

SELF-CARE MANAGEMENT FROM THE PERSPECTIVE OF HEART FAILURE PATIENTS

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ABSTRACT

Background: To explore the understanding of heart failure self-care management among patients. **Method:** A generic qualitative research design was employed, utilizing the Arabic language version of face-to-face interviews and a purposive sampling technique. A sample of 24 people treated for heart failure (HF) at a tertiary heart center in the Kingdom of Saudi Arabia was recruited from May 2024 to May 2025. **Results:** Patients' perceptions, beliefs, and readiness towards managing heart failure highlighted how limited awareness, emotional denial, and dependency on healthcare providers contributed to the inadequate and inconsistent self-care engagement behavior of the heart failure (HF) patients. **Conclusion:** This study emphasizes the need for HF symptom perception management education programs for patients, continuous professional development for healthcare providers, promotion of positive attitudes, and fostering interdisciplinary collaborations to improve HF self-care management among HF patients. Future research should examine how psychological stress affects coping in heart failure patients, explore organizational roles, and investigate how knowledge, attitudes, and clinical practices contribute to poor self-care, focusing on HCPs and caregivers.

Keywords: Self-care, heart failure self-care management, Saudi Arabia, barriers, facilitators, and perception.

PENDAHULUAN

Studies support that heart failure is an abnormal clinical condition characterized by dysfunction of the heart muscles, involving impaired cardiac pumping of blood throughout the body (Inamdar & Inamdar, 2016). It is associated with reduced levels of B-type natriuretic peptide, as well as pulmonary or systemic congestion. (Lam, C, & Solomon, S., 2021). It is a long-term diagnosis that requires consistent good practices, a sedentary lifestyle, and medication adherence to reduce the risk of mortality and morbidity. About 20% of patients with acute coronary syndrome admitted to hospitals had congestive heart failure in Saudi Arabia, receiving limited treatment upon admission (Albackr et al., 2013).

Self-care management involves the behaviors that patients adopt to maintain their health and make decisions about managing the signs and symptoms of heart failure (Riegel et al., 2011). As is known, heart failure is a costly condition to treat, often leading to impaired physical well-being and frequent hospitalizations due to exacerbations. According to the American Heart Association (2009), key domains of heart failure self-care include medication management, lifestyle modifications, symptom monitoring, timely use of health services, and maintaining social relationships (Clark et al., 2010).

Heart failure is a progressive and irreversible condition; however, it may improve or restore cardiac function by preventing myocardial injury and preserving renal function if treatment is followed according to established guidelines. There are two phases of acute heart failure syndrome management: the first phase involves stabilization during admission to the emergency department, followed by the second phase, which continues during hospitalization and extends into the post-discharge period

(Khan et al., 2008). Paying close attention is crucial for recognizing and responding to early signs of heart failure. This awareness can significantly impact how quickly help and support are provided, making a difference in giving timely assistance. A misleading diagnosis of the primary complaint in a heart failure patient can lead to incorrect management and may worsen the current symptoms. Furthermore, Jaarsma et al. (2020) summarized that the Heart Failure Association (HFA) recommendations on self-care for HF patients from the 2021 ESC guidelines are categorized into self-care behaviors that help maintain stability, monitor for changes, and respond appropriately to symptoms (self-care management behaviors).

Recently, there are many well designed heart failure registries have been conducted in Middle East Countries (MEACs) include GULF countries such as Saudi Arabia, and United Arab Emirates, it is not only limited to western countries, aim mainly to explore the gap between real life practice and the standard heart failure guidelines (Elasfar et al., 2019). Several studies related to heart failure self-care have been conducted in Western countries; however, they are limited in Saudi Arabia (AbuRuz et al., 2016; Al-Shamiri, 2013). Al Johani (2023) noted that, regarding self-care practices, which vary in individual and cultural characteristics, some Western self-care recommendations cannot be easily implemented into the Saudi context.

A knowledge gap exists between guidelines-directed clinical care for heart failure, clinical practice, and incomplete discharge checklists among cardiologists (Agarwal et al., 2019). It may affect patients with heart failure regarding self-care management after discharge home, leading to a worsened quality of life and increased physical and emotional distress. Educating patients and families on home weight monitoring with diuretics and follow-

up via mobile phones for regular contact with healthcare providers (Agarwal et al., 2019). Some patients may not follow up with cardiac specialty clinics due to various circumstances and instead seek medical treatment at the nearest hospital. Evidence shows that time constraints during consultations can lead to dissatisfaction among both doctors and patients (Al Busaidi et al., 2010).

