

# The effectiveness of a supportive educative group intervention on family caregiver burden of patients with heart failure

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## ABSTRACT

**Background:** Living with heart failure patients is a complex situation for family caregivers. Few studies have been conducted to examine the effects of interventional programs to ease this condition. The purpose of this study was to determine the effectiveness of a supportive educative group intervention in reducing family caregivers' burden of caregiving.

**Materials and Methods:** This randomized clinical trial was conducted at a selective teaching hospital in Isfahan, Iran in 2012. The intervention consisted of four weekly multimedia training sessions of 2 h that included education and family support for 50 family caregivers. Caregiver burden was measured using the Zarit Burden Interview (ZBI). Paired *t*-test, Student's *t*-tests, and repeated measures analysis of variance (ANOVA) were used to test for significant differences of the mean scores of burden between the intervention and control groups over a 3-month period.

**Results:** The intervention was successful in reducing caregiver burden over time both at the end of the intervention period ( $P = 0.000$ ) and 3 months after the intervention ( $P = 0.000$ ).

**Conclusions:** Nurses and other healthcare providers can use the findings of this study in order to implement effective programs to reduce family caregivers' challenges and to provide them more support.

**Key words:** Burden, family caregiver, heart failure, intervention, Iran, nursing, randomized clinical trial

## INTRODUCTION

Heart failure (HF), the final consequence of many cardiovascular diseases, is estimated to affect over 5.8 million people in the United States and over 15 million people in Europe.<sup>[1,2]</sup> Unfortunately, there is no reliable statistics about the number of HF patients in Iran because of poor facilities for registration of them. The prevalence of HF is expected to increase to 3500 cases per 100,000 people in the near future.<sup>[3]</sup>

Because of the chronic and debilitating nature of HF, family members often care for their patients for a decade or more.<sup>[4-7]</sup> Most often, one member of the family, such as the patient's spouse or child, takes over the caregiving tasks. As

HF progresses, family roles will also change.<sup>[8,9]</sup> A complex of elements is associated with the negative consequences of caregiving. HF family caregivers are involved in the high-extended duties of caregiving, which are related to monitoring of patient's signs and symptoms, managing medical and diet regimens, and dealing with frequent hospitalization, complex treatment devices, and financial impact of HF-related care.<sup>[1,6,9,10]</sup> Therefore, family caregiving for HF patients could be overwhelming and stressful. Caregivers often are placed in the situation of increasing burden.<sup>[11,12]</sup> Higher level of caregivers' burden might lead to earlier hospitalization and re-hospitalization of HF patients.<sup>[7]</sup>

Although the HF scientific literature describes caregiving experiences in the context of caregivers' burden and strain,<sup>[6,7,12,13]</sup> conversely few studies adopt an interventional program to reduce the caregivers' burden in the caregiving situation. The literature on interventions to reduce the negative consequences of caregiving suggests six distinct types of interventions for caregivers: psychoeducational intervention, supportive intervention, respite/adult day care, psychotherapy, interventions to improve care receiver competence, and multicomponent interventions.<sup>[14]</sup> Knight and colleagues asserted that just one approach program for assisting family caregivers may not be useful because

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caregivers have vastly different needs. Therefore, a multicomponent intervention as a combination of various interventions might have more advantages.<sup>[15]</sup>

In Iranian culture, there is a strong and intimate interpersonal relationship between family members. However, the situation for a family member who is suffering from a chronic illness is different; at first, there is a high level of family support; but the support reduces over time and both the patients and their families lose hope for the future.<sup>[16]</sup> Therefore, prolonged dealing with a chronic illness may impose a substantial burden for the other family members.

There is a low level of formal educative and supportive services for family caregivers in Iran.<sup>[17,18]</sup> A majority of HF patients are referred to the governmental hospitals, where there is heavy workload and lack of time; so, the healthcare team does not clearly address the specific needs of families.<sup>[19,20]</sup>

Considering the lack of routine supportive educative programs for HF family caregivers based on their specific needs and challenges, we aimed to determine the effectiveness of a supportive educative group intervention in decreasing family caregivers' burden of caregiving in this study.

