

# The Effect of a Family-Centered Care Intervention Model on the Health Literacy of Family Caregivers of Heart Failure Patients

## Abstract

**Background:** Heart failure (HF) is considered a chronic and debilitating condition that, in addition to imposing heavy costs on the individual and society, creates many problems and has numerous consequences for patients and their families. Caregivers face challenges in patient control and care due to insufficient awareness and knowledge. The purpose of the present study is to investigate the effect of the family-centered care (FCC) intervention model on health literacy in family caregivers of HF patients. **Materials and Methods:** This quasi-experimental, two-group study with a pretest-posttest design was carried out on 100 people assigned to the experimental and control groups. The study population included caregivers of HF patients admitted to the medical teaching centers of Shahrekord, Iran, in 2022. Data were collected using the Health Literacy for Iranian Adults scale. Data analysis also carried out using descriptive and inferential statistics. **Results:** The mean health literacy scores were not significantly different between the intervention and control groups before the intervention. However, the mean health literacy score and its dimensions were significantly increased in the experimental group compared to the control group ( $t = 30.12$ , degrees of freedom = 98,  $p < 0.001$ ). **Conclusions:** The FCC program, as a simple, practical, and efficient program, can reduce the challenges of family caregivers and support them more by improving their level of health literacy.

**Keywords:** Family caregivers, family centered, health literacy, heart failure, nursing

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## Introduction

One of the most common chronic heart diseases is Heart Failure (HF), which has been recognized as an important disease worldwide in the last 20 years.<sup>[1]</sup> It has affected more than 64 million people worldwide, and its prevalence shows an increasing trend.<sup>[2]</sup> HF is expected to affect more than 8 million people in the USA by 2030, which indicates a 46% increase in its prevalence. At 40 years of age, the risk of HF for both sexes is one person per every five people.<sup>[3]</sup> The incidence rate of HF in Iran was reported to be 8%, which is higher than the rates reported in other countries of the region.<sup>[4]</sup> Improving knowledge and awareness as well as empowering caregivers through post-discharge training and continuous care are important for patients.<sup>[5]</sup> Family is the first and most important source of support in the care of chronic patients in Iran.<sup>[6]</sup> Fulfilling the informational needs of caregivers can play an important role in different stages of involvement and, in

turn, in increasing the personal, physical, and mental capacity of caregivers.<sup>[7]</sup> Due to the lack of disease-related information, and unawareness of patient needs and care, the families cannot provide effective care,<sup>[8]</sup> because nurses are often not aware of the strengths and weaknesses of the patient and caregiver.<sup>[9]</sup>

Researchers have found that poor knowledge and providing insufficient information to cope with the diagnosis have a negative impact on caregivers' ability to take care of the patient. As the caregivers of HF patients have poor health condition, it is considered an important issue.<sup>[10]</sup> One of the most influential factors on the level of awareness and, as a result, more effective control of HF is the health literacy of the caregivers.<sup>[11]</sup> Health literacy is a set of skills, abilities, and capacities in different dimensions, and refers to the capacity of people to acquire, process, and understand basic health information and services to make appropriate health decisions.<sup>[12]</sup> According

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## Access this article online

**Website:** <https://journals.iwwo.com/jnmr>

**DOI:** 10.4103/ijnmr.ijnmr\_303\_24

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**How to cite this article:** Gholami L, Moghaddasi J, Raeisi H, Etemadifar S. The effect of a family-centered care intervention model on the health literacy of family caregivers of heart failure patients. Iran J Nurs Midwifery Res 2026;31:100-5.

**Submitted:** 22-Sep-2024. **Revised:** 08-Apr-2025.

**Accepted:** 09-Apr-2025. **Published:** 02-Jan-2026.

to the Center for Health Care Strategies, people with little health literacy are less likely to understand the written and spoken information provided by health professionals and follow their instructions and, therefore, have a poorer health status.<sup>[13]</sup> In a study conducted in five provinces of Iran, it has been reported that participants had sufficient, borderline, and insufficient health literacy in 28.1%, 15.3%, and 56% of cases, respectively. Research has shown that poor health literacy is a major obstacle in the education of patients with chronic diseases and their caregivers.<sup>[14]</sup>

