The effect of an educational program on illness uncertainty in mothers of children with type 1 diabetes: a quasi-experimental study

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Abstract

The mother is traditionally the primary caregiver for the child, and uncertainty is a major source of psychological distress for parents of sick children. As a result, the current study sought to investigate the impact of an educational program on illness uncertainty in mothers of children with insulin-dependent diabetes mellitus (IDDM). This is a quasi-experimental study with a pretest-posttest design, involving 40 mothers of children with IDDM. After visiting the research site and recruiting eligible mothers, the researcher used the purposive sampling method to randomly assign them to one of two intervention and control groups. Taking into account their needs and conditions, mothers were scheduled for at least three sessions, with a 30-minute interval every other day. The data analysis revealed no significant differences between the two groups in terms of child age and gender, mother age and education level, number of children, and duration of diabetes. There was a significant difference in the total score of uncertainty, total score of ambiguity, lack of clarity, lack of information, unpredictability, and their dimensions between mothers of diabetic children before and after the intervention (P=0.02). Based on the findings, it is recommended that the educational needs of children and their mothers be assessed upon admission and that educational content be prepared and taught accordingly, thereby helping to reduce illness uncertainty in mothers.

Introduction

The most common endocrine disease in childhood and adolescence is type 1 or insulin-dependent diabetes mellitus (IDDM). In the United States, one out of every 400 children and adolescents has diabetes.[1] The annual incidence of IDDM in Iran has been estimated at 3.7 cases per hundred thousand people. This figure varies worldwide from 1 to 35 cases per 100,000 people under 14 years of age. The incidence of IDDM is considered to be increasing in the world.[2] IDDM, in addition to the high mortality rate, is associated with many personal, family, and financial troubles, such as severe increase and decrease of blood sugar, food, and exercise restrictions, repeated insulin injections, musculoskeletal complications, physical disabilities and vascular problems that affect the lives of these patients.[3] The long-term adverse effects of this disease include retinopathy, nephropathy, and neuropathy.[4] Diabetes accounts for 25% of chronic kidney failure, the need for dialysis, and kidney transplants, and the most common cause of blindness.[5] Due to her extensive role in the family, the mother plays an important role in taking care of the children, and it is a fact that the children of

informed mothers have more chances for a healthy life because the mother is the first person who takes care of the child.[6] Uncertainty is a normal part of the disease experience and can exist in all stages of the disease including diagnosis, treatment, and prognosis. Illness uncertainty occurs when the patient is unable to determine the meaning of the illness-related events, so, it is considered an important psychological stressor for the patients.[7] Most people seek to reduce it or learn ways to cope with it.[8] Uncertainty can have major adverse effects on the psychological adjustment and the consequences of the disease.[9] Uncertainty is a major source of psychological distress for parents of sick children and is defined as the inability to determine the meaning of illness-related events.[10] Uncertainty is defined as "the inability to determine the meaning of illness-related events when the patient or his/her family are not able to determine the values of the events or cannot predict the consequences of the disease due to the lack of sufficient cues".[11] Uncertainty occurs when people are unable to form a cognitive framework to understand their situation and interpret the illness-related events, therefore, in most cases, it is accepted as an important stressor that most people seek a solution to reduce and cope with it.[12] Michel (1988), discussed in Oh *et al.*[10], states that people with acute and chronic diseases often experience uncertainty due to a lack of experience and ambiguity regarding the disease and its symptoms. Results of previous studies on illness uncertainty management showed that the highest level of uncertainty has been related to high levels of emotional distress, anxiety, and depression. Therefore, ambiguity about the illness, ambiguity, and unpredictability of the illness can cause anxiety in mothers.[13] Uncertainty in children's parents is due to the lack of information about the care plan, diagnosis, and severity of the disease.[14] Patient education is a purposeful, systematic, regular process and includes all educational activities related to the patients and their families, such as health education, care, and treatment, by which learning, in other words, changes are made in the patient's awareness, attitude, and skills. Subsequently, the competence and self-care ability of the patient as well as adherence to activities that increase health and well-being and prevent the occurrence of potential complications increase.[15] Patient education is one of the important dimensions of nursing care and one of the key roles of nurses in providing healthcare services.[16] One of the reasons for the failure to achieve the desired treatment outcomes in diabetic patients is the lack of patient participation in diabetes treatment because diabetic patients are responsible for the care and treatment of their disease.[17] Rahnama *et al.* showed in research that patient education can be effective in reducing diabetes complications.[18] Therefore, this study was conducted to investigate the effect of the educational program on illness uncertainty in mothers of children with type 1 diabetes.