## MATERIALS AND METHODS

This randomized controlled trial (RCT), as a part of a PhD dissertation, was conducted at Alzahra Hospital's

Patient and Family Education Center in Isfahan, Iran. The study examined the effectiveness of a supportive educative group intervention on family caregivers' burden of patients with HF over a 3-month period compared with routine care.

Family caregivers were conventionally selected from three educational hospitals ( $N = 136$ ) and then were randomly allocated using random number table to either the intervention group ( $n = 50$ ) or the control group ( $n = 50$ ). For random allocation, at first we coded the participants between 001 and 100. After that, by choosing the numbers from random number table, the first number was put in the A group and the second number in the B group. This process was continued until 50 participants were allocated in each group. Then, the two groups (A, B) were randomly assigned into the intervention and the control group. Figure 1 summarizes the selection stages of caregivers. The inclusion criteria of caregivers were: having several months experience of caregiving as a member of patient's family, age 18 years and above, having financially supported the patient, and having good communicational skills.

Family caregiver burden was evaluated using the Zarit Burden Interview (ZBI) at the baseline, end of the intervention period, and 3 months after the intervention in both the intervention and control groups. The results were compared between the groups at these times.

The primary family caregiver provided demographic and clinical information of caregivers and HF patients. Level of

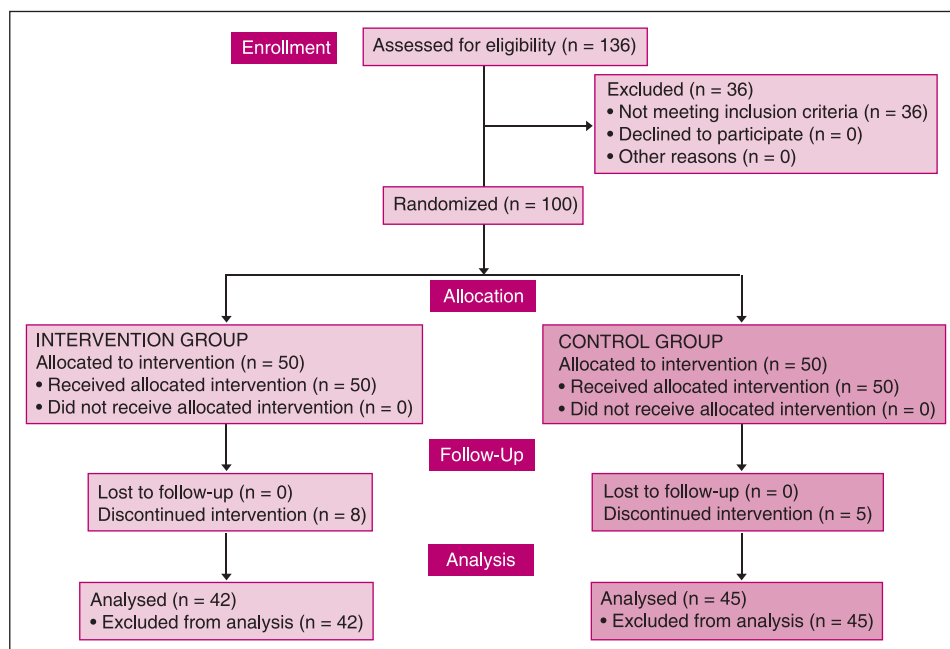


Figure 1: Number of family caregivers involved at each stage of the study

education, gender, age, employment and marital status, and cardiac ejection fraction (EF) of HF patients were collected as categorical variables.

