SOUTH EAST ASIA NURSING RESEARCH
Available on : https://jurnal.unimus.ac.id/index.php/SEANR

Research article

Living with heart failure: patients' lived experiences and multidimensional needs

Naila Rif'atin[1], Beti Kristinawati[2]

[1] Nursing Student, Nursing Study Program, Faculty of Health Sciences, Universitas Muhammadiyah Surakarta, Indonesia

[2] Department of Medical-Surgical Nursing, Nursing Study Program, Faculty of Health Sciences, Universitas Muhammadiyah Surakarta, Indonesia

Article Info

Article History:
Submitted: Sept 15th 2026
Accepted: Sept 30th 2026
Published: October 31st 2026

Keywords:
Heart Failure; Self Care; Patient Education as Topic; Emotional Regulation; Qualitative Research

Abstract

Heart failure affects patient's pyhsical and psychological health and their ability to perform daily activities. Previous studies have largely focused on intervention effectiveness, self-care outcomes or relationships between specific factors, leaving patients' overall subjective experience of adapting to heart failure insufficiently understood. This study explored patients' lived experiences and multidimensional needs while living with heart failure. A qualitative descriptive phenomenological design was used. Fifteen outpatients with heart failure were recruited using purposive sampling from a cardiology clinic in Surakarta and interviewed in depth. One nurse key informant provided contextual information on service and education processes, while only patient interview data informed coding and theme development. Data were analyzed using a modified Colaizzi procedure. Five themes emerged: (1) gaps in understanding and information needs about heart failure; (2) the need to strengthen self-care skills and response to symptoms; (3) the need for interpersonal and professional support in adapting to heart failure; (4) the need for emotional regulation and adaptive coping strategies in dealing with heart failure; and (5) the need for clear and practical education for heart failure management. These findings suggest that adaptation to heart failure involves interconnected cognitive, behavioral, social, and emotional needs and may inform patient-centered nursing support.

INTRODUCTION

Heart failure is a major global health problem, characterised by high morbidity and mortality, and a decline in patients' quality of life.[1] This condition occurs when the heart is unable to pump blood adequately to meet the body's metabolic needs.[2] Heart dysfunction can lead to reduced physical ability, shown by shortness of breath, fatigue, and activity intolerance, which limit functional capacity and daily activities.[3] Heart failure can also affect a patient's psychological well-being, including anxiety, depression, insomnia, loss of self-esteem, feelings of

Corresponding author:
Beti Kristinawati
bk115@ums.ac.id
South East Asia Nursing Research, Vol 8 No 3, October 2026
ISSN:2685-032X
DOI: https://doi.org/10.26714/seanr.8.3.2026.113-128

abandonment, uncertainty about the future, and limitations in physical and social activities.[4] The physical and psychological impacts require patients to adapt while living with the disease. Managing heart failure is a long process that includes medication, lifestyle changes, and patient involvement in maintaining their health.[5] A patient's adaptation is influenced by their experiences, understanding, psychological responses, and support during care.

Understanding the disease is a key aspect in managing heart failure. Limited information about health conditions can affect a patient's ability to carry out care.[6] Information provided according to the patient's needs can help in understanding the disease.[7] Patients' information needs vary based on their experiences and disease journey. Meeting these needs helps patients better understand their condition and heart failure management.[8] The ability to perform *self-care* is also an important part of managing heart failure because it requires active patient involvement in following treatment and adapting to changes in their health.[9] Various nursing interventions have been developed to improve self-care in heart failure patients through health education, motivational support, condition monitoring, and patient empowerment strategies. A systematic review on self-care improvement interventions in heart failure patients shows that changes in health behaviour are influenced by various interacting factors, including individual factors, environmental support, and patient motivation. These findings indicate that the success of self-care is not only determined by the delivery of health information but also affected by psychological and social factors, and the patient's experience during the adaptation process to heart failure.The process of maintaining self-care is also related to the patient's experience living with the disease, understanding of their health condition, and obstacles that arise during the adaptation process to heart failure.[10]

Patients with heart problems need to adjust not just to physical limitations, but also to emotional changes, the need for self-care, and the need for social support.[11] They can get support from their family to help with daily activities, sticking to their medication, and adjusting to the limitations caused by their condition.[12] Besides family support, healthcare workers also play a role in providing information, education, and guidance during the care process, while patients can also experience psychological pressure and unmet information needs.[13] This condition indicates that the need for information, self-care, support, and emotional responses are interconnected elements in the process of adjusting to heart failure. Previous qualitative research has shown that self-care is not only about carrying out care actions but also about understanding the illness, reacting to symptom changes, accepting support, and adjusting daily life to a chronic condition.[14] Therefore, understanding the patient's experience is really important to know their needs, obstacles, and level of readiness that need to be considered in patient-oriented nursing care.

These findings suggest that patients' experiences living with heart failure involve various interconnected aspects. Although previous studies have provided insights into how patients adapt and manage self-care while living with heart failure, that understanding still tends to focus on specific aspects of disease management. Understanding how information and education needs, self-care abilities, interpersonal and professional support, as well as emotional responses and adaptations arise and interact in patients' daily lives as part of the adaptation process to heart failure is still limited. This study expands the existing understanding by exploring these various needs in an integrated way from the perspective of patients' experiences, allowing the adaptation process to heart failure to be understood in a more multidimensional manner. Besides that, this study gives a

contextual picture of how these various needs arise and interact in heart failure patients receiving outpatient care at a Regional General Hospital in Surakarta.

