

Family Caregivers' Experiences of Caring for Patients With Heart Failure: A Descriptive, Exploratory Qualitative Study

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ABSTRACT

Background: Living with heart failure is a complex situation for family caregivers. Many studies addressing the challenges faced by heart failure family caregivers have already been conducted in Western societal settings. Sociocultural factors and perspectives influence the family caring experience and roles. The ethnic/culturally based differences in family caring behavior make this a subject worth further exploration and clarification.

Purpose: This study explores the experiences of family caregivers in Iran of caring for patients with heart failure.

Methods: A descriptive, exploratory, and qualitative approach was applied to gain authentic insight into the experiences of participants. Purposive sampling was used to recruit 21 family caregivers from three educational hospitals in Isfahan, Iran. Data were collected using semistructured interviews and field notes. Interviews and field notes were transcribed verbatim and concurrently analyzed.

Results: Three major themes emerged from the analysis of the transcripts: caregiver uncertainty, lack of familial and organizational support, and Allah-centered caring. Participants believed that they did not have the basic knowledge related to their disease and drugs. In addition, they received little guidance from the healthcare team. Lack of support and insurance as well as financial issues were major problems faced by the caregivers. They accepted the providence of Allah and noted that Allah always helps them accomplish their caregiving responsibilities.

Conclusions/Implications for Practice: The care performed by the caregivers of patients with heart failure exceeds their individual capabilities. Nurses, other healthcare providers, and health policy makers may use the findings of this study to develop more effective programs to address these challenges and to provide more effective support.

Sociocultural factors and perspectives were the primary factors affecting the caregiving experiences of participants in this study. Improved understanding of these factors and perspectives will help healthcare providers develop and implement suitable intervention programs for caregivers. Healthcare professionals should

develop context-based intervention programs to promote caregiver capabilities and encourage caregivers to participate to facilitate the caregiving roles of caregivers.

KEY WORDS:

family caregiver, qualitative study, heart failure, nursing, Iran.

Introduction

Heart failure (HF) is a prevalent, disabling disease associated with frequent hospitalization, high mortality, and high familial and societal costs (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Clark et al., 2012; Hwang, Luttik, Dracup, & Jaarsma, 2010). Over 15 million people in Europe and over 5.8 million people in the United States experience HF (Clark et al., 2012; Hwang et al., 2010). According to the Iranian Health Ministry's Management Center for Non-Communicable Diseases, the number of patients living with HF will increase to 3,500 cases per 100,000 population in the near future (Hekmatpou, Mohammadi, Ahmadi, Arefi, & Mohammad, 2009). Therefore, HF remains a major health problem globally.

Patients with moderate-to-severe degree of HF often are dependent on family members to perform their daily activities and manage their treatment process because of their poor physical, functional, and cognitive status (D'Alto, Pacileo, & Calabr, 2003; Jeon, Kraus, Jowsey, & Glasgow, 2010; Molloy, Johnston, & Witham, 2005; Pressler et al., 2009).

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Today, the caring role for patients with HF has expanded from healthcare providers to family caregivers. Today, millions of family members are serving as caregivers (Hwang et al., 2010; Nordgren, Asp, & Fagerberg, 2007; Saunders, 2008). Availability of a family caregiver is an essential factor in effectively managing the outcomes of HF such as mortality, readmission, and poor medication adherence (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Hwang et al., 2010; Saunders, 2008). Family caring for patients with HF may be overwhelming and stressful. Moreover, it may influence the physical and psychological health status of caregivers (Dunbar et al., 2008; Hwang et al., 2010; Pressler et al., 2009).

In Iran, despite the growing prevalence and incidence of HF, little is known about the numbers or experiences of HF family caregivers. This study found that, although researchers found that family caregivers effectively improve the condition of their hospitalized patient, the process of caring compromises the health condition of these caregivers. Patients with HF typically experience rehospitalization and a deteriorating health status. This in turn may impose many socioeconomic problems on these patients with HF, their families, and the healthcare system. Moreover, the healthcare teams, especially nurses, are not aware of the care context, which is delivered by the family caregivers, and improperly delivered care may harm the patients and the caregivers. Qualitative research is necessary to elicit the experiences of family caregivers because each experience is unique. Therefore, the research team, with members experienced in conducting qualitative studies, was interested to investigate the caring experiences of family caregivers of patients with HF.

Background

Studies in Iran have addressed the experiences and challenges of family caregivers in caring for patients with chronic diseases other than HF, including bipolar disorders (Shamsaei, Mohammadkhan Kermanshahi, & Vanaki, 2010), chronic renal failure (Abbasi et al., 2010), and Alzheimer's disease (Zohari, Khatoni, Abed, Alavi, & Yaghmaie, 2006).

