

**J Caring Sci**, 2020, doi: 10.34172/jcs.2020.026 https://jcs.tbzmed.ac.ir



# **Original Article**

# **Barriers to Self-care Among Patients with Heart Failure: A Qualitative Study**

# Reza Negarandeh<sup>1</sup>, Ali Aghajanloo<sup>2\*</sup>, Khatereh Seylani<sup>2</sup>

<sup>1</sup>Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

<sup>2</sup>Critical Care Nursing Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

# Article Info

Article History: Received: 1 Mar. 2020 Accepted: 14 July 2020 e-Published: xx xx xx

#### Keywords:

Heart failure, Self-care, Barriers, Qualitative research

**Corresponding Author:** Ali Aghajanloo

Email: aliaghajanloo2001@ yahoo.com

#### Abstract

**Introduction:** Heart failure is the most prevalent cardiovascular disease. It is the end stage of most cardiovascular diseases and is characterized by the reduced ability of the heart to pump enough blood to fulfill the metabolic needs of the body. Self-care is the basis of the management of chronic diseases such as heart failure. The aim of this study was to explore the barriers to self-care among patients with heart failure.

**Methods**: This was a qualitative content analysis. Participants were fourteen patients with heart failure and three healthcare providers who were purposively recruited from cardiac care centers in Zanjan, Iran. Data were collected through in-depth semi-structured interviews and were analyzed through the conventional qualitative content analysis approach proposed by Elo and Kyngäs.

**Results**: Self-care barriers -care among patients with HF were categorized into three main categories, namely personal factors, disease burden, and inefficient support system. Each category had three subcategories which were respectively lack of self-care knowledge, heart failure-related negative emotions, the difficulty of changing habits, progressive physical decline, comorbid conditions, financial strain, inadequate social support, healthcare providers' inattention to self-care, and limited access to healthcare providers.

**Conclusion**: Patients with heart failure face different personal, disease-related, and supportrelated barriers to self-care. Based on these barriers, healthcare providers can develop interventions for promoting self-care among patients with heart failure.

# Introduction

Heart failure (HF) is the most prevalent cardiovascular disease. It is the end-stage condition of most cardiovascular disease and is characterized by the reduced ability of the heart to pump enough blood to fulfill the metabolic needs of the body.<sup>1</sup> The prevalence of HF has significantly increased in recent years due to the aging of population and improved survival of patients with coronary artery disease.<sup>2</sup> The prevalence of HF among people over 45 years is 1%–2% in most countries and 3%–5% in the world. A study reported that at least 26 million people in the world suffer from HF.<sup>3</sup> The prevalence of HF in Asian countries is 1%–6% and is estimated to be 8.1% among elderly people in Iran.<sup>4.5</sup>

Despite many advances in HF management, HF is still associated with many different negative consequences for patients, families, and healthcare systems. It significantly reduces quality of life, results in frequent hospitalizations, and causes many deaths.<sup>6</sup> The annual death rate of HF is 16.5%. The highest and the lowest HF-related death rates are related to Africa (34%) and China (7%),

respectively.<sup>7</sup> HF also negatively affects survival, so that the five and ten-year survival rates of patients with HF are 44.5% and 24.5%, respectively.<sup>8</sup> It also results in frequent hospitalizations. The rates of rehospitalization during the first six and 12 months after hospital discharge are 28% and 31%, respectively.<sup>3</sup> consequently, a large part of healthcare resources is used for HF management. The costs associated with HF are 1%–2% of all healthcare-related costs in the world.<sup>9</sup> HF-related costs are almost four times greater than the costs related to the management of other health problems. A large part of HF-related costs are due to frequent and lengthy hospitalizations, most of which can be prevented through self-care.

Self-care is defined as a process of maintaining health through health promotion and disease management.<sup>10</sup> Self-care can significantly improve treatment outcomes and reduce HF-related burden. Patients who actively engage in self-care activities and closely adhere to treatment regimen have a higher survival rate, a better quality of life, and lower rehospitalization rate.<sup>11</sup> A study on adults with HF reported that compared with patients

<sup>© 2020</sup> The Author(s). This work is published by Journal of Caring Sciences as an open access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by-nc/4.0/). Non-commercial uses of the work are permitted, provided the original work is properly cited.

who had poor self-care, those with good self-care were by 56% less likely to experience death, rehospitalization, or emergency medical visits.12 Two review studies also reported that self-care promotion can significantly reduce mortality and rehospitalization rates and improve quality of life.<sup>13,14</sup> Yet, studies revealed the poor status of self-care among patients with HF. For instance, a study into the self-care behaviors of patients with HF in fifteen countries reported that their self-care status was below the optimal level, so that more than half of the participants did not regularly perform daily weight monitoring and physical activity.15 Studies in Iran also showed poor self-care among patients with HF. For instance, the total mean score of selfcare in a study was reported to be 16 in the possible range of 0-100.16 Another study reported that in the possible range of 0–100, the mean scores of self-care maintenance, self-care management, and self-care confidence were 33.8, 32.2, and 43.3, respectively.<sup>17</sup>

Poor self-care has many different reasons. A study reported that factors contributing to poor self-care were physical disability, ineffective coping with treatments, lack of knowledge, negative emotions, and personal characteristics.<sup>18</sup> A study in Iran also reported economical, sociocultural, individual, familial, environmental, medical, and disease-related limitations as the main factors contributing to poor self-care.<sup>19</sup> A meta-synthesis of qualitative studies also found that the most important barriers to self-care were the complex symptoms of HF, its complex treatments, lack of knowledge, psychological problems, and lack of support.<sup>20</sup>

Identifying the barriers to self-care is a prerequisite to the development of interventions for self-care improvement. However, most of the studies into the factors contributing to poor self-care were conducted in developed countries and their findings are not generalizable to other countries due to their different sociocultural and economical contexts. Studies in Iran were also conducted mainly using quantitative designs and hence, provided no detailed knowledge about these barriers due to the complexity and multidimensionality of the concept of self-care. Consequently, the present study was carried out to narrow these gaps. The aim of the study was to explore the barriers to self-care among patients with HF.

