

Research Paper:

Effect of Family-Centered Empowerment Model on the Care Burden of the Caregivers of Older Adults with Heart Failure



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ABSTRACT

Background: Developing a chronic disease, like heart failure in older adults disrupts the foundations of the family and imposes a heavy burden on family members. The aim of this study was to determine the effect of the Family-Centered Empowerment Model (FCEM) on the care burden of family caregivers of older adults with heart failure.

Methods: It was a quasi-experimental study with a controlled before and after design, which was conducted on 80 primary caregivers of older adults with heart failure referring to health centers affiliated with Kashan University of Medical Sciences, Kashan, Iran. The subjects were non-randomly assigned to either the control (n=40) or intervention (n=40) groups. The program was implemented based on the concepts of the model (perceived threat, self-efficacy, self-esteem, and evaluation) in eight 2-hour sessions, twice a week for four consecutive weeks. Both groups answered the Zarit Burden Interview (ZBI) in the beginning, in the end, and one month after the study. The data were analyzed by Chi-square, t-test, and the repeated measures ANOVA using SPSS 16 software.

Results: There was no significant difference between the two groups regarding the pretest mean score of care burden ($P>0.05$). However, the groups' mean score of care burden was significantly different immediately after the intervention ($P<0.05$) and one month after the study ($P<0.05$). The repeated measures ANOVA illustrated a significant difference between the mean scores of care burden in the three measurement time points ($P<0.0001$).

Conclusion: Implementation of the FCEM model reduces the burden of care in caregivers of older adults with heart failure. It is suggested that this model be used in training programs for older adults with heart failure and their caregivers.

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Highlights

- Heart failure is one of the most common cardiovascular disorders worldwide.
- Caregiver burden is the physical, psychological, and social responses of the caregiver to the imbalance between caring needs and their other tasks.
- The family-centered empowerment model reduces the caregiver burden in caregivers of older adults with heart failure.

Plain Language Summary

Heart failure is the inability of the heart to pump enough blood to meet the tissues' need for oxygen and nutrients, which could lead to shortness of breath, swelling of the ankles and legs, cognitive impairment, fatigue, lethargy, and weight gain due to fluid retention. Neglecting the training of patients with heart failure and their family caregivers is the most important defect in the process of treatment and caring for these patients, which makes the patients more likely to be readmitted to the hospital. Family caregivers experience many problems in response to the imbalance between meeting the caring needs of their patients and other tasks of themselves. The results of this study revealed that the family-centered empowerment model reduces the caregiver burden in family caregivers of older adults with heart failure.

1. Introduction

Hear Failure (HF) is one of the most common cardiovascular disorders worldwide. HF, often defined as congestive HF, is the inability of the heart to pump enough blood to meet the tissues' need for oxygen and nutrients (Casimir et al. 2013). Approximately 1% of the population over the age of 50 and 10% of older adults over the age of 80 suffer from HF (Salehi, Mehralin & Hasheminia 2016). The 5-year mortality of HF has been reported as 45% in women and 60% in men (Chong, Ding & Heng 2011). Shortness of breath, especially when lying down, swelling of the ankles and legs, cognitive impairment, fatigue, lethargy, and weight gain due to fluid retention are the most prevalent symptoms of HF (Chong, Ding & Heng 2011; Kato et al. 2009).

According to the New York Heart Association, HF has four classes in terms of its impact on daily activities. In class one (mild), there are no restrictions on physical activity. In class two (mild), there are slight restrictions in physical activity, in class three (intermediate) there are significant limitations in physical activity, and in class 4, doing any physical activity is accompanied by a feeling of discomfort (Nomali et al. 2017).

The incidence of HF in older adults is worrying and anxious for patients and their families (Rezai et al. 2017). The occurrence of chronic diseases in older adults disrupts the foundations of the family and imposes a heavy burden on family members (Kato et al. 2009).

Neglecting the education of patients with HF and their family caregivers is the most important defect in the process of treatment and caring for these patients, which makes the patients more likely to be readmitted to the hospital (Rezai et al. 2017; Utne et al. 2013) and increases the caregiver burden in their families.

