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Research Article

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Understanding disease and responding to symptoms: heart failure patients' perspectives on self-care information needs

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Abstract

Heart failure is a chronic condition that requires ongoing self-management. Patients need knowledge to understand their diagnosis, manage medications and lifestyle changes, monitor signs and symptoms, and know when to seek help. Nonetheless, there is limited understanding of patients' perspectives and experiences regarding their information needs. This study aimed to explore how patients with heart failure experience and perceive their information needs for self-care and for responding to changes in their health condition. A descriptive qualitative study was conducted at the outpatient cardiac clinic of General Hospital in Surakarta during July–August 2026. Fifteen adults with heart failure, classified as NYHA functional class II–III, were purposively recruited. Data collection and analysis proceeded iteratively, and recruitment continued until subsequent interviews no longer generated substantially new categories or relevant information. Data were collected through face-to-face semi-structured interviews and field notes. Interviews were audio-recorded with participants' consent and analyzed by identifying meaningful statements, coding, categorizing, and developing subthemes and themes. Five themes emerged: understanding heart failure and its implications, medication management, lifestyle management, monitoring signs and symptoms, and decision-making during symptom worsening. Participants described a range of responses to changes in their condition, from resting and taking medication to seeking family assistance or medical care. The findings suggest that information needs extend beyond understanding the disease to recognizing changes in health status and determining appropriate actions. Heart failure patients need information that supports understanding of disease changes and appropriate decision-making. Patient-centered and continuous nursing education involving family members may support effective self-care.

INTRODUCTION

Heart failure is a chronic condition that requires long-term management and self-care skills to maintain health and prevent worsening [1]. Management extends beyond medical treatment and includes medication use, lifestyle adjustment,

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monitoring of health status, and responding to changes in signs and symptoms [2]. Because much of this care occurs outside healthcare facilities, patients need information that enables them to understand their condition and carry out appropriate self-care in daily life [3]. Thus, information is an important component of supporting self-care among patients with heart failure.

Previous research has shown that information needs among patients with heart failure vary according to their condition and stage of care [4]. A systematic review of 25 studies reported that outpatients primarily needed information about the disease, signs and symptoms, and disease management, whereas inpatients more frequently needed information about treatment, risk factors, and heart failure in general [5]. These findings indicate that information needs are influenced by patients' circumstances and should be responsive to their experiences. Nurse-led education has also been reported to improve knowledge related to heart failure self-management [6]. However, this evidence provides limited insight into how patients interpret and apply such information in their daily lives, particularly when their health condition changes and they need to decide what action to take.

Understanding changes in symptoms is an important part of self-care because patients must determine how to respond to changes in their condition. Previous studies have described relationships between heart failure knowledge, symptom perception, and symptom management [7]. Qualitative research has shown that patients use different strategies to manage symptoms and may experience uncertainty about the actions they take [8]. Symptoms may also be interpreted as part of patients' usual condition, which can contribute to delays in seeking help [9]. Treatment-related decisional needs have been studied [10]. These findings underscore the importance of understanding how patients experience changes in their condition and the information they consider necessary to respond to those changes. This issue is particularly relevant in the outpatient cardiac care setting at General Hospital in Surakarta, where patients with heart failure receive ongoing care while continuing self-care in their daily lives.

Therefore, this study aimed to explore how patients with heart failure perceive and experience their self-care information needs in daily life. The research question was: How do patients with heart failure perceive and experience their self-care information needs in daily life?

METHODS

This study used a qualitative descriptive design to explore patients' perspectives on their self-care information needs while living with heart failure. The study focused on participants' descriptions of their experiences and information needs related to understanding heart failure, medication management, lifestyle adjustment, symptom monitoring, and responses to symptom worsening. A qualitative descriptive design was selected to present participants' experiences and perspectives in a direct and clinically relevant manner.

The study was conducted at the cardiac outpatient unit of General Hospital in Surakarta, Central Java, Indonesia, from July to August 2026. The unit provides ongoing outpatient care for patients with cardiovascular conditions, including those with heart failure who require continuous disease management and self-care. The outpatient setting was appropriate for exploring information needs because participants managed their condition in daily life beyond the hospital, including medication use, lifestyle adjustments, symptom monitoring, and responses to changes in their condition.

