The Effect of Family-Centered Empowerment Model on the Illness Perception in Heart Failure Patients: a Randomized Controlled Clinical Trial

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ABSTRACT

Introduction: Heart failure is a chronic medical condition that, despite the existing therapies, involves different aspects of an individual’s life (such as self-care capability). Illness perception is one of the most important variables which seem to improve the self-efficacy skills in chronic diseases such as heart failure. Therefore, this study aimed to investigate the effect of family-centered empowerment model on the perception of the illness in heart failure patients.

Methods: This clinical trial study was performed on 70 heart failure patients, assigned into control and experimental groups, admitted to the heart clinic of Hazrate Fatemeh hospital in Shiraz. After the convenience sampling, the patients were divided into two control and intervention groups by block randomization method. For experimental group, the family-centered empowerment modeling was done in 5 sessions. The research materials included demographic information and Brief illness perception questionnaires (B-IPQ). Data were analyzed using SPSS v.13 software. The statistical tests included Wilcoxon, Man-Whitney, and Independent t-test. P value less than 0.05 was considered as significant.

Results: In this study, both control and experimental groups were homogeneous with demographic information. Before the intervention in different dimensions of illness perception, all of the values in both groups were the same; However, after the intervention, a significant difference was observed in all of the dimensions of illness perception, except for Time line; so that the most and the least changes were related to the concern (1.09 (0.61) vs 3 (0.93)), and identity dimensions (0.97 (0.61) vs 2.11 (0.67), respectively.

Conclusion: On the basis of the above, it can be concluded that this model modifies the illness perceptions in heart failure patients. Cardiac nurses should consider family-based empowerment model as a treatment for heart failure patients.

Introduction

Cardiovascular diseases are one of the most common chronic diseases in the 21st century that are responsible for half of deaths in developing countries and decrease the manpower productivity, disabilities, economic damages and deaths. One of the most common chronic cardiac diseases is heart failure, known as a major and important disease worldwide over the past 20 years. Moreover, it can be one of the most common causes of admission and re-admission of patients over 65 years of age. The prevalence of re-admission among these patients has been estimated to be 23%-6. Heart failure is a chronic medical condition that, despite the existing therapies, involves different aspects of an individual’s life (such as self-care capability). The heart failure patients mostly have perfusion loss, low quality of life, and miss the individual and social roles leading to self-care inability.

Also, heart failure patients have various mental and physical symptoms such as Asthma, energy loss, weakness, fatigue, sleep disorders, depression and chest pain. These symptoms limit daily activities and thus entail nurses improving the self-care and self-efficacy skills in heart failure patients.

Illness perception is one of the most important variables which seems to improve the self-efficacy skills in chronic diseases. Illness perception is defined as beliefs and expectations a person has about himself or others expanded by various sources like experience and environment.

With illness perception, patients respond to symptoms of an illness by forming cognitive and emotional representations of the illness. Cognitive representation consists of "identity" (the symptoms that the patient identifies as part of the illness), the "cause" of the illness, the "timeline" for the illness, the degree of "personal/treatment control" the patients perceive they can exert over the illness and the perceived "consequences" of the illness on the patient’s life, illness "coherence" (how well the patients feels they understand the illness) and on the hand, the emotional representation (how much patients are emotionally affected by the illness) is defined as the assessments of illness...
Walker believes that recognition of illness perception has a predictive value in promoting the health behaviors in heart failure patients.\textsuperscript{19} Also, Groarke et al., declared that based on the illness perception, the health interventions can be helpful.\textsuperscript{20} Some researchers believed that nursing care is more helpful when it is based on the illness perception and the needs of patients. For instance, in a study, Broadbent et al., considered that how the patients perceive their heart failure can effect on the recovery process.\textsuperscript{21} In a similar study, Groarke et al., reported that illness perception is an important predictive factor of psycho-social reaction against the chest pain, independent of objective intensity.\textsuperscript{20} According to the studies done on illness perception, vivid perception about the experience of patients undoubtedly results in the recognition of factors effecting the compatibility and admission of the illness process.\textsuperscript{22}

Given that heart disease can accompany a person throughout his lifetime, and in addition to the patient, affects other family members and even the community, it is imperative that the patient be empowered to properly control the illness and improve the illness perception.\textsuperscript{19}

