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The Educational Needs of Iranian Family Caregivers of Patients with Advanced Heart Failure: A Qualitative Study

Abdolazim Tavakoli [1], Mahnaz Ilkhani [2, *], Tahereh Ashktorab [2], Camelia Rohani [2]

[1] Student Research Committee, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, IR Iran
[2] School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, IR Iran

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ABSTRACT

Background: Caregivers of heart patients are regarded as one of the key health resources in healthcare systems around the world. They play a major role in guidance and continuation of care. Nonetheless, they are often neglected in interventional programs even though paying attention to caregivers and their educational needs can enrich the educational interventions designed for this group of patients.

Objectives: This article aimed to explain the educational needs of the family caregivers of patients with Heart Failure (HF) from the perspective of key informants as a part of a sequential exploratory mixed method study.

Materials and Methods: In this study, 14 in-depth semi-structured interviews were conducted with key informants selected through purposive sampling. The data were analyzed using a regular interview and analysis plan based on a qualitative content analysis approach.

Results: The educational needs of the family caregivers were summarized as three themes: "basic care management education", "care with dignity", and "resilience development". The first theme consisted of gaining targeted knowledge and skills, crisis management, and improving patients' quality of life, all of which pointed to the caregivers' need for knowledge and skills in order to meet patients' basic needs, manage their critical situations, and help them achieve a higher quality of life. The second theme consisted of respecting patients and caregivers' accountability, which were relate to the educational needs of caregivers in terms of respecting patients' dignity during care and meeting their transcendent needs as proposed in the higher level of Maslow's hierarchy. The third theme dealt with maintaining caregivers' physical and psychosocial health, challenge management using internal and external resources, and promoting participatory care, which indicated the techniques needed to empower caregivers to continue proper caregiving and adapt to their caregiving role.

Conclusions: Family caregivers of HF patients need to learn resilience strategies and gain targeted knowledge about generous caregiving. Therefore, identifying the educational needs of this group of caregivers will play a major role in designing programs for their empowerment.

1. Background

The world's population is aging. Statistics published by the UN predicted that the world's population would reach 7.6 billion by mid-2017, including 13% (962 million) over the age of 60 years, and this latter figure has been estimated to reach 2.1 billion by 2050 (1). According to a 2012 National Health Interview Survey (NHIS), half of the adult American population suffered from at least one chronic disease, such as diabetes, cancer, stroke, and Heart Failure (HF) (2).

HF has been defined as a chronic syndrome that is one of the main causes of mortality in older adults. The prevalence of HF has been estimated to reach 46% by 2030 (3, 4). Given the long duration of the disease and its debilitating nature, caregivers of these patients experience a massive burden of care (5, 6). This excessive burden of

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**Corresponding author:* Mahnaz Ilkhani, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, Iran.
Tel: 0098-2188202508,
E-mail: m_ilkhani@sbmu.ac.ir.

care not only causes adverse physical and mental health effects for caregivers (7, 8), but it also results in further readmission of HF patients (9). The caregivers of patients with HF generally experience a lot of stress for a variety of reasons, including having to monitor patients' vital signs, attend to and facilitate compliance with complicated food and medication regimens, plan patients' daily lives, admit patients to the hospital, and deal with the heavy costs incurred by the disease (10, 11).

International clinical guidelines have emphasized the importance of involving patients and their caregivers in patient care and have attributed potential benefits to this involvement (12). Participation of patients and their family members in patient care and use of their ideas can increase the effectiveness of educational programs while significantly reducing the medical costs. This also causes all involved parties to feel that their views are valued and aids their understanding of the educational content (13-15). Despite the effective role of caregivers and the significant reduction of medical costs, few studies have investigated the needs of HF patients' caregivers (16). In a systematic review, Doherty et al. emphasized the need for a holistic approach to supporting HF patients' caregivers (17). In another review study, Lorraine et al. argued that the majority of interventional studies on the caregivers of HF patients have not been able to improve their quality of life. They partly attributed the ineffectiveness of these interventions to the absence of a qualitative needs-assessment consistent with the caregivers' lives and cultural backgrounds (18).

2. Objectives

This study aims to obtain a deep understanding of the educational needs of HF patients' caregivers in order to empower them to carry out proper caregiving to chronic HF patients and to describe the strategies needed to continue their care.

3. Materials and Methods

3.1. Design

The present study was part of a PhD dissertation with a combination method aiming to design an educational package for the family caregivers of HF patients. As a qualitative study, it aimed to explain the educational needs of the caregivers of chronic HF patients through face-to-face interviews using qualitative content analysis.