Participants were selected through purposive sampling based on predefined

eligibility criteria. Eligible participants were adults aged 18 years or older who had been diagnosed with heart failure, were classified as New York Heart Association (NYHA) functional class II–III, had experience managing their condition and practicing self-care, could communicate in Indonesian or Javanese, and were willing to participate in the study. Patients who were clinically unstable during data collection or who withdrew from the study were excluded. A total of 15 participants were included in the study. Recruitment was conducted among eligible patients attending the cardiac outpatient unit, and 15 participants were included in the final analysis.

Data were collected through face-to-face, semi-structured interviews conducted by the first author in an education room at the cardiac outpatient unit. Interviews lasted approximately 30–45 minutes and were conducted in Indonesian and/or Javanese, and quotations presented in English were translated by the first author while retaining the meaning of participants' statements.

The interview guide consisted of four predefined areas of inquiry: participants' general experiences of living with heart failure; universal self-care needs, including food, fluid intake, physical activity, and rest; self-care agency and barriers; and developmental or health-deviation needs related to heart failure. The guide used core open-ended questions followed by follow-up probes to encourage participants to elaborate on their experiences, including their understanding of heart failure, daily self-care activities, sources of information, symptoms, symptom management, health monitoring, and support needs. The interview guide is presented in Table 1.

Table 1.
Interview Guidelines

No.	Core open-ended question	Follow-up probes
1.	"Tell me how you first realized you had heart failure."	What did you know about heart failure at that time? What information did you receive?
2.	"How has your life been since you found out you have heart failure?"	How has your daily routine changed? What symptoms or difficulties have you experienced?
3.	"While managing your condition at home, what do you find easiest and hardest to do?"	What do you do regarding food/fluid intake, activity, rest, medicines, and monitoring your condition? What makes these activities easier or more difficult?
4.	"Where have you learned about how to manage heart disease so far?"	What information have you looked for? What information do you still need? Who or what sources have helped you?
5.	What do you usually do when your heart failure symptoms appear or become worse?	What symptoms do you monitor? How do you manage the symptoms? When do you seek help or contact a health professional? What support do you need when your condition changes?

With participants' consent, interviews were audio-recorded and supplemented by field notes. Participants were encouraged to describe their experiences in their own words. Interviews were conducted sequentially, and each interview was transcribed and analyzed before the subsequent interview to identify emerging information and categories.

Data were analyzed iteratively alongside data collection. After each interview, the interview recording was transcribed, and the transcript was read repeatedly to become familiar with the participant's account. Meaningful statements relevant to the study focus were identified and assigned initial codes. Similar codes were grouped into categories, which were then

organized into subthemes and broader themes. This process was repeated after each interview.

The interview guide contained predefined areas of inquiry related to self-care, but these areas were not treated as the final analytical themes. Instead, categories, subthemes, and themes were developed from participants' accounts during the analysis. The analysis focused on patterns in participants' descriptions of their information needs and self-care experiences. The developing categories and themes were reviewed against the coded statements and original transcripts to ensure that the findings remained grounded in participants' accounts.

Coding distinguished closely related themes according to the focus of participants' information needs. Statements concerning understanding the disease, its causes, heart function, and its implications for daily life were grouped under Theme 1. Statements concerning the recognition and monitoring of signs and symptoms were grouped under Theme 4, whereas statements concerning actions and decisions when symptoms worsened were grouped under Theme 5.

Data collection and analysis continued iteratively until data sufficiency was reached. After each interview, the transcript was reviewed against the preceding interviews to assess whether the participant's account generated new categories, substantially different information, or new aspects of the study focus. When subsequent interviews primarily confirmed existing categories and no substantially new categories or relevant information emerged, the data were considered sufficient. This assessment was made during the ongoing comparison of transcripts, codes, and developing categories rather than based on a predetermined sample size. After 15 interviews, the analysis no longer generated substantially new categories relevant to the study focus, and all 15 participants were included in the final analysis.

Trustworthiness was addressed through credibility, dependability, confirmability, and transferability. Credibility was supported by audio-recording the interviews with participants' consent, using probing questions to clarify participants' responses, and checking the transcripts against the original recordings. The coding and interpretation process was discussed between ES and BK until consensus was reached. Dependability was supported by systematically documenting the research process, including participant recruitment, data collection, transcription, coding, categorization, and development of subthemes and themes. Data analysis was conducted iteratively alongside data collection, with each interview analyzed before proceeding to the next interview. Confirmability was supported by grounding the analysis in participants' statements and maintaining a clear connection between meaningful statements, codes, categories, subthemes, and themes, with direct quotations used to demonstrate the basis of the findings. Transferability was supported by providing a clear description of the study setting, participant characteristics, and research procedures to allow readers to assess the applicability of the findings to similar contexts. Participant member checking and external audit were not conducted.

