

Experiences of Discharge Preparedness Among Patients with Chronic Heart Failure and Their Caregivers: A Phenomenological Study

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Objective: To explore the lived experiences of discharge readiness among older patients with chronic heart failure and their family caregivers during the hospital-to-home transition.

Patients and Methods: Guided by Husserlian descriptive phenomenology, we conducted in-depth, semi-structured interviews with 16 patient-caregiver dyads purposively sampled from three cardiology departments at a tertiary hospital in Heilongjiang Province, China, between July and September 2025. Data were analyzed using Colaizzi's seven-step method to uncover essential structures of the lived experience.

Results: Analysis revealed three core themes: (1) Cognitive ambiguity in illness understanding, characterized by reliance on symptom intuition and gaps in knowledge about disease mechanisms; (2) Emotional and relational struggles during psychological adjustment, including fear, role disruption, and efforts to preserve dignity; and (3) Perceived fragmentation of post-discharge support, marked by discontinuous care guidance, caregiver burden, and systemic barriers to healthcare access.

Conclusion: This study illuminates how older patients with heart failure and their caregivers navigate the transition home amid persistent uncertainty, emotional strain, and fragmented support. Findings underscore the need for transitional care models that provide structured illness education, integrate dyadic psychological support, and establish nurse-coordinated follow-up to enhance self-management and reduce readmission risk.

Keywords: chronic heart failure, discharge preparedness, patient and caregiver experiences, transitional care, phenomenological study

Introduction

Currently, there are over 60 million people living with heart failure worldwide, including approximately 12.1 million in China. Among hospitalized patients with heart failure in China, more than 70% are aged 60 years or older. Both the incidence and prevalence of heart failure increase steadily with age, and the five-year mortality rate is estimated to be around 65%, underscoring its status as a major public health challenge.^{1,2} Chronic heart failure is a progressive condition characterized by recurrent hospitalizations, complex medication regimens, and long-term self-management needs.³ It places a substantial burden on patients, families, and the healthcare system, particularly during transitions between care settings.⁴ Despite advances in pharmacological and device-based therapies, many patients experience frequent symptom exacerbations that necessitate repeated hospitalizations, highlighting the critical need for effective post-discharge support.⁵

The transition from hospital to home represents a particularly vulnerable period for patients with CHF. This phase demands complex self-management behaviors—including daily weight monitoring, strict sodium and fluid restriction, medication adherence, and timely recognition of subtle symptom changes—tasks that are often overwhelming without adequate preparation and support.⁶ Discharge preparedness, defined as the patient's and caregiver's perceived readiness



to manage care after leaving the hospital, is a key predictor of successful transitions and reduced readmission risk distinct.⁷ However, achieving adequate preparedness is especially challenging in the Chinese context, where formal community-based transitional care services remain underdeveloped.⁸ As a result, family members assume primary responsibility for post-discharge care—a role deeply rooted in Confucian values of filial piety and familial obligation. This creates a dyadic unit in which the experiences, needs, and coping strategies of both patients and caregivers are interdependent yet distinct.

The Healthy China 2030 initiative has prioritized the development of an integrated “hospital–community–family” care model to strengthen chronic disease management and improve continuity of care for older adults.⁹ Yet, the implementation of such models requires empirical evidence on the lived realities of patients and their families during critical care transitions. While qualitative studies have explored discharge experiences among heart failure patients in Western settings¹⁰ or focused solely on caregivers in Asia,¹¹ Lyons and Lee (2018) have conceptualized chronic illness management as a dyadic phenomenon, emphasizing that patients and caregivers mutually shape each other’s appraisals, behaviors, and well-being through ongoing interaction.¹² Existing literature often treats these groups in isolation, overlooking the relational dynamics and mutual influence that shape discharge preparedness as a shared process.^{13,14}

To address this gap, we conducted a descriptive phenomenological study grounded in the philosophical tradition of Edmund Husserl to explore the lived experiences of discharge preparedness among older adults with CHF and their family caregivers in China. Husserlian phenomenology was selected because it emphasizes the rigorous description of conscious experience as it is directly lived—setting aside theoretical assumptions (epoché) to uncover the essential structures of phenomena such as readiness, uncertainty, and support needs during the hospital-to-home transition.¹⁵ By capturing the voices of both members of the care dyad through this approach, our study aims to provide nuanced, contextually rich insights that can inform the design of culturally responsive, dyad-centered transitional care interventions in China and similar resource-constrained settings.