# **Materials and Methods**

This was a qualitative content analysis. This design is used for poorly known phenomena and provides in-depth data about the intended phenomenon through describing it in detail.<sup>21</sup>

Participants were fourteen patients with HF who were selected from the cardiac care wards of Valiasr and Mousavi hospitals, Zanjan, Iran, as well as outpatient care clinics in Zanjan, Iran. At the time of the study, these two hospitals had respectively 31 and 36 beds for patients with cardiac problems. Sampling was performed purposively and with maximum variation respecting participants' age, gender, educational level, and HF severity. Patients who had more than eighteen years old, definite diagnosis of HF by a cardiologist, and the ability to communicate verbally and share experiences were selected as participants.

For data collection, in-depth semi-structured interviews were held from May 2018 to August 2019. Interviews were guided using several open-ended questions such as "What problems have this disease caused for you?" "How do you manage your disease-related problems?" "What factors cause you problems in performing selfcare?" Moreover, probing questions were used to collect more in-depth data about participants' experiences. Examples of these questions were, "Can you explain more?" and "What do you mean by this?" At the end of each interview, the participant was asked whether he/she wanted to add anything else. All interviews were held in a quiet and private room in the study setting. The time and the duration of the interviews were arranged according to participants' preferences and physical conditions. Interviews were discontinued if participants reported fatigue. The duration of the interviews ranged from 35 to 75 minutes with a mean of 45. Data collection was continued up to data saturation. Interviews were recorded and immediately typed and analyzed using MAQDA 10.

The conventional qualitative content analysis approach proposed by Elo and Kyngäs was used for data analysis.<sup>21</sup> This approach includes three main phases, namely open coding, categorization, and abstraction. Before the analysis of each interview, its transcript was read several times to obtain a general understanding. During open coding, the data were carefully read line by line and all words, sentences, or paragraphs which were related to the study aim were extracted and coded. In the categorization phase, the codes were constantly compared with each other respecting their similarities and differences and codes with conceptual similarity were grouped together into categories. Meanwhile, categories were combined to form larger categories.

Trustworthiness of the data was ensured through the criteria proposed by Lincoln, namely credibility, transferability, dependability, and confirmability.<sup>22</sup> Credibility was maintained by allocating adequate time to data collection and analysis, establishing appropriate relationships with participants, constantly comparing the data with each other, asking participants to confirm the congruence of the findings with their experiences, and asking experienced qualitative researchers to confirm the accuracy of the data analysis. Transferability was ensured through sampling with maximum variation and clear description of the study participants and setting. Dependability or stability of the data was maintained using a standard guide for the interviews and holding and transcribing all interviews by a single person. Confirmability was also ensured through putting aside presumptions, documenting all steps of the data analysis, and member checking.

Study aims were fully explained to participants and they were ensured that participation in the study would be voluntary and their data would be handled confidentially. They were also free to unilaterally withdraw from the study and written informed consent was obtained from all of them.

# Results

Main participants were seven male and seven female patients with HF with an age mean (SD) of 65.75 (6.8) years in the range of 45–78. Two participants were widowed, one was divorced, and others were married. Their educational level varied from illiterate to Bachelor's degree. Besides these fourteen patients, we interviewed a physician and two nurses. Table 1 shows participants' characteristics.

Data analysis revealed that the barriers to self-care among patients with HF included three main categories, namely personal factors, disease burden, and inefficient support system. These three categories included nine subcategories as shown in Table 2 and explained in what follows.

# **Personal Factors**

This category included personal factors which affected patients' ability and motivation to engage in self-care activities. The three subcategories of this category were lack of self-care knowledge, HF-related negative emotions, and difficulty of changing habits.

# Lack of Self-care Knowledge

Lack of self-care knowledge was a major barrier to self-care highlighted by almost all participants. They had no adequate knowledge about HF, its etiology,

Table 1. Partici	pants' cha	aracteristics
------------------	------------	---------------

their medications, and the importance of daily weight monitoring, limited fluid intake, regular physical activity, and adherence to dietary regimen. The reasons for this lack of self-care knowledge were their low educational level, limited health literacy, and lack of comprehensive educational programs offered by healthcare settings. Participants reported that they had problems in acquiring, reading, and understanding their necessary health- and HF-related information and hence, they did not attempt to acquire such information. Rather, they resorted to the trialand-error method to manage their problems or acquired their necessary information from unreliable sources, which sometimes resulted in the acquisition of erroneous information. Patient educations by healthcare providers were also provided unsystematically and were inefficient due to their inapplicability and non-comprehensiveness as well as participants' inability to understand and use them due to their old age, hearing impairment, and forgetfulness. Lack of knowledge had resulted in some misconceptions and unhealthy behaviors. For instance, some participants believed that if they regularly took their

