



## The experiences of home care team members regarding the needs of family caregivers of heart failure patients in home health care services in Iran: A qualitative study

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### Original Article

#### Abstract

**BACKGROUND:** Home healthcare guidelines emphasize the engagement of family caregivers of heart failure (HF) patients in patient care at home. Thus, this study was conducted with the aim to explore the deep experiences of home care team members regarding the needs of family caregivers of HF patients in home healthcare services in Iran.

**METHODS:** The present qualitative study was performed with a conventional content analysis approach. Data were collected through in-depth, semi-structured interviews with 23 participants who were recruited through purposive sampling. The Data were analyzed using the Graneheim and Lundman method for conventional content analysis in MAXQDA Software.

**RESULTS:** The participants included 14 women and 9 men with the mean age of  $46.21 \pm 11.44$  years. After analyzing the interviews, 3 main categories and 15 subcategories were extracted. The main categories were “family caregiver’s unmet needs” (with 5 subcategories), “Empowering Informal Caregivers” (with 3 subcategories), and “access to a standard home healthcare system” (with 7 subcategories).

**CONCLUSION:** Deep understanding of the needs of family caregivers of HF patients in home health care services increases the quality of services, the quality of life (QOL) of the family, and prevents patients’ hospital readmissions. Moreover, it will contribute to our next project of the home healthcare guideline for HF patients in the health care system of Iran. Identifying the training needs of caregivers within the home health care services has an important role in the designing of education strategies in policy making programs at the level of the Ministry of Health or planning at lower levels of the health network.

**Keywords:** Heart Failure; Caregiver; Home Care; Palliative care; Qualitative Research

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#### Introduction

The prevalence of heart failure (HF) is increasing worldwide. HF affects approximately 6.5 million Americans and is described as a chronic disease with a poor prognosis.<sup>1</sup> In Iran, HF is one of the main causes of disability and death. Due to changes in the age pyramid of society and the aging of the population, the current prevalence of HF, which is 3500 patients per one hundred thousand people, is

estimated to increase in the near future.<sup>2</sup>

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Due to the chronic nature of HF, re-hospitalization is presently one of the major health problems in society. Despite advances in treatment methods, the risk of readmission has increased significantly. Today, unplanned readmission is considered as an indicator of poor health system performance. Patients with lower incomes are more likely to be re-admitted because they cannot benefit from follow-up services; however, this imposes higher treatment costs on them. Moreover, 50% of readmissions are preventable.<sup>3</sup> Numerous studies have shown that care based on nursing management has positive results in patients with HF and reduces re-admission rate among them.<sup>3-5</sup> One of the best models for continuing care for patients with HF is home care. Home care services are a key component of community-based care services that can help families engage in patient care and self-care.<sup>6</sup> The main mission of home care services is to maintain and restore the patient's independence so that the clients are able to meet their health needs at home using their abilities and the help of health care providers.<sup>7</sup> Family caregivers are an important factor in home care programs. International clinical guidelines emphasize the importance of patient and caregiver engagement in patient care. The quality of patient care at home depends on the mental and physical health of the caregiver as well as the amount of his/her knowledge and ability in managing the patient.<sup>8,9</sup> Ignorance of the capabilities and needs of patients and caregivers is the most important shortcoming in treatment and care strategies. Being a caregiver for a patient with HF is a strenuous task. Caring can create significant levels of stress for the caregiver and can affect their quality of life (QOL), including both work and social life. It can also have an economic burden and relationship, psychological, physical, and social consequences.<sup>9</sup> The results of a study showed that the QOL of family members of HF patients decreased in all dimensions and their depression symptoms increased over time.<sup>10</sup> Increased stress in caregivers will have numerous negative consequences, including family isolation, despair, and negative emotional and social support.<sup>11</sup> A study on the needs of caregivers of HF patients has shown that family needs in the care situation are influenced by socio-cultural factors and a person's worldview.<sup>12</sup> Because perceptions and behaviors are shaped by culture, these needs and the strategies for meeting them can vary depending on individual, cultural, and social differences.<sup>13</sup> To develop caregiver assistance programs, it is necessary to understand the