The increasing rate of new cases and readmission among heart failure patients in Saudi Arabia is also an overwhelming worldwide issue. By exploring the perceptions of self-care management among heart failure patients, the researcher identified the struggle between adaptation and adherence that influences their self-care routines and frequent readmissions. There are no standardized heart failure management protocols in Saudi Arabia (Al Habeeb W et al., 2019). Since 2019, the Saudi Heart Association (SHA) guidelines have been developed to bridge this gap in Saudi healthcare organizations, with minimal recommendations on self-care interventions, and few studies have been cited regarding heart failure self-care in Saudi Arabia (Al Habeeb et al., 2019; Aljohani, 2023). Studies in the Middle East were also conducted mainly using a quantitative design; hence, no studies have been conducted to explore heart failure self-care management from the perspective of heart failure patients in Saudi Arabia using a qualitative approach, resulting in limited knowledge about the concept of self-care. Thus, the outcome of this study will contribute to enhanced self-care knowledge among the Saudi population with heart failure.

METODE PENELITIAN

The research employed a qualitative descriptive methodology to explore patients with heart failure (HF)

understanding of self-care management for heart failure. An in-depth interview will be conducted with a group of heart failure patients from diverse backgrounds at one of the tertiary hospitals in the Eastern Province, Saudi Arabia. The participants for this research were selected using purposive sampling, a sampling technique that involves judgment sampling or nonrandom selection, which does not require underlying theories or a predetermined number of participants (Etikan et al., 2016). Twenty-four participants meeting the following inclusion criteria: diagnosed with heart failure with or without comorbidities, admitted to the selected Coronary Care Unit and Cardiac Ward, above 18 years old, of Saudi nationality, and fluent in Arabic or English. One hemodynamically unstable and critically ill patient and two participants who refused to obtain informed consent were excluded from this study.

The literature review forms the basis for the interview questions, which include three open-ended questions designed to explore the patient's perspective on the topic. The questions were: 1) Can you describe your perception of heart failure patients towards the disease, treatment, and its related effects? 2) Can you explain the barriers and facilitators towards heart failure self-care management? 3) Can you describe what you did, and what the caregiver did, to prevent worsening HF symptoms? The majority of participants spent, on average, less than 60 minutes answering questions. According to the guidelines, a sample size of 20 to 30 interviews is suggested as adequate until data saturation is achieved (Creswell, 2018).

A six-phase thematic analysis process was used to identify and analyze data patterns. The data obtained from the interviews were analyzed thematically, which makes it possible to systematically

find and analyze patterns of meaning within a set of qualitative data (Braun & Clarke, 2006). The first phase involved the research team reviewing and understanding the data through preparatory analysis. In the second phase, the researcher converted the data into a clear format using Microsoft Word and tabulated the results. Manual coding was performed to generate the initial codes. During the third phase, the team identified themes within these codes. A verification process in the fourth phase ensured the codes accurately reflected the original data by comparing themes to the datasets. In the fifth phase, the team addressed research questions, established connections, and provided descriptions under each theme to inform viewers. Finally, in the sixth phase, the team prepared a report based on the data analysis.

Ethical approval was obtained from the Kulliyah of Nursing Postgraduate Research and Ethics Committee (KNPGRC), the Kulliyah of Nursing Research Committee, and the IIUM Research Ethics Committee (IREC) in Malaysia. This was followed by approval from the Ethics Research Committee at the military hospital in Saudi Arabia, as well as the Institutional Review Board (IRB) of the Medical Services General Directorate of the Eastern Region Armed Forces Hospitals, Kingdom of Saudi Arabia. The confidentiality of participants will be maintained by not revealing their names or identities in the data collection, analysis, and reporting of the study findings.

HASIL

Throughout the data collection process, twenty-four participants agreed to participate in interviews. The background information about the participants is summarized in Table 1. The three themes identified were knowledge and

understanding, acceptance and adaptation, and self-care management practices.