Table 2. The barriers to self-care among patients with HF

Subcategories	Categories		
Lack of self-care knowledge			
HF-related negative emotions	Personal factors		
The difficulty of changing habits			
Progressive physical decline			
Comorbid conditions	Disease burden		
Financial strain			
Inadequate social support			
Healthcare providers' inattention to self-care	Inefficient support system		
Limited access to healthcare providers			

Age (y)	Gender	Educational level	Marital status	Occupation	Cardiac ejection fraction (%)	HF underlying cause
75	Female	Illiterate	Married	Housewife	25–30	Ischemic heart disease
78	Male	Illiterate	Married	Retired	30	unknown
63	Male	Illiterate	Married	Driver	15	Ischemic heart disease
63	Female	Illiterate	Married	Housewife	30	Aortic valve disease
70	Female	Illiterate	Widowed	Housewife	25-30	Ischemic heart disease
72	Female	Illiterate	Married	Housewife	35-40	Hypertension
60	Male	Primary	Married	Retired	25	Hypertension
61	Female	Secondary	Widowed	Housewife	30–35	Ischemic heart disease
60	Male	Primary	Married	Self-employed	25	Ischemic heart disease
55	Female	Illiterate	Divorced	Housewife	15	Ischemic heart disease
67	Male	Illiterate	Married	Retired	30	unknown
45	Female	Secondary	Married	Housewife and self-employed	35	Mitral valve disease
48	Male	Bachelor's	Married	Teacher	35	Ischemic heart disease
51	Male	Diploma	Married	Employee	25	Ischemic heart disease
31	Female	Bachelor's	Married	Nurse	_	_
40	Female	Bachelor's	Married	Nurse	_	_
33	Male	Cardiologist	Married	Physician	_	_

medications, they no would longer need to adhere to their dietary regimen. As healthcare providers had strongly emphasized the importance of adherence to medications and regular medical visits, most participants reported close adherence to their medications and had regular medical visits.

"After taking a high-fat food, I immediately take a lipidlowering pill to neutralize its effects» (P. 8).

# HF-Related Negative Emotions

HF-related negative emotions were a major barrier to selfcare among patients with HF. Fear was one of the most common emotions reported by participants. They noted that they and their family members always feel fear and apprehension due to disability, their uncertain future, unpredictability and aggravation of their disease, and lack of confidence in their abilities. Fear reduced their ability to independently perform self-care activities. Moreover, they had fear over others' judgment about their abilities and its subsequent social stigma. Therefore, they attempted to hide their illness from others, which required them not to perform some self-care activities or incompletely perform them.

# «In parties, I eat whatever they serve. I don't want to be different» (P. 2).

Hopelessness was another negative emotion among our participants which had been caused by HF chronicity and its incomplete management. Hopelessness in most cases had resulted in depression, impatience, anger, disinterest in life, and preference of death over life. Accordingly, some participants did not adhere to their medications and did not perform self-care activities due to hopelessness, which resulted in HF aggravation.

«I noticed several times that I didn't make meaningful recovery and hence, I developed mood problems. Then, I decided to abandon my treatments and didn't take my drugs» (P. 8).

# The Difficulty of Changing Habits

Changing unhealthy habits and engaging in new healthy behaviors were difficult for most participants. While attempting to change their habits, they were either unsuccessful or returned to their previous habits after a while. For instance, they noted that they adhered to selfcare activities while their symptoms aggravated or when they were hospitalized and then, they returned to their previous habits after their symptoms were alleviated or they were discharged from hospital. The most difficult habits to change were dietary habits and cigarette smoking. The most important reasons for their inability to change their dietary habits were the fact that low-salt and low-fat foods were not tasty for them.

«I used to eat high-salt and high-fat foods since youth and hence, I got used to eating these foods. Now, I have reduced salt and fat intake though my foods are still highsalt and high-fat» (P. 1).

# Disease Burden

The second main category of the study was disease burden which related to the problems associated with suffering from HF. The burden imposed on participants by HF and its treatments reduced their self-care ability. This main category consisted of three subcategories, namely progressive physical decline, comorbid conditions, and financial strain.

# Progressive Physical Decline

Most participants reported progressive physical decline as one of the major barriers to self-care. According to them, HF is a chronic disease which progressively deteriorates the patients' conditions. Most participants complained about physical weakness and having no energy for doing their activities. Reduced physical ability had prevented them from easily performing their activities or caused them weakness, fatigue, and dyspnea during activities. The severity of physical ability impairment varied from mild to severe. Participants with server physical ability impairment experienced problems even during light activities and needed frequent and long courses of rest during their activities. These problems had caused them negative psychological effects over time.

«Now, I get tired and get out of breathe very soon. I can't go walking» (P. 5).

# Comorbid Conditions

Comorbid conditions were another disease burden-related barrier to self-care among patients with HF. The most important comorbid conditions among participants were hypertension, diabetes mellitus, respiratory problems, osteoarthritis, and gastrointestinal disorders. To manage these conditions, participants needed to have different medical visits with different medical specialists, undergo different laboratory tests, and take numerous medications. They were dissatisfied with the large number and the side effects of their medications and hence, they sometimes avoided taking some of their medications or changed their doses. They also complained of confusion due to the numerous and different medical recommendations of different medical specialists and were unable to make appropriate decisions. Moreover, they had problems in differentiating among the symptoms of their comorbid conditions and hence, they had problems in having appropriate medical visits in case of symptom aggravation. «I have heart problem and diabetes mellitus and my kidneys do not work well. Therefore, I need to go to different doctors. Taking different drugs and controlling all these diseases are very difficult for me» (P. 7).