Although some methods and educational programs have been employed to improve the illness perception, they have not paid sufficient attention to the patient and his family.\textsuperscript{17,18} However, family-centered empowerment model is advantageous. The family-centered empowerment model is an Iranian model which aims to empower the family system (patient and other family members) to improve the health level. The family-centered empowerment model is designed to emphasize the effectiveness of patients’ role and other family members in three motivational, psychological (self-belief, self-control, and self-efficient) and the problem of the self-dimensions (knowledge, attitude, and perceived thread). This model originates from a qualitative research called “grounded theory” creating an applicable model after creating the conceptions, developing the conceptions, determining the psycho-social processes and deducing the key variable (family-centered empowerment), and also it has been enforced to promote the quality of life for chronic patients with iron deficiency anemia, thalassemia, hemophilia, diabetes, asthma and epilepsy.\textsuperscript{23}

Regarding the importance of patients’ illness perception as well as the importance of improving perception from illness, particularly for these patients, the majority of studies on heart failure patients have only focused on the other aspects and paid less attention to the patients’ illness perception, especially the improvement of illness perception through involving family members.

Therefore, this study aimed to investigate the effect of family-centered empowerment model on illness perception in heart failure patients (cognitive and emotional representation).

Materials and methods

This randomized clinical trial study was performed on experimental and control groups. The samples of research included heart failure patients referring to the heart clinic of Hazrate Fatemeh hospital in Shiraz selected by means of convenience method. The study began after the approval of Research deputy of Shiraz University of Medical Sciences and Alzahra Heart Center in Shiraz. Then, the participants were recruited.

The aims of study, the possibility of exclusion in case of unwillingness and confidentiality of personal information were explained to them. In case of satisfaction, the written informed consents were obtained from all of participants. The study was conducted according to Helsinki principals and financially supported by Shiraz University of Medical Sciences grants (NoCT-9378-7058) and registered in Iranian Registry of Clinical Trials (IRCT No: IRCT 2014072018468N3) of the Ministry of Health and Medical Education.

All patients filled out the questionnaires of demographic data and brief illness perception (BIPQ). Finally, the patients were divided into two experimental and control groups, using block randomization method with 6 blocks.

The inclusion criteria in the study was being within 18 – 65 age, having heart failure diagnosed by a cardiologist, being included in class II heart failure, the patient’s or family member’s (an active member who has the most important role in caring the patient) willingness to participate in the study, being poorly literate, knowing Farsi well, not having severe mental diseases and taking part in the same interventional program. The exclusion criterion was having class IV heart failure.

The number of samples was specified based on the previous studies\textsuperscript{23} and three patients in each group were determined based on the mean difference formula, using Power SSC with regard to type I error probability (α) equating to 0.05 and test power (B-1) equating to 90%, mean difference equating to 7.63 and SD= 0.72. This small sample size indicates the effectiveness of the model in previous studies. In order to prevent the attrition and regarding the resources available in each group, we selected 70 subjects in the two groups; 35 subjects each group (Figure1).

The instruments used in this study were a questionnaire including demographic data and BIPQ.

A) The questionnaire including demographic data was designed with regard to the comments of four cardiologists. It consisted of 7 questions to be filled out by the patients.

B) In order to review the illness perception, the B-IHQ was used. It provides a rapid assessment of illness perceptions, along the dimensions of consequences, timeline, identity, personal control, treatment control, emotional representation, concern and coherence. This questionnaire - the summary of illness perception - is a nine-point scale designed to investigate the cognitive and emotional representation of the patients. The scales rating 1 - 10 were presented in Likert scale (0-1 for none or very little; 2-3 for mild; 4-6 for average; 7-8 for severe; and 9-10 for highly severe). The causal representation was investigated by an open question asking the patient to make a list of three important causal factors in their
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There have been various studies to investigate the psychometric properties of BIPQ questionnaire. In this case, Broadbent et al., have performed a study in which the data were collected from six groups of patients with various illnesses. In this study, the internal reliability with Cronbach's alpha was 0.79-0.89 and retested at 3-6 week interval, also Pearson’s correlation coefficient was estimated at 0.50-0.75. The simultaneous validity was approved by comparing a short form of Illness perception questionnaire with the revised form of main version in which the correlation between two scales was reported to be 75%-82%. The psychometric of the mentioned materials in Iranian patients with heart disease has been investigated and the results suggested the content validity (>75%) and reliability (>0.8).