The phenomenological approach was adopted because it is suitable for deeply exploring the life experiences of individuals facing heart failure and the meanings they give to changes, needs, and adjustment processes while living with the condition. This approach allows researchers to understand how patients experience the need for information and education, carry out self-care, receive support, and manage emotional changes in daily life. This understanding is expected to provide a contextual picture of patient needs and be considered in developing nursing services that are more responsive to patient experiences. Based on this description, this study aims to explore the life experiences of heart failure patients in understanding information and education needs, self-care, support, and managing emotional changes as part of the adaptation process to a chronic illness.

METHODS

Research Design

This study used a qualitative method with a descriptive phenomenology design to illustrate the life experiences of heart failure patients as they deal with their condition. This method was chosen because the focus of the research is on the experiences as lived by the patients, including their need for information and education, self-care, support, and emotional changes during the adaptation process to heart failure. Descriptive phenomenology is based on the Husserlian perspective, which emphasizes describing life experiences and revealing the essence of phenomena as experienced by individuals. To support this descriptive approach, the researcher applied bracketing by recognizing and temporarily setting aside assumptions, past experiences, and initial understandings that could influence the data collection and analysis process.[15]

Participant

Participants were selected using purposive sampling, which means choosing participants based on characteristics and experiences relevant to the phenomenon and research objectives.[16] The researchers directly selected potential participants and approached patients who met the study criteria at outpatient services. Heart failure diagnosis and New York Heart Association (NYHA) functional classification were confirmed based on data recorded in the patients' medical records. A total of 17 patients who met the criteria were approached to participate in the study. Two patients declined to participate, so 15 patients gave their consent and took part in the study. All participants who had given consent completed the interview sessions, and none dropped out during the study.

The main inclusion criteria for this study are:

1. Patients with a medical diagnosis of heart failure.
2. Patients receiving outpatient care at the Regional General Hospital's cardiology service in Surakarta.
3. Patients with heart failure classified as New York Heart Association (NYHA) functional class II–III.
4. Patients aged 18 years or older.
5. Patients who can understand and communicate in Indonesian or Javanese.
6. Patients' written informed consent was obtained and records were kept during interviews.

The main participant exclusion criteria for this study include:

1. Communication disorders that hinder the interview process.
2. Cognitive impairments that prevent the provision of adequate information.

3. Health conditions that make it impossible to participate in the interview process.
4. Unwillingness to continue participating in the study.

Communication skills and cognitive function are assessed at the initial screening stage through direct interaction between the researcher and prospective participants. Communication skills are evaluated based on the participant's ability to understand questions and provide relevant responses in Indonesian or Javanese. Cognitive function is assessed based on the participant's ability to understand explanations about the study, follow the conversation, and give appropriate responses during the screening process. Participants who have communication or cognitive difficulties that could hinder the interview process are not included in the study.

Besides the main participants, this study involved one key informant, a nurse who serves as a service coordinator at the Cardiology Clinic of the Regional General Hospital in Surakarta. The key informant was chosen based on their experience in coordinating care for heart failure patients and their understanding of service and health education processes. The key informant provided contextual information about the services, patient education implementation, and management of heart failure patients. This information was not treated as a separate set of phenomenological data and was not included in the coding or phenomenological analysis. It was also not systematically compared with patient interview data, so it was not used for source triangulation or theme development. All research themes and subthemes were developed exclusively based on interview data from heart failure patients as the main participants.

Key informant criteria include:
1. Nurses who serve as service coordinators at the Heart Clinic of the Regional General Hospital in Surakarta.
2. Experience in heart failure patient care.
3. Willingness to provide information on the services and educational needs of heart failure patients.

Data saturation was assessed gradually during the data collection and analysis process by comparing codes, categories, and themes that emerged from each interview with previous interviews. No new codes, categories, or conceptual information appeared starting from the 12th participant interview. The next three interviews, with participants 13, 14, and 15, were conducted to confirm that no new information emerged and that the established theme patterns remained consistent. Based on the comparison results between interviews, the lead researcher determined that data saturation had been reached with 15 participants, and data collection was stopped.

Research Background

The study was conducted at the Cardiology Outpatient Clinic of the Regional General Hospital in Surakarta. The research site was selected because it provides care for patients with cardiovascular disease, including those with heart failure receiving outpatient care. Data collection took place from August to September 2026, using direct in-depth interviews with heart failure patients who met the study criteria. To protect participants' privacy, the interview is done in a place that's comfortable for them.

Research Instruments

The semi-structured interview guide was developed based on the research goals and focus, which are to explore the experiences of patients with heart failure related to information and education needs, self-care, support, and emotional changes during the

adaptation process to the illness. The interview guide was then reviewed by lecturers to ensure the clarity and relevance of the questions to the research objectives. Before the main data collection began, the interview guide was tested on two participants to assess the clarity of the questions and the flow of the interview. During the interview sessions, the researcher used follow-up questions based on the responses given by each participant to explore more deeply their experiences related to information and education needs, self-care, support, and emotional changes. The follow-up questions were tailored to the aspects that emerged from the participants' answers and were presented as open-ended questions so as not to steer participants toward a specific answer.

