

Original Article

Self-Care Management of Individuals with Heart Failure: A Qualitative Study

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Abstract

Background: Heart failure is an important health problem that is common in Turkey and the world.

Aim: The aim of this study is to clarify heart failure patient's status of self-care management.

Methods: This descriptive qualitative study was performed in the cardiology clinic of a university hospital. We included in this study 24 patients who were diagnosed with heart failure and who attended the cardiology clinic to manage their self-care. Data were collected by using a semi structured interview form and in-depth interviews. Data were analyzed by using content analysis.

Results: We determined two themes: facilitators and obstacles. Facilitators were composed of themes such as recognition of symptoms /do not want to experience symptoms, fear, family support, believing in the treatment, motivation and being forced. Besides, obstacles were composed of themes such as not giving up habits, lack of knowledge, not accepting the disease/ not minding, lack of self-confidence and fatalism.

Conclusion: Conclusively, it is important to provide training and consultancy about the diagnosis and treatment of the disease to ensure the motivation of patients during the disease management process. It has been suggested that nurses should have roles in providing education, consultancy, and motivation to patients.

Keywords: Heart failure, self-care, nursing, qualitative research.

Introduction and background

Heart failure (HF) is an important health problem that is frequently observed throughout the world; it decreases the functional capacities of individuals and affects self-care and quality of life (Mozaffarian et al, 2015; Yancy et al, 2013; Degertekin et al, 2012; McMurray et al, 2012). The importance of self-care and positive effects of the adherence of patients to the treatment and prognosis have been specified in guidelines that were prepared to develop the treatment and health care of HF patients. Adherence to treatment, diet,

exercise, weight monitoring, and recognizing and managing symptoms are the self-care behaviors related to HF. However, individuals fail in providing self-care for different reasons. It is difficult to ensure self-care in individuals with HF (Yancy et al, 2013; McMurray et al, 2012).

Dickson, Deatrck & Riegel, (2008) reported that patients did not have sufficient self-care management skills. They also stated that 61% of patients could maintain self-care, and 44% of them could ensure sufficient self-care management.

According to quantitative studies, having knowledge about age, gender, marital status, socioeconomic status, educational status, severity of symptoms, perception of self-efficiency, health perception, and self-care practices affected the self-care behaviors of patients (Chriss et al, 2004; Rockwell & Riegel, 2001). Artinian et al, (2002) reported that there was no statistically significant difference between self-care behavior scores and sociodemographic features, whereas they showed a significant difference between self-care knowledge scores and self-care levels of patients.

Dickson, Buck & Riegel, (2011) reported that HF patients had low self-care capacities, and they had difficulties in determining priorities for their self-care and applying the health care protocols. It was specified that having low levels of self-care skills negatively affected the patients' outcomes. Siabani, Leeder & Davidson, (2013) performed a qualitative meta-analysis in which they tried to determine the facilitators and barriers in the self-care management of HF patients. The barriers were having indistinguishable symptoms, experiencing severe symptoms, experiencing symptoms that trigger each other, having insufficient information on HF management, not using information in daily-life activities, and performing short-term training on HF.

Clinicians and academicians try to find the reasons why some individuals with HF can manage their comprehensive self-care activities sufficiently whereas others cannot. It is important that nurses understand the problems of HF patients from the patients' perspective during the management of the disease. Further, nurses should also learn how patients manage their self-care, and provide required training and consultancy to them.

It is important to determine how patients manage their diseases, and it is also crucial that nurses are aware of this issue. In Turkey, no study has been performed on the determination of self-care status of HF patients. In the literature, it has been determined that there are various problems of individuals with HF.

Moreover, this study is performed to determine the problems that are specific to Turkish culture in terms of self-care of patients. Accordingly, nurses

could provide better help to HF patients in Turkey if they knew the cultural difficulties related to the self-care.

Purpose of the study

Purpose of the study is to clarify heart failure patient's status of self-care management.

Methods

Design

This study was performed by using a descriptive, qualitative research method. The study was carried out in the cardiology clinic of a university hospital.

Participants and Settings

We included 24 HF patients who were 18 years old or older, who could communicate in Turkish, were well oriented, and volunteered to participate in our study. We excluded individuals from the study who had kidney failure (and dialysis treatment), cancer (and chemotherapy or radiotherapy), chronic obstructive pulmonary disease (having respiratory problems requiring ventilation support), cerebrovascular events that could limit the self-care management, rheumatoid arthritis, or hearing problems. The data collection was performed until the data started to repeat. The study sample size reached saturation upon the interview with the 20th patient, but we continued to interview with the remaining four patients. The descriptive features of patients are summarized in Table 1.

