

Caregiver burden among Iranian heart failure family caregivers: A descriptive, exploratory, qualitative study

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ABSTRACT

Background: Living with patients of chronic diseases such as heart failure (HF) is a difficult situation for the caregivers. This study explored the Iranian family caregivers' burden of caregiving for patients with HF.

Materials and Methods: Eighteen family caregivers of the HF patients from two governmental medical training centers in Isfahan, Iran were recruited using purposive sampling. Data were collected through face-to-face semi-structured interviews. Each interview was transcribed verbatim and was thematically analyzed concurrently.

Results: Four major themes emerged from the analysis of the transcripts: Lack of care-related knowledge, physical exhaustion, psychosocial exhaustion, and lack of support. Family caregivers believed that they have little knowledge about the patients' disease, drugs, and how to perform caregiving roles. They experienced negative physical and psychosocial consequences of full-time and highly extended caregiving roles, such as musculoskeletal disorder, fatigue, and sleep disturbance, and a high level of anxiety, stress, and social isolation. Caregivers believed that they receive little familial and organizational support on the emotional and financial dimensions of caregiving.

Conclusions: The findings of this study can be used by healthcare providers, especially nurses, to provide more effective social, informational, and professional support for family caregivers.

Key words: Caregiver burden, family caregiver, heart failure, Iran, nursing, qualitative study

INTRODUCTION

Over the past few years, the number of people who have been living with heart failure (HF) has increased significantly. Over 5.8 million people in the United States and over 15 million people in Europe suffer from HF.^[1,2] In Iran, the prevalence of HF will increase to 3500 cases per 100,000 people in the near future and cardiovascular diseases like HF will be the main cause of patients' morbidity and mortality, especially in Isfahan.^[3-5] Therefore, HF remains a major health problem globally.

Managing several debilitating consequences of HF is a complex issue for these patients. Thus, family caregivers perform most of the care provided to them.^[6,7] Family caregiving for HF patients is a complex situation. Caregivers

are involved in highly extended roles of caregiving related to monitoring and managing patients' signs and symptoms, medical and diet regimens, and dealing with patients' physical and cognitive impairments. Frequent hospitalization, complex treatment devices, and financial issues in the treatment process of HF patients may impose additional burden on the caregivers.^[7-9]

The burden of providing sustained care to these patients affects the well-being and general health of the caregivers.^[6] Caregiver burden as a multidimensional concept is defined by the mental, physical, financial, and social negative consequences of care experienced by the caregivers.^[9] The burden of HF caregivers may be associated with several factors of the caregiving situation, for example, the level of patient dependency, the number of caregiving duties, the level of caregiver's care-related knowledge and skill, the level of caregiver preparedness, and the accessibility to resources.^[8,9]

In Iran, despite the increasing prevalence of the HF and the likelihood of negative outcomes for caregivers, little is known about the burden of caregiving for HF patients. The researchers observed that when HF family caregivers came to the hospitals or clinics with their patients, they asked numerous questions about how they could deliver

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safety care, especially at home. In addition, most of them had lost their hope and felt incapable for continuing the caregiving roles.

The focus in healthcare system is still on the patient's needs, and the healthcare team, especially nurses, is not aware of the caregiving context that is delivered by the family caregivers, while this context may be harmful both for the patients and their caregivers. Therefore, the researchers were interested to investigate family caregivers' burden of caregiving for patients with HF.

In Iran, there are a few studies about the family caregivers' burden and their challenges. Moreover, most of them are about the caregivers' burden and implementing interventional programs to reduce it on some chronic illnesses other than HF, for example, the caregiver burden among hemodialysis caregivers,^[10] the effects of participation in support groups on Alzheimer's family caregivers' strain and their spiritual well-being,^[11] and the effectiveness of family training on family caregivers' burden of patients with mental disorders.^[12]

These studies have generally employed a quantitative approach. While caregiving on the other chronic illness has been described in greater depth, the burden of family caregiving for HF patients has been described rarely and the factors influencing caregiver burden are poorly understood. In addition, most of the Iranian nursing studies in the HF context especially focused on the patients' care or their needs. Researchers have studied the quality of life,^[13] the learning needs,^[14] and the self-care knowledge^[15] of patients with HF, while emphasis on patients' family and their challenges in the caregiving situation is essential.