Family caregiver burden was assessed using the ZBI questionnaire. The ZBI 22-item tool (caregiver burden scale) measures the level of perceived burden or distress associated with caregiving for a dependent patient. This scale has several questions for family caregivers about the psychological, physical, economical, and communication problems that cause distress and burden for the caregivers.

This questionnaire was translated and modified according to the Iranian cultural standards, and was applied in several studies.<sup>[21-23]</sup> Reliability of the scale was calculated using test-retest method on 10 family caregivers as a pilot study ( $r = 0.94$ ). The psychometric properties of the ZBI include an acceptable inter-item reliability and convergent validity, indicated by a Cronbach's alpha of 0.79 and a relation coefficient of 0.71 between the caregiver's global evaluation and ZBI scores.<sup>[24]</sup>

The questions are answered on a five-point Likert scale ranging from never (0) to always (4). To determine the total burden mean score, the scores were calculated by summing up the total chosen statement. By the proposed scaling of this tool, a score of <30 indicates mild, a score of 31-60 indicates moderate, and a score of >61 shows severe level of burden. Higher mean scores indicate greater perceived caregiver burden.<sup>[21,22]</sup>

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. Similar to another research, the development of the intervention program involved determining specific goals, design of content, selection of teaching-learning strategies to deliver the program, and creation of coordinated written or audiovisual materials.<sup>[25]</sup>

The supportive educative group intervention program consisted of four weekly multimedia training sessions of 2 h that included education and family support and were held for four consecutive weeks. Four supportive educative groups of 10 family caregivers were arranged with the same content. The interventional program was conducted by the same team consisting of a cardiologist physician, a psychiatric nurse, a cardiac nurse, and a clergyman.

In the orientation session, after the introduction, a written curriculum that identified the learning objectives and teaching contents for each session was given to the family

caregivers. Then, the family caregiver burden was assessed using the ZBI scale. During the sessions from one to four, the family caregivers were informed about the importance of caregiving from the viewpoint of Islam, disease, drugs, and how to deliver safety care. In addition, the family caregivers were taught how to manage patient's sign and symptoms efficiently and how to manage their time and care for themselves. Also, how to access familial and organization support and how to acquire more coping skills were taught in a group format by the same team of instructors. Supportive educative session included a variety of learning and supportive strategies and techniques such as Microsoft PowerPoint slideshows, an educational CD, a booklet, and an updatable web address ([www.moraghebin.blogfa.com](http://www.moraghebin.blogfa.com)), which were designed specially for family caregivers. The purpose and content of the multimedia training sessions are summarized in Table 1.

The first part of each session consisted of a lecture that was given by the instructors and the last part of each session (35 min) consisted of a group discussion period between the family caregivers and the instructors. During this, the caregivers described and shared their experiences in the caregiving situation and discussed about the alternative ways of learning and coping with their caregiving roles. The intervention group also received phone and personal consultations up to 3 months after the intervention in the patient and family education center.

The control group received routine hospital care. At the end of the intervention program, they participated in two multimedia training sessions. They received an educational booklet, a CD, and the web address, which were designed specially for family caregivers.

Demographic and clinical characteristics of the two groups were compared using the chi-square test. Between-group and inter-group comparisons of the variables were performed with Student's *t*-tests and paired *t*-test. Repeated measures analysis of variance (ANOVA) was used to test for significant differences between the mean scores of family caregivers' burden in the intervention and control groups. SPSS version 17 software was applied for statistical analysis and  $P < 0.05$  was considered significant.

All the participants were given verbal and written information about the purpose of the study. Written, informed consent was obtained from all family caregivers and they were free to withdraw from the study at any time. The ethics committee of the Isfahan University of Medical Sciences approved this study. The Iranian Registry of Clinical Trials (IRCT) registered the study with the reference number IRCT2013021212452N1.