This study included two control and experimental groups and the intervention was done on the experimental group taking 8 weeks; the control group received the routine treatments. In this study, in order to achieve the aims outlined before, a family-centered empowerment model was used. So, the family-centered empowerment model-based intervention was carried out in four steps. The intervention was done by two members of the research team who are experts in the implementation of family-centered empowerment model. So, the method of implementing educational intervention is the same for all contributors and has stable performance.

**Step 1 (perceive the threat)**
This step was taken in two 1-2 hour sessions. During these sessions, some information related to the heart disease. For the interpretation of the data included in the questionnaire (improvement/correction of illness perception based on the domains), the score of each domain was compared with itself and the report. There have been various studies to investigate the psychometric properties of BIPQ questionnaire. In this case, Broadbent et al., have performed a study in which the data were collected from six groups of patients with various illnesses. In this study, the internal reliability with Cronbach's alpha was 0.79-0.89 and retested at 3-6 week interval, also Pearson’s correlation coefficient was estimated at 0.50-0.75. The simultaneous validity was approved by comparing a short form of Illness perception questionnaire with the revised form of main version in which the correlation between two scales was reported to be 75%-82%. The psychometric of the mentioned materials in Iranian patients with heart disease has been investigated and the results suggested the content validity (>75%) and reliability (>0.8).

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**Step 1 (perceive the threat)**
This step was taken in two 1-2 hour sessions. During these sessions, some information related to the heart failure was presented to the patient and his attendant by group discussion and training manual.

**Session 1:** during the first session, cases like the nature of disease, pathophysiology, etiology and clinical demonstrations were educated by group discussion and training manual.

**Session 2:** during the second session, by asking 2-3 questions from the patients, what reserved from the previous session was assessed. Then, in this session, items like the side effects of disease, drug and food therapy were trained by group discussion and training manual.

**Step 2 (self-efficacy)**
**Session 3:** this step was taken within a 1-2 hour session. At the beginning of this session, what was acquired from the previous session was assessed by asking 2-3 questions of the patients. In this step, the problems were resolved by group study aiming at increasing the self-efficacy, self-esteem and self-control. For this purpose, the problem solving sessions were held in 3-5 person groups for the patients and their attendants, the patients practically faced with their problems and the process of problem solving, discussed their status and what they had done for solving similar problem, and then they chose solutions.

**Step 3 (self-belief)**
**Session 4:** this step was taken in a single one-hour session. In this step, the patients were asked to represent the discussed topics and what they’d learned in the previous sessions to the active members of family.

**Step 4 (assessment)**
**Session 5:** finally the assessment was done in this step. The control group received the routine and common trainings. After the completion of the intervention in experimental group, heart failure training pamphlets

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Figure 1. Consort flow diagram of the study
were handed out among them. Then, six weeks after the completion of intervention, an illness perception questionnaire was filled out by control and experimental groups.

The BIPQ was statistically analyzed regarding the aims of the study. Data were analyzed using SPSS 13 (SPSS Statistics; IBM Corporation, Chicago, Illinois, USA).

Normality test was done for quantitative dependent variables and non-parametric tests were done for non-normal distribution. For comparing the dimensions of cognitive and emotional representations before and after the educational intervention and also between both groups Wilcoxon non-parametric and Man-Whitney non-parametric test were used, respectively. For investigating the homogeneity of quantitative and qualitative demographic data, independent t-test and chi square test were used, respectively. P-value less than 0.05 was significant.

Results
The demographic data of samples are shown in Table 1. In the present study, there was no significant relationship between the quantitative demographic variables like age, BMI and the duration of disease. In an investigation of the qualitative variables of demographic data (education level, gender, history of diabetes, hyperlipidemia, blood pressure and smoking history), it was determined that both control and intervention groups were homogenous before the intervention, all dimensions of illness perception except for the time line were similar between the two groups (Table 2). There is a statistically significant difference between the cognitive and emotional dimensions, before and after the intervention (P<0.05). The most and the least changes were related to concern 1.09 (0.61) vs 3 (0.93), P <0.05 and identity dimensions 0.97 (0.61) vs 2.11 (0.67), P <0.05, respectively. Also, after the educational intervention, statistically significant difference was observed between the two groups in all dimensions of illness perception (P<0.05) except for the time line. But, the results from the present study did not show any significant differences between the cognitive and emotional dimensions in the control group in pretest and posttest. Also, the results suggested that, before the educational intervention, both groups mentioned the stress (31% and 28%) and some factors related to aging are the most (28.5% and 30.3%) as the important causal factors of cardiac diseases and reported that aging is a factor having the least effect (7% and 9.2%).