Materials and Methods

This is a quasi-experimental study that was carried out on 40 mothers with type 1 diabetic children who were referred to Imam Khomeini Hospital in Zabol in 2020 after obtaining the approval of the ethics committee (IR.ZBMU.REC.1399.050) and informed consent from the participants. The research participants were selected using purposive sampling and randomly divided into two groups. Inclusion criteria included having a child with type 1 diabetes diagnosed by a physician, mothers that do not work in a hospital, Farsi-speaking mothers, literate mothers, and residents in Zabol city, absence of diseases other than diabetes, absence of mother's anxiety disorders and depression. After explaining the purpose and necessity of the research project, questionnaires were provided to the participants. The data collection tool includes a two-part questionnaire including demographic information and a 31-item (Parents perception of uncertainty in illness scale Mishel) PPUIS. The demographic questionnaire includes questions on the child's age and gender, mother's age, occupation and level of education, number of children, child rank, age at onset of type 1 diabetes, history of diabetes in other children, history of diabetes in the family, place of residence and economic status. The second part of the questionnaire is a 31-item PPUIS. This scale was designed by Michel in 1983 as discussed in

Ho *et al.*[19] and its validity and reliability were measured by this study. Each item is scored based on a four-point Likert scale ranging from 1 (Strongly disagree) to 4 (Strongly agree). Items also required to reverse scoring and responses were reported as a total score. The validity index of PPUIS was reported 0.94 by Hossein Rezaei *et al.* and its reliability was calculated and confirmed using Cronbach's alpha ($\alpha = 0.91$).[22] The researcher gave the demographic questionnaire and PPUIS to mothers of children with diabetes in both intervention and control groups. In the control group, only the centre's routine training was provided. However, in the intervention group, in addition to the routine training, the educational intervention was carried out place. After determining the educational needs of the mothers of these children by asking relevant questions, the researcher wrote the educational content based on the educational objectives and according to authentic books under the supervision of the children's professors, which includes a simple definition of type 1 diabetes, causes, prevalence, symptoms, prognosis and treatment and drug therapy, diagnostic methods, sugar control methods, nutrition, ways to control anxiety, etc., individual training and providing educational booklets and providing educational CDs for diabetes and practical demonstrations of insulin injections, etc. The duration of the intervention is at least 30 minutes and was performed individually in the above center depending on the needs and requests of the mother. The intervention was carried out in at least three sessions based on the needs and conditions of the patient and with a 1-day time interval, *i.e.* three sessions in a week.[19] The instructor was the researcher and the time of the intervention session was coordinated by the mother, and the place of the intervention was the child's bed (when the mother is calm and has the conditions to receive the materials). The researcher also provided his phone number to the mothers of the intervention group so that they could call him if they had any questions. The researcher also followed them up via telephone for one month. The questionnaire was completed by the mothers after one month of follow-up via telephone.[20] The collected and coded data were analyzed using descriptive statistics (prevalence, percentage, mean, standard deviation, minimum, and maximum) and inferential statistics (independent t, paired t, ANOVA) in SPSS-21 software. P-value<0.05 was also considered as the significance level.

Results

The present study was conducted on 40 mothers with children with IDDM. The mean age of the studied mother and their children was 33.00 and 8.00 years, respectively. Also, the average duration of diagnosis of type 1 diabetes in children was 6.00±3.00 months. Of the 40 people included in the study, 25 mothers had children, 24 mothers had a bachelor's degree, 14 had a diploma, and 2 had a bachelor's degree. Also, the history of diabetes in other children, family, and relatives was 4, 13, and 27 cases, respectively. Sixteen and twenty-four of the mothers lived in rural areas and city, respectively. Moreover, 25 children had hospital admission due to diabetes. The results showed a statistically significant relationship between the age of mothers of children with diabetes and the sub-components of lack of clarity and unpredictability (p=0.012) and (p=0.001). In other words, the average score of the sub-components of lack of clarity and unpredictability in mothers with a higher average age was

significantly lower than those with a lower average age. There was no statistically significant relationship between other demographic information with the average score of dimensions and the total score of illness uncertainty ($p>0.05$). The results also showed a significant difference between the intervention and control groups in terms of the average score of the dimensions and the total score of PPUIC after the intervention ($p<0.05$). In other words, the intervention has reduced the score of PPUIC score. There was no significant difference in the total PPUIC score and its dimensions in the control group after the intervention ($p>0.05$; Table 1).