Only the results of a qualitative study on the barriers of readmission control among patients with congestive HF showed that patients' families faced with several challenges due to high readmission rate of HF patients and lack of social support for their patients. Researchers concluded that patients' family might not have a good cooperation in providing sustained care and treatment in the future.^[16] In this study, family members' challenges in the caregiving situation were not investigated deeply. There is no published research on the family caregivers' burden of caregiving for HF patients in Iran. Most of the studies about HF family caregivers' burden and challenges have been conducted in western countries, especially in the USA. These studies showed that HF caregivers faced with several challenges and needs in their caregiving. They mentioned the physical, psychosocial, educational, and financial needs of HF family caregivers.^[8,17-20]

Family caregiving is a phenomenon that reflects the social and cultural values of the family and its function in various societies.^[21] Dunbar (2008) and Pinquart and Sörensen (2005) asserted that family relationships, experiences, and roles in the family caregiving situation were influenced by the worldviews and socio-cultural elements.^[8,22] However, it is not known whether these factors influence the Iranian family caregivers' burden of caregiving for HF patients. More evidence is necessary to investigate specific and burdensome aspects of the family caregiving situation to guide nursing knowledge and care for HF family caregivers. The aim of this study was to explore the Iranian family caregivers' burden of caregiving for patients with HF.

MATERIALS AND METHODS

This study was a part of a PhD dissertation in nursing. A descriptive, exploratory, qualitative approach using thematic analysis was adopted to facilitate an in-depth investigation of the family caregivers' burden of caregiving for HF patients. This design is particularly appropriate for the areas where the nurses have little theoretical or practical knowledge.^[23-26]

This study was conducted at two governmental medical training centers in Isfahan, Iran, which are the main centers of cardiovascular disease treatment. These hospitals consist of two heart wards and two outpatient clinics.

Eighteen family caregivers of HF patients were recruited purposively. They were primary caregivers and 18 years of age or older. They did not serve as a caregiver for any other family member concurrently and have several months or more of experience in the caregiving roles. Family caregivers who had psychological or physical disorders and inability to communicate were excluded.

The first author selected the family caregivers. Staff of the cardiac wards helped the researchers by identifying the family caregivers who were able to describe their experiences of caregiving. Family caregivers who represent a maximum variation based on gender, age, marital, educational, employment, income status, length of caregiving, and relationship to patient were invited.

The data were collected through semi-structured, face-to-face interviews from February to June 2012. All interviews took place in a private setting, which was selected by the family caregivers: 15 interviews at the hospital, 2 interviews at the participants' workplace, and 1 interview was conducted at a patient's home.

Each interview began with an open question, "please tell me about your experiences of caregiving for this patient."

The next questions were based on the participant's response to the first question, for example, "please tell me about your challenges in the caregiving situation." The length of the interviews was 35–60 min. Interviews were recorded in a digital MP3 device and then were transcribed word by word. Data collection continued until no new information emerged. Data saturation was achieved through 18 interviews.

The data were thematically analyzed through five phases of the analysis.^[27] In the first stage, the transcripts were read several times and compared with the recorded data to ensure the accuracy of the transcription. Then, we started taking notes or ideas for coding the data text. The second stage involved producing the open codes from the transcripts, which resulted in 760 open codes. The third stage involved sorting the similar codes into potential categories and collating all the relevant codes within the identified subthemes using constant comparative data analysis technique, which resulted in 11 subthemes. In the fourth stage, we read all the collated extracts for the four emerging themes and considered whether they appeared to form a meaningful and coherent pattern. The analysis continued until all the thematic categories were saturated. Eventually, we defined and further refined the themes in the fifth stage.

In this study, Denzin and Lincoln's (2005) model of trustworthiness was used.^[28] Transferability was strengthened using heterogeneous sample of the participants with various demographic characteristics. Credibility was enhanced by prolonged interaction with the family caregivers, and by discussing about the findings with six of the interviewees as well as among the research team members (member-check).

Confirmability was strengthened using the memos to develop an audit trail of the research activities that were made through the research process. Dependability was enhanced through engaging three co-researchers from outside the research team, who have more experiences in qualitative data analysis (peer-check).

The Ethics Committee of the Isfahan University of Medical Sciences approved the study. All the family caregivers were given verbal and written information about the purpose and importance of the study. Written, informed consent was obtained from all the participants before each interview and they were free to withdraw from the study at any time.

RESULTS

In total, 18 family caregivers participated in the study. Their mean age was 43.7 years (range 20-50 years). A majority of them were females (77%), married (66%), patient's

daughters or spouses (67%), and they had moderate level of education (61%). Mean time enrolled in the patient care was 8.2 h/day (range 1-15 h) and average of the family income was 5600.000 Rials of Iran (\approx US\$ 1860) per month [Table 1]. The overall analysis of the data produced four themes based on the participants' burden of caregiving: lack of care-related knowledge, physical exhaustion, psychosocial exhaustion, and lack of support [Table 2].