Caregiver burden is the physical, psychological, and social responses of the caregiver to the imbalance between the caring needs of the patient and other tasks of the caregiver. This imbalance affects the caregivers' personal, social, physical, emotional, and financial status (Milbury et al. 2013). In this regard, caring for the elderly with HF creates many problems and pressures for the family caregivers of these patients (Dharmarajan et al. 2013).

High pressure on patients' caregivers may lead to family isolation, deprivation of social support, disruption of family relationships, inadequate patient care, and abandonment of the patient. Although poor self-care can exacerbate the disease, the quality of support and care provided by the family can also affect the quality of life of patients and their families (Milbury et al. 2013; Utne et al. 2013).

It has been reported that family caregivers of patients with type 2 diabetes experience a moderate burden (Bamari, Madarshahian & Barzgar 2016). Also, the family caregivers of patients with cancer have experienced a moderate burden (Mollaei et al. 2019). In another study, the family caregivers' burden of patients with breast cancer was reported as high (Vahidi et al. 2016). The patient's family is a key element in his/her recovery and

health (Rahimi Kordshooli, Rakhshan & Ghanbari 2018). Therefore, the empowerment of patients and their families has been considered in recent years. Promoting family members' caring knowledge and involving them in patient care help them gain a better understanding of the patient's condition, resolve patient problems more effectively, and better manage their physical and mental stress.

The Family-Centered Empowerment Model (FCEM) emphasizes individual effectiveness and the role of other family members in three dimensions of motivational, psychological (self-esteem and self-control), and problematic individual characteristics (knowledge, attitudes, and perceived threat) (Heidari et al. 2007). Family empowerment has three main characteristics, including the ability to review the required educational resources, the ability to make decisions and solve problems, and the ability to communicate to meet existing needs (Sanaie et al. 2014). The FCEM includes four major steps: (1) perception of threat, (2) self-efficacy, (3) self-esteem, and (4) evaluation. Therefore, in order to achieve the best result, it is expected that the FCEM can simultaneously increase knowledge, skills, values, and beliefs of self-confidence and self-control in the patients and their families (Moattari et al. 2012).

The FCEM helps plan, implement, and evaluate health care through reciprocal partnerships of caregivers, patients, and families (Bamari, Madarshahian & Barzgar 2016). Studies have shown that continuous training and empowerment of primary caregivers can significantly reduce patient readmission and mortality (Bamari, Madarshahian & Barzgar 2016; Mollaei et al. 2019).

The effects of the FCEM have been studied in various diseases. The application of FCEM could improve the lifestyle of patients with HF (Rahimi Kordshooli, Rakhshan & Ghanbari 2018). The effects of FCEM on reducing the care burden of caregivers of children with epilepsy (Shoghi, Shahbazi & Seyedfatemi 2019) and reducing the perceived threats in patients with HF (Rahimi Kordshooli, Rakhshan & Ghanbari 2018) has also been confirmed. However, the effect of using this model on the care burden of family caregivers of older adults with HF has not received much attention.

Accordingly, this study was carried out to determine the effect of using FCEM on the care burden in caregivers of older adults with HF.

2. Materials and Methods

Design, setting, and sample

This research was a quasi-experimental study with a controlled before and after design, which was conducted in 2019 on 80 primary caregivers of older adults with HF. Their patients were previously admitted to health centers affiliated with the Kashan University of Medical Sciences, Kashan, Iran.

Criteria for inclusion of caregivers were being primarily responsible for caring for the elderly with HF as a family member, caring for the patient for at least 6 months, and being literate. The patients were elderly people over 60 years with a definite diagnosis of HF and the absence of other major diseases, such as malignancies. Patient death, hospitalization during the study, change of the caregiver during the study, and being absent for more than two sessions were considered exclusion criteria.

The patients were found by reviewing the records available in the heart failure clinics of the health centers. They were then contacted via the available telephone number and their primary caregivers were invited to participate in the study. If the subject agreed to participate in the study, a meeting was held with the presence of groups of six caregivers and the objectives of the research were explained to them.