Discussion

The purpose of the present study was to determine the effect of the educational program on illness uncertainty in mothers of children with type 1 diabetes. The data analysis showed a significant difference in the average total score of uncertainty, ambiguity, lack of clarity, lack of information, unpredictability, and dimensions in mothers of diabetic children before and after the intervention. There was also no significant difference in the total score of uncertainty, ambiguity, lack of clarity, lack of information, unpredictability, and their dimensions in the control group before and after the intervention. In other words, the mothers of children with diabetes in the intervention group had a better score after the intervention, and the mothers of children with diabetes in the intervention group had no difference in the score obtained after the intervention compared to before the intervention. In this regard, Rezaei *et al.* conducted research titled "Effect of education on the perception of illness uncertainty and anxiety of mothers of children with febrile convulsions". The uncertainty score of mothers in the intervention group decreased from 87.53 to 65.30 after the intervention and in the control group from 85.80 to 84.18, which showed a significant difference between the two groups.[21] This study is consistent with the results of the present study. In the current study, the educational content includes the definition of diabetes, types of diabetes, complications of diabetes, type and amount of daily activity, and education about the drug regimen and effects, side effects and method of administration, and familiarity with the diet, type, amount and frequency of the diet in these patients. In other words, the educational content for mothers of children with diabetes was designed to improve the awareness and knowledge of these mothers. Therefore, similar to Rezaei *et al.*'s study, the present study showed that education helped to increase the knowledge and awareness of as well as reduce the illness uncertainty in mothers of children with diabetes, which is consistent with the results of previous studies. On the other hand, improving the illness uncertainty symptoms in mothers of children with diabetes has increased their ability and self-confidence, which in turn improves the quality of care for their children. Therefore, there is a relationship between increasing knowledge and awareness through educational programs for mothers of diabetic children and reducing illness uncertainty in them.

Sajjadi *et al.* in a descriptive-analytical study titled "The relationship between illness uncertainty, demographic and clinical factors with adherence to the treatment regimen in cancer patients" showed an inverse and significant relationship between illness uncertainty and adherence to the treatment regimen. In other words, the low uncertainty score makes cancer patients adhere to the treatment regimen more frequently, which is consistent with the results of the present study. Considering the significant relationship between illness uncertainty and adherence to the treatment regimen and significant predictability for adherence to the treatment regimen, nurses and healthcare providers can increase the level of adherence to the treatment regimen by considering uncertainty reduction strategies, and, finally, improve the quality of treatment and life of these patients.[22] The results of the present study emphasize the effective role of education in improving illness uncertainty and further reducing the incidence of morbidities and complications of diabetes. In a clinical trial, Sajjadi *et al.* investigated the effect of multimedia education on the illness uncertainty of breast cancer women. They showed no significant difference between the two groups in terms of the uncertainty score before the intervention, but a statistically significant difference was observed between the two groups one month and two months after the intervention. In other words, the educational program has improved the uncertainty score of cancer patients, which in turn facilitates the treatment process.[23] The results of this study are consistent with the results of the present study. Multimedia education can be effective in reducing the illness uncertainty of breast cancer women and helps nurses and healthcare providers facilitate the process of patient education to reduce such uncertainty. The results of the present study also showed a significant improvement in the uncertainty score after the intervention. The results of this study are also consistent with the results of the present study. According to the results of the present study and other studies, education plays a decisive role in improving the illness uncertainty in mothers of children with diabetes. Therefore, it is possible to

Table 1. Determination and comparison of the average score of illness uncertainty in mothers of children with diabetes in the intervention and control groups before and after the intervention.

Dimensions and parents' perception of uncertainty in illness	Intervention group		T	95% confidence interval	P-value
	Before intervention	After intervention			
Ambiguity	36.00±9.00	26.00±8.00	5	7.00	0.0001
Lack of clarity	31.00±9.00	26.00±8.00	5	6.00	0.0001
Lack of information	17.00±3.00	11.00±3.00	10	3.00	0.0001
Unpredictability	9.00±3.00	8.00±2.00	1	1.00	0.067
Parents' perception of uncertainty in illness	94.00±13.00	67.00±12.00	10	12.00	0.0001
Control					
Ambiguity	38.9±00.00	36.7±00.00	3	4.00	0.71
Lack of clarity	33.8±00.00	31.9±00.00	3	4.00	0.54
Lack of information	17.2±00.00	16.2±00.00	1	7.00	0.43
Unpredictability	10.4±00.00	9.2±00.00	2	2.00	0.87
Parents' perception of uncertainty in illness	99.11± 00.00	96.13±00.00	3	9.00	0.59

improve the illness uncertainty of mothers and ensure effective childcare by holding classes and workshops for mothers of diabetic children, especially chronic diabetes. It is recommended to conduct more studies in this area. The limitations of the present research included the non-cooperation of the mothers and the non-completion of the training course by the mothers.

Conclusions

Diabetes is one of the major public health challenges and one of the ten main causes of death in the world according to the latest global burden of disease study in 2020.The results of the present study showed that the illness uncertainty in mothers of children with diabetes was reported to be very high in both groups at baseline (intervention and control). However the illness uncertainty of mothers of children with diabetes has decreased in the intervention group after the intervention, so it is reported to be moderate. The illness uncertainty in the control group was still very high. Therefore, it can be stated that educational intervention has a significant effect in reducing the illness uncertainty of mothers. It is recommended that the educational content be used to help reduce the illness uncertainty of caregivers of children with diabetes.

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