**Table 1: The content of the supportive educative group program**

Session	Content	Goals	Methods
Orientation	Introducing of the instructors and family caregivers to each other and overview of the program with delivering a written curriculum of the program  Discussion of the importance of the program both for patients and caregivers Completion of a Zarit burden scale by family caregivers	To orient family caregivers about the program and to stabilize a trustful relationship between instructors and family caregivers	Lecture, question–answer
1	Emphasis on the importance of caregiver's roles in familial and societal health development according to Islam  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 side effects and to orient caregivers to the waning sign of recurrence	Lecture, question–answer Group discussion Delivering educational booklet
2	Discussion about the safety care and how to manage patient's symptom 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 the 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 patient, manage the stress, and receive more help from other family members)  Orientation toward problem-solving method and time management in caregiving situation	To promote coping strategies  To orient caregivers to stress management	Lecture, question–answer Group consultation  Personal phone consultation
4	Explanation of importance of self-care in caregiving (adequate sleep and rest, exercise)  Orientation of formal and informal educative and supportive resources and how to access them	To maintain and promote caregivers' physical and mental health  To increase caregivers' knowledge of supportive resources and how to link them	Lecture, question–answer, introducing resources (supplemental insurance, emergency medical services, advisory services, and patient education center)  Introducing the designed web address in Persian ( <a href="http://www.moraghebin.blogfa.com">www.moraghebin.blogfa.com</a> )

## RESULTS

In total, 100 family caregivers met the study criteria and were randomly allocated to either the intervention (50) or the control group (50). A total of 13 family caregivers (8 in the intervention group and 5 in the control group) [Figure 1] did not complete the program due to their patient's death, their busy schedule, and unknown reasons (attrition rate of 13%). The average age of the family caregivers in the intervention group was  $40.78 \pm 9.30$  years and in the control group was  $41.44 \pm 9.21$  years. The independent *t*-test showed no difference between the two groups ( $P = 0.0741$ ). Among the family caregivers, 38.1% were patients' daughters, 28.6% spouses, 19% patients' sons, 9.6% patients' brothers or sisters, and 4.7% were parents. A majority of the participants (76.2%) were married, 54.8% were housekeepers, and 26.2% had primary and middle year of education. The patients' mean age was 61.09

$\pm 11.08$  years, and most of them (59.5%) were males. Table 2 summarizes patients' and caregivers' additional demographic and clinical data.

Comparisons of the baseline mean scores of family caregivers' burden and demographic variables did not detect any statistically significant differences between the two groups ( $P \geq 0.05$ ).

The mean and standard deviation scores of burden in the intervention group were  $57.28 \pm 7.02$ ,  $36.15 \pm 6.37$ , and  $41.27 \pm 6.27$  at baseline, post-intervention, and 3 months post-intervention, respectively. The mean and standard deviation scores in the control group were  $56.02 \pm 6.60$ ,  $59.79 \pm 5.18$ , and  $60.94 \pm 5.32$ , respectively. The findings after completion of the intervention program and the 3-month post-intervention scores indicated statistically significant reduction in the family caregivers'

**Table 2: Demographic and clinical characteristics of the patients and their caregivers in the intervention and the control groups at baseline**