The main questions include:

1. How did you first find out that you had heart disease?
2. After learning about your heart condition, how do you manage your daily life now?
3. While dealing with heart failure, what do you find easiest and hardest to cope with?

The interviewer is an undergraduate Nursing student who has received training in conducting qualitative interviews before the data collection process began. In this study, the researcher acted as the main interviewer and was not involved in providing direct care or health services to the participants. Before the study was carried out, the researcher also had no personal or family relationships with the participants. The researcher's nursing education background could affect how they interact with participants and understand the experiences shared. Therefore, the researcher applied reflexivity and bracketing during the data collection and analysis process to recognize and minimize the influence of initial assumptions and understanding on the interview process and data interpretation.

Researcher Reflexivity

The researcher applied reflexivity throughout the study to recognize and manage the influence of background, experience, and initial understanding on the phenomenon being studied. In the descriptive phenomenological approach, the researcher used bracketing by recognizing and temporarily setting aside assumptions, previous experiences, and initial understanding so that participants' experiences could be understood from their own perspectives.[17] Before the interview process, the researcher reflected on their initial understanding of heart failure and patients' needs to identify assumptions that could potentially affect the research process. During the interviews, the researcher wrote reflective notes about thoughts, assumptions, and considerations that arose during interactions with participants. These reflective notes were reviewed again during the coding and theme review stages to help the researcher recognize initial assumptions that might influence data interpretation. During the process, the interpretations and themes developed are continuously checked against the statements and experiences found in the participants' transcripts, so the formation of themes remains based on participant data and not on the researcher's assumptions or initial understanding.

Data Collection and Data Analysis

Data collection was carried out through in-depth interviews using a semi-structured interview guide. The interviews were conducted after participants provided informed consent and lasted approximately 30–45 minutes. All interviews were conducted in Indonesian and audio-recorded with participants' permission. The recordings were then transcribed verbatim in Indonesian. Quotations selected for inclusion in the manuscript were translated into English by the lead researcher. The translated quotations were reviewed by a second researcher and compared with the

original Indonesian transcripts to ensure that the participants' intended meaning, context, and perspectives were preserved. All quotations included in the manuscript were subsequently rechecked against the original transcripts to ensure translation accuracy and consistency with the participants' voices.

Data analysis was carried out using a modified Colaizzi phenomenological procedure through the following steps:

1. Reading all interview transcripts repeatedly to gain a comprehensive understanding of the participants' experiences.
2. Identifying significant statements related to the experiences of heart failure patients.
3. Formulating the meaning of each significant statement based on the context of the experience shared by the participants.
4. Grouping similar meanings into categories, subthemes, and themes.
5. Preparing a comprehensive description of the experiences of heart failure patients based on the identified themes.
6. Formulating a fundamental structure that illustrates the essence of the participants' experiences.
7. Reviewing the results of the interpretation and theme development through discussions with other researchers experienced in qualitative health research, while still referring back to the participants' original interview data.

In the classic Colaizzi procedure, the final stage involves validating the results with the participants. However, participant validation was not carried out in this study. Instead, the interpretation of results and theme development were reviewed with other researchers and compared again with the participants' original interview data. Therefore, the analysis procedure in this study is reported as a modified Colaizzi procedure and not as a full application of the classic Colaizzi method.[18]

The coding process was done manually by the main researcher through a systematic reading of all the interview transcripts. The second researcher did not code the transcripts independently but reviewed the categories, sub-themes, and themes that had been developed by the main researcher. When there were differences in interpretation, these differences were noted in the analysis notes and discussed by referring back to the participants' original statements until an agreement was reached on the interpretation that best fit the data. The entire analysis process was documented through an audit trail that recorded the relationship between significant statements from the transcripts, the meanings formulated, the grouping into categories and sub-themes, and the development of the final themes. This documentation was used to maintain transparency and traceability of the analysis process from the raw data to the formation of the research themes.

Determining Data Saturation

Data saturation is determined during the process of data collection and analysis. Data collection is stopped when additional interviews no longer yield new information about the experiences of heart failure patients. Determining data saturation involves evaluating the development of codes, categories, and themes that emerge from each interview. [19] Data saturation is repeatedly assessed throughout the research process by comparing the latest interview results with previous analyses. Additional interviews are considered no longer to provide new contributions if no new codes are found, no new categories or meanings emerge, and the themes that have formed show a consistent pattern of experiences among participants.

Indicators of data saturation include:

1. No new codes emerge from additional interviews.
2. No new categories or meanings appear during analysis.

3. Existing themes show a consistent pattern across participants' experiences.
4. Additional interviews yield only repeats of previously collected information.

The decision to stop data collection is made when the collected data can adequately describe the life experiences of heart failure patients and no new conceptual information is found from the next participants.

Ethical Considerations

This study received ethical approval from the Health Research Ethics Committee (HREC) under number M327/II/HREC/2026. Before data collection began, all participants were provided with information about the study's purpose, the interview procedures, the benefits of the research, possible discomforts that might arise, and their rights while participating in the study. Written informed consent was obtained from all participants before the interviews took place. Participants were free to refuse to answer certain questions or to stop the interview at any time without any impact on the healthcare services they receive. Participant confidentiality was maintained by using specific codes instead of real names in interview transcripts, research documents, and reports. All research data were used solely for research purposes and securely stored by the researchers. There is no expected physical risk during the study. However, psychological discomfort is still possible, as the interviews relate to patients' experiences of living with a chronic illness. Participants are free to stop the interview at any time if they feel uncomfortable.