needs of different ethnic groups and communities.<sup>14</sup>

Current evidence shows that home healthcare services are one of the important components of the healthcare system. There are 704 licensed home healthcare centers in 30 provinces of Iran, and they are evolving.<sup>15</sup> Currently, the private sector has authorities for home healthcare centers. These centers and also some hospitals affiliated to medical universities provide home healthcare services with different approaches.<sup>16</sup> Improving the management of general and specific home healthcare services for HF patients, as chronic patients with complex caring needs, requires qualitative and quantitative research in this area. Qualitative research is the best way to study human phenomena and evaluate different perspectives, because human, social, cultural, and relational dimensions and values cannot be fully explored through quantitative approaches.<sup>17</sup> The qualitative research can enrich our understanding of the needs of family caregivers of patients with HF in home healthcare services. To the best of our knowledge, there has been no qualitative research investigating the needs of caregivers of HF patients during receiving home healthcare services in Iran. This qualitative study was conducted with aim to explore deep experiences of participants regarding the needs of family caregivers of HF patients in home healthcare services in Iran.

## Materials and Methods

This qualitative study with conventional content analysis approach was part of a larger project aiming at adapting the "clinical guideline of home care for patients with HF in the healthcare system of Iran". The code of ethics was obtained from the Research Ethics Committee of Shahid Beheshti University of Medical Sciences, Iran, (IR.SBMU.PHARMACY.REC.1398.056). Before interviewing the participants, they were asked to sign an informed consent form. The participants were assured of the confidentiality of their information and informed that they can withdraw at any time without fear of penalty.

In this study, 23 participants were recruited using purposive sampling. Data were collected through 23 in-depth and semi-structured interviews by the first author with participants who were involved in the care of patients with HF. In this qualitative study, as we wanted access to the deep and wide experiences of individuals involved in this area, we recruited all health care team members and interviewed them about "the needs of family

caregivers who received home health care services for their patients with heart failure". We included family caregivers, patients, and health care providers. The study inclusion criteria for the family caregivers were having experience of caring for a HF patient in the family and using home healthcare services. The inclusion criterion defined for the members of the healthcare team was having at least two years of experience of providing healthcare services to HF patients. The inclusion criteria for HF patients were being diagnosed by a specialist physician based on the New York Heart Association (NYHA) classification and classified as class III and IV of the disease, being at least 20 years old, having experience of receiving home healthcare services, and being able to communicate verbally and answer interview questions. Interviews were performed in a quiet and secluded place in the hospital, physicians' offices, home care centers, and participants' homes at a time convenient to them. In-depth, semi-structured interviews were conducted individually. All interviews were recorded and lasted from 30 to 50 minutes. Family caregivers were asked questions such as "What is your experience of using home care services?", and "What problems or needs did you have while receiving home care services?" Health care providers and specialists were asked the following question: "Based on your experiences, what are the needs of family caregivers in a home healthcare services program for HF patients?" Thus, an attempt was made to provide an opportunity for the participants to share their experiences. To encourage participants to provide more in-depth information, the researcher also asked questions such as "Could you explain further?" and "Could you give an example?"

MAXQDA software (Version 10; VERBI GmbH, Berlin, Germany), a qualitative data analysis program, was utilized for qualitative data analysis. Data were analyzed using the conventional content analysis method recommended by Graneheim and Lundman (2004).<sup>18</sup> Immediately after the interviews, the researcher transcribed the recorded interviews. To gain a general understanding, the researcher listened to the interviews several times. Then, semantic units were identified in the transcriptions and initial coding was performed with low level of abstraction compared to meaningful units. After interviewing participant 20, no new codes were extracted and data saturation was reached. Nevertheless, 3 more interviews were conducted to ensure that data saturation has been reached. The primary codes were classified according to their

similarities and differences, and thus, subcategories were formed. Similar subcategories were then integrated to form categories.

In this study, the Lincoln and Guba criteria for qualitative studies were used to evaluate the trustworthiness of the findings.<sup>19</sup> To enhance the credibility of the data, different strategies, including diversity among research participants in terms of age, gender, occupation, work experience, and education, were implemented. The researcher spent sufficient time collecting data to ensure prolonged engagement with and immersion in the data. The interviews were transcribed and the extracted codes were reviewed by 4 participants. The results of the qualitative data analysis were evaluated by 4 external referees with doctoral degrees from 2 different universities to ensure conformability of the data. To ensure dependability, we used the same questions for data collection. We also tried to precisely explain all the processes of the research and attended audit trials to ensure transferability.