Lack of care-related knowledge

This was a major theme in explaining the concept of family caregiving for patients with HF. The subthemes of

Table 1: Characteristics of family caregivers of patients with heart failure

Characteristics	Number of participants (N=18)
Age (years)	
20-30	4
31-40	6
41-50	8
Gender	
Female	14
Male	4
Marital status	
Married	12
Single	6
Relationship to patient	
Spouse	5
Patient's daughter	7
Patient's son	4
Other relatives	2
Education level	
University studies	4
High school	3
Middle year	2
Primary	9
Employment status	
Homemaker	11
Employed	4
Unemployed	3
Length of caring (hours per day)	
1-5	4
6-10	8
11-15	6
Family income (per month)	
<4000.000 Rials (\approx US\$ <133)	6
4000.000-5999.000 Rials (\approx US\$ 133-200)	5
6000.000-7999.000 Rials (\approx US\$ 200-266)	4
>8000.000 (\approx US\$ >266)	3

Table 2: Burden of caregiving for patients with heart failure in perspective of Iranian family caregivers

Theme	Subthemes
Lack of care-related knowledge	Lake of knowledge about the disease and drugs, lack of source of information, empirical caring without scientific knowledge
Physical exhaustion	Full-time caregiver, overwhelming by extended roles and role confliction, attempt to consider religious and ethical issue in caregiving
Psychosocial exhaustion	Loss of hope, high level of anxiety and fear, social isolation
Lack of support	Lack of familial support and lack of organizational support

this theme were “lack of knowledge about the disease and drugs,” “lack of source of information,” and “empirical caring without scientific knowledge.” It was observed that the family caregivers did not have the basic knowledge about the disease, drugs, and medication administration:

“Although I take care of him for several years, but I did not know what his heart’s problem was actually ... we have a box of different drugs at home ... sometimes I don’t know even their names.” (caregiver 6)

In addition, their little care-related knowledge was formed empirically during patient care without accessing to the scientific information. One participant said:

“I take care of him with my own experiences ... sometimes I don’t know if what I’m doing for him is right or wrong ... for example, when I want to shower him, I open the bath room door to facilitate his berating.” (caregiver 3)

Although most of the family caregivers wanted to receive more care-related knowledge, their informational needs remain unmet even in the hospital due to lack of source of information. One participant said:

“We hospitalized him several times but nobody (healthcare team) has told us anything about appropriate patient care at home ... they have not enough time and there was no specific place to give us information in the hospital.” (caregiver 12)

Physical exhaustion

This is another major theme. The subthemes of this theme were “full-time caregiver,” “overwhelming by extended roles and role confliction,” and “attempt to consider religious and ethical issue in caregiving.” Most of the family caregivers mentioned that due to the debilitating nature of the disease, their patients were dependent on them in many activities of daily living and they had to serve as a full-time caregiver:

“As a mobile phone, I should be available for him always ... when I want to go for cooking or shopping, he gets angry immediately and tells me sit down here and not to move ... I am a house keeper woman ... I

do my house work when he sleeps ... I cannot handle my house work properly.” (caregiver 10)

In addition, family caregivers were overwhelmed by their extended duties and roles. Most of them were married women who had to act as a caregiver for their loved ones, as a mother for her child and as a wife for her husband. They spent a lot of the time in providing sustained care in a wide range of activities such as dressing, showering, and managing treatment processes such as giving several drugs or going to the hospital and clinic visits. Therefore, they experienced more physical disorder, strain, and role confliction. One participant explained:

“Previously she could do daily works herself, but when the disease worsened day by day, she was dependent on me more ... I had to help her for going to the WC, showering, changing the clothes and eating the drugs ... now I have shoulder and back pain.” (caregiver 8)

Another participant said:

“My kids told me ‘it seems that everything in our life is dad and we have forgotten’... I could not find an opportunity to handle their works ... sometimes they had to do cooking or washing clothes themselves.” (caregiver 14)

Family caregivers attempted to consider religious and ethical issues in the caregiving time. For example, when patient’s clothes and bed were stained with urine, they washed them regularly. This issue got repeated several times and led to more physical strain for them:

“When she wets herself (with urine), my job just begins ... I wash all the clothes and her bed by my hands ... I hang them on the rope under the sun ... this problem bothers me in the Ramadan month particularly, because we want to go to the mosque and pray more.” (caregiver 9)