Ethical considerations

Written permission was obtained from the university hospital (B.30.2DEU.0.H1.70.83-443) and as well as ethical approval was obtained from University Ethical Committee (28.07.2010 date and 2010/08-13 number). The aim of the study was explained to patients, and those who agreed to participate were included in our study. The written consent forms of patients were obtained.

Data Collection

An in-depth interview method was used to collect the data. We used a semi structured interview form, which was prepared in line with the literature (Dickson & Riegel, 2009; Riegel & Carlson, 2002). Interviews were performed in an appropriate room in the clinic with stable patients.

The interviews took approximately 20 to 50 minutes and were recorded by obtaining the permission of patients.

Data Analysis

We listened to the recorded interviews, transformed them into written form, and applied content analysis. Data were encoded (open coding) according to the meanings, the related codes were gathered (axial coding), themes were created (selective coding), and the data were interpreted (Speziale & Carpenter, 2007; Yildirim & Simsek, 2006).

During the process of reporting findings, various statements of participants were given to show how we classified themes. These statements were kept in their original language as much as possible. The age and gender of patients were indicated in the end of sentences between “{}” signs.

Results

In the study, two main themes (facilitators and obstacles) and 11 subthemes were specified that show how individuals with HF manage self-care (Table 2).

Facilitators

Under the main facilitators theme, there were the following subthemes: recognizing the symptom and not wanting to experience the symptom, fear, family support, belief in the treatment, motivation, and being forced.

Recognizing symptoms/do not want to experience symptoms

Some participants stated that they experienced frequent symptoms such as edema, weight gain, fatigue, and shortness of breath. It was difficult for them to live with these symptoms. When patients could recognize the symptom, they stated that their awareness increased, they knew the reason for the symptom, and they also knew how to behave (what to do and what not to do) when they experienced it.

They also specified that they were aware of their weight gain when they realized the compression of socks on their wrists or tightening of their belt.

“I weigh myself in every one or two days and I can also measure my weight with the help of the hole of my belt. When one hole tightens more, you can believe that you are normal and healthy. When I cannot button up my trousers, I can believe that I have extra weight and I can understand this via weighing myself more often. I try to limit myself when I have extra weight.” (70-year-old male)

Fear

Some of the individuals with HF stated that they were afraid of death because some of their relatives passed away because of heart disease, and they specified that they tried to manage with the disease and not to have the same destiny as those relatives.

Further, they were also afraid of stroke and dialysis, which they thought would increase the probability of death.

“The fear of death let me to quit drinking alcohol. Currently, I do not like the smell of alcohol and I do not know the reason. I drink very rare but I do not drink everyday as before. Smoking is the same. I am afraid of death and I feel this deep fear in my soul. These are triggering factors. Thus, it helps me to quit drinking alcohol.” (60-year-old male)

Family Support

Patients stated that their motivation increased when they received sufficient support from their families.

“My wife is already very conscious about it. She directs me. She knows how to stop me. That’s enough. For instance, we have a walk, it is sufficient for today. She is conscious about it and she helps me in this regard.” (67-year-old male)

Belief in the treatment

Some patients believed that they might heal because the treatment was beneficial, and they perceived the treatment as beneficial.

Further, they believed in their doctors and the trust between them, and their doctors increased their motivation.

“I use my medication properly. I pay attention to nutrition; I try not to eat salty and heavy food as much as I can. I have a walk regularly. This is what I can mention. In my opinion, the most important is to use medication and comply with recommendation of the doctor. I am doing it till now and there has not been more damage since I had the first infarct.” (67-year-old male)

Motivation

Some patients believed that they could control their disease and their motivation increase because they knew that they would be better and healthy in this way.

“In case one is conscious, she/he can live longer; I experienced it. My life is now focused on not to be sick. I hope that my heart will heal with my new life style because I experienced that my results were improved with the effect of my new life style.” (67-year-old male)

Being forced

Some patients stated that they had to live this situation because their disease was a chronic disease and they experienced symptoms frequently.

“You cannot believe that it happens to you. You find it strange. But then, you have to get used to it. You have to comply with recommendations of the doctor. When you get used to it, you think that there are worse cases compared to your health status. You think that yours is good. So, you manage the live somehow.” (77-year-old female)

Obstacles

Under the obstacles theme, there were subthemes including not giving up habits, lack of knowledge, not accepting the disease/not minding, lack of self-confidence, and fatalism.

Not giving up habits

Some patients stated that they continued their old habits when they perceived that their health status was good. They specified that it was hard to adapt to a new life style.