Compared with other chronic illnesses, differences specific to the context of HF such as frequent hospitalization, continuous need for sign and symptoms monitoring, and recent advances in cardiac-assist devices may induce challenges specific to HF caregivers (Bakas et al., 2006; Dunbar et al., 2008; Pressler et al., 2009).

Iranian nursing studies about the HF context specifically focus on patient care. However, the challenges faced by the families of patients with HF directly affect the success and effectiveness of care delivery. For example, researchers have studied the quality of life (2006), the learning needs (Rafii, Shahpoorian, Naasher, Azarabaad, & Hosseini, 2009), and the self-care knowledge of patients with HF (Habibollahzade, Baghaei, Abolfathi, & Gasemzade, 2001) and the application of the readmission caring model to control complications of patients with congestive HF (Hekmatpou et al., 2009).

Many studies on the challenges faced by HF family caregivers have been conducted in Western countries, especially in the United States. These studies have highlighted several psychosocial, physical, financial, and educational needs of HF caregivers (Clark et al., 2009; Hupcey, Fenstermacher, Kitko, & Fogg, 2011; Pressler et al., 2009; Walden et al., 2001).

Family-provided care is a phenomenon that reflects the social values and function of families in society (Aein, Alhani, Mohammadi, & Kazemnejad, 2009; Pinguart & Sorensen, 2005). Some researchers have asserted that family experiences and roles in the family caring situation are influenced by sociocultural factors and perspectives (Dunbar et al., 2008; Pinguart & Sorensen, 2005). The behaviors of families differ among ethnic/cultural groups, which makes exploring this phenomenon necessary.

Conducting open conversations with the caregivers about their experiences is a practical way to improve nursing care for patients with HF and their caregivers. Furthermore, it may increase the holistic nursing knowledge. Increased understanding of the experiences of caregivers helps nurses determine how to best support caregivers based on their individual challenges and capabilities.

Methods

Design

This inquiry is a part of a PhD dissertation. It was conducted using a descriptive, exploratory qualitative approach to present an authentic insight into the experiences of participants. This approach is particularly appropriate for areas in which nurses have little theoretical or practical knowledge (Bahrami, 2011; Glacken, Kernohan, & Coates, 2001; Khosravan, Salehi, Ahmadi, Sharif, & Zamani, 2010).

Setting and Participants

This study was conducted at three educational hospitals in Isfahan, Iran, which are the main centers for cardiovascular disease treatment in Iran. These hospitals are composed of three heart wards and two outpatient clinics.

Twenty-one family caregivers were purposively recruited and enrolled after obtaining written, informed consent from each. Participants were 18 years or older and primary caregivers with several months or more of caring experience. In addition, they were caregivers to one family member only. Caregivers with physical or psychological disorders or with communication difficulties were excluded from the study.

The staff of the cardiac wards and a nurse coordinator of the outpatient clinics introduced the researchers to caregivers capable of describing their experiences. The first author selected the family caregivers for recruitment as participants. Those who were invited to participate in the study represented a maximum variation in their experiences with regard to age, gender, education, marital status, income, employment status, relationship to the patient, and duration of caring.

Data Collection

Data were collected using semistructured, face-to-face interviews and field notes between February and July 2012. All interviews took place in private settings designated by the participants, with three interviews conducted at the participants' place of work, 16 conducted at the hospital, and two conducted at the home of the patient. Each interview began with the open question: "Tell me about your experiences of caring for this patient." The next questions were based on the participant's response to the first question, for example, "Explain about your feelings regarding your caring role" or "Tell me about your challenges in the caring situation." The interviews lasted between 25 and 65 minutes, were recorded using a digital audio system, and were transcribed verbatim.

Because of the need to capture evidence using research-specific coding and to observe the interaction of participants with their patients and the healthcare team, all field notes were written based on nonformal observation at different times of the day at the hospitals.

The research process was based on inductive reasoning, and the data collection process continued until no new information emerged. Data saturation was achieved after 21 interviews and six field notes had been taken.

Data Analysis

The data were thematically analyzed to identify patterns or major themes and to reflect the experiences of participants (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011; Stott, 2007). Data collection and analysis were carried out concurrently. It began with the first interview and field notes, which led the researchers to ask more probing questions in the subsequent interviews (Birks & Mills, 2011).

Data analysis began by reading the transcripts several times and comparing the transcribed text with the recorded data to ensure the accuracy of the transcription. Then, each transcript was coded line-by-line individually using constant comparative data analysis. The codes were compared with each other to identify similarities and differences (Corbin & Strauss, 2008). Eventually, to form subthemes and themes, the similar codes were grouped. The same approach was used to analyze the field notes.