Data Validity

The validity of the data in this study was assessed based on four trustworthiness criteria in qualitative research: credibility, transferability, dependability, and confirmability.[20] Credibility was supported through the researcher's direct involvement in data collection, conducting in-depth interviews, repeatedly reading the transcripts, and reviewing the interpretation results and theme development together with other researchers experienced in qualitative research. This review was done by referring back to the participants' original interview data. Transcripts were not returned to the participants, and member checking was not done. Information from key informants was only used as contextual information about patient services and education, not included in the coding or theme development process, and not used as source triangulation. Transferability is supported by providing descriptions of participant characteristics, the research context and location, data collection processes, and the phenomena being studied so that readers can assess the applicability of the findings to similar contexts. Dependability is supported through an audit trail that documents the research stages, from participant selection, interviews, transcription, identification of significant statements, formulation of meanings, development of categories and subthemes, to the formation of the final themes. Confirmability is supported through the researcher's reflective notes and documentation of the analysis process. The reflective notes are reviewed during coding and theme review to help recognize the influence of the researcher's assumptions and initial understanding, and to ensure interpretations remain grounded in the participants' experiences.

RESULTS

This study involved 15 patients with heart failure as the main participants, as presented in Table 1. Participant characteristics varied in age, gender, time since heart failure diagnosis, New York Heart Association (NYHA) functional class, and comorbidities. Heart failure diagnosis and NYHA functional class were confirmed based on information documented in the participants' medical records.

Table 1. Characteristics of Research Participants (n=15)

Code	Age (years)	Gender	Time since diagnosis	NYHA functional class	Comorbidities
P1	59	Male	1 year	II	Diabetes Mellitus
P2	45	Male	8 months	II	Hypertension
P3	55	Female	6 months	II	Hyperthyroidism
P4	73	Male	7 months	II	Hypertension
P5	47	Female	3 years	III	Hypertension
P6	54	Male	5 years	III	Hypertension
P7	61	Female	8 months	II	Hypertension and diabetes mellitus
P8	63	Male	3.5 years	III	Hypertension
P9	51	Male	2 years	II	None
P10	53	Male	1.5 years	II	Hypertension
P11	63	Male	2 years	II	None
P12	67	Male	5 months	II	None
P13	65	Male	1.3 years	II	None
P14	40	Female	2.3 years	II	Hypertension
P15	48	Male	6 years	III	Hypertension

In addition to the main participants, this study involved one key informant, the nurse coordinator of the cardiology service. The key informant provided contextual information regarding the service setting, patient education, and the management of patients with heart failure. This information was not included in the coding or phenomenological analysis and was not systematically compared with the patient interview data. Therefore, it was not used for source triangulation or theme development. All themes and subthemes were developed exclusively from the interview data of the 15 patients with heart failure as the main participants.

Phenomenological Analysis Results

Data analysis using Colaizzi's phenomenological method yielded five main themes describing heart failure patients' experiences of living with their illness, as shown in Table 2. These five themes include: (1) gaps in understanding and information needs about heart failure; (2) The need to strengthen self-care skills and response to symptoms; (3) the need for interpersonal and professional support in adapting to heart failure; (4) The need for emotional regulation and adaptive coping strategies in dealing with heart failure; and (5) the need for clear and practical education for heart failure management.

Table 2. Themes, Subthemes, and Main Meaning of Heart Failure Patient Experiences

Theme	Subtheme	Main Meaning
The gap in understanding and information needs about heart failure	Basic knowledge and the process of diagnosing heart failure	Patients go through a gradual process in recognising their illness, from the appearance of symptoms to getting a diagnosis.
	Understanding the causes and risks of heart failure	Patients have different understandings about the causes, risk factors, and possible worsening of the disease.
	The need for explanations about heart failure, prevention, recovery, and treatment	Patients need information about the illness and how to live life after diagnosis.
The need to strengthen self-care skills and response to symptoms	Recognising symptoms and physical limitations	Patients become aware of symptoms such as shortness of breath and fatigue and recognise their physical limitations in daily life.
	Adjusting daily activities to physical condition	Patients adjust their daily activities according to their physical condition and bodily limits.
	Maintaining treatment and follow-up routines	Patients take medication and attend regular follow-up visits as part of heart failure management, although some experience difficulties in maintaining these routines consistently.

Theme	Subtheme	Main Meaning
The need for interpersonal and professional support in adapting to heart failure	Sources of support and family strengthening while dealing with heart failure	Family becomes a source of support in helping patients go through their illness.
	Family involvement in heart failure care	The family helps the patient with medication, check-ups, activities, and lifestyle.
	Information, guidance, and support for healthcare workers in caring for heart failure	Healthcare workers help patients through information and support during treatment.
The need for emotional regulation and adaptive coping strategies in dealing with heart failure	Emotional response when finding out a diagnosis and facing treatment	The patient experienced emotional changes after finding out about the illness.
	Fear and worry while dealing with heart failure.	The patient feels worried about their condition and how the illness is progressing.
	How to calm yourself and adjust your life after heart failure	Patients use certain strategies to accept and live with their illness.
the need for clear and practical education for heart failure management	Education for understanding and managing heart failure	Patients need clear and understandable information about their condition and its management.
	Practical guidance for managing heart failure in daily life	Patients need practical guidance on responding to symptoms, seeking medical help, and managing their condition at home.