# Financial Strain

Financial strain was also a barrier to self-care, though its effects on participants varied. HF may result in employment loss and thereby, reduce income. Meanwhile, periodical medical visits, laboratory tests, medications, dietary regimens, frequent hospitalizations, and frequent transportations increase patients' expenses. Income decline and expense increase may impose financial strain on patients and limit their self-care ability. Participants noted that due to financial problems, they needed to prioritize medical procedures and self-care activities. Such prioritization might cause the low priority of some aspect of self-care.

«If I afford, I will have a medical visit at the time determined by my doctor. Otherwise, I avoid medical visit and just buy my drugs from pharmacy» (P. 10).

# Inefficient Support System

The third main category of the barriers to self-care among patients with HF was inefficient support system. This category pertained to factors which negatively affected the support available for self-care. The three subcategories of this category were inadequate social support, healthcare providers' inattention to self-care, and limited access to healthcare providers.

# Inadequate Social Support

Because of their difficult conditions, patients with HF need strong support for self-care. Support services for these patients should aim at their empowerment. Yet, participants were dissatisfied with the inadequacy of social, familial, governmental, and healthcare support. They reported the need for both financial and emotional support, though assigned higher priority to financial support. The only source of support for them was their family members, particularly their male children.

«All of my children deals with their own lives and hence, my wife and I are now alone. My disease-related costs are very heavy. I wouldn't need to work hard if the government supported us» (P. 9).

# Healthcare Providers' Inattention to Self-care

The starting point of self-care is healthcare settings. Effective self-care will not happen until healthcare systems take systematic measures for self-care promotion. Healthcare providers' inattention to self-care was mainly due to problems such as their heavy workload, limited professional autonomy, lack of comprehensive hospital discharge programs, and limited accountability to discharged patients. Such inattention and limited professional support for self-care caused participants problems in understanding the importance of self-care and performing self-care activities. Lack of comprehensive self-care promotion also caused healthcare providers not to feel responsibility towards self-care promotion.

«In our system, nobody values self-care. Nobody will punish me if I don't take any measure for self-care promotion» (P.15).

# Limited Access to Healthcare Providers

Participants' limited access to healthcare providers was

also a barrier to self-care. Patients with old age and financial problems as well as those who were alone or lived in distant areas had difficulties in accessing healthcare providers and services.

«I can't have a visit with a medical specialist because I need to go a long way and have no private vehicle. There is a healthcare center in our village. I take my drugs there and ask a general physician to re-prescribe them» (P. 10).

Moreover, care continuity was not maintained due to the lack of family physicians and community health nurses. Therefore, patients were not monitored after hospital discharge and did not adhere to self-care activities.

«In our country, nobody is responsible for monitoring the conditions of community-dwelling patients. Moreover, we don't have community health nurses or a system that monitors patients after hospital discharge to check whether they adhere to their treatment regimens. Consequently, discharged patients are re-hospitalized after several weeks or months» (P. 13).

# Discussion

This study explored the barriers to self-care among patients with HF. Findings came into three main categories, namely personal factors, disease burden, and inefficient support system.

As one of the personal factors, lack of self-care knowledge was the most common barrier to self-care. Previous studies on patients with HF also reported this lack and introduced it as a barrier to self-care.<sup>20,23</sup> our findings also showed limited patient education by healthcare providers and patients' low health literacy as the main factors contributing to such lack of self-care knowledge. Two earlier studies also showed that self-care had a significant relationship with patients' health literacy.<sup>24,25</sup> adequate knowledge about HF and its management is the basis of successful self-care.<sup>26</sup> Therefore, comprehensive educational programs are needed to improve patients' self-care ability.

Another personal barrier to self-care was HF-related negative emotions. This barrier negatively affected both self-care knowledge and behaviors. In line with this finding, a study reported that patients with HF experience fear, social isolation, and loss of control, which cause them psychological distress, depression, anxiety, and hopelessness.<sup>27</sup> Similarly, several other studies reported the association of psychological distress with poor self-care behaviors.<sup>26,28</sup> Negative emotions can reduce patients' motivation and mental energy for self-care and reduce the effectiveness of educational interventions. Given the high prevalence of psychological distresses among patients with HF, their early diagnosis and management can help promote patients' self-care and improve their quality of life.<sup>26,29</sup>

The difficulty of changing habits was the third personal barrier to self-care in the present study. Moreover, while

some patients were successful in changing some of their unhealthy habits, they were unable to adhere to new habits over time. In line with this finding, patients with HF in former study reported changing unhealthy habits and integration of self-care recommendations into daily activities as a constant struggle and a difficult task.<sup>10</sup> Another study also reported that counseling programs for behavior modification are not routinely implemented because they are time-consuming and hence, new approaches are needed for changing unhealthy habits and behaviors.<sup>30</sup> The most important barriers to change habits are socioeconomic status, age, cultural beliefs, educational level, comorbid conditions, and mental disorders.<sup>31</sup> Changing unhealthy habits and behaviors needs not only knowledge improvement, but also active involvement of patients and their family members through providing them with practical training and improving their selfefficacy.32

Disease burden was the second main category of the barriers to self-care. One of the subcategories of this category was progressive physical decline. It restricted participants' ability to perform their daily activities and made them dependent on others for performing their self-care activities and adhering to the treatment regimen. Consequently, they were unable to perform selfcare activities without others' help in case of symptom aggravation. A former study also reported physical limitations as a barrier to self-care among patients with HF.19 impaired physical functioning is one of the main consequences of HF. It is associated with poor prognosis, loss of independence, and low quality of life.<sup>33</sup> Patients with HF have low physical health status which limits their physical ability and gives them a sense of uselessness.<sup>34</sup> A study showed that one third of patients with HF had limited levels of physical activity and did not perform the regular physical activity due to physical deterioration.<sup>35</sup> Functional deterioration reduces patients' physical and mental energy for doing activities and thereby, reduces their functional capacity. Reduced functional capacity reduces their engagement in physical activities which in turn further lowers their physical and mental energy. Well-designed programs and interventions are needed to stop this vicious circle. Contrary to our findings, a former qualitative content analysis study did not report reduced physical functioning as a factor affecting self-care.<sup>36</sup> This contradiction may be due to the fact that compared with our participants, participants in that study were younger and had less severe physical problems.