## Results

The study participants included 23 HF patients, their families as caregivers, and nurses with work experience in the cardiology department, cardiologists, and psychologists. Table 1 shows the demographic characteristics of the participants.

The data were analyzed using the conventional content analysis method proposed by Graneheim and Lundman (Table 2). Table 3 shows an example of data analysis. Following the analysis of the interviews, 720 codes and 15 subcategories were extracted, which formed 3 main categories (Table 4).

### **Main category 1: Family caregivers' unmet needs**

Understanding and meeting the needs of family caregivers of patients with HF can directly affect home care delivery. However, a large number of family caregivers' needs remain unmet or are inadequately met. Unmet needs can lead to poor QOL, higher levels of depression, worsening neuropsychiatric symptoms, and increased destructive behaviors. This main category consisted of 5 subcategories.

*Psychological needs:* Existing shortcomings, restless periods during home care, worries, and care burden caused severe psychological stress for the caregivers. The mental condition of the patients, the fear of the patient's death, lack of support and their own illness, lack of understanding on the part of the patient, and lack of accurate information about the diagnosis and course of the disease were problems that stressed out the caregivers most.

**Table 1.** Demographic characteristics of the participants (n = 23)

No.	Sex	Age (year)	Education level	Work experience (year)	Occupation	Participant's role
1	Female	45	Bachelor's degree	23	Nurse	Homecare team member
2	Female	44	Master of Science	23	Nurse	Homecare team member
3	Female	35	PhD	10	Nurse	Homecare team member
4	Female	33	PhD	8	Nurse	Homecare team member
5	Female	35	Bachelor's degree	2	Nurse	Homecare team member
6	Female	38	Master of Science	10	Psychologist	Homecare team member
7	Female	41	Master of Science	13	Psychologist	Homecare team member
8	Male	44	Master of Science	21	Nurse	Homecare team member
9	Male	36	Master of Science	11	Psychologist	homecare team member
10	Female	38	Cardiologist	9	Physician	Homecare team member
11	Female	44	Cardiologist	13	Physician	Homecare team member
12	Male	35	Cardiologist	7	Physician	Homecare team member
13	Male	54	General Practitioner	27	Physician	Homecare team member
14	Male	60	Master of Science	30	Nursing Faculty	Faculty member of the university
15	Female	52	Primary school	-	Homemaker	Family caregiver
16	Female	33	Master of Science	-	Employee	Family caregiver
17	Male	36	High school diploma	-	Freelance	Family caregiver
18	Female	60	Primary school	-	Homemaker	Family caregiver
19	Female	64	Bachelor's degree	-	Retired	Family caregiver
20	Male	45	Bachelor's degree	-	Employee	Family caregiver
21	Male	64	Bachelor's degree	-	Retired	Patient
22	Male	69	Primary school	-	Retired	Patient
23	Female	58	Primary school	-	Homemaker	Patient

*Unmet physical needs:* Long-term care of patients, in addition to affecting the soul and psyche of caregivers, causes physical injury or burnout. There are also many needs that are not met and are ignored by the non-continuous home care program in Iran, and this further increases the care burden of family caregivers. The study participants noted that ignorance of the physical needs of family caregivers made them unable to care for the patient well.

*Support for timely access to formal and informal services:* Caregiver support includes receiving support from the groups she/he attends, which may be mandatory such as family, or may be optional such as support groups. Most caregivers do not receive enough support.

*Self-care:* The impact of chronic disease on the family not only disrupts patients' lives, but also that of caregivers. The transfer of care from hospital to home imposes a burden of care on the family and causes physical, psychological, and social problems in caregivers, thus reducing their QOL and

ultimately leading to negligence and malpractice. Self-care is one of the most important things to do as a caregiver.

*Family safety in the home care program:* Addressing the safety of home care is an important issue. Findings of the study showed that one of the important challenges of home care was the feeling of lack of safety by the family and the patient.

### **Main category 2: Empowering informal caregivers**

Empowering the family improves the quality of home care. The purpose of empowerment is to create a partnership between the nurse and the family through responsibility and cooperation. Educating the family, developing skills, and reinforcing family efforts can strengthen and improve care management for HF patients. This main category included 3 subcategories.