Theme 1. Gaps in understanding and information needs about heart failure

Heart failure patients have diverse ways of understanding the condition they are experiencing. Some patients only find out they have heart failure after experiencing symptoms and undergoing medical examinations. In contrast, others are already aware of heart problems but do not fully understand the disease's causes or the connection between their heart condition and the symptoms they feel. The process of recognising the disease happens gradually, from the onset of symptoms through examinations to the point at which the patient receives a diagnosis. Patients' experiences in understanding heart failure are related to their initial knowledge about the disease, their understanding of its causes and risks, and the need to obtain information to live life after diagnosis.

Some participants had difficulty distinguishing heart failure from other cardiac conditions encountered during their illness journey. Although all participants had a clinically confirmed diagnosis of heart failure, some described their condition primarily through other cardiac diagnoses that were more familiar to them. One participant explicitly stated that they did not understand heart failure and instead described their cardiac condition in terms of coronary artery blockage:

"If it's heart failure, I wouldn't know, but before Ramadan I was hospitalised. It turned out there was a blockage in my heart's blood vessels. Then the doctor here suggested going to the hospital. So eventually, the first step was to have a scan. The scan showed that my heart was 70–80% blocked, so I was referred to the hospital." (P1)

This account illustrates a gap in the participant's understanding of heart failure, as the participant described their cardiac illness mainly through the coronary blockage identified during examination rather than demonstrating a clear understanding of heart failure as a distinct condition.

Unlike that experience, another patient was already aware of a heart problem but still struggled to understand how heart function related to their symptoms.

"There's no blockage. It's just that the blood vessels are too big, so the heart can't pump blood because the pump is too big. And that's

related to the lungs. So when I couldn't breathe, it was because there was fluid in the lungs. I don't really understand the connection between the heart and the lungs, or how the fluid in the lungs works." (P2)

Besides that experience, some patients understand their heart failure through connections with other illnesses they have experienced before.

"Because I have a history of hyperthyroidism. After being examined, it turned out my heart condition is related to the hyperthyroidism I had before." (P3)

Beyond understanding the diagnosis and causes of the disease, patients also express a need for information on heart failure, relapse prevention, recovery, and treatment. This need arises because patients still have questions about what they can do to maintain their health.

One patient said:

"I want health information, especially about the heart. What is needed is knowledge; I still need an explanation about the disease. How to prevent it, information so it won't happen again, and how I can get back to being healthy." (P9)

That experience shows that patients' information needs change throughout the course of the illness. Some patients need a basic understanding of the condition they're dealing with, while others need information on prevention, treatment, and how to maintain their health after heart failure.

Theme 2. The need to strengthen self-care skills and response to symptoms

Living with heart failure required participants to make adjustments in how they managed their daily activities and treatment. Participants described learning to recognise changes in their physical condition, particularly shortness of breath and fatigue, and adjusting their activities according to their physical limits.

One participant described becoming more aware of physical limitations when performing daily activities:

"If I walk a bit fast, I still get out of breath. If I get too tired, my chest feels heavy and tight. So now I have to know my own limits, I can't treat it the same as before I got sick." (P7)

Self-care also involved maintaining treatment routines, including taking medication and attending regular follow-up visits. However, maintaining these routines was not always easy, particularly when participants had to manage several medications.

"The medicine has to be taken regularly and I need to check in every month. Sometimes I forget because there are so many medications, but I still try to take them consistently because I'm afraid my condition will get worse if I don't." (P8)

These experiences show that self-care while living with heart failure involved recognising physical limitations, adjusting daily activities, and maintaining treatment routines. Participants also described challenges in consistently carrying out these self-care practices in their daily lives.

Theme 3. The need for interpersonal and professional support in adapting to heart failure

According to participants, adapting to the changes associated with heart failure involved receiving support from family members and healthcare professionals. Family support included assistance with follow-up visits, medication, dietary management, daily activities, and emotional encouragement. Healthcare professionals provided information and guidance that helped participants understand their condition and treatment.

One of the patients talked about the family support they received:

"The most important thing is family, namely my wife and child. They always remind me to check up, take medicine, and manage my food. When I feel scared or worried, they always encourage me to stay calm and continue treatment." (P3)

Family members were also directly involved in participants' daily care, including accompanying them to follow-up visits and helping them maintain treatment and dietary routines. One participant described this involvement:

"My children always come with me during check-ups, remind me to take my medication, and help manage my meals so I do not eat carelessly like I used to. " (P12)

Healthcare workers also play a role in helping patients understand their condition and go through their treatment process. Patients say that getting explanations and guidance from healthcare workers makes them feel more confident in following their treatment.

"The doctor explains the heart condition and the medication taken, so you better understand why you need to keep taking the medicine and what you need to watch out for. If you have any complaints, you can also ask during the check-up." (P15)

Although some patients get support from family and healthcare workers, the kind of support each patient receives varies. Support from family actively helps patients with their care, while involvement from healthcare workers helps patients gain understanding and confidence in following their treatment. These experiences show that both interpersonal and professional support are important parts of how patients adapt to heart failure.