3.2. Participants

According to objective of qualitative studies, purposive sampling was conducted and interviews were performed following the completion of informed consents by the participants (key informants); i.e., patients, caregivers, and medical personnel.

The inclusion criteria for patients consisted of a history of at least one hospitalization for HF problems over the past year, NYHA classification III or IV confirmed by a physician, ability to speak fluently and with the right tone of voice in the interviews, and lack of psychological disorders. The inclusion criteria for caregivers consisted of free caregiving to a family member over the past six months and not suffering from chronic physical or psychological diseases. Finally, the inclusion criteria for medical personnel consisted of having at least two years of work experience providing care or treatment to HF patients.

3.3. Data Collection

The interviews were held in a quiet environment in hospital wards, campuses, doctors' offices, or residential addresses in Tehran as per participants' preferences. The interviews and data collection process lasted from January to September 2017. The participants were selected with maximum diversity in terms of culture, gender, age, and level of education in order to increase transparency. The interviews began with warm-up questions based on the category to which the participants belonged; for example, "What caregiving tasks do you perform for your patient (heart patient) or "What needs to be done?". The interviewer then delved into the issue and continued with probing questions according to the participants' answers and the interview guide. The interview guide was designed by the research team based on a brief review of qualitative and quantitative studies conducted by other researchers on the lived experiences and needs of caregivers (Table 1). The interviews ended with the following open question: "Is there anything else you wish to discuss?", and the researcher declared readiness to delve further into the participants' overlooked experiences and views on future occasions.

3.4. Data Analysis

The data were analyzed using the Graneheim and Lundman method (19). After each interview, the entire recorded interview was transcribed verbatim and reviewed and listened several times to obtain a general understanding. Meaning units were then identified and the initial coding was performed with a low level of abstraction in relation to the meaning units. The four criteria proposed by Lincoln and Guba were applied to achieve trustworthiness of the study (20).

To ensure credibility, the researcher spent sufficient time collecting data, submerging in the data, and presenting the meaning units and initial codes to the research team

Table 1. Interview Questions

What tasks do you perform to care for your patient?
What knowledge and support do you need for performing these tasks?
What are your needs for controlling and managing this situation?
When and how do you prefer to receive this education?
What barriers should be removed to facilitate the highest efficiency and quality in performing your role as a caregiver to a heart patient?
What changes have occurred in your personal life since you began performing your caregiving role?
What measures are needed to be taken for you to adapt to these changes in your life?
What supportive resources are available to you inside and outside your family?

for confirmation and feedback. To meet the dependability condition, the data were audited by four external experts, key informants were selected from different groups, and their experiences and views were carefully recorded. Finally, the codes were reviewed by the participants and experts to ensure transferability and confirmability.

No new codes were extracted after the 14th interview, and data saturation was thus reached. MAXQDA-10 was used for management and homogeneity of the data.

The initial codes were clustered according to their similarities and differences and subcategories were thus formed. Similar categories were then put together to form comprehensive categories. By combining the categories, the theme demonstrating the underlying meaning was determined. By constantly going back and forth between the interviews and the themes and codes, the researcher tried to further validate the results.

3.5. Ethical Approval

Ethical permission was obtained from the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran, Iran (IR.SBMU.PHNM.1395.642). The researcher obtained written informed consents from the participants prior to the interviews, asked their permission to record the interviews, and assured them of the confidentiality of their conversations and their right to withdraw from the study at any time with no consequences.

4. Results

A total of 14 interviews were held with key informants who were mostly female (n = 10). The mean age of the participants was 42.6 years, ranging from 28 to 57 years. The participants consisted of three patients, seven caregivers, three nurses, and one physician. The mean duration of the interviews was 39.7 minutes, ranging from 21 to 70 minutes (Table 2).

Based on the experiences of the participating key informants, the educational and empowerment needs of the caregivers of HF patients were categorized into three themes and eight subthemes (Table 3).

4.1. Basic Care Management Education

The first and foremost educational need of the family caregivers of HF patients was gaining knowledge and competence in providing basic patient care. They needed to know what types of care to provide. The subthemes comprising this theme were gaining targeted knowledge and skills, crisis management, and improving patients' quality of life.

4.2. Gaining Targeted Knowledge and Skills

Caregivers' lack of knowledge can act as a barrier and deprive patients of access to proper and efficient care.