The sample size was estimated based on the findings of a former study (Mollaei et al. 2019) and the formula for comparing two means. Then, considering the type I error of 0.05, type II error of 0.20, μ_1 of 55.37, and μ_2 of 43.68, the sample size was estimated to be 32 per group. However, considering a possible dropout of 20%, the sample size increased to 40 per group.

A total of 108 patients and their primary caregivers were consecutively assessed for eligibility, of whom 28 cases were excluded (19 lacked the inclusion criteria and 9 were dissatisfied with participation in the study). Those with inclusion criteria were non-randomly allocated to the control ($n=40$) and experimental ($n=40$) groups. No one lost the follow-up during the study (Figure 1).

Instruments

The data were collected by a demographic information form and Zarit Burden Interview (ZBI). The demographic questionnaire included items on the caregiver's age, sex, marital status, occupation, and education, as well as the patient's HF class, and the duration of HF. The ZBI (Cre-

spo et al. 2005) consists of 22 items that are answered on a 5-point Likert scale from 0 (never) to 4 (always). Accordingly, the total scores can range between 0 and 88. Scores 0-20 indicate no burden, whereas scores 21-40, 41-60, and 61-88 are regarded as moderate, moderate to the severe, and severe burden, respectively. The validity and reliability of the Persian version of the ZBI have already been assessed in earlier studies and the scale's test-retest reliability coefficient and Cronbach's alpha were reported as 0.85 and 0.88, respectively (Mollaie et al. 2019). Pahlavanzadeh also assessed the reliability of this scale with a test-retest reliability coefficient of 0.94 (Pahlavanzadeh, Navidian, & Yazdani 2010). The Cronbach's alpha was calculated to be 0.78 in the current study.

Intervention

Before the intervention, all the participants completed the demographic questionnaire and ZBI. The training program was then developed and implemented based on the FCEM steps, including perceived threats, self-efficacy promotion, self-esteem promotion, and evaluation for the intervention group. Training packages (i.e., pamphlets and training cards) were developed by the researchers using literature review and nursing and medical books, and confirmed by a group of cardiologists and nursing faculty members.

The program was implemented in four 10-person groups in four 120-minute sessions two days a week for four weeks. Each step was presented in two sessions. All the training sessions were presented by the first researcher with the support of a cardiologist and a psy-

Table 1. The outline of the program based on the Family-Centered Empowerment Model

Steps	Objectives	Content	Method	Presenter
Step one (perceived threat)	<ul style="list-style-type: none"> - Introducing the role of caregiver in ensuring the patient's health - Improving the participants' knowledge and skills about the disease, strengthening realistic expectations regarding the prognosis and treatment of the disease 	<ul style="list-style-type: none"> - The roles of caregiver and family in disease control and patient care - Challenges of the family in patient care - Strategies to promote caregiver support - The nature of the disease 	Lecture, question and answering, group discussion, sharing caregivers' experiences, PowerPoint presentation, educational booklet	Cardiologist, the researcher
Step two (promotion of self-efficacy)	<ul style="list-style-type: none"> - Improving the participants' knowledge and skills about medication therapy - Increasing the caregiver's readiness in caring for the patient - Improving caregiver's confidence and control over the patient care - Improving the caregiver's and patient's communication skills and adaptability in patient care - Reducing the stress and pressure caused by the care provision 	<ul style="list-style-type: none"> - The importance and the role of medications in preventing disease recurrence - Familiarity with medications, side effects and related care - Adaptation skills, stress management skills, effective communication with the patient, problem solving methods and time management 	Lecture, question and answering, group discussion, sharing caregivers' experiences, educational CD, telephone counseling and follow-up	The researcher, a psychiatric nurse
Step three (promotion of self-esteem)	<ul style="list-style-type: none"> - Maintaining and promoting the health of the caregiver - Increasing the caregiver's information about the accessible support resources and how to use them - Increasing the caregiver's information on how to care for the patient - Increasing the caregiver's readiness to care for the patient, improving the caregiver's confidence and control over the patient care situations 	<ul style="list-style-type: none"> - The importance of self-care (adequate sleep and rest, receiving psychological support from family and others) - Introducing the available support resources and educational services - Patient care during the crisis of symptoms, when and how to refer the patient to medical centers when a crisis occurs 	Lecture, question and answering, telephone counseling and follow-up	The researcher
Step four (evaluation)	Determining perceived threat, self-efficacy and self-esteem of the caregivers	<ul style="list-style-type: none"> - Summarizing the content presented in previous sessions - Answering to the questionnaire and final evaluation 	Lecture, question and answering, PowerPoint presentation	The researcher