Moreover, most of the elderly patients preferred to have the same-sex family caregiver, particularly when they need to be dressed or showered:

“It is true that she is my mother, but when she wanted to take a shower, I couldn’t help her ... I am a man ... she is embarrassed and also I couldn’t.” (caregiver 4)

Psychosocial exhaustion

Another theme that was derived from the experiences of family caregivers was psychosocial exhaustion. The subthemes of this theme were “loss of hope,” “high level of anxiety and fear,” and “social isolation.” Most of the family caregivers were discouraged when they recognized

that their loved ones had lost their capabilities because of HF and prolongation of treatment process:

“When I looked at my husband, I felt hurt ... I saw he was disabled more day by day ... this was very painful. I wish that one day he will be healthy again and able to work himself.” (caregiver 4)

Another participant responded:

“Do you know how long she has the heart problem and I take care of her? I did everything for her to be healthy, but it seems that her disease would never be cured ... we are so much tired.” (caregiver 13)

Most of the family caregivers experienced high level of fear, anxiety, and sleep disturbance, which was associated with unpredictable nature of the disease. They believed that they did not know how to manage emergencies such as severe dyspnea, whenever they were alone in the caregiving, especially at night:

“When his breath gets shortened at night, I feel so much fear and anxiety ... I cannot sleep ... sometimes I tell my son, ‘come here and sleep with us.’” (caregiver 9)

Another participant explained:

“When his condition worsened, I telephoned to the other family members (patients’ sister or brother) or emergency services whenever necessary ... I felt that I couldn’t handle this situation alone and my patient may be lost.” (caregiver 3)

In addition, family caregivers believed that serving as a full-time caregiver, several responsibilities in the caregiving role restricted them to their home and their familial relationships and social activities were reduced dramatically:

“I felt his illness has affected my life exactly ... I felt that my patience and tolerance is not like how it was in the past ... I have not participated in the families celebrations and the mourning ceremonies recently ... I feel that my life is out of my control.” (caregiver 16)

Another participant said:

“Since he is so sick, we have not been able to travel; I would love to go to a pilgrimage and tour ... unfortunately it is not possible for me.” (caregiver 2)

Lack of support

This is another main theme. The subthemes of this theme were “lack of familial support” and “lack of organizational support.” Most of the family caregivers experienced the loneliness and the frustration due to lack of support, which

included especially financial and social support from the healthcare system and from the other family members who lived with them or were close to them. One participant said:

“Although we hospitalized him regularly, but my other family members little know about our financial problems ... I had to take a loan for buying his heart machine ... I feel that I cannot follow the treatment process in the future.” (caregiver 6)

Another participant said:

“My relatives and neighbors seldom ask about our situation. they ask and help me earlier ... Now everybody has several problems in his or her life ... my main problem is just financial now.” (caregiver 18)

Insufficient coverage of the health insurance, especially in the private medical centers, and the high costs of treatment even at the governmental hospitals were also major problems for both the family caregivers and their patients. They mentioned despite having the health insurance, the main part of patients’ treatment costs had to be paid by the family:

“My father has the health insurance, but most of the specialist offices do not accept his health insurance ... we had to pay most of the treatment costs ourselves without the insurance.” (caregiver 5)

Another participant explained:

“We are tired of spending so much money to receive the treatment ... he has been hospitalized continuously ... The government should pay more attention to us by giving more financial support and discount on the hospitals costs.” (caregiver 11)

DISCUSSION

This is the first qualitative study that explored the Iranian family caregivers’ burden of caregiving for the HF patients, which is aimed on providing a deeper understanding of their challenges and related factors to their burden.

As presented in the results, four main themes were extracted. Lack of care-related knowledge clearly formed an important element in the family caregivers’ burden of caregiving.