General understanding of the disease and its etiology, treatment process, disease progress at the time of diagnosis,

Table 2. The Demographic Characteristics of the Participants

Participant	Gender	Age	Marital	Education Level	Kind of Experience	Length of Acquaintance (Years)	Employment Status	Duration of Interview (Minutes)
1	Female	33	status	Bachelor's degree	Caregiver	9	Homemaker	50
2	Female	42	M*	Bachelor's degree	Caregiver	10	Homemaker	70
3	Female	49	M	Primary school	Caregiver	5	Homemaker	33
4	Female	51	M	High school diploma	Caregiver	4	Homemaker	36
5	Male	57	M	Primary school	Patient	9	Retired	21
6	Female	29	M	Bachelor's degree	Nurse	5	Employed	50
7	Female	34	S**	High school diploma	Caregiver	3	Homemaker	35
8	Male	47	M	Bachelor's degree	Caregiver	4	Employed	43
9	Male	51	M	High school diploma	Patient	7	Retired	21
10	Female	40	M	MD	Physician	15	Employed	39
11	Female	28	M	Bachelor's degree	Nurse	16	Employed	51
12	Female	35	S	PhD	Nurse	11	Employed	28
13	Male	59	S	Primary school	Patient	12	Retired	39
14	Female	43	M	Bachelor's degree	Caregiver	6	Homemaker	46

* Married, ** Single

Table 3. Educational Needs of the Family Caregivers of HF Patients

Theme	Subtheme
Basic care management education	Gaining targeted knowledge and skills, crisis management, improving patients' quality of life
Care with dignity	Respecting the patients, caregiver accountability
Resilience development	Maintaining the physical and psychosocial health of the caregivers, challenge management using internal and external resources, promoting participatory care

threatening and exacerbating conditions, and introducing the prescribed medications and their side-effects were among the needs that were found to have a major role in empowerment of the caregivers.

"Caregivers need to know about the entire course of the disease. They should not face unfamiliar and new issues and only then realize that this was part of the course of the disease" (P10, physician).

4.3. Crisis Management

Given the unpredictable nature of the disease, caregivers of HF patients should always be alert, so that when the patient's condition becomes critical, they can confidently take the necessary measures while prioritizing needs and preventing waste of time.

"I never lose my nerves in emergency conditions, whether I have to give him a sublingual pill or take him to the hospital, and there have been times when I've had an oxygen capsule with me in the taxi or ambulance. I mean, I've always been by his side and not once have I not been with him when he's come down with the disease" (P3, caregiver).

4.4. Improving Patients' Quality of Life

Given the progressive disability resulting from HF, patients sometimes feel helpless in their most elementary daily needs and their abilities are often affected by this feeling. While understanding these patients' emotional and psychological states, caregivers should predict these needs and manage the patients' daily activities by understanding their stresses.

"Take him out and involve him in activities he can handle. If he resists and does not want to go, keep insisting; don't give in by saying that it's better for him to stay home and get better" (P5, patient).

4.5. Care with Dignity

In addition to knowing what actions to take, caregivers should know how to take these actions and properly meet the patients' needs. This theme consisted of two subthemes; i.e., respecting patients and caregiver accountability.

4.6. Respecting Patients

Caregivers need to put themselves in patients' shoes to understand their feelings and capabilities and respect their human rights through compassionate caregiving.

"In my view, kindness is most important for someone with heart disease; it is the best medicine. Sometimes, the patient takes his medicine for the sake of his caregiver, because he understands his concerns" (P9, patient).

"My husband is very old. Wherever we go, people ask, 'What is the matter with your father? Why have you brought your dear father along with you?', and I've always responded, 'No, he's my husband', I have never said that he's my father or anything else" (P2, caregiver).

4.7. Caregiver Accountability

According to the key informants, merely giving care consistent with patients' dignity is not sufficient and caregivers have to learn to be accountable, as well. Accountability can be accomplished by active measures that help patients to be independent, ongoing presence by the patient's side, moderation of disturbing factors, and improvement of commitment to care, all leading to generous patient care.

"Even if my mother doesn't feel that it is my duty to get to her on time, I take the traffic into account and try to get there on time and be with her when she is alone and needs me. I do not only go when someone else is with her to turn it into a get-together" (P7, caregiver).

"My husband was very worried when he was going to undergo angiography, so I got permission from the person in charge of the angiography ward and went to see him for just one minute and told him that I was with him and he should not worry" (P2, caregiver).

4.8. Resilience Development in the Caregiver

The caregivers of HF patients should learn how to motivate themselves to continue with treatments and caregiving and prevent themselves from becoming burnt out while adapting to the conditions. The subthemes of this theme were maintaining the physical and psychosocial health of caregivers and challenge management using internal and external resources.

4.9. Maintaining the Physical and Psychosocial Health of Caregivers

Caregivers can benefit from spiritual notions and learn defense mechanisms to increase their patience and vitality and promote their own and the patients' health by receiving support and care from the patients and their relatives.