Rigor

The present research applied Denzin and Lincoln's (2005) model of trustworthiness. Credibility is the evaluation of whether the research findings represent a "credible" conceptual interpretation of the data. This study enhanced credibility through the data gathering methods used (interviews and field notes), the prolonged engagement with the participants (6 months), the discussion of findings among the research team, and the checking of the transcript codes with all of the participants.

Transferability is the degree to which the findings of a study can be applied or transferred beyond the bounds of the

project. This study strengthened transferability by using heterogeneous participants with various demographic characteristics from three different hospitals.

Confirmability measures how well the findings are supported by the collected data. This study enhanced confirmability by using reflective memos to develop an audit trail of the research activities that were made through the research process.

Dependability assesses the quality of the integrated processes used to collect and analyze data. This study enhanced dependability by engaging the co-researchers in data analysis.

Ethical Considerations

The ethics committee of Isfahan University of Medical Sciences approved this study. The participants were informed of the purpose and design of this study and the voluntary nature of their participation and that they could withdraw at any time. The researchers guaranteed the confidentiality of the information that they provided and assured that no individual would be identified in any publication arising from the study. Permission to digitally record the interviews was obtained from each participant. All interviews were done in private settings designated by the participants. Informed consent was obtained from all participants.

Results

Twenty-one family caregivers participated in the study. Their mean age was 41 years (range = 20–50 years). Most were women (76.20%), married (57.14%), the daughter or spouse of the patient (71.42%), and recipients of a primary or middle school education (57.16%). Participants provided care to their patient for an average of 8.5 (range = 1–15) hours per day. The average income of participant families was 5,400,000 rials (approx. US\$1800) per month (Table 1). The overall analysis of the data produced the three following themes based on the participants' experiences of caring: caregiver uncertainty, lack of familial and organizational support, and Allah-centered caring (Table 2).

Caregiver Uncertainty

This was a major theme in explaining the concept of family caring for the patients with HF. The subthemes of this theme were "lack of knowledge about the disease and drugs," "inaccessible and unreliable source of information," "lack of guidance from the healthcare team," and "unpredictable nature of the disease and caring with stress and ambiguity."

Lack of knowledge about the disease and drugs

Most of the participants noted that they did not have the basic knowledge about the disease, drugs, and medication administration:

TABLE 1.
Characteristics of the Participants

Characteristic	n	%
Age (years)		
20–30	6	28.58
31–40	7	33.33
41–50	8	38.09
Gender		
Female	16	76.20
Male	5	23.80
Marital status		
Married	12	57.14
Single	9	42.86
Relationship to patient		
Spouse	6	28.57
Patients' daughter	9	42.85
Patients' son	4	19.04
Other relatives	2	9.54
Educational level		
University studies	5	23.80
High school	4	19.04
Middle year	2	9.52
Primary	10	47.64
Employment status		
Homemaker	13	61.90
Employed	5	23.80
Unemployed	3	14.30
Length of caring (hours per day)		
1–5	5	23.80
6–10	9	42.85
11–15	7	33.35
Family income (per month)		
<4000.000 rials (≈ <US\$133)	7	33.33
4000.000–5999.000 rials (≈US\$133–200)	6	28.57
6000.000–7999.000 rials (≈US\$200–266)	5	23.80
>8000.000 (≈ >US\$266)	3	14.30

I had known his heart did not work well, but, I did not know why his leg swelled or his breath shortened.... He took many drugs. Whenever I decided to give him the drugs, I felt I would make a mistake (Caregiver 3).

In addition, perceived lack of knowledge lessened as participants provided patient care:

I learned a few things gradually.... For example if her breath became short during night sleep, I should elevate her head by adding more pillows.... I do care for her using my own experiences and no one instructed me that she must be in this position (Caregiver 8).

Because of the participants' knowledge deficit and misconceptions about the treatment process, they changed treatment regimens arbitrarily. For example, one participant said:

I told myself, Warfarin is a dangerous drug and it might be fatal. I heard it could cause uncontrolled bleeding.... So I decided to stop administering it (Caregiver 7).

Inaccessible and unreliable sources of information

Although most of the participants attempted to receive more information about the disease and the drugs, these needs usually remained unmet:

I tried to find information about the disease and drugs any way I could, like by reading drugs' brochures, and magazines and by watching TV. But I felt I knew nothing (Caregiver 17).