Table 1: The demographic characteristics of the participants (n=24)

Demographic characteristic	f	%
Age:		
30-50	9	37.5
51-80	15	62.5
Marital status:		
Married	22	91.7
Divorce	2	8.3
Race:		
Saudi	24	100
Gender:		
Male	21	87.5
Female	3	12.5
Level of education:		
Secondary school	12	50
University	12	50
Employment status:		
Employed	5	20.8
unemployed	6	25
Retiree	13	54.2
Living arrangement:		
Alone	2	8.3
Spouse	1	4.17
Family	20	83.3
Parent	1	4.17

Theme 1: Knowledge and Understanding of HF condition

Initially, the participants were asked about their perceptions of heart failure as a disease, its treatment, and its related effects. Knowledge and understanding of one's health condition are essential for effective self-care management, shaping how individuals perceive, accept, and respond to their illness. Misunderstandings about their condition can lead to ineffective self-care practices, delays in seeking treatment, or reliance on misinformation. The participants expressed that they did not expect they be diagnosed with heart failure disease, such as *"not aware"*, *"do not have"*, *"no idea to talk"*, or *only" family*

history of hypertension". For instance, one of the participants expressed:

"I do not know. Not much, I do not understand well. I do not have any history of sick family, everyone is good. No, I do not know I have a heart problem." (Patient 17, 48 years old, Male)

Understanding of their condition, including its causes, symptoms, and treatment, varies among individuals, with some possessing accurate knowledge while others may have misunderstandings that affect their ability to make informed decisions. The evaluations of participants support this echo. Patient 13, he understood perfectly his current condition after one of the procedures done about 2 years ago:

"I have a weak heart. I had a pacemaker insertion 2 years ago. The doctor said to me that. I need to go to Riyadh for a heart transplant. I do understand what they explained to me about my condition. I have heart failure." (Patient 13, 47 years old, Male)

Knowledge and understanding are the primary keys to the perception of HF self-care management among HF participants. Most participants reported a lack of knowledge about the disease and self-care management recommendations, especially participants with multiple comorbidities. As clarified in the subsequent theme, the participants also recognised the acceptance and adaptation of the HF condition.

Theme 2: Acceptance and Adaptation of HF condition

Acceptance and adaptation to a condition are also key aspects of self-care. Some of the participants in this study reported that they are accepting their fate after being diagnosed with heart failure. Then they will try to adjust their lifestyle, working environment, strict diet intake,

taking prescribed medication, and follow-up.

"Of course, what has happened to me now affects my life, and all aspects physically, mentally, and emotionally. Praise to the Almighty God, Allah, for everything." (Patient 4, 62 years old, Male)

The ability to adapt positively often depends on the level of support from healthcare providers, caregivers, and personal coping mechanisms. Furthermore, the participants elaborate more about their willingness to engage in effective management strategies. Patient 4 is aware of his condition; he went directly to the hospital for further treatment. He said that:

"I was recently diagnosed with heart failure. I am experiencing chest pain, shortness of breath, and dizziness. My doctor told me to seek emergency medical treatment if I have these symptoms. That is why I'm here. Everything was fine, and I do not think this treatment is a burden. It is for my good." (Patient 4, 62 years old, Male)

Others reported gradually accepting their condition, learning to incorporate necessary lifestyle changes and treatment regimens into their daily lives. For patients with heart failure, self-care management involves adjusting their activity level, modifying their diet, seeking support, and consulting healthcare professionals if they notice any abnormal changes or shifts in their current symptoms. One participant, as reported by his wife (caregiver), noticed some behavioral and psychological changes in him (Patient 9). He stated that:

"All of this is due to systemic lupus erythematosus (SLE). I did not have a heart problem before. I believe my autoimmune disease, SLE, is causing inflammation in my heart valve, affecting my brain and spleen. The last time I had a fever, shortness of breath, and was disoriented, according to my wife, I did not even recognize her. She is the one who sent me

to the hospital.” (Patient 10, 50 years old, Male)

Patient 10 clarified that the ‘sudden changes’ of his behaviors include disorientation, fever, and shortness of breath, which may correlate to his autoimmune disease (SLE), affecting his life, and later, the doctor diagnosed him with heart failure. Most of the perceptions of heart failure patients regarding the disease, treatment, and its related effects encompass emotional responses and acceptance of the diagnosis. More details about the perception of self-care management practices among HF patients that emerged were provided in the subsequent theme.

Theme 3: Self-Care Management Practices

Self-care management plays a crucial role in enabling individuals with heart failure to monitor symptoms, adhere to medication regimens, and manage their overall health status. Findings from this study revealed that several participants showed limited engagement or interest in self-care practices. Some expressed total disengagement from essential self-monitoring behaviors, especially those with multiple comorbidities, which increases their risk of deterioration. For instance, one participant shared their dependency on the caregiver:

“Medications, I skipped some of my medications that day, that is why I ended up here. (Sad) Diet intake, anything I eat. Salt, sugar, everything. No restrictions for me. My daughter cooks for me, and sometimes my housemaid prepares food for me. I skipped some of my appointments because nobody was available to take me to the hospital. Exercise, no more I have body pain in my legs and stomach. I experience shortness of breath when engaging in any physical activity. No weight monitoring. Blood sugar monitoring, yes,

only sometimes; I have the machine. I just took the medications.” (Patient 20, 69 years old, Male)

However, a lack of knowledge or interest in self-monitoring may lead to poor health outcomes or an increased reliance on healthcare services during acute exacerbations. Surprisingly, in this study, one of the participants, Patient 8, declared that he takes the medicine only on a particular day:

“I do not have a Blood pressure monitoring machine at home. Sometimes I check my blood pressure in the hospital; if the reading is within an acceptable measurement, I will not take medication. I will take medicine on a certain day, especially only on Wednesday”. (Patient 8, 39 years old, Male)

Notably, some participants had made significant lifestyle adjustments following diagnosis and adhered to recommended self-care practices. For instance, Patient 5 shared:

“I quit smoking and always follow up with my doctor. I stick to a healthy diet as recommended by my doctors. I take my medications on a regular schedule, before meals. During follow-ups, my doctor reviews my medications after checking my blood tests. I keep track of my cholesterol and blood pressure at home. I weigh myself every 3 to 4 days. I used to do boxing and martial arts for work, but now I have slowed down and do not get stressed. I only do light exercise, like short walks on weekends.” (Patient 5, 52 years old, Male)

Effective self-monitoring practices, such as tracking weight, blood pressure, blood sugar levels, and physical activity, contribute the early identification of complications and enable timely intervention. Patient 7 described his self-care routine:

“Diet, mostly low salt. I take medications as prescribed. I have a BP machine because I take hypertension

meds. I exercise daily with simple movements I was taught. Sometimes, I walk slowly outside. I monitor my weight every 2 to 3 days. The hospital sends appointment reminders, and I set them on my phone. My daughter also reminds me of upcoming check-ups.” (Patient 7, 54 years old, Male)

While some actively engage in managing their condition, others face significant barriers, including a lack of knowledge, motivation, physical limitations, or dependency on caregivers.

PEMBAHASAN

To address this aim, the study employed a qualitative research design to gather in-depth insights from HF patients. The findings were organized and presented across three main areas: patients’ perceptions and understanding of heart failure, which influence their self-care management practices. This study examines the understanding of self-care management among HF patients, presenting findings related to the research objectives, relevant literature, and broader contextual factors surrounding heart failure care.

Self-care management for HF encompasses essential practices, including maintaining a healthy diet, engaging in regular physical activity, recognizing the signs of worsening symptoms, and responding appropriately to changes in health, such as taking extra diuretics for fluid congestion or consulting a healthcare provider for treatment. This study found that the HF patients struggle to manage their condition effectively. Similar findings were reported by Bezerra Giordan et al. (2022) and Al-Harrashi et al. (2023), that many HF patients struggle to follow self-care recommendations and the complexity of the entire self-care process, due to a lack of knowledge, difficulty in

recognizing symptoms, low motivation, limited ability, or lack of confidence in their routine tasks.

The findings of this study also showed that the delays in recognizing the signs and symptoms of heart failure can lead to patients having strokes and spending a long time recovering in critical care, which increases their risk of mortality. In this study, some of the participants admitted to taking double the recommended dose of blood thinner tablets for several days due to forgetfulness. This finding is supported by some studies, that patients often do not receive systematic counseling from healthcare providers due to age-related changes, including age, hearing loss, and forgetfulness (Negarandeh et al., 2021; Asadi et al., 2019), which can make it difficult for heart failure patients to care for themselves at home (Asadi et al., 2019). A heart failure patient who lacks confidence and neglects self-care at home can experience worsening of their condition symptoms.

Interestingly, although half of the participants in this study had higher levels of formal education, many still lacked adequate knowledge of HF symptoms and self-care management. This aligns with past research indicating that even educated patients may suffer from low health literacy if health education is not tailored or reinforced within healthcare settings (Negarandeh et al., 2020; Al Johani, 2023). Several participants admitted to being confused and not fully understanding their diagnosis and the signs and symptoms of heart failure. This finding, supported by Heo et al. (2021), shows that due to knowledge gaps, many individuals with HF symptoms use a ‘wait and see’ strategy, leading to long delays in seeking treatment, not consulting healthcare providers, and experiencing a lack of information or negative encounters with healthcare providers. Awareness and

education should focus more on patients and families about the severity of the signs and symptoms of heart failure.