“I cannot eat food without salt; it is my taste (smiling).” (77-year-old male)

Lack of information

Some patients stated that doctors did not inform them sufficiently, and they did not know what to do at home, what to pay attention to, which problems they might be faced with, and when they should visit the doctor.

“I did not know that my heart is insufficient. Doctors said that it is not and that’s all. I had a swelling in my abdomen last year; I came here. I had a swelling in my abdomen maybe due to the cold weather. I do not feel anything about my heart. I do not have any pain or hurt and if this swelling heals, I do not have any problem, Thanks to God.” (60-year-old female)

Not accepting the disease/not minding

Some participants stated that they did not mind their health problems.

“I am not afraid of death. I do not have any concern about the problems of my heart as others and I’m not obsessed with my illness. I do not think about the symptoms which affect my heart. I do not limit myself and I eat what I want and I wander around as I wish.” (64-year-old male)

Fatalism

Some patients accepted their health status because they believed that there was nothing they might do to manage their disease.

“You cannot do anything, what God says, it happens. It does not occur what we want.” (76-year-old female)

did not have self-confidence during daily life at home and they might not solve the problem if they were alone at home.

“I cannot know to what extent I can manage this. I cannot claim that I can manage my disease. It is possible that it is because of us.” (45-year-old male)

Lack of self-confidence

In the interview, some patients stated that they

Table 1 Features of Individuals Included in the Sample Group (n= 24).

Features	n	%
Gender		
Female	12	50.0
Male	12	50.0
Education Status		
Illiterate	1	4.1
Primary school	15	62.5
Secondary School	4	16.7
High education	4	6.7
Marital Status		
Married	17	70.8
Single	7	29.2
Employment Status		
Employed	1	4.1
Unemployed	23	95.9
NYHA Stage		
II	15	62.5
III	9	37.5
	X±SD	
Age	64.95 ± 8.73	
Diagnosis duration	8.56 ± 6.18	
EF %	40.20 ± 13.22	

Table 2 The Main Theme and Subthemes Intended for How Heart Failure Patients Manage Their Self-Care

Main Theme	Theme
Facilitators	Recognizing of symptom/do not want to experience the symptom Fear Family support Belief in the treatment Motivation Being forced
Obstacles	Not giving up habits Lack of information Not accepting the disease/not minding Fatalism Lack of self-confidence

Discussion

Because of our study, we determined the two themes (facilitators and obstacles) expressed by participants about their self-care management of HF.

Facilitators

HF patients experience symptoms frequently, and these symptoms influence daily-life activities, family, work, and social life. HF patients specified that living with symptoms such as shortness of breath, edema, chest pain, weakness, fatigue, and insomnia was difficult, and they stated that they did not want to live with these symptoms. Europe & Tyni Lenne, (2004) showed that patients shaped their behaviors according to their perceptions of signs and symptoms. Rockwell & Riegel, (2001) determined the factors that affect self-care and found that symptom severity is an important parameter. Individuals who experienced frequent symptoms were good at recognizing severe symptoms and participated in their self-care actively.

However, the ones with mild HF had difficulties in recognizing symptoms and in understanding the aims of self-care. In our study, patients who recognized the symptom and did not want to experience it paid attention to self-care activities.

Having knowledge about the disease and the treatments facilitated patients to recognize the symptoms.

In this study, patients stated that they were afraid of stroke as well as death. Therefore, they specified that they comply with recommendations for treatment and suggestions of their doctors.

We also showed that they were aware of the severity of their health status and they knew that it was important to be careful. Being afraid of the disease has also been shown to be a positive triggering factor for patients to ensure self-care.

The acute initiation of symptoms such as shortness of breath and angina led to life-and-death perceptions which patients tended to prioritize (Stromberg & Jaarsma, 2008).

In our study, individuals specified that their self-care was positively affected when they received sufficient support from family members/health care providers or from their social environment. Social support increased the self-management of patients and provided benefit. In studies, patients have stated that social support is one of the main contributory factors in the management of their health status (Harkness et al, 2015; Gallagher, Luttk & Jaarsma, 2011; Heo et al, 2009).

Efficient family support to HF patients during their treatment and care process has influence in the development of self-care behaviors.

It was determined that participants who were trained by health professionals had strong belief in the treatment, and their self-care was also positively influenced.

When patients found benefit from the treatment, their belief in the treatment and in health professionals increased. The trust between the patient and the health professional was very important. Efficient communication skills and ensuring patient confidence ensures patient empowerment.

In this study, it was shown that the symptoms receded when patients complied with the treatment process. Patients stated that they felt themselves better and their motivation increased when they did not experience symptoms. Their motivation increased because of the positive outcome of their behaviors.