The second subcategory of the disease burden main category was comorbid conditions. In addition to HF, most participants suffered from other health problems and hence, experienced greater difficulty in performing self-care activities. In line with this finding, a former study reported a significant relationship between the number of comorbid conditions and self-care ability, so

that patients with more chronic conditions had lower self-care ability.<sup>37</sup> Comorbid conditions complicate treatments, increase costs, necessitate frequent medical visits and hospitalizations,38,39 reduce patients' selfefficacy, and thereby, undermine their self-care ability.<sup>37</sup> Specialist HF nurses can provide patients with tailored education and facilitate communication among different healthcare providers, particularly for managing patients' comorbid conditions.<sup>40</sup> A comprehensive approach to the management of HF and comorbid conditions can improve prognosis.<sup>38</sup> Yet, a study reported that healthcare providers do not pay adequate attention to comorbid conditions among patients with HF.41 Therefore, clear clinical guidelines and close collaboration and coordination among different healthcare providers are needed for the effective management of all problems of patients with HF.

Financial strain was the third subcategory of the disease burden main category. HF imposes heavy costs on patients and their families and thereby reduces patients' self-care ability. Moreover, as HF is not considered as a special disease in Iran, afflicted patients do not receive governmental or organizational support and experience different financial problems. A former study also reported financial problems as one of the barriers to treatment adherence.<sup>42</sup> Financial problems are also associated with low quality of life, poor health status, lengthy recovering, limited medication adherence, and hence, increase the number of medical visits and hospitalizations.43 Low socioeconomic status was one of the reasons for financial strain in the present study. Similarly, an earlier study reported a significant relationship between poor socioeconomic status and disease burden.<sup>44</sup> Contrary to our findings, a study showed that financial strain had limited effects, if any, on health-related behaviors.<sup>45</sup> An explanation for this contradiction is the fact that most of our participants were retired or unemployed and hence had limited income, while most participants in that study were employed and had less financial concerns.

Inefficient support system was the third main category of the barriers to self-care among patients with HF. Inadequate social support was one of the subcategories of this category. In line with this finding, a former study reported lack of appropriate social support as a barrier to self-care.46 Patients need support from their families in order to effectively perform self-care activities. Although our participants were relatively satisfied with their family support, this support did not cover all aspects of self-care and was not constant. Similarly, a previous study showed that patients with HF receive weak social support.47 Moreover, our participants were dissatisfied with the support provided to them by their relatives, society, and healthcare system. As social support has a direct relationship with self-care ability,48 patients who receive strong support from their support system face limited barriers to treatment adherence.<sup>49</sup> In other words, support can empower patients for self-care and reduce their dependence on others. Yet, support should not be overwhelming so as to make patients passive in self-care and make them dependent on others.

Limited access to healthcare providers was another subcategory of the inefficient support system. We found that patients who lived in suburban and distant areas and those with low socioeconomic status had limited access to healthcare providers and services. Although most self-care activities are performed by patients, some self-care aspects are guided and supported by healthcare providers.<sup>10</sup> Therefore, patients need to have easy access to healthcare providers and hence, managerial and organizational barriers to such access should be identified and removed.<sup>50</sup> Clinical guidelines also highlight the importance of facilitating patients' access to multi-level and multidisciplinary healthcare services in order to improve their health and reduce the number of hospitalizations.<sup>51</sup> Patients and family members in a former study also reported that periodical visits and access to healthcare providers were important to support self-care.<sup>52</sup> Therefore, healthcare systems need to develop strategies to make specialized healthcare services easily accessible.

Healthcare providers' inattention to self-care was the third subcategory of the inefficient support system main category. Participants reported that they received limited support for self-care from healthcare providers and system. Self-care has many benefits not only for patients, but also for healthcare systems. One of the main goals of healthcare systems is to improve health for all. Self-care can help achieve this goal without imposing heavy strain and costs on patients and healthcare systems. Effective self-care needs the systematic support of healthcare system in order to improve patients' knowledge, skills, and self-efficacy.53 Healthcare providers' emphasis on the effectiveness and the importance of self-care can positively affect patients' engagement in self-care activities.54 Thereby, healthcare providers can play a significant role in empowering patients for self-care. Yet, organizational and educational limitations as well as limitations related to their job description are barriers to healthcare providers' engagement in self-care promotion activities.<sup>55</sup> Changes in the philosophy of healthcare systems are needed to increase the importance of self-care and encourage patients to seriously engage in self-care and decisionmaking activities.55

Among the strengths of the study were its qualitative design and data collection through in-depth interviews, both of which helped obtain a deep understanding of patients' experiences of the barriers to self-care. Meanwhile, the study had several limitations. For instance, as sampling was done in public healthcare centers, most participants were illiterate or barely literate and had moderate to low socioeconomic status. Therefore, findings may not be generalizable to patients with high educational levels and high socioeconomic status. Further studies on patients with high educational levels and high socioeconomic status are recommended to explore their experiences of the barriers to self-care.