This issue was confirmed in the field notes:

When the doctor finished the patient visit, Mrs. ... (patient's daughter) returned to the patient's room and asked her mother, "Mom, did he discharge you?" Her mother answered "Yes." Mrs. ... said, "Okay, did you ask the doctor whether you can take aspirin or not?" The patient said, "What should I ask? The doctor wrote drugs in my insurance booklet and left." Mrs. ... said, "Oh Mom, you must tell him that aspirin hurt your stomach before," and then said angrily, "They did not allow me to stay in the room when the doctor was visiting Mom ... Now, I have

TABLE 2.
Experiences of Caring for Patients With HF: The Perspective of Iranian Family Caregivers

Theme	Subtheme
Caregiver uncertainty	<ul style="list-style-type: none"> • Lack of knowledge about the disease and drugs • Inaccessible and unreliable sources of information • Lack of guidance from the healthcare team • Unpredictable nature of the disease and caring with stress and ambiguity
Lack of familial and organizational support	<ul style="list-style-type: none"> • Loneliness in caring • Ignored caregivers in healthcare system • Inadequate health insurance and financial issue
Allah-centered caring	<ul style="list-style-type: none"> • Trust in Allah and accept his providence • Commitment in caring • Self-devotion in caring

Note. HF = heart failure.

to consult the doctor again and talk to him about aspirin” (May 10, 2012, 10:30 a.m.).

Lack of guidance from the healthcare team

Participants believed that the healthcare teams are busy and thus are unable to provide them with adequate information. Moreover, there was no designated, reliable source of information in the hospital:

Several times, I went and asked the doctors or the nurses about my patient’s condition.... They did not have enough time to answer my questions or told me that this information is not essential for you (Caregiver 16).

Unpredictable nature of the disease and caring with stress and ambiguity

Participants noted that their patients’ condition and signs and symptoms changed continuously and that they did not know how to manage emergencies such as severe dyspnea and blood pressure crisis. They experienced high levels of stress, anxiety, and ambiguity:

We went to the bathroom. First, I opened the hot water tap to warm the bathroom.... I began to wash him.... A few minutes later he fell off from the chair and he was breathing hard.... I did not know what to do. I just took him out immediately (Caregiver 12).

Another participant said:

Sometimes when he is sleeping, I place a mirror over his mouth to be sure that he is breathing. Also, when I want to cook, I will move his bed to the kitchen so that I can check to make sure that he is still breathing (Caregiver 3).

Lack of Familial and Organizational Support

This is another major theme, the subthemes of which are “loneliness in caring,” “ignored caregivers in the healthcare system,” and “inadequate health insurance and financial issues.”

Loneliness in caring

Most of the participants experienced loneliness in caring because of a lack of support from other family members. According to them, they received little help with the social and emotional demands of caring or with managing their tasks. One participant said:

In my family, everyone does his or her job.... My brother and sisters live with us, but they don’t help much, and sometimes I am alone (Caregiver 2).

Furthermore, they stated that they received little support from other family members or friends who were living close to them:

Relatives and neighbors seldom come here (patient’s home).... They do not know about our situation.... Only my sister-in-law comes here occasionally (Caregiver 13).

Ignored caregivers in the healthcare system

Participants mentioned feeling ignored in the healthcare system, noting that the healthcare team focuses attention on the patient and typically forgets the family.

In the hospital, no one listens to us.... I asked them [the healthcare team] how can I help him to be healthy again?... But nobody considers our questions.... It seems like we have been forgotten (Caregiver 19).

For many of the participants, financial issues were a major concern because of the frequent hospitalizations and clinical visits of their patients:

In recent months, we had to hospitalize him several times...we are tired of spending so much money to pay for expensive medications and treatments.... The government should pay more attention to us by giving a discount on hospital bills (Caregiver 21).

Inadequate health insurance and financial issues

Lack of health insurance services was a major problem for the participants. They confided that the health insurance system pays only a small proportion of the costs of treatments and that the families of patients must pay for the majority. This problem was more common for participants whose patients were in private medical centers:

Most of the medical and doctors’ offices do not accept her health insurance—particularly specialists and private hospitals.... Last night we transferred Mom to a private hospital. We paid all the costs for her laboratory tests, doctors’ visits, and drugs without insurance (Caregiver 10).

In addition, participants who were responsible for income-earning activities such as carpet weaving at home had to miss their job to care for their patients. Some of them lost their jobs, potentially leading to additional financial problems:

I had a secretarial job, but I had to take some time off to stay with Mom in the hospital.... Finally my boss told me that they did not want me anymore (Caregiver 17).

Allah-Centered Caring

Another derived theme from the experiences of participants was “Allah-centered” caring. The subthemes of this theme were “trust in Allah and accept his providence,” “commitment in caring,” and “self-devotion in caring.”