Table 1. Demographic data of samples in control and intervention groups

| Variable                   | Control group N (%) | Intervention group N (%) | P       |
|---------------------------|---------------------|--------------------------|---------|
| Age*                     | 52.20 (9.49)        | 50.23 (8.28)             | 0.52    |
| Duration of illness*      | 30.12 (64.34)       | 23.23 (40.73)            | 0.39    |
| BMI*                     | 23.69 (4.04)        | 24.23 (5.62)             | 9.62    |
| Level of education        |                     |                          | 0.56    |
| Elementary                | 21 (36.8)           | 11 (31.4)                |         |
| Guidance school           | 7 (20)              | 7 (20)                   |         |
| High school               | 2 (19.7)            | 9 (25.7)                 |         |
| Diploma                   | 2 (19.7)            | 2 (5.7)                  |         |
| Above diploma             | 1 (18.5)            | 6 (17.1)                 |         |
| Gender                    |                     |                          | 0.8     |
| Female                    | 19 (54.3)           | 21 (60)                  |         |
| Male                      | 16 (45.7)           | 14 (40)                  |         |
| History of diabetes       |                     |                          | 0.44    |
| Yes                       | 9 (25.7)            | 13 (37.1)                |         |
| History of high blood pressure |                 |                          | 0.20    |
| Yes                       | 9 (25.7)            | 15 (42.9)                |         |
| History of blood fat      |                     |                          | 0.31    |
| Yes                       | 9 (25.7)            | 14 (40)                  |         |
| History of smoking        |                     |                          | 0.45    |
| Yes                       | 13 (37.1)           | 10 (28.6)                |         |

*Mean (SD)

After the educational intervention, the experimental group referred to life style as one of the important factors which causes heart failure and has many effects (36%). They mentioned that aging does not have so much effect on cardiac diseases (5%). In control group, after the educational intervention, the effect of stress and life style on cardiac diseases was the same (27% and 30.5) and also these two factors and aging are the most and least important factors, respectively (8.7%). Table 2 shows the comparison of scores of cognitive and emotional representations between both groups before and after the educational intervention. The comparison of scores of illness perception in both groups before and after the intervention is shown in Table 3.

Table 2. Comparing the scores of illness perception in control and intervention groups before and after the intervention

| Time Dimensions       | Control group | P   | Z    | Intervention group | P   | Z    |
|-----------------------|---------------|-----|------|---------------------|-----|------|
|                       | Before the    | After the    |       | Before the         | After the   |     |
|                       | intervention  | intervention |       | intervention       | intervention |     |
|                       | Mean (SD)     | Mean (SD)    |       | Mean (SD)          | Mean (SD)   |     |
| Consequences          | 2.74 (0.65)   | 2.80 (0.63)  | 0.69  | -3.89              | 2.86 (0.84) | <0.001  |
| Time line             | 2.74 (0.81)   | 2.77 (0.80)  | 0.94  | -0.06              | 2.69 (0.75) | 0.60  |
| Personal control      | 1.51 (0.98)   | 1.43 (0.94)  | 0.58  | -0.54              | 1.17 (0.82) | <0.001  |
| Treatment control     | 2.37 (0.69)   | 2.09 (0.88)  | 0.097 | -1.66              | 2.06 (0.83) | <0.001  |
| Identity              | 2.03 (0.61)   | 2.11 (0.67)  | 0.53  | -0.63              | 2.40 (0.73) | <0.001  |
| Concern               | 3 (0.84)      | 3 (0.93)     | 0.89  | -0.13              | 3.43 (0.60) | <0.001  |
| Integrity             | 0.86 (0.77)   | 0.97 (0.89)  | 0.61  | -0.50              | 0.69 (0.67) | <0.001  |
| Emotional representation | 2.77 (0.54) | 2.80 (0.53)  | 0.81  | -0.23              | 3.06 (0.48) | <0.001  |
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Table 3. Comparing the scores of illness perception between control and intervention groups before and after the intervention