The treatment and health care process of HF patients is complicated, and patients should be followed regularly. As the severity and frequency of symptoms increase, patients need regular health service to heal, and they feel compelled to receive health care to live with their disease.

When patients experience exacerbation of symptoms that they describe as very difficult, they perceive that they should live with these symptoms. Harkness et al, (2015) performed a meta-analysis to determine the self-care strategies of HF patients and found that patients wanted to ensure their self-care and they were ready to do whatever was required.

Obstacles

Some HF patients continue their old habits when they do not care about the self-care activities to manage their disease. Some of these individuals ignore their disease when they continue their old habits. They want to continue their daily life as it was before the diagnosis.

Having enough knowledge about the disease is sometimes insufficient to attain behavioral change. Various HF patients have problems in transforming

their knowledge into behavior. Both patients and their families are affected during the adaptation period of patients, which can make it difficult to give up habits (Granger et al, 2009).

In our study, we showed that patients did not have enough information about disease management and treatment. When some patients were asked about their particular symptom management behaviors, they gave statements such as, “I do not know what to do, I sit and wait for the symptom to heal and if it continues I visit the health professionals.”

It has been emphasized in various studies that patients should be informed about their disease and the disease management (Artinian et al, 2002; Wright et al., 2003). Goodman et al, (2013) stated that the disease management of HF patients was weak when patients lack sufficient information about their health status. Stull et al, (1999) performed a study in which they examined how individuals adapted to their disease and indicated that patients and their families needed more information related to the diagnosis.

Some frequently observed situations in the society can also complicate the adaptation of individuals to the treatment. The information that “one should drink eight glasses of water daily for a good health” has been known to obstruct the HF patients who choose to limit their liquid intake (Das & Grimmer-Somers, 2012).

Individuals can misunderstand some self-care activities, such as compliance with diet (Rogers et al, 2000), daily weight follow-up (Riegel & Carlson, 2002), recognition of symptom (Horowitz, Rein & Leventhal, 2004), success of the treatment (Kaholokula et al, 2008), and seeking help (Rodriguez et al, 2008), because of a lack of information, and such misunderstandings can negatively affect self-care behaviors.

Health professionals should provide the required information and consultancy to patients. However, health professionals alone are insufficient to inform patients because of the negative outcomes of health care systems.

During interviews, some of the patients stated that they were informed by doctors. In our study, it was obvious that nurses did not have roles in the

follow-up of these patients and their trainings. Lack of nurses in the field of HF could be another reason for the lack of patient information.

In this study, we showed that patients did not mind their symptoms when they did not accept their disease. Inversely, when patients accepted their disease, they perceived their situation as weakness.

According to the meta-analysis of Harkness et al, (2015) it was determined that some patients postponed receiving health care from health professionals because they were afraid of being hospitalized even though they were aware of the decompensation findings. Horowitz et al, (2004) stated that HF patients did not care about their health status when they did not experience severe symptoms.

Therefore, it is very important that nurses train patients so they understand the importance of recognizing symptoms early and taking precautions.

Cultural beliefs contribute to misconceptions about HF. Patients can believe that HF occurs because of stress and old age (Dickson et al, 2012). In our study, individuals with HF did not pay attention to symptoms of the disease, and they thought that symptoms had developed because of stress, old age, and difficulties in their work life. Accepting their disease and having patient identification mean loss of power for individuals.

Some individuals were convinced that God would help them in the disease management and they believed that ‘What God says, happens,’ in some cases. Individuals take refuge in their faith when they think that there is nothing to be done about their disease. Some individuals focus on spiritual approaches (live with faith and deepening their faith) during the HF disease process (Riegel & Carlson, 2002; Rhodes & Bowles, 2002). It has been stated by some individuals with HF that they do not believe that they can cope with their disease because of sudden changes in their health status. Health-related events led patients to lose their faith in themselves during the struggle with symptoms of HF.

It is possible that individuals feel themselves insufficient because of the progressive nature of

the disease, lack of information, and lack of an opportunity to develop their skills related to disease management.

Conclusion

Our study suggests that individuals with HF should be informed by health professionals on how to gain skills to manage their own self-care. In addition, nurses should enhance the motivation of HF patients and support them to change their behaviors according to the disease and adopt a new life style.

Trainings about HF diagnosis, treatment, symptoms, and coping with symptoms should be performed by specialist nurses. Health professionals should ensure motivation in patients to help them become effective in self-care management. Nurses should work in cooperation with families to ensure the social support of the patient. Patients should be followed regularly by specialist nurses, and nurses should provide consultancy to patients during hospitalization, in the clinic, and at home.

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