chiatric nurse (Table 1). At the end of each session, the topics were summarized, participants' questions were answered, and the date and purpose of the next session were announced. At the beginning of the next session, caregivers were asked questions to ensure that they understood what was presented in the previous session.

The researchers also provided participants with their phone numbers; hence, they could call and get advice if they had any questions. Also, the first researcher contacted the subjects once a week to be informed about the implementation process of the programs. Both groups received routine care (self-care, diet, medication, physical activity, and daily activities); however, at the beginning and end of the intervention, care measures, such as controlling blood pressure and blood sugar were taken to encourage them to stay in the study. Immediately after the intervention and one month later, all the subjects were invited to the health center again and completed the ZBI.

Data analysis

The data were analyzed using the SPSS software version 16. (SPSS Inc., Chicago, IL, USA). The normality of quantitative variables was examined using the Kolmogorov-Smirnov test. Descriptive statistics (frequency, percentage, mean, and standard deviation) were used to describe and classify the data. The Chi-square test was

used to compare the mean of demographic and clinical variables. The t-test was used to compare the mean caregiver burden scores between the two groups before, immediately after, and one month after the intervention. Repeated measures Analysis of Variance (ANOVA) was used to compare the mean caregiver burden between the three measurement time points. The level of significance was set at <0.05 .

3. Results

The Mean \pm SD age of the older adults in the intervention and the control groups was 68.02 ± 8.62 and 67.6 ± 8.40 , respectively. Also, the Mean \pm SD age of the caregivers in the intervention and control groups was 40.8 ± 6.55 and 41.80 ± 5.12 , respectively. Other demographic characteristics are shown in Tables 2 and 3. The Chi-square test showed no significant difference between the intervention and the control groups respecting participants' demographic characteristics ($P>0.05$; Tables 2 and 3).

There was no statistically significant difference between the groups respecting the pretest mean scores of ZBI ($P>0.05$). However, the mean caregiver burden score was significantly different between the intervention and the control groups, immediately after ($P<0.05$) and one month after the intervention ($P<0.05$). The results of repeated measures ANOVA illustrated a significant differ-

Table 2. Characteristics of the older adults with heart failure in the control (n=40) and intervention (n=40) groups

Variables	No. (%) or Mean \pm SD		P*	
	Control Group	Intervention Group		
Sex	Female	26(65)	26(65)	1
	Male	14(35)	14(35)	
Education level	Below high school diploma	24(60)	23(57.5)	0.39
	High school diploma and over	16(40)	17(42.5)	
Marital status	Single	9(22.5)	11(27.5)	0.78
	Married	31(77.5)	29(72.5)	
Occupation	Employed	21(52.5)	22(55)	0.96
	Unemployed	19(47.5)	18(45)	
Heart failure class	Class II	22(55)	24(60)	0.76
	Class III	18(45)	16(40)	
	Age, year**	67.6 \pm 8.40	68.2 \pm 8.62	0.80
	Duration of heart failure, year**	3.92 \pm 1.45	3.90 \pm 1.33	0.94

*Chi-square test; **Independent t-test.