Theme 4. The need for emotional regulation and adaptive coping strategies in dealing with heart failure

Patients with heart failure described varying emotional responses after learning about and living with their condition. Some participants experienced fear and worry related to the possibility of worsening symptoms, recurrence, physical limitations, and uncertainty about their health, while others described gradually becoming calmer and more accepting of their condition.

One participant described fear and worry after learning about the heart condition, followed by greater acceptance after receiving an explanation from the doctor:

"At first, I was scared, especially when I heard the word heart, which is considered a serious illness. I was also worried about relapsing and not being able to do activities as usual. After meeting and getting an explanation from the doctor, I started to accept this illness and felt calm." (P4)

Fear could also re-emerge when participants experienced changes in their physical condition. One participant described worry associated with episodes of shortness of breath:

"If they feel short of breath, sometimes they get scared, wondering if their illness is getting worse, especially if it happens at night, which leads to many thoughts about their heart condition." (P5)

Patients not only show fear and worry, but also make an effort to accept their illness and adjust to heart failure. Acceptance is achieved by changing habits, maintaining health, and trying to do activities according to the body's ability.

One patient explained:

"At first, it was difficult to adjust because of all the changes. But gradually, I learned to

accept it by praying, constantly asking for forgiveness, and following the advice given by the doctor." (P6)

In order to deal with their condition, some patients also employ coping strategies include trying to think optimistically, lowering anxiety, becoming closer to God, and concentrating on their treatment. Despite the limits brought on by the illness, heart failure patients' coping mechanisms enable them to go about their everyday lives. The experiences of patients demonstrate how their emotional reactions to the illness evolve over time. While some people learn to accept their sickness and adapt using various coping mechanisms, others still experience anxiety when symptoms arise or when their condition changes.

Theme 5. The need for clear and practical education for heart failure management

Patients with heart failure expressed a need for education that was clear, understandable, and relevant to the practical challenges they encountered in daily life. Participants valued explanations that used simple language and helped them understand what actions they should take in managing their condition.

One participant described the value of understandable explanations:

"Education is usually given directly by the doctor, explained in easy-to-understand language. That way, we understand what needs to be done and what actions need to be taken." (P9)

Participants also described a need for practical guidance on how to respond when symptoms occurred. Such information helped them understand what actions could be taken when they experienced changes in their condition.

"Fear sometimes comes up when you feel short of breath or unwell. So, it's important to be told how to deal with situations like that so you don't panic and know what to do." (P5)

Participants also expressed a need for practical information that could be applied in daily life, including when to seek medical help and how to respond when symptoms worsened.

"They need to be informed about what to do during a flare-up or when having symptoms, and when to go to the hospital." (P10)

These experiences indicate that patients need education that is easy to understand and provides practical guidance for managing heart failure and responding to changes in symptoms.

DISCUSSION

The findings of this study describe living with heart failure as a multidimensional experience involving understanding of the illness, self-care, social support, emotional adjustment, and educational needs. These aspects were not experienced separately. Participants' accounts showed that understanding their condition, recognising physical changes, carrying out daily self-care, receiving support, and managing emotional responses often occurred together as part of living with heart failure.

Participants in this study described a need for information that could help them understand heart failure, interpret changes in their condition, and determine appropriate responses in daily life. Previous qualitative research has similarly shown that patients with heart failure may experience uncertainty and difficulties in understanding and managing their condition as part of everyday self-care.[14] This finding is also consistent with the heart failure health literacy literature, which highlights the importance of understanding and using health information in disease

management, communication with healthcare professionals, and care-related decision-making.[21] In the present study, participants described limited understanding as a practical challenge when interpreting changes in their condition and deciding how to respond. Rather than establishing a causal relationship between understanding and self-care, these accounts illustrate how information needs were experienced as part of living with heart failure. Participants particularly valued information that was understandable, practical, and relevant to their current condition.

Self-care was experienced as more than adherence to treatment. Participants described recognising physical limitations, adjusting activities according to their condition, taking medication, and attending regular follow-up visits. Previous research on the self-care experiences of patients with heart failure has similarly reported challenges related to recognising symptoms, maintaining health behaviours, and deciding how to respond when the condition changes.[22] The present findings are consistent with these experiences and further illustrate how self-care was described through everyday efforts to recognise bodily limitations, adjust activities, and maintain treatment routines.

Support from family members and healthcare professionals was another important part of participants' experiences. Family members were involved in practical aspects of care, including medication reminders, follow-up visits, dietary management, and daily activities, while also providing emotional reassurance. Healthcare professionals were mainly described as sources of information and guidance related to treatment and symptom management. Previous research involving patients with heart failure and their caregivers has similarly shown that challenges in self-care are experienced within a broader context that includes support from others.[23] In this study, family and professional support occurred alongside participants' efforts to maintain treatment routines and adjust to physical and emotional changes. This illustrates that self-care was experienced within family and healthcare relationships rather than solely as an individual activity.