*Caregiver training support:* Family caregivers of HF patients need to know what to do as a caregiver, which is an important part of the family caregiver's responsibility.

**Table 2.** Conventional content analysis process according to Graneheim and Lundman

Stage 1	Stage 2	Stage 3
Personal interviews	Strategic samplings	Average duration of 40 minutes
Transcribed verbatim	Analysis with four researchist	Continuous discussion of the material
Coding according to the Graneheim and Lundman approach		Meaning unit, condensation codes, abstraction into subcategories and main categories

**Table 3.** An example of data analysis

Main categories	Subcategories	Primary codes	Quotation
Family caregivers' unmet needs	Psychological needs	Fear of being alone	I am also afraid to be alone after his death.

Participants addressed the need to be educated, receive necessary information about the disease, its signs and symptoms, how to manage the symptoms and side effects of medications, end of life care, and working with medical devices.

*Training for emotional support of the patient:* Participants stated that their patients need emotional support, calmness, and confidence more than anything else, and that family-centered care play an important role in ensuring the health and well-being of patient. They should know how they can keep their patients peaceful and happy.

*Family's empowerment to participate in care programs:* Having a care plan that enables the individual, family, and informal caregivers to be fully involved in evaluating and deciding on care is one of the most important factors in home care. Involvement of patients, families, and caregivers in comprehensive care planning is essential to the management of conditions, building of social relationships, and improvement of understanding and adherence to diet and medications.

### **Main category 3: Access to a standard home care system**

The next main category was access to a standard home care system. One of the successes of the home care program is the defining of home care as one of the pillars of health services in the structure of the health system. By defining home care in the structure of the health system, it can evaluate and improve the standard of home care. This main category contained 7 subcategories.

*Need for interdisciplinary cooperation:* Selecting skilled and capable people, building and developing skills, and increasing the strengths and confidence of the interdisciplinary home care team ensure that they are able to fulfill their potential roles in providing standard care. This collaboration includes all members of the home care team and stakeholders, including the patient and his/her family.

*Need for Continuous home care for HF patients:* Having an ongoing relationship in care to integrate the care services a person needs reduces the possibility of a gap in the patient care. At present, the functions of families and home care providers in Iran are mostly fragmented.

*Need for Home palliative care services:* For the most part, HF is an untreatable disease. It is a progressive disease with a high rate of morbidity and mortality.

In order to reduce the high rate of hospital readmissions, palliative care should be integrated as routine care with home health care programs.

*Need for Insurance coverage:* Most patients and their caregivers were concerned about the financial burden of the disease. The high cost of home care services was also a major problem for families given that home care services in Iran are not currently covered by insurance.

*Need for effective communication with the family:* The nurses' experiences indicated the importance of effective communication with family caregivers from the first day. Empathetic listening to the patient and his/her family was considered essential. The participants believed that the needs of patients and their families, and their problems and expectations in the home care program could be identified through effective interpersonal communication.

*Need for establishing a positive culture for home care:* The cultural issues of home care in Iran have not received enough attention, and the cultural issues are still unknown to some families.

*Need for standardizing the home environment for patient care:* The home care team members need some resources at home. They should evaluate and improve the structural standards of the home environment for patient care. Planning to control crisis, injury after a fall, and a reduction in daily activities, and even paying attention to air quality, and ensuring the safety of the bathroom of the house are necessary to guarantee the enhancement of the quality of patient care in the home care environment.

## **Discussion**

This qualitative study showed that caring for a patient suffering from HF may affect the family caregivers' health, which may in turn have negative health consequences for the patients. The home healthcare team can help family caregivers through meeting their needs. This study explored the deep experiences of our participants regarding the needs of family caregivers of patients with HF in home healthcare services in the healthcare system of Iran. From our qualitative results, the 3 main categories of "family caregivers' unmet needs", "empowering informal caregivers", and "access to a standard home healthcare system" were extracted.