Some participants refused treatment and disagreed with the diagnosis, seeking alternative opinions from other hospitals. This may be due to a lack of awareness and low educational levels among the participants. This point, elucidated by Skouri et al. (2024), stated that in the Middle East and Africa, many patients with HF lack understanding of their condition, requiring thorough explanations, lifestyle adjustments, and guidance to help them resume normal activities. Therefore, to promote sustainable and accessible care, HF patients must be educated on the importance of seeking timely medical care, starting at the primary care level, through targeted social media campaigns and educational initiatives at medical centers, schools, and specific communities (Tash et al., 2023).

The findings of this study indicated that readiness for self-care management in heart failure among participants also needs to be emphasized. Some participants in this study reported accepting their fate after a heart failure diagnosis, then focused on adjusting their lifestyle, work environment, following a strict diet, taking prescribed medication, and attending follow-up appointments. Similar findings by Asadi et al. (2019) mentioned that self-care involves patients' acceptance of and adherence to their treatment plan, which improves outcomes and reduces hospital readmissions by mitigating the effects of illness. But some participants reported their reluctance to accept the diagnosis of HF. Different findings by Li et al. (2018) stated that patients with chronic heart failure require informed decision-making based on individual and situational factors, including treatment adherence, sodium and fluid restrictions, weight monitoring, exercise, and medication compliance. These

elements demand lifestyle modifications and the implementation of effective coping strategies among HF patients.

This study demonstrated that acceptance of illness is crucial for self-care practices among HF patients. Some of the participants displayed denial about their condition, which certainly affects their self-care management at home. This was in line with the previous study, which found that HF patients who are in denial have poorer self-care compliance (Mlynarska et al., 2018). As a result, most participants with denial behavior tend to have poor heart failure self-care management with crucial coping strategies. Others reported gradually accepting their condition, learning to incorporate necessary lifestyle changes and treatment regimens into their daily lives. Some of the participants possibly tried to comfort themselves to avoid worrying too much by using denial as a coping strategy to continue living with HF. A similar study reported that heart failure patients use coping strategies, like denial and repression, to adjust to their condition (Nordfonn et al., 2020). Their ability to adapt positively to their diagnosis often depends on the level of support from healthcare providers, caregivers, and personal coping mechanisms. Another study related to these findings is that patients frequently choose to bypass self-care information, avoiding the difficulties involved in maintaining routines and making personal decisions, which are essential coping strategies (Li et al., 2019). These actions are important ways for HF patients to cope and manage their health effectively.

Findings from this study revealed that several participants demonstrated limited engagement in their self-care practices. The majority of the participants reported having less interest in heart failure self-care practices, particularly in areas such as medication adherence, symptom monitoring, dietary regulation, and physical

activity. Some participants openly admitted to skipping medications, disregarding dietary restrictions, or failing to attend scheduled follow-ups. Others reported a lack of motivation. This finding, supported by Negarandeh et al. (2020), revealed that HF patients employed trial-and-error methods to manage problems from unreliable sources, resulting in misunderstandings of information related to HF issues. Some participants showed disengagement from self-monitoring, particularly those with multiple comorbidities, increasing their HF deterioration risk. This is due to most participants struggling to identify HF symptoms, relying solely on the healthcare system for information (AlJohani, 2023).

This study highlighted how perceptions of illness, emotional denial, and overall readiness to engage in self-care influence the effectiveness of self-management in heart failure. Without addressing these perceptions and readiness, the well-designed clinical interventions may fall short. As such, improving self-care among HF patients requires more than just sharing information; it also involves promoting self-awareness, building trust, and equipping patients to manage their condition with confidence..

KESIMPULAN

This study offers insights into the understanding of heart failure (HF) self-care management from the perspective of HF patients in Saudi Arabia. It examines various perceptions influencing HF patients' self-care management, including knowledge, understanding, acceptance, habits, health-related beliefs, psychological issues, comorbidities, and socially based values. Managing self-care for HF patients is challenging due to lifelong disease progression. Participants struggle with symptom management, mainly due to poor

adherence to self-care measures like daily weight monitoring and sodium intake, and a lack of confidence in managing exacerbations without consulting healthcare professionals (HCPs). Enhanced education on HF symptoms for HCPs is needed to improve early recognition, starting from discharge. The study finds that positive attitudes, intrinsic motivation, and social support are associated with improved knowledge and adherence, particularly in Saudi Arabia. Misunderstanding highlights the need for improved patient education. Future research should explore psychological stress, organizational factors, and the links between knowledge, attitudes, and practices affecting self-care, involving HCPs and caregivers.

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