Ethical approval was obtained from the Health Research Ethics Committee of RSUD Dr. Moewardi, Surakarta, under approval number EC 333/II/HREC/2026, issued on 4 March 2026. Before each interview, participants were informed about the study objectives, interview procedures, voluntary nature of participation, and their right to withdraw from the study. Written informed consent was obtained before data collection.

Interviews were conducted in a manner that allowed participants to participate

comfortably. Data were reported using participant identifiers rather than names to maintain confidentiality. Audio recordings, transcripts, and other research data were stored securely and were accessible only to ES and BK. The data were retained until completion of the research process.

RESULTS

A total of 15 participants were included in the study. Analysis of the interview data yielded five themes describing information needs regarding self-care, ranging from understanding the disease to determining actions to take when symptoms worsened. The presentation of results focuses on the experiences and information needs that emerged from the participants' narratives, with direct quotes used to support each statement.

Participant Characteristics

Participant characteristics included age, sex, education, occupation, New York Heart Association (NYHA) functional class, duration of heart failure, and comorbidities. Participant characteristics are presented in Table 2.

Table 2.
Participant characteristics (n = 15)

Characteristic	Result
Age (years)	40–70
Sex	Male: 10 (66.7%); Female: 5 (33.3%)
Education	Elementary school: 1 (6.7%); Junior high school: 3 (20.0%); High school: 9 (60.0%); Bachelor's degree: 2 (13.3%)
Occupation	Laborer: 3 (20.0%); Teacher: 2 (13.3%); Merchant: 4 (26.7%); Housewife: 3 (20.0%); Private-sector employee: 3 (20.0%)
NYHA Functional Class	NYHA Class II: 10 (66.7%); NYHA Class III: 5 (33.3%)
Duration of heart failure	1–3 years: 11 (73.3%); >3 years: 4 (26.7%)
Comorbidities	Diabetes mellitus: 6 (40.0%); Hypertension: 7 (46.7%); Kidney disease: 2 (13.3%)

Note: Age is presented as a range because individual age data are not shown. Categorical data are presented as the number of participants n (%).

Summary of Themes

The resulting themes are presented in Table 3. The table serves as a summary and does not replace the description of the results or the participants' quotes.

Table 3.
Summary of themes regarding self-care information needs among heart failure patients

Theme	Summary of Results
Theme 1. Information needs to understand the condition and implications of heart failure	Participants needed information to understand their diagnosis, causes or medical history, heart condition and function, and the implications of heart failure for daily activities.
Theme 2. Information needs regarding medication management	Participants needed information regarding the names and functions of medications, how to use them, adherence, benefits, and barriers to following treatment.
Theme 3. Need for information on lifestyle management	Participants needed information regarding dietary and fluid intake, physical activity, and adjustments to daily activities following symptom worsening.
Theme 4. Information Needs for Monitoring Signs and Symptoms	Participants needed information to recognize and monitor changes in signs and symptoms and to understand what changes indicated a worsening condition.
Theme 5. Information needs for decision-making symptom worsening	Participants needed information about what actions to take when symptoms worsened, including initial responses, family involvement, and when to seek medical care.

Theme 1. Information needs to understand the condition and implications of heart failure

Participants needed information about their diagnosis, causes or medical history, heart condition, heart function, and the impact of heart failure on daily activities. Some participants reported learning about their condition after undergoing examinations and receiving explanations from healthcare professionals.

"I asked to be taken to the hospital because I have a heart problem." (Inf 1)

The information participants received about their heart condition included pumping function, valve condition, and the condition of the heart's blood vessels.

"My pumping function has dropped to twenty percent." (Inf 2)

"The doctor said I need surgery because both of my heart valves are problematic." (Inf 4)

Theme 2. Information needs regarding regarding medication management
Participants described information needs related to medication names and functions, medication use, adherence, and the benefits of treatment. Information about medications was primarily obtained from healthcare providers. One participant recalled receiving an explanation about the function of the prescribed medication:

"The doctor explained the function of the medication." (Inf 6)

Some participants knew the function of the medications they were taking, including those used to help eliminate fluid.