| Time dimensions         | Before the intervention | P  | Z  | After the intervention | P  | Z  |
|-------------------------|-------------------------|----|----|-------------------------|----|----|
|                         | Intervention Mean (SD)  |    |    | Control Mean (SD)       |    |    |
| Consequences            | 2.86 (0.84) 2.74 (0.65) | 0.42| -0.79 | 0.80 (0.7) 2.80 (0.63)  | < 0.001 | -6.94|
| Time line               | 2.69 (0.75) 2.74 (0.81) | 0.68| -0.40 | 0.97 (0.51) 2.77 (0.80)  | 0.59 | -6.77|
| Personal control        | 1.17 (0.82) 1.51 (0.98) | 0.12| -1.51 | 3.23 (0.49) 1.43 (0.94)  | < 0.001 | -6.46|
| Treatment control       | 2.06 (0.83) 2.37 (0.69) | 0.11| -1.59 | 3.49 (0.56) 2.09 (0.88)  | < 0.001 | -6.11|
| Identity                | 2.40 (0.73) 2.03 (0.61) | 0.1 | -2.37 | 0.97 (0.61) 2.11 (0.67)  | < 0.001 | -5.78|
| Concern                 | 3.43 (0.60) 3 (0.84)    | 0.1 | -2.33 | 1.09 (0.61) 3 (0.93)    | < 0.001 | -6.46|
| Integrity               | 0.69 (0.67) 0.86 (0.77) | 0.36| -0.90 | 2.49 (0.70) 0.97 (0.89)  | < 0.001 | -5.82|
| Emotional representation| 3.06 (0.48) 2.77 (0.54) | 0.2 | -2.20 | 1.20 (0.58) 2.80 (0.53)  | < 0.001 | -6.91|

Also, Table 4 shows the frequency of illness perception with regard to the cause of disease in samples, before and after the intervention in both groups.

Table 4. Distribution of frequency of illness perception with regard to the cause of disease in samples before and after the intervention

| Groups reason      | Control group | Intervention group |
|--------------------|---------------|--------------------|
|                    | Before        | After              | Before        | After              |
| Stress             | 31            | 30                 | 28            | 33.3               |
| Inheritance        | 13            | 14                 | 11            | 9                  |
| Diabetes           | 10.6          | 12                 | 12.3          | 15.6               |
| Life style         | 28.5          | 27                 | 30.3          | 36.8               |
| Aging steps        | 7             | 8.7                | 9.2           | 5.4                |
| No answer          | 9.9           | 8.3                | 10.2          | 0                  |

Discussion

In this study, the effect of family-centered empowerment model was investigated on illness perception (cognitive and emotional representation) in heart failure patients. Overall, after the educational intervention, the heart failure patients perceived the all dimensions better than before (consequences, personal control, treatment control, identity, concern, integrity and emotional representation); except for the time line dimension which the patients considered their illness less chronic after the intervention. Given the non-significant changes of time line, interpretation in this dimension may not be correct or even possible, and further consideration should be given to this topic in future studies.

In other words, the results showed that all of the above mentioned dimensions, except for the time line, were significantly different before and after the intervention. Also, there was a significant difference between the control and experimental group, which underlines the effect of family based empowerment model on the illness perception in heart failure patients. With regard to the results from the present study, the key point is the significant changes from the illness perception of experimental group rather than the control group. So that the biggest and the smallest changes were related to the concern and identity, respectively. In the present study, regarding the dimension of consequences, patients considered that their illness had effect on their life, but after the intervention, they found it less effective.

These results were in line with those of the study aiming at changing the incorrect and negative perception and the viewpoint of patients about the side effects of heart attack. They concluded that, by doing a short hospital intervention, there will be considerable positive changes in viewpoint of patients about the heart attack regarding the above-mentioned dimensions. In the present study, there was a significant difference in dimensions of concern, consequences, treatment control (curability), emotional representation and integrity in heart failure patients before and after the intervention.