**Table 4.** Extracted main categories, subcategories, and quotations of the qualitative data

Main categories	Subcategories	Quotations
Family caregivers' unmet needs	Psychological needs	"I cannot talk to him because it always ends in a fight. My needs are not important to anyone at all. When I want to talk to him, he always shouts. I tell him not to eat things that are bad for him, but he says it is not my business and he wants to die. I am also afraid to be alone after his death." (Participant 15, Family caregiver)
	Unmet physical needs	"I myself have pain in my legs and I have osteoarthritis and diabetes. Well, I am a human, and I get tired too. I can no longer drag my body. The situation is kind of like a gradual death for me." (Participant 18, Family caregiver)
	Support for timely access to formal and informal services	"Unfortunately, there is no informational support available. We do not have any training programs for family caregivers. We do not provide educational videos for the patient and caregiver unless they request it. Both patients and their families need guidance to reduce stress and to accept the illness." (Participant 13, Physician)
	Self-care	"Even if the caregiver is young, he/she needs care too because being overburdened can cause depression and disrupt his/her personal life. Only when his/her own needs are met can he/she help the patient. Otherwise, he/she himself will suffer from mental and physical problems." (Participant 1, Nurse)
	Family safety in the home care program	"We know nothing about the health care provider who comes to our home to care for our patient." (Participant 23, Family caregiver) "In the hospital, nurses and doctors are all present and insure that the patient receives the best treatment, but at home, despite the advice of the nurse, the patient may still take medications at irregular times." (Participant 3, Nurse)
Empowering Informal Caregivers	Caregiver training support	"I like to learn things about my patient, to know how to take care of her, to know about medicines and healthy foods, so that no problem arises. I want to know about my patient's condition, what I need to do if she gets sick so that she gets better faster." (Participant 17, Family caregiver)
	Training for emotional support of the patient	"I want my spouse to understand me. I do not want to bother or upset him. My body has lost its function. I am worried that I will die. Unless you are in my situation, you cannot understand. If only she could treat me kindly and properly, it would make me feel good." (Participant 21, Patient)
	Family's empowerment to participate in care programs	"We cannot decide about the patient alone. If the quality of care is important, the patient and family should be involved in all stages of home care from planning to implementation and evaluation." (Participant 2, Nurse)
Access to a standard home healthcare system	Need for interdisciplinary cooperation	"If I knew that the health care providers and the doctor do their job well, I would have no stress for my patient." (Participant 16, Family caregiver)
	Need for continuous home care of HF patients	"We can provide all kinds of health care services, such as physical and mental, at home, but these services are not continuous. For example, the nurse only sets up the intravenous infusion and leaves. The housekeeper does the cleaning and other chores and leaves. The patient has no guardian and is left alone. It is not clear who should follow and monitor her/him." (Participant 3, Nurse)
	Need for Home palliative care services	"When we have a vulnerable family with a HF patient, we should be very alert and plan for a long-term period . . . .we should see the future of the family...they need or they will need specific health care services at home for their patient. If we intend to decrease the number of hospital readmissions of these patients....they need special home care services or home palliative care services." (Participant 14, Faculty member)

**Table 4.** Extracted main categories, subcategories, and quotations of the qualitative data (continue)

Main categories	Subcategories	Quotations
Access to a standard home healthcare system	Need for Insurance coverage	"Families have a lot of problems. Their highest priority problems are economic ones. The cost of home care services is high. Many patients are not able to pay for these services. I wish home care services were covered by insurance." (Participant 1, Nurse )
	Need for effective communication with the family	"The nurse's connection with us and behavior toward our patient is an important priority for me because he/she is going to care for our loved one, enter into the privacy of our home, and live with us." (Participant 16, Family caregiver)
	Need for establishing a positive culture	"Although I have a full-time job, I take care of my mother myself. I think I can give her the best care. It is my duty as a child to take care of my parents. Really, I do not want to handover the care of my mother to home care companies." (Participant 16, Family caregiver)
	Need for standardizing the home environment for patient care	"The environment of the house should be safe and standard, for example, no stairs and large doors for the bathroom, so that I can move around with a wheelchair; also I need access to an oxygen capsule and other medical equipment...." (Participant 20, Family caregiver)