"There's a medication to help eliminate fluid through urination." (Inf 3)

Some participants followed the instructions and medication schedule provided by healthcare providers.

"I take my medication right on time." (Inf 14)

In addition to following their treatment schedules, some participants experienced barriers to taking their medication. These barriers included forgetting to take their medication when they were busy and skipping doses when they felt their condition had improved.

"Sometimes I forget to take my medication when I have an event." (Inf 14)

"Sometimes I don't take my medication if I'm already feeling better." (Inf 3)

Some participants could not recall the names of the medications they were taking.

"I don't know the name of the medication by heart." (Inf 12)

Theme 3. Need for information regarding lifestyle management

Participants needed information about dietary guidelines, fluid restrictions, physical activity, and adjustments to daily activities. Regarding dietary guidelines, participants try to avoid certain foods, especially salty foods.

"If there's salty food, I don't eat it." (Inf 1)

Fluid intake is managed according to healthcare providers' recommendations.

"The nurse has already set my fluid intake, so I follow her advice." (Inf 3)

In addition to receiving information from healthcare professionals, participants also sought information about lifestyle habits via their cell phones.

"I look up information on my phone, like what foods to avoid, what activities to steer clear of, and what exercises to do." (Inf 10)

In their daily lives after experiencing heart failure, participants adjusted their activities accordingly.

"Back then, I used to work in the rice fields, farming was very hard work for me, but now I never go to the fields anymore." (Inf 4)

Theme 4. Information Needs for Monitoring Signs and Symptoms

Participants recognized changes in their physical condition through symptoms such as shortness of breath, chest pain, fatigue, cold sweats, and changes in heart rate.

"My heart feels unstable when I have trouble breathing and chest pain." (Inf 8)

"Usually, when I sleep, I get cold sweats and shortness of breath, that's one way I know my condition isn't stable." (Inf 15)

In addition to recognizing changes through symptoms, some participants monitor their condition using devices, particularly to check their heart rate.

"I wear a watch that tracks my heart rate." (Inf 2)

Shortness of breath also affected the participants' sleep.

"When I have an episode, I can't sleep. My breathing feels like it's cutting out, so I have trouble sleeping." (Inf 12)

When shortness of breath occurs, participants adjust their sleeping position to alleviate their symptoms.

"For example, if I suddenly feel short of breath, I have to sleep with my head elevated using four pillows." (Inf 1)

Although participants could recognize some symptoms, their ability to determine whether changes indicated a worsening or potentially dangerous condition varied. One participant stated:

"I didn't know my condition was life-threatening." (Inf 1)

These accounts showed that participants sought information about recognizing meaningful changes in their condition and identifying symptoms that may indicate worsening.

Theme 5. Information needs for decision-making during symptom worsening

When symptoms worsened, participants described different responses, including resting, taking their prescribed medication, asking family members for help, and seeking medical assistance.

"If my heart is beating fast, I rest." (Inf 2)

For some participants, resting and taking medication were the first steps they took when symptoms appeared.

"Mostly, if my condition gets worse, I just rest, sleep, and take my medication." (Inf 10)

When symptoms did not improve after initial actions, participants sought medical help.

"I take medication for shortness of breath; if it doesn't get better over time, I go to the ER." (Inf 15)

When medical evaluation was needed, some participants involved their family members.

"If it flares up, I immediately tell my child to get me checked out." (Inf 6)

Participants also described attending routine check-ups as part of their ongoing care.

"Routine checkups once a month." (Inf 8)

DISCUSSION

Summary of Key Research Findings

This study shows that the information needs for self-care among heart failure patients encompass five interrelated aspects: understanding the condition and implications of heart failure, medication management, lifestyle management, monitoring signs and symptoms, and decision-making when the condition worsens. These five themes indicate that patients' information needs are not only related to knowledge about the disease but also to the ability to apply that information to manage their care and determine actions in daily life.

Understanding the Condition and Implications of Heart Failure

Understanding the condition and implications of heart failure is an important part of self-care. Participants need information about the diagnosis, causes or

medical history, heart condition, pumping function, valve disorders, and the impact of the disease on daily activities. This information helps patients understand their condition and relate it to the changes they experience in their daily lives.