One of the ways to empower the family is the implementation of family-centered care (FCC), which establishes a close relationship between caregivers and the family. Considering that these interventions are cheap, safe, and, at the same time, effective, they can help the family caregivers of patients and increase the quality of their specialized care.<sup>[15]</sup> FCC includes four components: respect, receiving information, participation in care, and cooperation. Benefits of FCC include a reduction in stress and negative impacts of hospitalization, ensuring the adequacy of the discharge plan, and providing comfort and support to the patient.<sup>[10]</sup> Literature review showed that there have been few studies on the effects of the FCC intervention on HF patients. This model aims to recognize the needs of the family, and is based on a comprehensive philosophy and nursing care method in which the patient and the family are considered, accepted, and recognized as a unit of care by the healthcare providers; therefore, the present study aims to investigate the effect of FCC intervention on the health literacy of family caregivers of HF patients.

## Materials and Methods

The current research is a quasi-experimental study with a pretest–posttest design and experimental and control groups, and it was undertaken over a period of 3 months. From among 133 caregivers of HF patients admitted to Shahrekord Medical Teaching Centers, Iran, in 2022, 100 eligible people were selected. The convenience sampling method was used in the present study. According to the proposed sample size formula, the power of the test is 80% ( $\beta = 0.20$ ), the confidence interval is 95% ( $\alpha = 0.05$ ), and the standard deviation is 9. The number of patients needed in each group was calculated to be 50, and block randomization method with a block size of six was used. The inclusion criteria included age 18–65 years, having a family relationship with the patient, a history of at least 6 months of patient care, HF confirmed by a cardiologist, presence of echocardiography in the hospitalization file and an ejection fraction lower than 40% (class C and D),<sup>[16]</sup> non-participation in similar interventions, and reading and writing literacy. The exclusion criteria included unwillingness to continue participating in the study, undergoing surgery in the last month, and absence from the educational intervention for more than two sessions or patient death.

The intervention program was developed based on the results of a preliminary qualitative study that determined family caregivers' experiences of HF patients, which was confirmed by an expert panel and the existing literature.<sup>[17]</sup> The experimental group received the FCC intervention model, in addition to routine education and care. The intervention program consisted of five weekly multimedia training sessions of 1–2 h that included education and family support, which were held for five consecutive weeks. Five educative groups of 10 family caregivers were arranged with the same content. The control group only received routine hospital education and care. In the first session, after introduction, the researcher provided the family caregivers with a written curriculum that identified the learning objectives and teaching contents for each session. Then, the family caregiver's health literacy was assessed using the Health Literacy for Iranian Adults (HELIA) scale. In the second and fifth sessions, the family caregivers were informed about the nature and process of the disease, etiology and prevention, symptoms, course and prognosis, the misconceptions regarding HF, the importance of drug treatment and its role, how to care and deal with disease symptoms, the role of the caregiver and the family in controlling the disease, the problems of the family and caregivers of HF patients, the importance of self-care, and the development of skills needed to adapt to the role of the caregiver. In addition, the family caregivers were taught how to access resources providing support and educational services and the conditions in which it is necessary to refer patients to medical centers. The topics were presented using group discussion, educational booklets and Compact Disks, and PowerPoint. The purpose and content of the training sessions are summarized in Table 1. The health literacy level of the caregivers was also measured as an outcome variable using the HELIA scale in the last session and 2 months after the intervention.

The data collection tools employed in this study were a demographic characteristics form and the HELIA scale. The HELIA scale includes 33 items in the five areas of access (six items), reading skills (four items), comprehension (seven items), evaluation (four items), and decision-making and application of health information (12 items). The total mean score of the questionnaire was divided into four classes: insufficient (>50%), not very sufficient (50.1%–66%), sufficient status (66.1%–84%), and excellent score (84.1%–100%). The construct validity of the questionnaire was confirmed with 33 items in five dimensions using exploratory factor analysis. Furthermore, the reliability of this questionnaire was confirmed using Cronbach's alpha method with an alpha of 0.72–0.89.<sup>[18]</sup> Data analysis was carried out using descriptive statistics (mean, standard deviation, number, and percentage) and inferential statistics (*t*-test and analysis of variance [ANOVA]) in Statistical Package for the Social Sciences software (version 22; IBM Corp., Armonk, NY, USA).

