test. Concerning intra-group comparisons, paired t-test was used accordingly. Also, in order to investigate the effect of interventional variables on dependent variables, we used

covariance test using SPSS software version 19 with 95% confidence level.

Results

This clinical trial was performed on 60 mothers with children aged 1-12 years with epilepsy admitted to educational hospitals in Bojnurd. In this study, 30 mothers with epileptic children participated in family-centered empowerment sessions and 30 mothers with epileptic children were considered as control group. The mean score of quality of life between the two groups was not significantly different at the beginning of the study; but the mean score of quality of life was significantly different 2.5 months after the intervention in the two groups. The mean quality of life score in the intervention group was 60 ± 17 and in the control group it was 45.6 ± 23 ($P < 0.03$). The mean scores of different dimensions of quality of life in the two groups at the start of the study and 2.5 months after the intervention are shown in Table 1.

Also, the mean and standard deviation of different dimensions of quality of life before and after the intervention were statistically significant as shown in Table 2.

Table 1. Mean scores of different aspects of quality of life in the two groups at the start of the study and 2.5 months after the intervention

Mean scores of quality of life		Physical Health	Mental Health	Social Relationship	The environment of life	General Health
at the start of the study	Intervention group	50.1±11.2	45.7±3.5	53±19.1	40.9±19.4	57.4±18.3
	Control group	56.6±31.8	52.9±14.7	56.8±20.1	50.4±14.7	64±14.9
	P-value	0.41	0.14	0.55	0.08	0.22
2.5 months after the intervention	Intervention group	73.1±45.8	64.5±34.9	55±20.1	56.2±20.3	60±17
	Control group	45±31.8	42.7±15.9	33.3±26.2	34.2±17.2	45.6±23
	P-value	0.03	0.01	0.006	0.001	0.03

Table 2. Mean and standard deviation of different dimensions of quality of life before and after the study

Mean scores of quality of life	Physical Health	Mental Health	Social Relationship	The environment of life	General Health
Before intervention	50.1±11.2	45.7±3.5	53±19.1	40.9±19.4	57.4±18.3
After intervention	73.1±45.8	64.5±34.9	55±20.1	56.2±20.3	60±17
P-value	0.04	0.02	0.001	<0.001	0.002

The mean age score of mothers participating in family-centered empowerment sessions was 34.4 ± 7.08 and the mean age score of the control group was 31.3 ± 4.3 years. There was

no statistically significant difference between the two groups ($P = 0.1$). The demographic characteristics of the two groups are shown in Table 3.

Table 3. Demographic characteristics of the two study groups

Variables	mothers participating in family-centered empowerment sessions	Control group	P-value
Mother's age (M ± SD)	34.4±7	31.3±4.3	0.10
Child's age	5.9±3.9	4.8±3	0.32
Number of children	2.7±2.1	2.2±0.63	0.27
Duration of infection	3.8±3.2	2.7±2.1	0.29
Attack count	1.8±0.94	1.7±1.2	0.79
Duration of care	6.3±3.5	4.3±3	0.07
Mother's educational level	under the diploma	27(90)	0.23
	Upper diploma	3(10)	
Job	Governmental	9(30)	0.51
	Non-Governmental	21(70)	
Father's level of education	under the diploma	22(78.9)	0.08
	Upper diploma	8(21.1)	
Monthly income	At a reasonable rate	16(57.9)	0.17
	Less than full	14(42.1)	

* Significance level at 0.05

As shown in the table above, the two groups did not differ significantly in terms of demographic variables as they were matched regarding demographic variables. We measured the impact of intervention by using covariance analysis test. The results showed that the mean score of quality of life among mothers participating in family-centered empowerment sessions was more than the control group and it was statistically significant ($P < 0.03$). Therefore, participation in family-centered empowerment sessions had a more effective role in

increasing the quality of life of mothers with epileptic children. According to the effect size, 24.8% of the changes in the mean score of quality of life were due to the desired intervention.