Materials and Methods

Research Subjects

A purposive, maximum variation sampling method was used to select patients with chronic heart failure and their family caregivers. The study was conducted from July to September 2025 in three cardiology departments of a tertiary hospital in Heilongjiang Province, China.

Methods

Researcher Background and Preparation

The research team was led by senior nursing researchers with extensive clinical and academic experience in chronic heart failure management, including over 10 years of practice in cardiology settings. The primary interviewer was a graduate nursing student conducting a supervised research practicum. Prior to data collection, the interviewer completed a six-month clinical immersion in heart failure clinics, engaging in patient observations and interdisciplinary care discussions to develop contextual sensitivity to patients’ lived experiences.

Importantly, the interviewer had no prior or ongoing clinical relationship with any participant, and all interviews were conducted independently of the participants’ care teams. At the outset of each interview, she clarified her role as a researcher (not a clinician) and assured participants that their responses would remain confidential and would not affect their medical care. To enhance reflexivity, she maintained brief field notes after each interview to reflect on emerging assumptions and emotional responses, which were discussed during team debriefings to support interpretive transparency.

To ensure methodological rigor, the interviewer received formal training in phenomenological inquiry, including in-depth interview techniques, active listening, and principles of thematic analysis. Data coding and analysis were conducted under the supervision of an experienced qualitative researcher, with regular team meetings to discuss emerging themes and ensure interpretive credibility. The inclusion and exclusion criteria of the respondents are shown in [Table 1](#).

Table 1 Interviewees Inclusion and Exclusion Criteria

Participant Group	Inclusion Criteria	Exclusion Criteria
Patients	(1) Adults aged 18 and above; (2) Patients diagnosed with CHF by a physician; (3) Voluntarily participated in the study and signed an informed consent form.	(1) having a previous history of mental disorder or intellectual disability; (2) being unable to use speech for normal communication; (3) suffering from other serious systemic diseases or malignancies, as indicated by previous medical records.
Caregivers	(1) No communication barrier; (2) Informed consent and voluntary participation.	(1) Paid caregivers; (2) Cognitive impairment or previous history of mental illness.

Data Collection

Phenomenology is a qualitative research approach aimed at exploring and interpreting the lived experiences of individuals in relation to a specific phenomenon. This study specifically adheres to Husserlian descriptive phenomenology, which seeks to uncover the essential structures of conscious experience by returning “to the things themselves” (*zu den Sachen selbst*) and suspending preconceived assumptions through *epoché* (bracketing).¹⁵ Consistent with this philosophical orientation, our analysis prioritizes faithful description over interpretation, focusing on how discharge preparedness is directly lived and co-experienced by patients and their caregivers.

Notably, we intentionally treated each patient–caregiver pair as a single analytical unit (a “dyad”) rather than analyzing their accounts separately. This dyadic approach aligns with recent conceptualizations of chronic illness management as a shared, interactive process (Lyons & Lee, 2018)¹² and allows us to capture the relational dynamics, mutual influences, and co-constructed meanings that shape discharge preparedness—thereby preserving the interdependent nature of their lived experiences.

An interview guide was developed through a multi-stage process that integrated evidence from the literature, clinical expertise, and Patient and Public Involvement (PPI).¹⁶ Specifically, two patient representatives with lived experience of chronic heart failure and one family caregiver participated in reviewing and refining the initial questions to ensure clarity, relevance, and sensitivity to real-world concerns. This PPI-informed approach enhanced the authenticity and patient-centeredness of the interview instrument.¹⁶ The final interview guide is presented in Table 2. For illustration, the first two questions interview guide were: (1) How did you and your caregiver discover the onset or worsening of chronic heart failure this time? What was the process of seeking medical care like? (2) How

Table 2 Outline of Interviews with Interviewees

Participant Group	Interview Outline
Patients and Caregivers	(1) How did you and your caregiver discover the onset or worsening of chronic heart failure this time? What was the process of seeking medical care like? (2) How much do you and your caregiver know about chronic heart failure (for example, its causes, symptoms, treatment, and prognosis)? (3) During the patient’s treatment and recovery period, how have your roles changed between you and the caregiver? (4) How has the illness affected the patient’s daily life and psychological well-being? What difficulties has the caregiver encountered in the caregiving process? (5) Do you and your caregiver feel prepared for discharge? What do you think discharge preparation includes, and where do you feel there are gaps or unmet needs? (6) After discharge, what are your plans for disease management at home (eg, medication, diet, rehabilitation exercises)? What specific guidance do you hope to receive? (7) After returning home, what are your main needs regarding home-based care? How would you prefer healthcare providers to offer support (eg, in-person visits, phone calls, online platforms)?

much do you and your caregiver know about chronic heart failure (for example, its causes, symptoms, treatment, and prognosis)?