The need for information regarding the signs, symptoms, and management strategies for heart failure has also been reported in previous studies [5]. This need is broader in the present study because participants require not only information about the disease but also an explanation of how their heart condition relates to physical changes and daily activities. A more contextual understanding can help patients connect their condition with the care they need to provide for themselves at home.

A lack of understanding regarding the relationship between the disease and physical changes can make it difficult for patients to recognize significant changes in their condition [11]. Education should help patients understand the connection between the disease, physical changes, and possible treatment options, rather than merely providing definitions or basic information about heart failure.

Medication Management

Participants described information needs related to medication functions, medication use, adherence, and the benefits of treatment. Some participants were able to explain the function of their medication, while others described following the medication schedule provided by healthcare professionals. These accounts suggest that medication-related information was not limited to knowing the name of a medication but also included understanding its purpose and how it should be taken consistently.

Some participants described difficulties with medication adherence, particularly forgetting to take medication when they were busy and skipping medication when they felt better. These accounts suggest that knowing about medication does not necessarily translate into consistent medication-taking behavior. Previous research has also highlighted the importance of patients' decisional needs related to heart failure medications [10]. In this context, medication education may need to address not only medication functions but also practical challenges in maintaining treatment routines.

The findings therefore suggest that medication-related information should be provided in a way that connects the prescribed treatment with patients' daily routines. However, the present study describes participants' reported experiences and information needs and does not establish the effectiveness of any particular educational strategy.

Lifestyle Management

Lifestyle management is one of the information needs that must be incorporated into daily routines. Participants require information regarding diet and fluid intake, physical activity, rest, and adjusting activities according to their condition. While undergoing treatment, participants take various measures based on their individual experiences, such as avoiding salty foods, managing fluid intake, adjusting their activity levels, and seeking information via their cell phones.

Lifestyle information should be conveyed not only as general recommendations, but also in the form of explanations that can be applied in everyday situations and tailored to the patient's condition. Patients use various strategies to manage their symptoms, but some still face knowledge gaps and uncertainty regarding the effectiveness of the measures they take [8]. Realistic and context-specific education is necessary so that patients can integrate dietary, fluid, activity, and rest management into their self-care routines.

Monitoring Signs and Symptoms

Participants monitored signs and symptoms by using their bodily sensations as a basis for assessing changes in their condition. Participants recognized shortness of breath, chest pain, cold sweats, changes in heart rate, and sleep disturbances as signs of changes in their condition. Some participants also used devices to monitor their heart rate. These findings indicate that participants were able to notice changes in their physical condition, but noticing symptoms did not necessarily mean that they could judge the severity or significance of those changes. This distinction was reflected in the participants' accounts, as one participant stated, *"I didn't know my condition was life-threatening" (Inf 1)*. This account suggests that recognizing a symptom was not always accompanied by an understanding of how serious the change in condition was.

Perception of symptoms is a crucial part of the self-care process because patients need to recognize changes in their bodies and make sense of those changes. Symptom perception involves monitoring, awareness of bodily changes, and evaluating the meaning of those changes [12]. In this study, the ability to sense symptoms was not always accompanied by the ability to recognize worsening symptoms. Some participants experienced symptoms but were not yet aware that their condition was unstable. This situation highlights the need for education that helps patients compare their current condition with their usual state, recognize meaningful changes, and understand the actions they need to take.

Decision-Making During Symptom Worsening

Decision-making during a worsening of symptoms relates to how patients respond to changes in their symptoms through care actions. Participants take various actions, ranging from resting and taking medication to asking family members for help, consulting with healthcare providers, and seeking medical assistance when their condition does not improve. These choices are related to the patient's assessment of changes in their condition as well as the outcomes of the initial actions taken.

The results of this study are consistent with previous research showing that patients employ situational *self-care* strategies and experience uncertainty regarding changes in symptoms and the effectiveness of the strategies they use [8]. Delays in seeking help may also be related to symptom burden and factors that influence the ability of patients and their families to recognize worsening symptoms [13]. The participants' accounts suggest an interpreted pattern in which some patients noticed a change in their condition, took an initial action, and then considered whether further assistance was needed based on how their symptoms changed. For example, some participants described resting or taking medication when symptoms appeared, while others reported seeking help when their symptoms did not improve. However, this pattern should be understood as an interpretation of the participants' narratives rather than as a formally demonstrated decision-making pathway, and the accounts did not indicate that all participants followed the same sequence. Without clear guidance, patients may be uncertain about when self-management is no longer sufficient and when professional assessment is needed. Educational materials should explain the relationship between symptoms, initial actions, monitoring of response, and the decision to seek help. This framework can also help families understand when they need to take a more active role in assisting the patient.