Table 3. Characteristics of the caregivers in the control (n=40) and the intervention (n=40) groups

Variables	No. (%) or Mean±SD		P*	
	Control Group	Intervention Group		
Sex	Female	25(62.5)	1	
	Male	15(37.5)		
Education level	Less than high school diploma	18(45)	0.39	
	High school diploma and over	22(55)		
Marital status	Single	10(25)	0.78	
	Married	30(75)		
Occupation	Employed	22(55)	0.96	
	Unemployed	18(45)		
Age, year**		41.8±5.12	40.8±6.55	0.51

*Chi-square test; **Independent t-test.

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ence between the mean ZBI scores in the three measurement time points ($P<0.0001$). In other words, over time, the mean caregiver burden scores significantly decreased in the intervention group, while it did not significantly change in the control group. The effect of the group variable was also statistically significant ($P<0.05$; Table 4).

4. Discussion

HF imposes many physical, psychological, social, and economic burdens on patients' families (Thornton et al. 2008) and caregivers of these patients perceive high levels of burden (Ponikowski et al. 2014; Savarese & Lund 2017). Families and caregivers with less supportive resources are more likely to suffer from a high burden and stress (Carlson & Miller 2017).

The present study showed that the implementation of FCEM reduced the caregiver burden in caregivers of older adults with HF. Some studies have examined

the effect of this model on the burden perceived by the caregivers of patients with Parkinson's disease (Shoghi, Shahbazi & Seyedfatemi 2019) and cancer (Bagheri et al. 2019) and reported that it could significantly decrease the caregiver burden. It has also been reported that training the family can improve patients' clinical status and social functioning as well as relatives' perceived burden (Magliano et al. 2006). Using the FCEM significantly increased the perceived self-efficacy in caregivers of patients undergoing heart valve replacement (Abedini, Zareiyan & Alhani 2020). Nonetheless, Garcia et al. reported that a family-centered intervention did not significantly affect family functioning, health behaviors, medication follow-up, knowledge of the disease, and caregiver burden (García-Huidobro et al. 2011). This difference might be related to the differences in subjects, settings, cultural contexts, and training methods.

Our findings along with the aforementioned studies confirmed that implementation of FCEM is effective in

Table 4. The Mean±SD burden scores in the three measurement time points

Variable	Group	Intervention			P*		
		Before	Immediately After	After One Month			
		Mean±SD			Group	Time×Group	Time
Caregiver burden	Intervention	69.93±0.40	57.05±0.37	44.08±0.49	<0.0001	<0.0001	<0.0001
	Control	69.89±0.50	69.90±0.38	69.97±0.56			
	P [‡]	0.93	<0.001	<0.001			

*Repeated measure analysis; [‡]Independent t-test.

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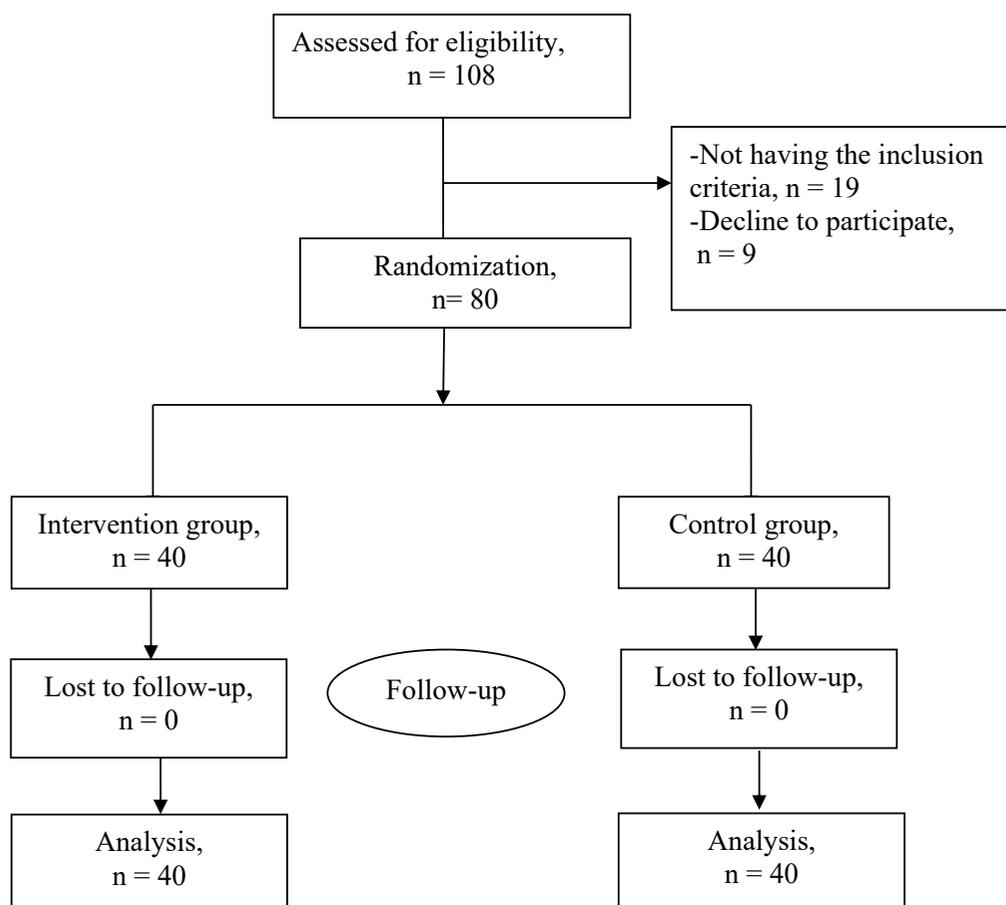