Prior to each interview, the study's purpose and significance were explained to participants, and assurances of audio recording confidentiality and data anonymity were provided. Written informed consent was obtained before data collection began. Interviews were conducted in a quiet and private setting, either in a designated consultation room or an unoccupied patient room within the cardiology unit, to ensure confidentiality and minimize interruptions. Participants were encouraged to share their perspectives openly and were assured they could pause or withdraw at any time. Each interview lasted between 30 and 40 minutes. If a participant experienced discomfort, illness, or fatigue during the session, the interview was immediately suspended or rescheduled.

Ethical Consideration

This study was reviewed and approved by the Institutional Review Board of the Second Affiliated Hospital of Qiqihar Medical University (Approval number: [2025]04–013-01). All participants provided written informed consent prior to data collection. The principles of confidentiality and anonymity were strictly maintained throughout the research process. Participation was entirely voluntary, and participants were informed of their right to withdraw at any time without affecting their clinical care.

Data Organization and Analysis

All interview transcripts were produced within 24 hours of data collection to ensure accuracy and contextual fidelity. Data were anonymized, archived, and organized using NVivo 11.0 qualitative data analysis software. The primary researcher and one independent Master of Science in Nursing student, trained in phenomenological analysis, independently analyzed the data using Colaizzi's seven-step method. This included coding significant statements, extracting meaning units, and developing themes. Any discrepancies in interpretation were resolved through discussion during research team meetings until consensus was achieved.

The sample size was guided by the principle of information saturation, which was assessed iteratively throughout data collection. After every few interviews, the research team reviewed emerging codes and thematic patterns. By the 14th patient–caregiver dyad, no substantially new themes or insights were arising from the data. To ensure robustness, we conducted two additional dyadic interviews (total $N = 16$), during which the core themes remained stable and no novel categories emerged—confirming that saturation had been achieved.

The specific methods were as follows:¹⁷ (1) repeatedly reading the text word-by-word; (2) selectively excerpting content related to the and extracting meaningful units; (3) coding meaningful units; (4) summarizing the codes, identifying the same concepts, or features, and summarizing and condensing the codes into themes; (5) describing the themes in detail; (6) summarizing the similar themes and further condensing the themes; and (7) returning the results to the interviewees, verifying authenticity, and if there is disagreement, inviting another researcher to go back to the interview data to check the coding process, restructure the themes, and return to the participants for validation.

Quality Assurance and Trustworthiness

To ensure methodological rigor, we implemented the following quality control strategies: (1) verbatim transcription was independently performed by two researchers, with discrepancies resolved through discussion; (2) data analysis was conducted by two team members using Colaizzi's method, and unresolved disagreements were referred to a third researcher for consensus; (3) the primary interviewer contacted selected participants by phone within 48 hours of initial coding to clarify ambiguous statements and confirm intended meanings; (4) regular peer debriefing sessions were held among the research team to review interpretations and reduce bias; (5) member checking was performed with six patient–caregiver dyads, who reviewed summaries of key themes for accuracy and resonance; and (6) an audit trail was maintained to document all analytical decisions.

Results

A total of 16 pairs of participants, including patients and family caregivers, were recruited. The demographic and clinical characteristics of the participants are summarized in Table 3.

A total of three themes and nine sub-themes were identified. The themes and sub-themes included the following: (1) Cognitive Ambiguity in Understanding Illness (relying on intuitive symptoms to judge disease progression, limited understanding of disease mechanisms and treatment principles, and delayed cognitive recognition due to twisted diagnostic pathways); (2) Seeking Balance Amid Psychological Struggles (psychological transition from fear and resistance to acceptance, emotional fluctuations perceived as triggers of illness, and striving to maintain dignity and family roles amid illness); and (3) Craving Sustained Care Amid Fragmented Support (discontinuity in post-discharge guidance and strong demand for information, caregiver resource exhaustion and role conflict, and poor healthcare accessibility and economic pressure intersect to affect treatment continuity).