Demographic and clinical characteristics		Patients (number and percentage)		Family caregivers (number and percentage)	
		Intervention (%)	Control (%)	Intervention (%)	Control (%)
Gender	Male	25 (59.5)	29 (64.4)	10 (23.8)	7 (15.6)
	Female	17 (40.5)	16 (35.6)	32 (76.2)	38 (84.4)
Age (years)	20-39	2 (4.8)	0 (0)	21 (50)	21 (46.7)
	40-59	17 (40.5)	19 (42.3)	20 (47.7)	24 (53.3)
	>60	23 (54.7)	26 (57.8)	1 (2.4)	0 (0)
Marital status	Single	4 (9.5)	0 (0)	10 (23.8)	5 (11.1)
	Married	38 (90.5)	45 (100)	32 (76.2)	40 (88.9)
Educational level	Illiterate	10 (23.8)	14 (31.3)	0 (0)	0 (0)
	Primary	18 (42.9)	19 (42.2)	13 (31)	15 (33.3)
	Higher and more	14 (33.4)	12 (26.6)	29 (69)	30 (66.7)
Occupational status	Housekeeper	16 (38.1)	13 (28.9)	23 (54.8)	26 (57.8)
	Employee	4 (9.5)	4 (8.9)	14 (33.3)	17 (37.8)
	Unemployed	13 (31)	19 (42.2)	0 (0)	0 (0)
	Student	0 (0)	0 (0)	4 (9.5)	2 (4.4)
	Retired	9 (21.4)	9 (20)	1 (2.4)	0 (0)
Ejection fraction (EF)	<15%	6 (14.3)	7 (15.6)	0 (0)	0 (0)
	16-30%	31 (73.8)	32 (71.1)	0 (0)	0 (0)
	>31%	5 (11.9)	6 (13.3)	0 (0)	0 (0)

burden mean scores compared with the baseline scores in the intervention group and an increase in the control group. The mean burden scores of family caregivers were significantly different in the baseline, post-intervention, and 3 months post-intervention both in the intervention group ( $F = 145.49$ ,  $P = 0.000$ ) and in the control group ( $F = 12.5$ ,  $P = 0.000$ ). The results are summarized in Table 3. Statistical analysis showed a considerable decrease from baseline to post-intervention ( $t = 14.12$ ,  $P = 0.000$ ) and a mild increase from post-intervention to 3 months post-intervention ( $t = 10.63$ ,  $P = 0.000$ ) in the intervention group [Table 4]. In addition, statistical analysis indicated marginal increase from the baseline to post-intervention ( $t = -3.16$ ,  $P = 0.003$ ) and from the post-intervention to 3 months post-intervention ( $t = -1.65$ ,  $P = 0.105$ ) in the control group [Table 4]. In other words, decrease of the mean burden scores in the intervention group was significant compared with the control group. These data demonstrate that this group intervention reduced the caregiver burden, so that the mean burden score reduced considerably from 57.28 before the intervention to 36.15 after the intervention. This decrease remained low at 3 months post-intervention.

## DISCUSSION

To our knowledge, this is the first quantitative interventional study on family caregivers' burden of HF patients in Iran.

**Table 3: Family caregiver mean burden scores and standard deviation at baseline, post-intervention, and 3 months post-intervention**

Variables	Intervention group		Control group		Student's t-test P value
	M	SD	M	SD	
Baseline	57.28	7.02	56.02	6.60	$P=0.394$
Post-intervention	36.15	6.37	59.79	5.18	$P=0.000^*$
Three months post-intervention	41.27	6.27	60.94	5.32	$P=0.000^*$
RM-ANOVA	$(F=145.49, P=0.000)^{**}$		$(F=12.5, P=0.000)^{**}$		

\*Statistically significant at post-intervention and 3 months post-intervention between the intervention group and the control group at 0.05 level. \*\*Statistically significant among baseline, post-intervention, 3 months post-intervention values both in the intervention and the control groups

The findings of this study showed that involving the primary family caregivers in a short-term (4-week) supportive educative group intervention that combines care-related information, coping strategies, and time management training, with attention to family caregiver support has a significant effect on reducing the family caregiver burden.

In the present study, the caregiver burden considerably decreased after the intervention up to the end of the program in the intervention group. However, family caregivers in the control group had substantial increases in their burden scores during the same period. These issues

**Table 4: Comparison of family caregiver mean burden scores at baseline, post-intervention, and 3 months post-intervention in the intervention group and control group**