Trust in Allah and accept his providence

Participants believed that Allah always helps them. They have trusted in Allah and accepted the providence of Allah for their patients. They noted that having strong relationship with Allah may improve their power for caring:

We have Allah.... As Allah gives us a disease; he gives the cure too.... I ask Allah to cure all sick people whenever I pray and read Qur'an.... I see the effects of my prayers on my patient's condition (Caregiver 19).

Another participant said:

Nothing will happen without the providence of Allah.... I pray whenever I feel tired. It calms my mind.... I am sure that Allah rewards all of my efforts (Caregiver 1).

Commitment in caring

The participants noted that they would continue patient care wholeheartedly. They believed that Allah arranged for them to care for their patients and that they should treat their responsibility seriously:

Parents are a gift from Allah.... When we were unable to care for ourselves (in childhood), they did everything for us and now this is our turn.... We must do whatever we can (Caregiver 12).

Self-devotion in caring

Participants pointed to their self-devotion in caring. They expressed that they believed that the needs of their patient were more important than their own or their personal tasks.

I was accepted by a college far from my hometown.... I returned home after two months and I stayed with Mom.... To me my Mom is more important than college (Caregiver 11).

Another participant said:

I took care of him full time.... I had joint pain in my knees, but I did not consider it.... His disease was more important than me.... When he gets better, I will have more time for myself (Caregiver 6).

Discussion

This is the first qualitative study that explored the caring experiences of Iranian family caregivers of patients with HF. It

was designed to provide a deeper understanding of their experiences and their challenges, and three main themes emerged.

In our study, we found that participant's uncertainty formed an important element of the participants' experiences of caring. Uncertainty, often determined as the inability to define the meaning of disease-related events, emerges in the face of situations marked by unpredictability and inadequate information. Similar findings were reported by Hebert and colleagues (Hebert, Schulz, Copeland, & Arnold, 2009). In this study, most participants reported uncertainty related to both medical and practical issues. These common types of uncertainty reflect a need for information that usually must be provided by the healthcare team regarding the diagnosis and prognosis and how to perform caregiving roles.

Lack of knowledge about the disease and drugs and of guidance from the healthcare team contributed to the uncertainty found in our study. This phenomenon was similar to the findings of the previous studies (Clark et al., 2009; Hupcey et al., 2011; Luttk et al., 2007; Pressler et al., 2009; Walden et al., 2001). Moreover, lack of access to reliable sources of information and continuous exposure to unpredictable situations of caring with ambiguity are contributors to caregiver uncertainty and distress that were newly identified in this study. Several previous studies had noted that caregivers required adequate caregiving knowledge to provide safe care, to cope with caregiving roles, and to reduce their anxiety and distress (Clark et al., 2009; Fukui, 2004; Given, Sherwood, & Given, 2008).

This study showed that most patients with HF are admitted to government hospitals, where the heavy workload leaves healthcare teams little time to address the challenges of caring faced by caregivers. Moreover, nurses often provide secondary preventative care for patients (care and treatment) rather than primary preventive care (education). This issue has been noted in some studies in Iran (Heidary, Mazloom, & Ildarabadi, 2012; Warmaghani, Arab, Zerati, & Akbari, 2010). In addition, because of lack of systemic education and support, participants have little chance to receive guidance. This finding is supported by a study on the family caregivers of patients with schizophrenia (Pahlavanzadeh, Yazdani, & Navidian, 2010). Similar to Fukui's study (Fukui, 2004), our findings showed that the provision of appropriate care-related knowledge to family caregivers of patients with HF is a crucial step toward reducing distress in caregivers, which is critical to improving the quality of life and the quality of caring in caregivers.

Another important issue identified in this study was the lack of familial and organizational support. Most participants reported receiving little help or support from the healthcare team, health insurance system, and other family members on the social, emotional, and financial needs aspects of caring.

Previous studies have identified financial issues and lack of health insurance as major concerns for HF family caregivers (Hupcey et al., 2011; Hwang et al., 2010; Pressler et al., 2009). In our study, participants face a unique condition of caring because of lack of familial and organizational support. Although Iranian culture emphasizes strong

familial ties, the situation is different for those family members that are experiencing a chronic illness. Although a high level of initial family support is typically shown, over the time, this support weakens as both patients and families lose hope for the future. This matter was confirmed in a study by Kazemi and colleagues (Kazemi et al., 2011).