The distinction between self-care and the need to seek help is a crucial part of patients' information needs. Participants who choose to rest or take medication first need clear information about conditions that can still be managed on their own, as well as signs indicating the need for help

from a healthcare professional. Information regarding warning signs, initial actions, when to contact a healthcare professional, and conditions requiring immediate assistance enables patients to make more informed decisions when their condition worsens.

Family involvement is also part of the decision-making process when a patient's condition worsens. Some participants sought help from their children or other family members when their condition changed. Education about warning signs and actions to take during a deterioration should be provided not only to patients but also to family members involved in their care.

Research Contributions

The main contribution of this study is that heart failure patients' information needs extend beyond disease knowledge to the practical use of information in daily self-care. Participants' accounts showed needs related to medication management, lifestyle, symptom monitoring, and decisions during symptom worsening. These findings highlight the importance of nursing education that is linked to patients' real-life situations and the actions they may need to take, rather than focusing only on general disease information.

Implications for nursing practice and education

Nursing practice may consider focusing education on patients' ability to use information, rather than merely on the delivery of educational material. Nurses may use the teach-back approach to assess whether patients can explain their medical condition, medication use, lifestyle adjustments, signs of symptom worsening, and appropriate actions [14]. As a proposed educational practice, teach-back may help nurses identify gaps in patients' understanding that could otherwise remain unnoticed if evaluation were limited to asking whether patients had received education. However, the effectiveness of teach-back was not evaluated in the present study.

A simple *action plan* can help patients and their families determine what steps to take when the patient's heart failure condition changes [15]. The plan may include signs of worsening that need to be monitored, initial actions that can be taken, when to contact a healthcare provider, and when to seek immediate care at a healthcare facility. Families should be involved in developing and understanding the plan, as they can serve as a source of support when the patient's decision-making ability declines.

Digital technology can be utilized as a tool to support *self-management* and monitoring in patients with heart failure [16]. Some participants in this study searched for information using their cell phones, indicating that digital media has the potential to help patients revisit information that has already been provided and to support monitoring. However, its use should be directed as a complement to education and monitoring by healthcare professionals, not as a substitute for interaction with them.

Strengths and limitations of the study

The strength of this study lies in its direct exploration of patients' experiences regarding their information needs for self-care through in-depth interviews. The use of semi-structured interviews, recordings made with participants' consent, field notes, verbatim transcripts, *coding* discussions, and cross-checking of transcripts against recordings supports the traceability of the analysis process.

This study has several limitations. First, the study involved 15 patients with NYHA Class II–III heart failure from a single care setting. Therefore, the findings are context-specific and may not represent the experiences of patients with different clinical

characteristics, disease severity, backgrounds, or care contexts. Rather than statistical generalizability, the applicability of the findings should be considered in relation to the similarity of the study context and patient characteristics. Second, the data were based on participants' self-reported experiences and may have been influenced by recall or social desirability, as participants may not have remembered all previous information or may have described their experiences in ways they considered appropriate. Third, the interviews were conducted by a single interviewer, which may have influenced the data collection and interpretation. Although coding and interpretation were discussed between ES and BK until consensus was reached, the influence of the interviewer's perspective cannot be completely excluded. Finally, data were collected during a single period and therefore may not capture changes in patients' information needs over the course of their illness. The findings should consequently be considered in relation to the specific care context when assessing their transferability to other settings.

CONCLUSION

The self-care information needs of patients with heart failure include understanding the condition and its impact, medication management, lifestyle adjustments, monitoring signs and symptoms, and decision-making when their condition worsens. These needs are not only related to knowledge about the disease but also to the patient's ability to use that information for daily care, recognize changes in their condition, and determine when to seek help from a healthcare professional. Nursing education should be provided on an ongoing basis, tailored to the patient's needs and abilities, and should involve family members: particularly in recognizing worsening symptoms and determining necessary actions. Future research could develop and test educational interventions that help patients recognize when their condition is worsening and determine when to seek help, in accordance with the characteristics and context of care.

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