In this study, most of the caregivers reported lack of disease- and drug-related knowledge and these common types of knowledge deficits reflected the need for information that usually must be provided by the healthcare team. Lack of disease-and drug-related knowledge was similar to the findings of the previous studies conducted in western countries.^[17-20]

In our study, inaccessibility to reliable source of information and caregiving with the empirical knowledge which was formed during patient care and may be incorrect were the new findings that contributed to additional burden on the caregivers and the risk of caregiving without the scientific knowledge. The results of several studies showed that family caregivers required care-related knowledge in order to cope with caregiving roles, to provide safety care, and to reduce burden and distress.^[18,29,30]

In Iran, most of the HF patients are referred to the governmental clinics and hospitals where there is a lot of workload; therefore, the healthcare team has little time to address family caregivers' informational needs. Also, the nurses often emphasized on the secondary level of preventative care, particularly for patients in hospitals, rather than primary level prevention.^[31,32] There is no educative system for family caregivers and they have little opportunity to receive guidance for delivering safety care to their patients.^[33] The provision of adequate care-related knowledge for the family caregivers could be a principal step toward reducing caregivers' burden.^[29,30]

Physical exhaustion was another important issue that emerged in this study. Many of the caregivers as married women believed that several responsibilities in the caregiving role, especially considering the religious and ethical issues, which were added to duties of the housekeeping, were beyond of their physical ability and tolerance. Therefore, they experienced high level of physical disorder, fatigue, and role confliction.

Some of the findings were similar to the findings of the previous studies. For example, Hupcey (2011) and Pressler (2009) reported physical issue that was related to the difficult tasks in the HF patients' caregiving.^[7,19] In our study, attempt to consider religious issue in the caregiving was a new finding that contributed to more physical strain for the caregivers. Using diuretic drugs will increase the frequency of urination and the potentiality of urinary incontinency in HF patients. In the Islamic rules, patient's urine is mentioned as an unclean matter (Najes). Whenever any thing, such as clothes and human body, is stained by it, it must be washed with a lot of water in order to be cleaned again, especially before the daily prayers, fasting, and going to the mosque. Therefore, Muslim family caregivers may spend a part of their caregiving time to this issue, based on their religious beliefs. Thus, they experience more strain when it is repeated continuously. Overall, caregivers experience a negative consequence of caregiving, whenever they attempt to balance their caregiving roles with other duties.^[34]

Psychosocial exhaustion clearly formed an important element in the family caregivers' burden of caregiving.

Most of the family caregivers experienced sadness, fear, anxiety, depression, sleep disturbance, loss of hope, restriction in familial relationships, and social isolation. These findings were consistent to the findings of the previous studies.^[8,19,35,36] These common types of psychosocial issues reflected the need for more psychosocial support that usually must be provided by the healthcare team and other family members of the patient. Family caregiving for HF patients was associated with high level of stress, anxiety, and burden. These issues were related to caregiver's depression as well as HF patient's depression.^[8] Therefore, involvement with other family members, providing more care-related knowledge, professional support, and resource to reduce caregivers' psychosocial exhaustion should be considered.

Lack of support was another theme that emerged in the current study. Most of the family caregivers experienced loneliness and frustration in caregiving, which included particularly lack of financial and social support from the healthcare system and from the other family members. Insufficient coverage of the health insurance, especially in the private medical centers, and the high costs of the patients' treatment have become the major concerns for them. Previous studies in developed countries had also clarified that the financial and health insurance issues were the major problem for the caregivers.^[1,7,19] In our study, the caregivers had a unique caregiving condition due to lack of familial and organizational support. Based on the Iranian culture, when there is a chronic illness, 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.^[24]

In addition, in the current economical status with high economical inflation rate and economical sanctions, the monthly family income is not sufficient to meet the high costs of patients' treatment. In addition, due to overlaps of the health insurance services, patients' families should pay the main proportion of the patients' treatment costs.^[37] Several studies showed that the caregivers who had low incomes and inadequate social support might experience more distress and burden. Thus, providing more formal support and resources for them may reduce their burden, patients' readmission, costs of treatment, and disturbances of patients' treatment process.^[8,38,39] The findings of the current study should be interpreted according to its limitations. This study included small sample and is not wholly reflective of the variations found within Iranian culture. Also, sampling was done purposively; a non-probability method. These issues might limit the generalizability of our results. In order to increase transferability, a larger sample of family caregivers from a wide population including both private and governmental hospitals could be studied in future surveys.

CONCLUSION

Our results showed that the HF family caregivers not only experienced care-related knowledge deficit, physical and psychosocial exhaustion, but also experienced lack of support. Quality of care, which is delivered by the family caregiver, is reduced in the situations where the basic support, resources, and care-related knowledge are not available for them. These issues not only contribute to caregivers' burden and stress but also deteriorate patients' condition as well. Therefore, healthcare providers, policymakers, and other family members of the patients must work together in order to help the family caregivers acquire more care-related knowledge and support. So, implementing family caregiver-centered programs to educate and support the HF patients and their family caregivers and linking them to more formal social resources are essential. The issue of how and if HF family caregivers experienced burden is complex and warrants further research.

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