The participants in this study faced difficult economic conditions because of the high costs of medical care and patient care. The average monthly income for families was inadequate to cover these high costs. In addition, because of the lack of support and the gaps in health insurance services, families were required to pay for most of the patients' treatment costs. Therefore, as Davari (2010) mentioned, the number of families with chronically ill members that live below the poverty line increases each year. In our study, those participants with lower incomes and inadequate social support experienced more distress. Thus, providing these more vulnerable individuals with more formal support and resources may reduce their anxiety, the duration of patient hospitalization, the disturbances of treatment process, and the costs of treatment. This issue was also reported in several previous studies on family caregivers (Cox, Hayter, & Ruane, 2010; Dunbar et al., 2008; Ziegert, Fridlund, & Lidell, 2006).

Allah-centered caring formed an important element of the experiences of caring for participants. Most of the participants accepted their loved one's illness as the providence of Allah. They believed that the opportunity for patient care was given by Allah. Therefore, they attempted to improve their caregiving capabilities through their religious beliefs and accepted the providence of Allah and trusted in Allah. In the current study, these religious and spiritual beliefs helped participants cope with their tasks and provide responsible caring despite the existence of the myriad of problems such as lack of support and financial worries. In this regard, a qualitative study by Pattenden, Roberts, and Lewin (2007) that investigated the perspectives of patients and their caregivers about living with HF concluded that the cultural and religious beliefs of Muslim patients and their caregivers affected their perceptions on the meaning of health and treatment (Pattenden et al., 2007).

These findings are consistent with our findings. "Islam means submission to the will of Allah and a Muslim is a person who submits to the will of Allah" (Cheraghi, Payne, & Salsali, 2005). Islam provides definitive caring beliefs, orders, and principles that have strong cultural influences on family members' beliefs and practices in Muslims' societies. In Islam, caring means to be sensitive, responsible, and concerned in committing to act in the "right" way to achieve perfection (Hasnain & Rana, 2010; Rassool, 2008). Thus, healthcare providers, especially nurses, play an important role in supporting family caregivers by considering and enhancing their religious beliefs and cultural issues.

Limitations

The findings should be interpreted with an appreciation of the limitations of this study. Although the researchers attempted

to consider maximum sample variation by selecting participants who represented various age, gender, educational achievement, relationship to patient, and financial status groups, the sampling population was limited to three government-run medical centers. In addition, we used a purposive nonprobability sampling method to enroll our participants. These issues may limit the generalizability of results. The current study included a small sample that may not wholly reflect the variation within Iranian culture. To increase transferability, a larger sample of family caregivers from a wide population that includes both private and governmental hospitals should be recruited in future surveys.

Conclusions

The quality of patient care is reduced in situations where basic-care-related knowledge, support, and resources are not available to caregivers. This deficit contributes to caregiver uncertainty and burdens as well as deteriorates the condition of the patients under their care. The religious and cultural beliefs of caregivers help them cope with caring tasks and provide responsible caring. The healthcare providers, policy-makers, and patients' families should cooperate to help the caregivers to acquire more care-related knowledge, skills, and support. Therefore, implementing appropriate interventions such as psychoeducational interventions and linking the caregivers to resources should be considered.

Relevance to Clinical Practice

Our results show that sociocultural factors and perspectives influence the care experiences of caregivers. There is an essential need to understand the factors that contribute to a negative or positive experience for the caregivers. Without this knowledge, healthcare providers are poorly positioned to develop and implement suitable intervention programs to help family caregivers. Thus, the healthcare team should promote caregivers' capabilities by teaching coping strategies and providing more information and formal support.

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References

- Abbasi, A., Asayesh, H., Rahmani, H., Shariati, A., Hosseini, S., Rouhi, G., & Molaei, E. (2010). Burden of care and related factors in caregivers of hemodialysis patients. *Journal of Gorgan Bouyeh Faculty of Nursing & Midwifery*, 1, 26-33.