# Conclusion

Patients with HF face different personal, disease-related, and support-related barriers to self-care which can be categorized as personal barriers, disease burden, and inefficient support system. Exploration of these barriers in the present study can be considered as the first step to their removal. Healthcare providers, managers, and authorities can use these findings to conduct contextbased educational interventions, psychological counseling, and financial support to promote self-care among patients with HF and thereby, improve HF treatment outcomes and patients' quality of life.

# Acknowledgements

This article resulted from a PhD dissertation in Nursing approved by Tehran University of Medical Sciences, Tehran, Iran. We are thankful to the administrators of the University and the participants of the study.

#### **Ethical Issues**

The Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran, approved this study (code: IR.TUMS.VCR. REC.1397.109). The study adhered to all ethical principles for human subjects.

### **Conflict of Interest**

The authors declare no conflict of interest.

# **Author's Contributions**

RN: Conception of the study and design, supervision of data collection and analysis. Drafted manuscript and critically revised the article. AA: Conception of the study and design, data collection and analysis. Drafted manuscript. KS: Conception of the study and design, supervision of data collection and analysis. Drafted manuscript and critically revised the article.

# **Research Highlights**

#### What is the current knowledge?

- Self-care has many advantages for patients with HF.
- HF patients face numerous barriers in achieving optimal selfcare.
- Self-care barriers should be considered as the most important issue in improving self-care in patients with HF.

#### What is new here?

- Self-care barriers in HF patients include personal, diseaserelated, and support-related barriers.
- Based on the results of this study, it is suggested that health care providers should consider well-known barriers to self-care.
- Researchers would conduct a tailored intervention for overcoming to personal, disease-related, and support-related barriers of self-care

# References

- Liou HL, Chen HI, Hsu SC, Lee SC, Chang CJ, Wu MJ. The effects of a self-care program on patients with heart failure. J Chin Med Assoc. 2015; 78(11): 648-56. doi: 10.1016/j. jcma.2015.06.004
- Coats AJS. Ageing, demographics, and heart failure. Eur Heart J Suppl. 2019; 21(Suppl L): L4-L7. doi: 10.1093/ eurheartj/suz235
- Savarese G, Lund LH. Global public health burden of heart failure. Card Fail Rev. 2017; 3(1): 7-11. doi: 10.15420/ cfr.2016:25:2
- Ahmadi A, Soori H, Mobasheri M, Etemad K, Khaledifar A. Heart failure, the outcomes, predictive and related factors in Iran. Journal of Mazandaran University of Medical Sciences. 2014; 24(118): 180-8. [Persian]
- Reyes EB, Ha JW, Firdaus I, Ghazi AM, Phrommintikul A, Sim D, et al. Heart failure across Asia: same healthcare burden but differences in organization of care. Int J Cardiol. 2016; 223: 163-7. doi: 10.1016/j.ijcard.2016.07.256
- Bos-Touwen I, Jonkman N, Westland H, Schuurmans M, Rutten F, de Wit N, et al. Tailoring of self-management interventions in patients with heart failure. Curr Heart Fail Rep. 2015; 12(3): 223-35. doi: 10.1007/s11897-015-0259-3
- Dokainish H, Teo K, Zhu J, Roy A, AlHabib KF, ElSayed A, et al. Global mortality variations in patients with heart failure: results from the International Congestive Heart Failure (INTER-CHF) prospective cohort study. Lancet Glob Health. 2017; 5(7): e665-e72. doi: 10.1016/s2214-109x(17)30196-1
- Taylor CJ, Ordóñez-Mena JM, Roalfe AK, Lay-Flurrie S, Jones NR, Marshall T, et al. Trends in survival after a diagnosis of heart failure in the United Kingdom 2000-2017: population based cohort study. BMJ. 2019; 364: l223. doi: 10.1136/bmj.l223
- Lesyuk W, Kriza C, Kolominsky-Rabas P. Cost-of-illness studies in heart failure: a systematic review 2004-2016. BMC Cardiovasc Disord. 2018; 18(1): 74. doi: 10.1186/ s12872-018-0815-3
- Jaarsma T, Cameron J, Riegel B, Stromberg A. Factors related to self-care in heart failure patients according to the middle-range theory of self-care of chronic illness: a literature update. Curr Heart Fail Rep. 2017; 14(2): 71-7. doi: 10.1007/s11897-017-0324-1
- Buck HG, Dickson VV, Fida R, Riegel B, D'Agostino F, Alvaro R, et al. Predictors of hospitalization and quality of life in heart failure: a model of comorbidity, self-efficacy and self-care. Int J Nurs Stud. 2015; 52(11): 1714-22. doi: 10.1016/j.ijnurstu.2015.06.018
- Lee CS, Moser DK, Lennie TA, Riegel B. Event-free survival in adults with heart failure who engage in selfcare management. Heart Lung. 2011; 40(1): 12-20. doi: 10.1016/j.hrtlng.2009.12.003
- Jonkman NH, Westland H, Groenwold RH, Ågren S, Atienza F, Blue L, et al. Do self-management interventions work in patients with heart failure? An individual patient data meta-analysis. Circulation. 2016; 133(12): 1189-98. doi: 10.1161/circulationaha.115.018006
- 14. Ruppar TM, Cooper PS, Mehr DR, Delgado JM, Dunbar-Jacob JM. Medication adherence interventions improve heart failure mortality and readmission rates: systematic review and meta-analysis of controlled trials. J Am Heart