Emotional experiences also formed part of participants' adjustment to heart failure. Fear and worry were described particularly when symptoms occurred or when participants considered the possibility that their condition might worsen. Over time, some participants described greater acceptance and different ways of coping, including following medical advice, seeking support, and, for some, engaging in spiritual practices. Previous qualitative research on adaptation to heart failure has also described emotional adjustment as part of patients' experiences of living with the condition.[5] These emotional experiences occurred alongside practical concerns about symptoms, treatment, and limitations in daily activities, indicating that emotional adjustment formed part of participants' broader experience of living with heart failure.

The relationship between the themes was evident in participants' everyday accounts. Uncertainty about symptoms represented an information need but was also described alongside decisions about how to respond to changes in physical condition. Recognition of bodily limitations occurred together with adjustments in daily activities, while medication and follow-up routines were often described alongside family support. Family and professional support also appeared in participants' accounts of reassurance and emotional adjustment. These examples illustrate how cognitive, behavioural, social, and emotional experiences occurred together rather than as separate components of living with heart failure.

Education emerged as an important component of participants' experiences

because they wanted information that was clear, understandable, and relevant to situations encountered in daily life. In particular, participants valued practical guidance about symptoms and when medical assistance should be sought. Previous research on symptom-perception education in heart failure has similarly shown the relevance of education that supports symptom recognition and appropriate self-care responses.[24] In the present study, however, educational needs were experienced within a broader context that also included self-care practices, family and professional support, and emotional responses. Education was therefore experienced as one component of the broader process of adapting to heart failure rather than as an isolated need.

Cognitive experiences were reflected in participants' understanding of heart failure and their information needs; behavioural experiences were evident in self-care practices and adjustments in daily activities; social experiences emerged through support from family members and healthcare professionals; and emotional experiences included fear, uncertainty, acceptance, and coping. Previous adaptation and self-care studies have described several of these dimensions individually.[5,14] The present study extends this literature by showing how these dimensions occurred together in participants' everyday experiences. For example, uncertainty about symptoms was described alongside decisions about self-care, while family and professional support occurred alongside treatment routines, health information needs, and emotional reassurance. Thus, the contribution of this study lies not simply in identifying cognitive, behavioural, social, and emotional needs, but in illustrating how participants experienced these dimensions as interconnected aspects of adapting to heart failure.

These findings may inform patient-centred nursing assessment and education. In addition to physical symptoms, assessment may consider patients' understanding of heart failure, their experiences in carrying out self-care, available family or professional support, emotional responses, and current educational needs. Participants' accounts also indicate the relevance of clear and practical health information that can be related to situations encountered in daily life. Family involvement and supportive communication with healthcare professionals may also be considered according to each patient's needs and circumstances.

This study has several limitations. The study was conducted in a single outpatient cardiology setting and included patients with NYHA functional class II–III. Therefore, the findings may not fully reflect the experiences of patients in other healthcare settings or those with different levels of heart failure severity. Participants were recruited purposively from patients attending the outpatient cardiology clinic, so the findings represent the experiences of those who met the study criteria and agreed to participate. Member checking was not conducted; therefore, the researchers' interpretations were not directly confirmed by the participants. To support the credibility of the findings, the interpretations and developed themes were reviewed with other researchers and repeatedly checked against the original interview data. Another limitation concerns the translation process. The interviews were conducted and transcribed in Indonesian, while quotations included in the manuscript were translated into English. Although the translated quotations were checked against the original transcripts to preserve participants' intended meanings, some nuances of expression may have been affected during translation. These limitations should be considered when interpreting the findings.

CONCLUSION

The findings indicate that the lived experiences of patients with heart failure involve a multidimensional process of adaptation encompassing understanding of the illness, self-care, interpersonal and professional support, emotional adjustment, and educational needs. Cognitive, behavioural, social, and emotional dimensions were experienced as interconnected aspects of living with heart failure. The contribution of this study lies in providing an integrated description of these dimensions from the perspective of patients receiving outpatient heart failure care. These findings may inform patient-centred nursing assessment and education by highlighting the importance of considering patients' information needs, self-care experiences, available support, emotional responses, and the need for clear and practical health education.

ACKNOWLEDGMENT

The researcher would like to thank all the participants who were willing to help and share their experiences during the data collection process. Also, thanks to the management and staff of Surakarta Regional General Hospital, especially the Heart Clinic, for granting permission and support for the research. Thanks also to everyone who provided assistance throughout the research process. This study did not receive any specific funding from commercial, public, or nonprofit organizations. Every stage of the research was conducted independently and funded by the researcher themselves.

CONFLICT OF INTEREST

The author states that the objectivity and results of this research are not affected by any conflicts of interest.