The category of "family caregivers' unmet needs" was illustrative of "the psychological needs of family caregiver." It showed that long-term care of patients with HF had negative psychological effects on family caregivers. The family caregivers in our study experienced fear, death anxiety, depression, and despair. These findings were consistent with the results of previous studies. It was revealed that family care for HF patients was associated with high levels of stress and anxiety, which were related to depression in the caregiver and patient.<sup>20,21</sup> Earlier studies have identified a number of possible causes for the caregiver's distress, which included lack of knowledge about patient care, physical fatigue due to performing many caring tasks, maintenance of a work-life balance, worries about the future, inability to do what they used to do, less sexual intimacy, social isolation, and poor social and professional support.<sup>22,23</sup> Therefore, in a home care program, sharing caring tasks in the family, access to necessary patient care information, and professional support should be taken into consideration in order to reduce caregivers' mental fatigue. Caregivers need to remember to perform self-care. Through accurate planning and support, care can be very useful. "Support for timely access to formal and informal services" was another important subcategory extracted from our results. Family caregivers felt lonely and lacked support in caring for their patient. Evidence shows that caregivers feel more secure as the home care program is implemented through teamwork and the nurse supports the caregivers through training and ensuring her/his support in the home health care

setting.<sup>24</sup> A combination of different sources of support can ensure that both caregivers and patients maintain their physical and mental health.<sup>25</sup>

"Family safety in the home care services program" was one of the most important concerns of families receiving home care. The safety of the patient, family, caregiver, and health care provider is inextricably linked, interconnected, reciprocal, and interdependent.<sup>26</sup>

"Empowering informal caregivers" was another main category extracted in this study. Given that home care services are mostly provided intermittently in our health care system, family caregivers must have sufficient self-efficacy to care for their patient with HF. Providing training in a home care program is one of the important strategies for strengthening caring competency in family caregivers in caring for their patient. In one study, having enough information about available health care services and being aware of the prognosis of the disease was associated with the burden of care. This reveals the importance of providing information to patients and their families about what is expected in the future.<sup>27</sup> The role of the family in planning and decision-making seems essential for the implementation of the home care program. The collaboration between the patient and his/her family and the home health care team can improve the patient's health. In the nurse decision model presented in the study by Irani et al., patient and family participation in the decision-making process is emphasized.<sup>28</sup>

The third extracted category was "access to a standard home care system". HF is a serious chronic condition, and the management of the

physical and psychosocial distress of the patients is more challenging during the progression of the disease. These patients have a high hospital readmissions rate with high morbidity and mortality rates.<sup>3</sup> Thus, long-term continuous care and palliative care should be integrated as routine care in their caring programs.<sup>25</sup> Due to these patients' need for long-term care and the high cost of treatment, the continuity of care is not easy. Family and home care agencies are involved in patient care. Therefore, caregivers of HF patients need to obtain information about patient care and symptom management, so that they can continue caring for their patients.<sup>29</sup> In one study, interventions and suggestions for patient care were provided via phone to caregivers by a nurse or a member of a multidisciplinary team.<sup>25</sup> The home care plans should be dynamic and continuous, enabling periodic evaluations and rapid feedback. The home health care program should be designed in such a way that the patient can receive multidisciplinary health care services from different specialists.<sup>28</sup> The home care plan should specify how the assessment is performed, and how and when the care plan is implemented. The care coordinator should be an experienced nurse who is a member of the home health care team. Due to the fact that medical equipment or facilities are needed to care for HF patients at home, coordination among the family, the patient, and the specialists involved in the home health care team is necessary.<sup>30</sup> The financial issues and insurance coverage of the home health care services was one of the important challenges of the family caregivers in our study. Caregivers may also take work leave to provide care. However, there is no law to support caregivers in our country. In addition, given the lack of health insurance coverage for home care services, out-of-pocket expenses constitute a large portion of the patients' treatment costs. Previous studies have also shown that financial problems and health insurance coverage were the most important problems for caregivers.<sup>12</sup>

Personal relationships are an important part of living, working, and visiting in home care. Similarly, one of the subcategories in this study pointed to the importance of "effective communication with the family". Bauer et al. found that communication is a key category that supports the formation of constructive relationships between staff and the family.<sup>31</sup> Moreover, cultural issues for using home care services have not received enough attention in Iran. Introducing home care services and the

capabilities of the home health care team, especially nurses, to families is of great importance. Thus, establishing a positive culture and planning health care services for the decentralization of the hospital, and consequently, the smaller unit of the family, is principal.<sup>14</sup>

In the healthcare system of Iran, home healthcare services are evolving. Currently, the private sector and some university hospitals provide home healthcare services for patients. Therefore, one of the limitations of the study was lack of access to families with HF patients and their health care team members. This was a qualitative study; therefore, the findings cannot be generalized to other communities. Another limitation of the study was the selection of participants in the research setting, which was made difficult due to the COVID-19 pandemic. It is suggested that in future studied HF patients and their family caregivers be provided with specific home healthcare programs or models, or home palliative care services.