**Table 1: Program content based on family-centered care intervention**

Session	Content	Goals	Methods
Orientation	Introduction of the instructor and family caregivers to each other and delivering an overview of the program and a written curriculum of the program Discussion of the importance of the program both for patients and caregivers Completion of a health literacy scale by family caregivers	To orient family caregivers to the program and to create a trustful relationship between the instructor and family caregivers	Lecture, question–answer
1	Emphasis on the importance of the caregiver’s roles in familial and societal health development Discussion about HF etiology, signs and symptoms, prevention, and prognosis Orientation toward several common HF drugs and their dangerous side effects and explanation of the importance of drug therapy in HF treatment process and in prevention of recurrence	To identify the role of caregivers in health development To understand the disease, its symptoms, and prognosis To recognize the effects of drugs and their side effects on the decrease of the recurrence of signs and symptoms	Lecture, question–answer group discussion Delivering educational booklet
2	Discussion about safety care and how to manage patient’s symptoms and refer the patient in an emergency situation Orientation toward the importance and need to change patient’s lifestyle (mobility and exercise, diet regimen, and quit smoking)	To promote their capability in caregiving To increase caregivers’ confidence and control on caregiving roles	Lecture, question–answer group discussion Delivering educational CD
3	Discussion about adaptation to caregiving roles by promoting coping strategies and skills (efficient communication with the patient, managing stress, and receiving more help from other family members) Orientation toward problem-solving method and time management in caregiving situations	To promote coping strategies To orient caregivers to stress management	Lecture, question–answer group consultation Personal phone consultation
4	Explanation of the importance of self-care in caregiving (adequate sleep and rest, and exercise)	To maintain and promote caregivers’ physical and mental health	Lecture, question–answer, introducing resources (supplemental insurance, emergency medical services, advisory services, and patient education center)

CD=compact disk, HF=heart failure

### Ethical considerations

This study was approved by the Research Ethics Committee of Shahrekord University of Medical Sciences, Iran, with the code of ethics IR.SKUMS.REC.1400.241. After obtaining the relevant permissions, written informed consent was obtained from all the patients’ caregivers to participate in the study. Confidentiality of information, privacy of patients, not imposing any costs on patients, and voluntary participation were among the ethical considerations that were taken into consideration.

### Results

Results showed that the mean age of the caregivers in the experimental and control groups was 37.53 (10.05) and 39.28 (10.64) years, respectively. Moreover, the results of statistical tests showed no significant statistical differences between the two groups in terms of individual characteristics [Table 2].

Independent *t*-test results indicated that the mean score of health literacy before the intervention was not

significantly different between the two groups ( $p > 0.05$ ) [Table 2]. However, 2 months after the intervention, the scores in the intervention group were significantly higher than those in the control groups ( $t = 30.12$ , degrees of freedom = 98,  $p < 0.001$ ). The mean score of health literacy 2 months after the intervention was compared with the same score before and after the interventions in the experimental group, and the results showed no significant change in this score. After 2 months, the mean score remained almost constant, although it initially significantly increased, which indicates the stability of the intervention effect over time. Repeated measures ANOVA showed a statistically significant change in the mean health literacy score in the caregivers of HF patients in the intervention group between the three study stages ( $F(1, 98) = 320.56$ ,  $p < 0.001$ ). Results of this test also showed a significant change in the mean score of health literacy in the caregivers of HF patients in the control group between the three study stages ( $F(2, 196) = 280.45$ ,  $p < 0.001$ ), but the significance of these changes was much higher in the intervention group [Table 3].