Discussion

In the present study, the mean score of quality of life between the two groups was not significantly different at the beginning of the study, but it was significantly different

between the two groups 2.5 months after the start of the empowerment program. In this regard, the mean score of quality of life in the intervention group (participation in family-centered empowerment sessions) was significantly more than the control group ($P = 0.03$). Also, the mean scores of different dimensions of quality of life 2.5 months after the intervention were significantly different between the two groups. In fact, the mean score of quality of life in physical, mental, and social dimensions were significantly higher than the control group. Since the mean score of quality of life in the pre-test of the two groups did not differ significantly and there was no significant difference between the two groups in terms of demographic variables, this significant change can be attributed to the type of intervention. Compared to healthy children, children with epilepsy and their families have considerably more restrictions on the general health, physical function, ability to perform social roles due to physical-psychological problems, mental problems, self-esteem, perceptions of health, an impact on family time and activities. Children with epilepsy usually need to take antiepileptic drugs daily and there is a need for regular visits to the doctor and be treated with a diet. Epilepsy treatment may also have side effects including drowsiness, irritability, headache and nausea. It is therefore clear that knowledge of the disease is a critical factor to successfully treat epilepsy. False beliefs and negative attitudes of parents about their child's disease, often due to their lack of awareness, can endanger their general health. Positive attitudes toward disease not only help self-confidence among people with epilepsy but also help them to better control epileptic seizures. On the other hand, knowing the parents' skills and the possible constraints of the disease can help in the treatment of the child, prevention or better

controlling regarding the behavioral or emotional problems (16).

Evidence shows that implementing a family-centered empowerment program can increase the quality of life of patients with multiple sclerosis (5). This finding is consistent with our results. Also, empowerment program can increase the quality of life in mothers who had a child with a urinary tract infection (17). By the same token, implementation of the empowerment model can enhance the quality of life in adolescents with major thalassemia (3). In children with diabetes and asthma, a series of organized training programs is used as part of the standard child care program (18). A study conducted by Sanaie et al., to investigate the effect of family-centered empowerment on self-efficacy and self-esteem in patients undergoing coronary artery bypass graft surgery, showed improvement in the two self-efficacy and self-esteem indices in patients, which was in accordance with this study(19).

There are also educational programs for children with epilepsy and their families, but these programs are often aimed at increasing information on the disease, existing therapeutic options, the socio-occupational success of patients and reducing fears about the disease (20). Some studies showed that participation in an empowerment program improves the quality of life of diabetic patients. But similar to that for diabetics, we did not find the empowerment program for mothers with epileptic children.

These studies show that the use of empowerment programs increases the confidence and ability of solving problems in parents with disable children(21). Also, the implementation of the empowerment program increases the capacity of self-care in a patient.

Asgharpour et al evaluated the effect of an educational program on self-management in patients with epilepsy. The results showed significant differences between the experimental and control groups in terms of self-management (8). In Asgharpour study, medication therapy training, information related to epilepsy, types of seizures, issues associated with immunity and lifestyle of epileptic patients were delineated and the results were evaluated after one-month follow-up. However, empowerment program in this study was more comprehensive and included assessment of mothers' quality of life during 10 weeks.

One of the limitations of this study was the lack of precise control over study samples for education through other media and sources.

Conclusion

In the present study, the mean score of quality of life in the mothers who participated in family-centered empowerment

sessions was significantly more than the control group. Therefore, in the area of health care in order to provide patient-based communication a lot of emphasis should be placed on empowerment. Implementation of empowerment programs will improve the coping ability of mothers who have children with critical illnesses, and improve the psychological and social conditions of children. Taking into account the prominent role that mothers play in patient care and the serious and negative impact of childhood diseases on mothers, family and society, family-based empowerment programs are recommended.

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Conflicts of interest

Authors declare that they have no conflict of interest.

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