### Conclusion

The present study explored the experiences of the participants regarding the needs of family caregivers of HF patients in home healthcare services in Iran. The unmet needs of family caregivers can reduce the quality of home healthcare services, which can impact the QOL of the family. These findings indicate the need for the development of interventions to increase family caregivers' ability to manage caring for their HF patients at home. Developing an effective home healthcare program for patients with HF requires the assessment of structural and cultural needs along with a comprehensive physical, social, and psychological evaluation of the patients and their caregiver. The understanding gained of the needs of family caregivers of patients with HF in this study will assist the authors in preparing some parts of the home healthcare guideline for HF patients in the healthcare system of Iran, which will be released in the near future.

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### Conflict of Interests

Authors have no conflict of interests.



### Authors' Contribution

The study was designed by L.H, CR, R.E, and F.B. All authors have read and approved the manuscript. L.H was the main interviewer, and collected and analyzed the data. L.H, C.R, RE, and F.B have made substantial contributions to the conceptualization, design of the study, and interpretation of the study findings. All authors have contributed to the drafting and critical revision of the manuscript. All the authors are responsible for the content and have approved this final version of the manuscript.

### References

- Benjamin EJ, Blaha MJ, Chiuve SE, Cushman M, Das SR, Deo R, et al. Heart Disease and Stroke Statistics-2017 Update: A Report From the American Heart Association. *Circulation* 2017; 135(10): e146-e603.
- Ahmadi A, Etemad K, Khaledifar A. Risk factors for heart failure in a cohort of patients with newly diagnosed myocardial infarction: a matched, case-control study in Iran. *Epidemiol Health* 2016; 38: e2016019.
- Vernon D, Brown JE, Griffiths E, Nevill AM, Pinkney M. Reducing readmission rates through a discharge follow-up service. *Future Healthc J* 2019; 6(2): 114-7.
- Reese RL, Clement SA, Syeda S, Hawley CE, Gosian JS, Cai S, et al. Coordinated-Transitional Care for Veterans with Heart Failure and Chronic Lung Disease. *J Am Geriatr Soc* 2019; 67(7): 1502-7.
- Linden A, Butterworth S. A comprehensive hospital-based intervention to reduce readmissions for chronically ill patients: a randomized controlled trial. *Am J Manag Care* 2014; 20(10): 783-92.
- Lewin WH, Schaefer KG. Integrating palliative care into routine care of patients with heart failure: models for clinical collaboration. *Heart Fail Rev* 2017; 22(5): 517-24.
- Cook C, Cole G, Asaria P, Jabbour R, Francis DP. The annual global economic burden of heart failure. *Int J Cardiol* 2014; 171(3): 368-76.
- Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K. "We are doing it together"; The integral role of caregivers in a patients' transition home from the medicine unit. *PLoS One* 2018; 13(5): e0197831.
- Wingham J, Frost J, Britten N, Jolly K, Greaves C, Abraham C, et al. Needs of caregivers in heart failure management: A qualitative study. *Chronic Illn* 2015; 11(4): 304-19.
- Pressler SJ, Subramanian U, Kareken D, Perkins SM, Gradus-Pizlo I, Sauve MJ, et al. Cognitive deficits in chronic heart failure. *Nurs Res* 2010; 59(2): 127-39.
- Bidwell JT, Lyons KS, Lee CS. Caregiver Well-being and Patient Outcomes in Heart Failure: A Meta-analysis. *J Cardiovasc Nurs* 2017; 32(4): 372-82.
- Bahrami M, Etemadifar S, Shahriari M, Farsani AK. Informational needs and related problems of family caregivers of heart failure patients: A qualitative study. *J Educ Health Promot* 2014; 3: 113.
- Zamanzadeh V, Rassouli M, Abbaszadeh A, Alavi Majd H, Nikanfar AR, Mirza Ahmadi F, et al. spirituality in cancer care: A qualitative study. *Journal of Qualitative Research in Health Sciences* 2014; 2(4): 366-78.
- Pharr JR, Dodge Francis C, Terry C, Clark MC. Culture, Caregiving, and Health: Exploring the Influence of Culture on Family Caregiver Experiences. *ISRN Public Health* 2014; 2014: 689826.
- Tehran Times. Interview with the Nursing Deputy of Health Minister. 300 New Home Care Centers to Start Operation [Online]. [cited 2021 June 11]; Available from: URL: <https://www.tehrantimes.com/news/430326/300-new-home-care-centers-to-start-operation>
- Ansari M, Rassouli M, Akbari ME, Abbaszadeh A, Akbarisari A. Palliative Care Policy Analysis in Iran: A Conceptual Model. *Indian J Palliat Care* 2018; 24(1): 51-7.
- LoBiondo-Wood G, Haber J. *Nursing research: Methods and Critical appraisal for evidence-based practice*. St. Louis, Mo: Mosby/Elsevier; 2021.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24(2): 105-12.
- Lincoln YS, Guba EG. *Naturalistic Inquiry*. Thousand Oaks, CA: SAGE Publications; 1985.
- Bozkurt ZS, Sunbul M, Zincir S, Aydin SE, Oguz M, Feriha CF, et al. Burden and depressive symptoms associated with adult-child caregiving for individuals with heart failure. *ScientificWorldJournal* 2014; 2014: 641817.
- Lacerda MS, Prado PRD, Barros ALBL, Lopes JL. Depressive symptoms in the family caregivers of patients with heart failure: an integrative review. *Rev Gaucha Enferm* 2019; 40: e20180057.
- Vellone E, Chung ML, Cocchieri A, Rocco G, Alvaro R, Riegel B. Effects of self-care on quality of life in adults with heart failure and their spousal caregivers: testing dyadic dynamics using the actor-partner interdependence model. *J Fam Nurs* 2014; 20(1): 120-41.
- Vellone E, D'Agostino F, Buck HG, Fida R, Spatola CF, Petruzzo A, et al. The key role of caregiver confidence in the caregiver's contribution to self-care in adults with heart failure. *Eur J Cardiovasc Nurs* 2015; 14(5): 372-81.
- Ellington L, Cloyes KG, Xu J, Bellury L, Berry PH, Reblin M, et al. Supporting home hospice family