The data are consistent with the results of Broadbent et al., study suggesting the considerable effects on dimensions of concern, consequences, treatment control, emotional representation and integrity after the intervention. They reported that patients considered the disease more curable after the intervention while they found less concern, consequences and emotional representation related to disease. So, the previous studies approved that training the patients on illness perception may increase their perception of the dimension of concern, consequences, treatment control, emotional representation and integrity. Also Broadbent et al., concluded that educating heart failure patients about illness perception could decreases stress and improve the health state of patients in intervention group rather than the control group. In fact, the above mentioned results approve of or are consistent with the results of the present study.

The present study is not consistent with the results of Alsén et al., in terms of the dimensions of time line and illness control. They observed that the patients’ illness perception will change after the heart attack with regard to time line and illness control. Although these patients considered these conditions acute and severe at the very early stages of illness, they believed its chronicity.

However, in the present study, the patients considered the illness less chronic after the educational intervention. They also concluded that personal control (controllability) and treatment control (curability) had been improved in their study, which is consistent with the results of the present study. It seems that the reason for the difference in perception of the time line in the study of Alsén et al., is due to the type of research and intervention. Alsén’s study is a descriptive research while ours is an interventional one. It does not sound quite likely that controlling the disease could make the patient’s illness chronic after the intervention. As
previously mentioned, further studies are needed in this area to identify the changes in the time line dimension.

Besides, the heart failure patients considered stress and life style as the most important reasons of illness. These results are relatively similar to those of the study in which the patients with cardiovascular diseases regarded diet, inheritance and stress as the most important causes of their illness. Also, in another study, the patients who had survived a heart attack mentioned high cholesterol and lack of activity as the reasons of the illness. Thus, in previous studies, the inheritance, stress and life style were known as the most important factors of illness.

Regarding the dimensions of cognitive and emotional representations before the intervention, comparing the mean of scores of illness perception suggested that these two groups were homogeneous; but after the intervention, the mean of score of illness perception in intervention group was different from that in the control group.

The obtained results show that the empowerment model has an effect on the illness perception relating to the concern, consequences, treatment control (curability), emotional representation, personal control, integrity and identity. These results are consistent with those of the studies done by Rakhshan et al., aiming at investigating the effect of Leventhal - based education on the illness perception of patients with pacemaker, where they concluded that after doing the training intervention, patients expected a little consequence and intensity compared to pre-intervention, they found their illness controllable and curable, had more integrity with their illness and showed less concern and anxiety. They also concluded that patients with pacemakers considered their illness more chronic after the educational intervention while in the present study, the empowerment model did not affect the illness perception in heart failure patients regarding the time line which there was no consistence. This difference might have resulted from the mode of training used in both groups. Specially, in the study by Rakhshan, the educational program was designed with respect to the needs which needs to be considered in future studies.

In a study done on survivors of heart attack, researchers declared that not only did the intervention make positive changes in viewpoints of patients who had experienced a heart attack, but also there was an improvement in functional consequences of patients. Although, in the mentioned study, various factors have been considered in prediction models. In the present study, with regard to the emotional and cognitive representation, the perception of heart failure was investigated before and after the educational intervention. Accordingly, the results of the aforementioned study confirmed those of the present study regarding the positive changes made after the educational intervention in viewpoint of heart failure patients as well as patients who experienced a heart attack.

Karol et al., concluded that training illness perception decreases the mental stress in heart failure patients. Also, Paryad et al., concluded in their study that there is a direct relationship between illness perception and general self-efficacy in patients with cardiovascular diseases. The others believed that nursing care will be more effective when it’s based on the patient’s illness perception and experience.

One of the limitations of the study was the problems that the participants had attending the educational classes, so it is recommended that web- based studies be designed for this group of patients to minimize the problems of attending educational classes. Subjects were hired from hospital-affiliated universities; results should not be generalized to all Iranian patients or patients with similar traits from other regions or countries. Further studies are recommended in other clinical settings, chronic diseases and other aspects of heart failure patients based on the family-centered empowerment model.

Conclusion

Finally, with respect to rising the heart failure cases, its effects on the patients’ life and the importance of illness perception in controlling this disease, it is required that nurses seek to find ways to improve illness perception. This study suggested the effects of family based empowerment model on illness perception. Accordingly, this model is used for improving and modifying the illness perception in heart failure patients. Cardiac nurses should consider the family based empowerment model as a treatment for heart failure patients.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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