Variables	Intervention group		Paired t-test P value	Control group		Paired t-test P value
	M	SD		M	SD	
Baseline	57.28	7.02	$t=14.12$ $P=0.000$	56.02	6.60	$t=14.12$ $P=0.000$ **
Post-intervention	36.15	6.37		59.79	5.18	
Baseline	57.28	7.02	$t=10.63$ $P=0.000^*$	56.02	6.60	$t=10.63$ $P=0.000$ **
Three months post-intervention	41.27	6.27		60.94	5.32	
Post-intervention	36.15	6.37	$t=-10.79$ $P=0.000^{**}$	59.79	5.18	$t=-10.79$ $P=0.000$ **
Three months post-intervention	41.27	6.27		60.94	5.32	

\*Statistically significant decrease at 0.05 level, \*\*Statistically significant increase at 0.05 level

suggest that this program not only resulted in a reduction in the family caregivers' burden after the intervention but also prevented an increase of burden in the control group.

We have been unable to find a similar study in our review of HF literature. Only Duhamel and colleagues (2007) have evaluated the effects of a family nursing intervention for congestive heart failure (CHF) caregivers in an interventional qualitative study. They concluded that this program facilitated the humanistic care and increased satisfaction among CHF family caregivers.<sup>[26]</sup>

Most of the interventional programs for family caregivers were conducted on some chronic diseases other than HF. For example, in an interventional quantitative study to investigate the short-term effects of group and individual support programs for caregivers of the stroke patients, Van den Heuvel and colleagues (2000) concluded that these programs (support group program and home visit) contribute to an increase in confidence on care-related knowledge and use of active coping strategies significantly. They recommended implementation of more interventional programs for caregivers that focus on coping and providing information.<sup>[27]</sup>

Similar findings were also reported in other studies evaluating interventional group programs for caregivers of schizophrenia and mood disorders,<sup>[21]</sup> multiple sclerosis,<sup>[28]</sup> dementia,<sup>[24]</sup> and hemodialysis patients.<sup>[22]</sup>

There are some commonalities between caregiving experiences within the context of chronic illness. Therefore, training family caregivers on basic care-related knowledge, time management methods, providing additional formal support, and facilitating of activities of daily living may

reduce their burden. This, in turn, may improve the quality of life in both patients and family caregivers.<sup>[29]</sup>

Family caregivers who have high level of burden might be impeded in their ability to work effectively both in their roles as well as providing support for HF patients.<sup>[10,30]</sup> Since a family caregiver is a crucial element of patient care, if the burden on a family caregiver continues, patient's care and support might be dramatically compromised, especially at home.<sup>[31]</sup>

We have observed that the supportive educative group intervention that was specifically developed for HF family caregivers in Iran can positively reduce the burden of caregiving. Thus, the healthcare providers, especially nurses, can play an important role in supporting the family caregivers by considering and implementing this program.

## CONCLUSION

These findings provide clear evidence that the supportive educative group intervention can be an effective intervention for Iranian HF family caregivers. The supportive educative group intervention, which was used in the current study, is a simple, cheap, and practical program, and it not only could reduce family caregivers' burden of caregiving significantly but also could increase the capabilities and confidence of family caregivers in the caregiving situation at home. This, in turn, can prevent long hospital admissions and re-hospitalization of HF patients.

Because there are some commonalities within the context of caregiving for chronic diseases, it is also likely that this program will be applicable for other chronic illnesses. Further studies should be performed to evaluate and obtain more precise estimates of the contribution of the specific components of this program in reducing caregivers' burden. The healthcare policymaker and healthcare professionals, especially nurses, should provide a suitable context for implementing and encouraging the family caregivers to participate in interventional programs aimed to facilitating caregiver roles.

## LIMITATION

Findings of the current study must be considered within its limitations. Family caregivers' personal perceptions of caregiving could have differed in the interventional and the control groups, based on the economical, personal, and familial differences. The researchers attempted to control this issue by random allocation of the caregivers to the groups. Reduction in family caregivers' burden was confirmed for a relatively short follow-up period of 3 months, compared to other studies with a long-term follow-up period. Therefore, further studies are needed to confirm the long-term effects of this supportive educative group intervention in the future.

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