Repeated measures ANOVA showed a statistically significant difference in the mean score of health

**Table 2: Frequency distribution of caregivers of heart failure patients according to demographic characteristics**

	Group Variable	Intervention group <i>n</i> (%)	Control group <i>n</i> (%)	<i>p</i>
Gender	Female	27 (54)	33 (66)	0.31
	Male	23 (46)	17 (34)	
Education	Pre-diploma	10 (20)	7 (14)	0.83
	Diploma	12 (24)	11 (22)	
	Associate degree	7 (14)	4 (8)	
	Bachelor's degree	13 (26)	20 (40)	
	Postgraduate and higher	8 (16)	8 (16)	
Marital	Single	18 (36)	16 (32)	0.60
	Married	34 (68)	32 (64)	
Employment	Unemployed	15 (30)	11 (22)	0.36
	Employed	26 (52)	21 (42)	
	Student	3 (6)	8 (16)	
	Retired	2 (4)	3 (6)	
	Homemaker	4 (8)	7 (14)	

literacy dimensions (reading, access, understanding, decision-making, and appraisal) in the pre-intervention and post-intervention phases ( $p < 0.001$ ). Among the components of health literacy, the decision-making and behavior component and the appraisal and reading component had the highest and lowest scores, respectively [Table 4].

## Discussion

The present study was conducted with the aim of investigating the effect of a program based on FCC intervention on the health literacy of the caregivers of HF patients. Results of the present research showed that FCC was effective on the health literacy of family caregivers of HF patients in the experimental group. Results of this research showed that the mean health literacy score of most of the family members of HF patients was at an insufficient level before the intervention, but it was at a sufficient level after the intervention. This result shows that informational support can greatly increase the level of health literacy of caregivers. Khorami<sup>[19]</sup> conducted a study on the effectiveness of FCC intervention on the knowledge

**Table 3: Determining and comparing the mean health literacy score of caregivers of heart failure patients before, immediately after, and 2 months after the intervention in the experimental and control groups**

Variable	Group		<i>p</i> -value of intergroup comparison
	Intervention Mean (SD)	Control Mean (SD)	
Before the intervention	39.78 (7.65)	36.60 (7.53)	0.05
Immediately after the intervention	66.04 (4.45)	36.54 (5.77)	>0.001
Two months after the intervention	65.34 (4.49)	39.98 (7.47)	>0.001
<i>p</i> -value of intragroup comparison	>0.01	>0.001	–

SD=standard deviation

**Table 4: Determining and comparing the mean score of the health literacy dimensions of the caregivers of heart failure patients before, immediately after, and 2 months after the intervention in the experimental and control groups**

Variable		The time level	Group		<i>p</i> -value of intergroup comparison
			Control Mean (SD)	Intervention Mean (SD)	
Dimensions of health literacy	Read	Before the intervention	12.06 (2.94)	12.20 (3.01)	0.82
		Immediately after the intervention	12.02 (2.45)	14.64 (2.02)	>0.001
		Two months after the intervention	12.24 (3.01)	14.62 (2.17)	>0.001
	Access	Before the intervention	14.18 (2.91)	15.20 (3.49)	0.12
		Immediately after the intervention	13.88 (2.34)	20.82 (2.99)	>0.001
		Two months after the intervention	15.26 (3.41)	20.50 (3.07)	>0.001
	Understanding and comprehension	Before the intervention	16.52 (5.08)	17.84 (4.06)	0.16
		Immediately after the intervention	16.74 (4.56)	25.64 (3.96)	>0.001
		Two months after the intervention	17.92 (4.00)	25.48 (3.88)	>0.001
	Decision-making	Before the intervention	26.40 (4.42)	27.36 (6.74)	0.4
		Immediately after the intervention	25.32 (4.23)	47.22 (5.48)	>0.001
		Two months after the intervention	26.94 (6.04)	46.10 (5.94)	>0.001
	Assessment	Before the intervention	9.50 (2.28)	10.42 (10.33)	0.05
		Immediately after the intervention	10.04 (1.42)	13.94 (2.17)	>0.001
		Two months after the intervention	10.42 (2.33)	14.0 (1.97)	>0.001