Assoc. 2016; 5(6). doi: 10.1161/jaha.115.002606

- Jaarsma T, Strömberg A, Ben Gal T, Cameron J, Driscoll A, Duengen HD, et al. Comparison of self-care behaviors of heart failure patients in 15 countries worldwide. Patient Educ Couns. 2013; 92(1): 114-20. doi: 10.1016/j. pec.2013.02.017
- Zamanzadeh V, Valizadeh L, Jamshidi F, Namdar H, Maleki A. Self-care behaviors among patients with heart failure in Iran. J Caring Sci. 2012; 1(4): 209-14. doi: 10.5681/ jcs.2012.029
- Siabani S, Driscoll T, Davidson PM, Najafi F, Jenkins MC, Leeder SR. Self-care and its predictors in patients with chronic heart failure in western Iran. J Cardiovasc Nurs. 2016; 31(1): 22-30. doi: 10.1097/jcn.00000000000211
- Riegel B, Carlson B. Facilitators and barriers to heart failure self-care. Patient Educ Couns. 2002; 46(4): 287-95. doi: 10.1016/s0738-3991(01)00165-3
- 19. Aboutalebi Daryasari G, Memarian R, Vanaki Z, Kazemnezhad A, Naderi N. Limitations of self-care behaviour in heart failure patients-a qualitative research with approach Orems theory. Biomed Res. 2016; Special Issue: S437-S42.
- Siabani S, Leeder SR, Davidson PM. Barriers and facilitators to self-care in chronic heart failure: a meta-synthesis of qualitative studies. Springerplus. 2013; 2: 320. doi: 10.1186/2193-1801-2-320
- Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008; 62(1): 107-15. doi: 10.1111/j.1365-2648.2007.04569.x
- Lincoln YS. Naturalistic inquiry. In: Ritzer G, ed. The Blackwell Encyclopedia of Sociology. Blackwell Publishing; 2007. doi: 10.1002/9781405165518.wbeosn006
- 23. Zeng W, Chia SY, Chan YH, Tan SC, Low EJH, Fong MK. Factors impacting heart failure patients' knowledge of heart disease and self-care management. Proc Singapore Healthc. 2017; 26(1): 26-34. doi: 10.1177/2010105816664537
- 24. Cajita MI, Cajita TR, Han HR. Health literacy and heart failure: a systematic review. J Cardiovasc Nurs. 2016; 31(2): 121-30. doi: 10.1097/jcn.00000000000229
- Razazi R, Mohamad Aliha J, Amin A, Taghavi S, Ghadrdoost B, Naderi N. The relationship between health literacy and knowledge about heart failure with recurrent admission of heart failure patients. Res Cardiovasc Med. 2018; 7(3): 123-9. doi: 10.4103/rcm.rcm\_12\_18
- Hwang B, Moser DK, Dracup K. Knowledge is insufficient for self-care among heart failure patients with psychological distress. Health Psychol. 2014; 33(7): 588-96. doi: 10.1037/ a0033419
- Jeon YH, Kraus SG, Jowsey T, Glasgow NJ. The experience of living with chronic heart failure: a narrative review of qualitative studies. BMC Health Serv Res. 2010; 10: 77. doi: 10.1186/1472-6963-10-77
- Kessing D, Denollet J, Widdershoven J, Kupper N. Psychological determinants of heart failure self-care: systematic review and meta-analysis. Psychosom Med. 2016; 78(4): 412-31. doi: 10.1097/psy.000000000000270
- 29. Kessing D, Denollet J, Widdershoven J, Kupper N. Self-care and health-related quality of life in chronic heart failure: a longitudinal analysis. Eur J Cardiovasc Nurs. 2017; 16(7): 605-13. doi: 10.1177/1474515117702021
- 30. Habibović M, Broers E, Piera-Jimenez J, Wetzels M,

Ayoola I, Denollet J, et al. Enhancing lifestyle change in cardiac patients through the Do CHANGE System ("Do Cardiac Health: Advanced New Generation Ecosystem"): randomized controlled trial protocol. JMIR Res Protoc. 2018; 7(2): e40. doi: 10.2196/resprot.8406