- Aein, F., Alhani, F., Mohammadi, E., & Kazemnejad, A. (2009). Parental participation and mismanagement: A qualitative study of child care in Iran. *Nursing & Health Sciences, 11*(3), 221–227. doi:10.1111/j.1442-2018.2009.00450.x
- Bahrani, M. (2011). Meanings and aspects of quality of life for cancer patients: A descriptive exploratory qualitative study. *Contemporary Nurse, 39*(1), 75–84. doi:10.5172/conu.2011.39.1.75
- Bakas, T., Pressler, S. J., Johnson, E. A., Nauser, J. A., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research, 55*(3), 180–188. doi:10.1097/00006199-200605000-00004
- Birks, M., & Mills, J. (2011). *Grounded theory: A practical guide*. London, England: Sage.
- Cheraghi, M. A., Payne, S., & Salsali, M. (2005). Spiritual aspects of end-of-life care for Muslim patients: Experiences from Iran. *International Journal of Palliative Nursing, 11*(9), 468–474.
- Clark, A. M., Freyberg, C. N., McAlister, F. A., Tsuyuki, R. T., Armstrong, P. W., & Strain, L. A. (2009). Patient and informal caregivers' knowledge of heart failure: Necessary but insufficient for effective self-care. *European Journal of Heart Failure, 11*, 617–621. doi:10.1093/eurjhf/hfp058
- Clark, A. M., Savard, L. A., Spaling, M. A., Heath, S., Duncan, A. S., & Spiers, J. A. (2012). Understanding help-seeking decisions in people with heart failure: A qualitative systematic review. *International Journal of Nursing Studies, 49*(12), 1582–1597. doi:10.1016/j.ijnurstu.2012.05.010
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London, England: Sage.
- Cox, A., Hayter, M., & Ruane, J. (2010). Alternative approaches to "enhanced observations" in acute inpatient mental health care: A review of the literature. *Journal of Psychiatric & Mental Health Nursing, 17*(2), 162–171. doi:10.1111/j.1365-2850.2009.01507.x
- D'Alto, M., Pacileo, G., & Calabr, R. (2003). Nonpharmacologic care of heart failure: Patient, family, and hospital organization. *The American Journal of Cardiology, 91*(9), 51–54. doi:10.1016/S0002-9149(02)03338-6
- Davari, M. (2010). Economic challenges of health system in Iran. *Health Information Management, 8*, 915–918.
- Denzin, N. K., & Lincoln, Y. S. (2005). *Handbook of qualitative research*. London, England: Sage.
- Dunbar, S. B., Clark, P. C., Quinn, C., Gary, R. A., & Kaslow, N. J. (2008). Family influences on heart failure self-care and outcomes. *Journal of Cardiovascular Nursing, 23*(3), 258. doi:10.1097/01.JCN.0000305093.20012.b8
- Fukui, S. (2004). Information needs and the related variables of Japanese family caregivers of terminally ill cancer patients. *Nursing & Health Sciences, 6*(1), 29–36. doi:10.1111/j.1442-2018.2003.00170.x
- Given, B., Sherwood, P. R., & Given, C. W. (2008). What knowledge and skills do caregivers need? *American Journal of Nursing, 108*(9), 28–34. doi:10.1097/01.NAJ.0000336408.52872.d2
- Glacken, M., Kernohan, G., & Coates, V. (2001). Diagnosed with hepatitis C: A descriptive exploratory study. *International Journal of Nursing Studies, 38*(1), 107–116. doi:10.1016/S0020-7489(00)00046-8
- Habibollahzade, H., Baghaei, R., Abolfathi, L., & Gasemzade, P. (2001). Study on causes of heart failure and evaluation of knowledge and attitude towards the disease. *Journal of Medical Council of Islamic Republic of Iran, 19*, 85–89.
- Hasnain, R., & Rana, S. (2010). Unveiling Muslim voices: Aging parents with disabilities and their adult children and family caregivers in the United States. *Topics in Geriatric Rehabilitation, 26*(1), 46–61. doi:10.1097/TGR.0b013e3181cd6988
- Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement: Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management, 37*(1), 3–12. doi:10.1016/j.jpainsymman.2007.12.010
- Heidary, A., Mazloom, S. R., & Ildarabadi, E. (2012). Nursing's position in health care delivery system in Iran. *Iranian Journal of Nursing Research, 7*, 37–44.
- Hekmatpou, D., Mohammadi, I., Ahmadi, F. E., Arefi, S. H., & Mohammad, R. (2009). The effectiveness of applying "making sensitivity to re-admission caring model" on controlling congestive heart failure complications among hospitalized patients in Tehran cardiovascular centers. *Medical Journal of Iran University, 17*, 33–49.
- Hupcey, J. E., Fenstermacher, K., Kitko, L., & Fogg, J. (2011). Palliative needs of spousal caregivers of patients with heart failure followed up at specialized heart failure centers. *Journal of Hospice & Palliative Nursing, 13*, 142. doi:10.1097/NJH.0b013e31820ce15e
- Hwang, B., Luttk, M. L., Dracup, K., & Jaarsma, T. (2010). Family caregiving for patients with heart failure: Types of care provided and gender differences. *Journal of Cardiac Failure, 16*(5), 398–403. doi:10.1016/j.cardfail.2009.12.019
- Jeon, Y. H., Kraus, S. G., Jowsey, T., & Glasgow, N. J. (2010). The experience of living with chronic heart failure: A narrative review of qualitative studies. *BMC Health Services Research, 10*(1), 77. doi:10.1186/1472-6963-10-77
- Kazemi, M., Nasrabadi, A. N., Hasanpour, M., Hassankhani, H., & Mills, J. (2011). Experience of Iranian persons receiving hemodialysis: A descriptive, exploratory study. *Nursing & Health Sciences, 13*(1), 88–93. doi:10.1111/j.1442-2018.2011.00586.x
- Khosravan, S., Salehi, S., Ahmadi, F., Sharif, F., & Zamani, A. (2010). Experiences of widows with children: A qualitative study about spousal death in Iran. *Nursing & Health Sciences, 12*(2), 205–211. doi:10.1111/j.1442-2018.2010.00522.x
- Luttk, M. L., Jaarsma, T., Veeger, N., Tijssen, J., Sanderman, R., & van Veldhuisen, D. J. (2007). Caregiver burden in partners of heart failure patients; Limited influence of disease severity. *The European Journal of Heart Failure, 9*(6–7), 695–701. doi:10.1016/j.ejheart.2007.01.006
- Molloy, G., Johnston, D., & Witham, M. (2005). Family caregiving and congestive heart failure. Review and analysis. *The European Journal of Heart Failure, 7*(4), 592–603. doi:10.1016/j.ejheart.2004.07.008
- Nordgren, L., Asp, M., & Fagerberg, I. (2007). An exploration of the phenomenon of formal care from the perspective of middle-aged heart failure patients. *European Journal of Cardiovascular Nursing, 6*(2), 121–129. doi:10.1016/j.ejcnurse.2006.06.002
- Pahlavanzadeh, S., Yazdani, M., & Navidian, A. (2010). The effect of psycho-education on depression, anxiety, and stress in family caregivers of patients with mental disorders. *(BEHBOOD) The Scientific Quarterly Journal, 14*, 228–236.
- Pattenden, J., Roberts, H., & Lewin, R. (2007). Living with heart failure; patient and carer perspectives. *European Journal of Cardiovascular Nursing, 6*(4), 273–279. doi:10.1016/j.ejcnurse.2007.01.097

- Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90–106. doi:10.1093/geront/45.1.90
- Pressler, S. J., Gradus-Pizlo, I., Chubinski, S. D., Smith, G., Wheeler, S., Wu, J., & Sloan, R. (2009). Family caregiver outcomes in heart failure. *American Journal of Critical Care, 18*(2), 149–159. doi:10.4037/ajcc2009300
- Rafii, F., Shahpoorian, F., Naasher, Z., Azarabaad, M., & Hosseini, F. (2009). The importance of learning needs of congestive heart failure patients from patients' and nurses' perspective. *Iran Nursing Journal, 22*(57), 19–30.
- Rahnavard, Z., Zolfaghari, M., Kazemnejad, A., & Hatamipour, K. (2006). An investigation of quality of life and factors affecting it in the patients with congestive heart failure. *Journal of Faculty of Nursing and Midwifery of Tehran University of Medical Sciences, 12*, 77–86.
- Rassool, G. H. (2008). The crescent and Islam: Healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advanced Nursing, 32*(6), 1476–1484. doi:10.1046/j.1365-2648.2000.01614.x
- Saunders, M. M. (2008). Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research, 30*(8), 943–959. doi:10.1177/0193945908319990
- Shamsaei, F., Mohammadkhan Kermanshahi, S., & Vanaki, Z. (2010). Survey of family caregiver needs of patients with bipolar disorder. *Scientific Journal of Hamadan University of Medical Sciences, 17*, 57–63.
- Stott, A. (2007). Exploring factors affecting attrition of male students from an undergraduate nursing course: A qualitative study. *Nurse Education Today, 27*(4), 325–332. doi:10.1016/j.nedt.2006.05.013
- Walden, J. A., Dracup, K., Westlake, C., Erickson, V., Hamilton, M. A., & Fonarow, G. C. (2001). Educational needs of patients with advanced heart failure and their caregivers. *The Journal of Heart and Lung Transplantation, 20*(7), 766–769. doi:10.1016/S1053-2498(00)00239-4
- Warmaghani, M., Arab, M., Zerati, H., & Akbari, S. A. (2010). Factors influencing the choice of public and private hospitals in Tehran. *Hospital Journal, 10*, 45–52.
- Ziegert, K., Fridlund, B., & Lidell, E. (2006). Health in everyday life among spouses of haemodialysis patients: A content analysis. *Scandinavian Journal of Caring Sciences, 20*(2), 223–228. doi:10.1111/j.1471-6712.2006.00400.x
- Zohari, S., Khatoni, S., Abed, S. Z., Alavi, M. H., & Yaghmaie, F. (2006). Problems of main caregivers of Alzheimer patients referring to Alzheimer Association in Tehran. *Journal of Nursing & Midwifery, Shahid Beheshti University of Medical Sciences and Health Services, 16*(53), 64–72.