SD=standard deviation



of home care of caregivers of chronic renal failure patients undergoing hemodialysis in Taleghani and Imam Khomeini hospitals of Urmia, East Azerbaijan, Iran. The results showed that FCC is effective in improving the knowledge of caregivers of hemodialysis patients. Moreover, FCC can provide the appropriate conditions for the physical and mental recovery of patients with kidney failure, which is consistent with the present study. The results of a study by Masoodi *et al.*<sup>[20]</sup> showed that the empowerment of caregivers increases their knowledge, understanding, and skills, helps caregivers in effective care, and improves their role performance. Furthermore, in a study of the effect of the FCC intervention on the knowledge of the caregivers of patients admitted to the burn ward, Amini *et al.*<sup>[21]</sup> showed that training patient care education to the patient caregivers led to an increase in their care knowledge in different areas of care. The results of a study by Wu *et al.*<sup>[22]</sup> showed that decrease in the level of health knowledge of HF patients and their family members had an effect on the knowledge and self-care of the patients, and the low health literacy of family members also affects the knowledge of the caregiver and the patient. The results of these studies confirm the results of the present study. Comparison of the results of the present study with other findings in this field shows that family empowerment increases knowledge and attitude, improves performance, increases self-care capacity, leads to improved quality of care and accelerated recovery of patients, and reduces complications in patients. The results of a study by Marzangi *et al.*<sup>[23]</sup> showed that HF patients had inadequate and borderline health literacy. In a study on patients with multiple sclerosis, Sedghi *et al.*<sup>[24]</sup> reported the health literacy of these patients to be at an adequate level. The difference between the results of this research and the current research can be due to the difference in the studied populations, data collection methods, and cultural and ethnic background. Results of the present study showed that the caregivers of HF patients had a moderate level of health literacy in all five dimensions after the intervention. Among the health literacy components, decision-making and behavior component and appraisal and reading component had the highest and lowest scores, respectively. Literature review of the studies conducted between 2014 and 2022 showed no study that measured the dimensions of health literacy after the intervention. However, in a study of health literacy and factors related to it in ischemic heart patients, Adib-Hajbaghery *et al.*<sup>[25]</sup> found that most of the participants had moderate literacy. In their study, the highest mean score was also related to decision-making and behavior and the lowest mean score was related to reading skills. Contrary to the results of the present study, Afshari *et al.*<sup>[26]</sup> and Sharafi and Amini<sup>[14]</sup> showed that the participants had an insufficient understanding. If caregivers and patients are taught the right information, they will be able to understand and comprehend the information. Paying more attention to appropriate education and providing information in simple

and understandable language for all patients and their caregivers are among the top health education priorities. Unlike the present study, the appraisal dimension was at an insufficient level in a study by Bozorgzad *et al.*<sup>[27]</sup> To enable caregivers and patients to adequately evaluate health information, they should have access to complete and reliable information sources. Therefore, it is necessary to pay more attention to appropriate programs for training and transferring treatment information to patients and their caregivers as well as increasing the response capacity of healthcare staff. Caring for chronic diseases requires support and increased caregiver understanding of their caring responsibility. Health literacy-based education has an effect on the outcomes of HF. It is essential to have skills for monitoring and interpreting information, making accurate decisions, compliance, providing a care booklet, using support resources, cooperating with other treatment staff, and adapting to the healthcare system to improve the level of knowledge and skills of caregivers and empower them. Thus, safe and low-cost caregiver empowerment programs are a priority. It is suggested that this intervention be investigated in other caregivers of patients with cardiovascular disease and chronic diseases. The effect of this intervention on variables such as satisfaction with the care provided, anxiety, and stress should also be investigated. One of the limitations of the present research is its small sample size, which was overcome by choosing the most accurate people with a valid sampling method.

## Conclusion

Results of the present research reveal that the FCC intervention improves the level of health literacy of caregivers of HF patients. This intervention can increase the capabilities and confidence of family caregivers in caregiving at home. This, in turn, can prevent long hospital admissions and rehospitalization of HF patients. As there are some commonalities within the context of caregiving for chronic diseases, it is also likely that this program will be applicable to other chronic illnesses. This treatment plan as a nursing intervention and as an easy, low-cost, and available method can provide a suitable context for implementing and encouraging family caregivers to participate in interventional programs aimed at facilitating caregiver roles.

## Acknowledgements

This study resulted from a master's thesis approved by the Vice-Chancellor of Research and Technology of Shahrekord University of Medical Sciences with the code IR.SKUMS.REC.1400.241. The authors would like to express their gratitude to the caregivers of patients participating in the study.

## Financial support and sponsorship

Shahrekord University of Medical Sciences.

## Conflicts of interest

Nothing to declare.

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