- Berra K. Challenges of changing lifestyle to reduce risk for cardiovascular disease. J Cardiovasc Nurs. 2010; 25(3): 223-7. doi: 10.1097/JCN.0b013e3181cec7e4
- 32. Spaling MA, Currie K, Strachan PH, Harkness K, Clark AM. Improving support for heart failure patients: a systematic review to understand patients' perspectives on self-care. J Adv Nurs. 2015; 71(11): 2478-89. doi: 10.1111/jan.12712
- 33. Dunlay SM, Manemann SM, Chamberlain AM, Cheville AL, Jiang R, Weston SA, et al. Activities of daily living and outcomes in heart failure. Circ Heart Fail. 2015; 8(2): 261-7. doi: 10.1161/circheartfailure.114.001542
- 34. Pihl E, Fridlund B, Mårtensson J. Patients' experiences of physical limitations in daily life activities when suffering from chronic heart failure; a phenomenographic analysis. Scand J Caring Sci. 2011; 25(1): 3-11. doi: 10.1111/j.1471-6712.2010.00780.x
- Klompstra L, Jaarsma T, Strömberg A. Physical activity in patients with heart failure: barriers and motivations with special focus on sex differences. Patient Prefer Adherence. 2015; 9: 1603-10. doi: 10.2147/ppa.s90942
- Dickson VV, McCarthy MM, Howe A, Schipper J, Katz SM. Sociocultural influences on heart failure self-care among an ethnic minority black population. J Cardiovasc Nurs. 2013; 28(2): 111-8. doi: 10.1097/JCN.0b013e31823db328
- Vellone E, Riegel B, D'Agostino F, Fida R, Rocco G, Cocchieri A, et al. Structural equation model testing the situation-specific theory of heart failure self-care. J Adv Nurs. 2013; 69(11): 2481-92. doi: 10.1111/jan.12126
- Ruiz-Laiglesia FJ, Sánchez-Marteles M, Pérez-Calvo JI, Formiga F, Bartolomé-Satué JA, Armengou-Arxé A, et al. Comorbidity in heart failure. Results of the Spanish RICA Registry. QJM. 2014; 107(12): 989-94. doi: 10.1093/qjmed/ hcu127
- Riegel B, Jaarsma T, Strömberg A. A middle-range theory of self-care of chronic illness. ANS Adv Nurs Sci. 2012; 35(3): 194-204. doi: 10.1097/ANS.0b013e318261b1ba
- 40. Glogowska M, Simmonds R, McLachlan S, Cramer H, Sanders T, Johnson R, et al. Managing patients with heart failure: a qualitative study of multidisciplinary teams with specialist heart failure nurses. Ann Fam Med. 2015; 13(5): 466-71. doi: 10.1370/afm.1845
- 41. Lawson CA, Solis-Trapala I, Dahlstrom U, Mamas M, Jaarsma T, Kadam UT, et al. Comorbidity health pathways in heart failure patients: a sequences-of-regressions analysis using cross-sectional data from 10,575 patients in the Swedish Heart Failure Registry. PLoS Med. 2018; 15(3): e1002540. doi: 10.1371/journal.pmed.1002540
- 42. Dhaliwal KK, King-Shier K, Manns BJ, Hemmelgarn BR, Stone JA, Campbell DJ. Exploring the impact of financial barriers on secondary prevention of heart disease. BMC

Cardiovasc Disord. 2017; 17(1): 61. doi: 10.1186/s12872-017-0495-4

- 43. Campbell DJ, King-Shier K, Hemmelgarn BR, Sanmartin C, Ronksley PE, Weaver RG, et al. Self-reported financial barriers to care among patients with cardiovascular-related chronic conditions. Health Rep. 2014; 25(5): 3-12.
- Sicras Mainar A, Navarro Artieda R, Ibáñez Nolla J. Economic impact of heart failure according to the effects of kidney failure. Rev Esp Cardiol (Engl Ed). 2015; 68(1): 39-46. doi: 10.1016/j.rec.2014.02.021
- 45. Prentice C, McKillop D, French D. How financial strain affects health: evidence from the Dutch National Bank Household Survey. Soc Sci Med. 2017; 178: 127-35. doi: 10.1016/j.socscimed.2017.02.006
- 46. Allemann H, Strömberg A, Thylén I. Perceived social support in persons with heart failure living with an implantable cardioverter defibrillator: a cross-sectional explorative study. J Cardiovasc Nurs. 2018; 33(6): E1-e8. doi: 10.1097/jcn.00000000000523
- Mansouriyeh N, Poursharifi H, Taban Sadeghi MR, Seirafi MR. The correlation between social support and self-care in patients with heart failure: the mediating role of illness perception. Journal of Health Promotion Management. 2017; 6(5): 43-50. doi: 10.21859/jhpm-07036. [Persian]
- Graven LJ, Grant JS. Social support and self-care behaviors in individuals with heart failure: an integrative review. Int J Nurs Stud. 2014; 51(2): 320-33. doi: 10.1016/j. ijnurstu.2013.06.013
- 49. Khaledi GH, Mostafavi F, Eslami AA, Rooh Afza H, Mostafavi F, Akbar H. Evaluation of the effect of perceived social support on promoting self-care behaviors of heart failure patients referred to the Cardiovascular Research Center of Isfahan. Iran Red Crescent Med J. 2015; 17(6): e22525. doi: 10.5812/ircmj.22525v2
- 50. Ross H, Howlett J, Arnold JM, Liu P, O'Neill BJ, Brophy JM, et al. Treating the right patient at the right time: access to heart failure care. Can J Cardiol. 2006; 22(9): 749-54. doi: 10.1016/s0828-282x(06)70290-2
- Inamdar AA, Inamdar AC. Heart failure: diagnosis, management and utilization. J Clin Med. 2016; 5(7). doi: 10.3390/jcm5070062
- Liljeroos M, Agren S, Jaarsma T, Strömberg A. Perceived caring needs in patient-partner dyads affected by heart failure: a qualitative study. J Clin Nurs. 2014; 23(19-20): 2928-38. doi: 10.1111/jocn.12588
- Yazdani S, Akbarilakeh M. Iranian national self-care support system pattern. J Minim Invasive Surg Sci. 2016; 5(4): e41637. doi: 10.17795/minsurgery-41637
- Narasimhan M, Allotey P, Hardon A. Self care interventions to advance health and wellbeing: a conceptual framework to inform normative guidance. BMJ. 2019; 365: 1688. doi: 10.1136/bmj.1688
- 55. Coates V. Role of nurses in supporting patients to selfmanage chronic conditions. Nurs Stand. 2017; 31(38): 42-6. doi: 10.7748/ns.2017.e10742