- caregivers: Insights from different perspectives. *Palliat Support Care* 2018; 16(2): 209-19.
25. Nicholas Dionne-Odom J, Hooker SA, Bekelman D, Ejem D, McGhan G, Kitko L, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. *Heart Fail Rev* 2017; 22(5): 543-57.
  26. Guise V, Anderson J, Wiig S. Patient safety risks associated with telecare: a systematic review and narrative synthesis of the literature. *BMC Health Serv Res* 2014; 14: 588.
  27. Sterling MR, Dell N, Piantella B, Cho J, Kaur H, Tseng E, et al. Understanding the Workflow of Home Health Care for Patients with Heart Failure: Challenges and Opportunities. *J Gen Intern Med* 2020; 35(6): 1721-9.
  28. Irani E, Hirschman KB, Cacchione PZ, Bowles KH. Home health nurse decision-making regarding visit intensity planning for newly admitted patients: a qualitative descriptive study. *Home Health Care Serv Q* 2018; 37(3): 211-31.
  29. Jackson CT, Trygstad TK, DeWalt DA, DuBard CA. Transitional care cut hospital readmissions for North Carolina Medicaid patients with complex chronic conditions. *Health Aff (Millwood)* 2013; 32(8): 1407-15.
  30. Nikbakht NA, Shahsavari H, Almasian M, Heydari H, Hazini A. Designing a Process Model of Home Care Service Delivery in Iran: A Mixed Methods Study. *Int J Community Based Nurs Midwifery* 2019; 7(4): 288-99.
  31. Bauer M, Fetherstonhaugh D, Tarzia L, Chenco C. Staff-family relationships in residential aged care facilities: the views of residents' family members and care staff. *J Appl Gerontol* 2014; 33(5): 564-85.