"I try to forget and leave things to God's will. Still, I am grateful to God, this too shall pass, and soon it'll be forgotten" (P4, caregiver).

4.10. Challenge Management Using Internal and External Resources

The caregivers of HF patients stated that the heavy burden of care, constant worries, and the need to always be by the patient's side meant that they had no time left for themselves and were deprived of taking part in their favorite activities or holding certain jobs. Caregivers should therefore solve their problems and challenges by learning time management and problem-solving skills, finding internal and external sources of support, and seeking to maintain family integrity.

Regarding time-management skills, one participant said: "I wish I could go to work, but office works are from 8 A.M. to 4 P.M. How am I to leave my mother alone all this time? I barely manage to do all the chores" (P7, caregiver).

"I wake up in the middle of the night a lot and listen to see if she's still breathing or not" (P4, caregiver).

About using internal and external resources, one participant explained: "Caregivers should learn to be light-hearted and have a sense of humor and open up to family members and close friends and lighten things up for themselves" (P10, physician).

4.11. Promoting Participatory Care

The key informants argued that involving patients and caregivers in care was one of the main components that empowered caregivers. In fact, caregivers need to be empowered through an effective, balanced, and consistent relationship with the medical team. Caregivers can avoid isolation and reduce the heavy burden of care through measures, such as participation in care, facilitating the medical team's activities, sharing their home care duties, interacting with peers, and using other people's experiences.

"It would be very helpful both spiritually and materially if caregivers could learn about and closely observe similar cases. We have a charity system here and we introduce the better-off caregivers to others and then, they help each other out" (P12, nurse).

5. Discussion

Given its debilitating and progressive nature, HF makes patients increasingly dependent every day to a point where they need help and support from caregivers for their most basic needs. The first theme extracted in this study was largely consistent with the first to third needs proposed in Maslow's hierarchy and showed the caregivers' need for information and knowledge to ensure competent caregiving. Similar studies conducted in the past also noted a lack of adequate information resources, caregivers' confusion with respect to care, and their urgent need to obtain knowledge in different areas such as HF, treatment process, proper monitoring, medication therapy, and measures and skills needed for management of patients in various situations (21, 22).

Training caregivers to provide dignified patient care was one of the themes extracted in the present study that mostly described the caregivers' educational needs in terms of properly meeting their patients' needs as proposed at higher levels of Maslow's hierarchy. The caregivers of HF patients need to know what actions they should take as caregivers and also need to learn how to provide this care properly in a way that does not threaten the patients' dignity. Studies conducted on this subject have shown that awareness about the concept of dignity when performing patient care could reduce the focus on the way care is given at the expense of ignoring human dignity, and promote the participation of patients and those involved in their care and treatment while increasing the caregivers' accountability (23-25). In a qualitative study entitled "Dying with dignity", Hemmati et al. argued that considering the dignity of end-stage patients in view of their particular culture was one of the main components of care that could reduce patients' suffering (26).

Teaching caregivers to develop their resilience was another theme extracted in the present study. Although patients' caregivers are family members who try to be fully supportive of their family, this support diminishes over time, leaving both patients and caregivers in despair (27, 28). Given the extended duration of HF compared to other chronic diseases, need for 24-hour care, and heavy costs of treatment, caregivers experience burnout and continuation of care can thus be disrupted (29, 30). Therefore, caregivers of HF patients need to learn resilience skills and improve self-management to empower themselves further to carry on providing care to their heart patients. In a review study on the problems experienced by caregivers of HF patients, Grant et al. argued that given the numerous problems of caregiving, multifaceted interventions could help this group offer proper care to patients (6).

One of the limitations of the current study was the participants' gender imbalance as females comprised the majority of the subjects due to the purposive sampling design. Another study limitation was the exclusion of patients and caregivers with psychological disorders as per the eligibility criteria, which might have reduced the transferability of the results. Hence, future interventional studies based on needs-assessment are recommended to consider the needs of this population separately.

5.1. Conclusion

As one of the most influential factors involved in the recovery of chronic HF patients, the family caregivers of these patients need to learn resilience strategies and gain targeted knowledge and skills in order to be able to provide care while respecting the patients' dignity and to empower themselves to meet the patients' needs. The needs extracted in this study can play a significant role in planning interventional measures and designing a treatment plan for heart patients and their family caregivers.

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Authors' Contribution

Study concept and design: Abdolazim Tavakoli; Mahnaz Ilkhani. Acquisition of data and literature review: Abdolazim Tavakoli. Analysis and Interpreted the data and Drafting of the manuscript: Mahnaz Ilkhani, Tahereh Ashktorab, Camelia Rohani, Abdolazim Tavakoli.

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