BIBLIOGRAPHY

1. Shahim B, Kapelios CJ, Savarese G, et al. Global Public Health Burden of Heart Failure: An Updated Review. *Card Fail Rev*; 9. Epub ahead of print 2023. https://doi.org/10.15420/cfr.2023.05
2. Bozkurt B, Coats AJS, Tsutsui H, et al. Universal definition and classification of heart failure: a report of the Heart Failure Society of America, Heart Failure Association of the European Society of Cardiology, Japanese Heart Failure Society and Writing Committee of the Universal Definition of Heart Failure. *Eur J Heart Fail* 2021; 23: 352–380. https://doi.org/10.1002/ejhf.2115
3. McDonagh TA, Metra M, Adamo M, et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. *European Heart Journal* 2021; 42: 3599–3726. https://doi.org/10.1093/eurheartj/ehab368
4. Westas M, Melnikov S. Prevalence and Outcomes of Fears in Advanced Heart Failure: Differences Across Disease Stages. *Current Heart Failure Reports*; 22. Epub ahead of print 1 December 2025. https://doi.org/10.1007/s11897-025-00705-0
5. Zhao Q, Zhang J, Ye Y, et al. Experiences of disease adaptation in patients with heart failure: a qualitative study. *Clin Nurs Res* 2022; 31: 1287–1295. https://doi.org/10.1177/10547738221082208
6. Stahlman S, Huizar-Garcia S, Lipscomb J, et al. Implementation of a heart failure educational intervention for patients with recent admissions for acute decompensated heart failure. *Front Cardiovasc Med*; 10. Epub ahead of print 2023. https://doi.org/10.3389/fcvm.2023.1133988
7. Veskovic J, Cvetkovic M, Tahirovic E, et al. Depression, anxiety, and quality of life as predictors of rehospitalisation in patients with chronic heart failure. *BMC Cardiovasc Disord*; 23. Epub ahead of print 1 December 2023. https://doi.org/10.1186/s12872-023-03500-8
8. Jenkins HR, Rupert DJ, Etta V, et al. Examining Information Needs of Heart Failure Patients and Family Companions Using a Previsit Question Prompt List and Audiotaped Data: Findings From a Pilot Study. *J Card Fail* 2022; 28: 896–905. https://doi.org/10.1016/j.cardfail.2021.11.012
9. Jaarsma T, Hill L, Bayes-Genis A, et al. Self-care of heart failure patients: practical management recommendations from the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2021; 23: 157–174. https://doi.org/10.1002/ejhf.2008.

10. Kristinawati B, Sukartini T, Tanaya VY, et al. Nursing interventions to enhance self - care in heart failure : a systematic review interpreted through the COM - B model. *Springer Nat*; 15. https://doi.org/10.1186/s13643-026-03280-0

11. Bahrodi PS, Safa A, Ajorpaz NM, et al. Heart failure patients' experiences of self-care neglect: a content analysis. *BMC Cardiovasc Disord*; 24. Epub ahead of print 1 December 2024. https://doi.org/10.1186/s12872-024-04347-3

12. Zahedifard T, Mirzaei-Najmabadi K, Khadivzadeh T, et al. Care Needs of Patients with Heart Failure: A Systematic Review. *Acta Fac Medicae Naissensis* 2024; 41: 175–185. https://doi.org/10.5937/afmnai41-48670

13. Huesken A, Hoffmann R, Ayed S. Persistent effect of nurse-led education on self-care behavior and disease knowledge in heart failure patients. *Int J Nurs Sci* 2021; 8: 161–167. https://doi.org/10.1016/j.ijnss.2021.03.002

14. Min D, Lee J, Ahn J-A. A qualitative study on the self-care experiences of people with heart failure. *West J Nurs Res* 2023; 45: 646–652. https://doi.org/10.1177/01939459231169102

15. Shorey S, Ng ED. Examining characteristics of descriptive phenomenological nursing studies: A scoping review. *J Adv Nurs* 2022; 78: 1968–1979. https://doi.org/10.1111/jan.15244

16. Ahmad M, Wilkins S. Purposive sampling in qualitative research: A framework for the entire journey. *Qual Quant* 2025; 59: 1461–1479. https://doi.org/10.1007/s11135-024-02022-5

17. Olmos-vega FM, Stalmeijer RE, Varpio L, et al. A practical guide to reflexivity in qualitative research : AMEE Guide No . 149. *Med Teach* 2023; 45: 241–251. https://doi.org/10.1080/0142159X.2022.2057287

18. Praveena KR, Sasikumar S. Application of Colaizzi ' s Method of Data Analysis in Phenomenological Research. 2021; 21: 914–918. https://doi.org/10.37506/mlu.v21i2.2800

19. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med*; 292. Epub ahead of print 2022. https://doi.org/10.1016/j.socscimed.2021.114523 H

20. Ahmed SK. The pillars of trustworthiness in qualitative research. *J Med Surgery, Public Health* 2024; 2: 100051. https://doi.org/10.1016/j.glmedi.2024.100051

21. Ionescu R, Allen LA, Breathett K, Fowler BK, Jackson EA, Kundrick J, Ogunniyi MO MJ. Health Literacy in Heart Failure. *Elsevier Behalf Am Coll Cardiol Found*; 4. Epub ahead of print 2025. https://doi.org/10.1016/j.jacadv.2025.101608

22. Heo S, Moser DK, Lennie TA, et al. Self-care strategies and interventions needed in patients with heart failure: From patient perspectives- a qualitative study. *Eur J Cardiovasc Nurs* 2021; 20: 540–546. https://doi.org/10.1093/eurjcn/zvaa033

23. Wu Q, Pei H, Zhang L, et al. Self-care challenges of patients with heart failure from the perspectives of patients and caregivers: A qualitative study. *Geriatr Nurs (Minneap)* 2024; 58: 446–458. https://doi.org/10.1016/j.gerinurse.2024.06.005

24. Sousa JP, Oliveira C, Pais-Vieira M. Symptom perception management education improves self-care in patients with heart failure. *Work* 2021; 69: 465–473. https://doi.org/10.3233/WOR-213491