Figure 1. The study flow diagram

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decreasing the burden perceived by the family caregivers of older adults with HF. Tan (2006) also emphasized that accompanying a family member with the patient in educational classes not only improves the quality of care but also increases the effectiveness of training in preventing complications of the disease and reduces the burden on the caregiver (Tan 2006). In this regard, caregivers' satisfaction will increase and their perceived caring burden will decrease (Abedini, Zareiyan & Alhani 2020; Magliano et al. 2006). Using the empowerment model focusing on the management of care programs leads to reduced burden of care and improving the role of caregivers. Therefore, considering the effectiveness of this intervention and the persistence of its effect over time, it is recommended to implement FCEM programs for caregivers of patients with HF.

5. Conclusion

The results of the study showed that the implementation of the FCEM reduces the burden of care in caregivers of older adults with HF. Therefore, special attention

should be paid to empowering the families of these patients. Due to the ease and low cost of this program and the high prevalence of HF, nurses and other health care providers are recommended to train and empower family members of patients with HF using FCEM. It is recommended that similar studies be performed on caregivers of patients with other heart diseases and heart problems using random group assignments. It should be noted that differences in the level of learning of family caregivers as well as the difficulty of transmitting what they have learned to elderly patients in the family have been beyond the control of the researchers.

Ethical Considerations

Compliance with ethical guidelines

The permission to conduct the study was obtained from the Ethics Committee (Code: IR.KAUMS.NUHEPM.REC.1398.065) and Vice Chancellor for Research of Kashan University of Medical Sciences. All the study participants signed written informed consent, and all their rights were observed according to the latest version of the

Helsinki Declaration. The subjects were assured that participating in the study would not cost them anything. They can withdraw from the study at any time. Their participation or withdrawal would not affect their treatment process.

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Authors' contributions

Conceptualization: Ismail Azizi-Fini and Sedighe Jafari-Diziche; Design: Ismail Azizi-Fini and Fateme-Sadat Izadi-Avanji; Definition of intellectual content: Ismail Azizi-Fini, Seyed Majid Derakhshandeh and Fateme-Sadat Izadi-Avanji; literature search: Ismail Azizi-Fini and Sedighe Jafari-Diziche; Data acquisition: Sedighe Jafari-Diziche, Seyed Majid; Data analysis: Fateme Atoof; Manuscript preparation: Ismail Azizi-Fini and Sedighe Jafari-Diziche; Manuscript editing and manuscript review: Ismail Azizi-Fini, Seyed Majid Derakhshandeh, and Fateme-Sadat Izadi-Avanji.

Conflict of interest

The authors declared no conflict of interest.

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