The three themes of discharge preparedness among patients with chronic heart failure and their caregivers are presented in Table 4 (P for patient, C for caregiver)

Table 3 Characteristics of the Study Participants

ID	Relationship Type	Gender	Age (Years)	LVEF (%)	NYHA Class	Occupation	Education Level	Health Insurance Type
P1	Father-Daughter	Male	74	40	III	Retired	Elementary	Employee Insurance
C1		Female	47			Freelance Work	High School	
P2	Father-Son	Male	72	48	II	Farmer	Elementary	Rural Cooperative
C2		Male	45			Worker	Junior High	
P3	Mother-Daughter	Female	31	45	III	Charge Clerk	College	Employee Insurance
C3		Female	63			Retired	High School	
P4	Father-Daughter	Male	76	64	II	Retired	High School	Rural Cooperative
C4		Female	54			Farmer	Elementary	
P5	Mother-in-Law-Daughter-in-Law	Female	65	34	II	Retired	Elementary	Rural Cooperative
C5		Female	38			Freelance Work	Secondary School	
P6	Mother-Daughter	Female	58	50	IV	Retired	Elementary	Rural Cooperative
C6		Female	29			Sales	Secondary School	
P7	Husband-Wife	Male	74	53	II	Retired	College	Employee Insurance
C7		Female	74			Retired	Junior High	
P8	Husband-Wife	Male	70	38	IV	Farmer	Junior High	Rural Cooperative
C8		Female	67			Farmer	Elementary	
P9	Father-Son	Male	72	60	IV	Retired	High School	Employee Insurance
C9		Male	43			Freelance Work	Bachelor Degree	
P10	Husband-Wife	Male	76	58	II	Retired	High School	Employee Insurance
C10		Female	72			Retired	Elementary	
P11	Mother-Son	Female	80	40	III	Farmer	Elementary	Rural Cooperative
C11		Male	46			Driver	Junior High	
P12	Husband-Wife	Female	72	53	III	Farmer	Elementary	Rural Cooperative
C12		Male	75			Retired	Elementary	
P13	Father-Daughter	Male	74	47	IV	Farmer	High School	Rural Cooperative
C13		Female	50			Freelance Work	High School	
P14	Mother-Son	Female	73	35	IV	Retired	Elementary	Rural Cooperative
C14		Male	56			Freelance Work	High School	
P15	Brother-Sister	Male	50	36	III	Freelance Work	Junior High	Employee Insurance
C15		Female	55			Retired	High School	
P16	Father-Daughter	Male	68	55	II	Retired	Junior High	Rural Cooperative
C16		Female	41			Nurse	Bachelor Degree	

Note: P for Patient, C for Caregiver, LVEF refers to the percentage of blood pumped out of the left ventricle with each beat, and NYHA Classification indicates the severity of heart failure symptoms according to the New York Heart Association guidelines.

Table 4 Themes and Sub-Themes in Discharge Preparedness Among Patients with Chronic Heart Failure and Their Caregivers

Theme	Subtheme	Representative Statements from Interviews
Cognitive Ambiguity in Understanding Illness	Relying on Intuitive Symptoms to Judge Disease Progression	P1: "It started with swelling, you know, leg pain. Then I couldn't even walk properly. That's when I came back to the hospital." C1: "His belly was full of ascites—whole-body fluid retention. Couldn't pee it out. Press your finger in, and it left a dent."
	Limited Understanding of Disease Mechanisms and Treatment Principles	P2: "I feel like I've learned a lot now... there's a dead spot at the heart's apex, plus emphysema—bad for the airways. Some common medications, I can even buy them myself now." C3: "I watch these things on the app—Douyin. Mostly, it's doctors explaining stuff. Otherwise, I wouldn't know much about heart and lung issues. Who'd think he'd get this disease?"
	Delayed Cognitive Recognition Due to Twisted Diagnostic Pathways	P1 I: "At first, how could I know if this disease could even be cured? But it actually got better. At first, yes, I felt a lot of pressure." P7: "I've never called an ambulance. I try not to. If you call one, everyone sees it—Who's dying now?—feels kind of awkward." C7: "Last year, around 10 p.m., he couldn't breathe, felt suffocated... I called my kid, and he drove over."
Seeking Balance Amid Psychological Struggles	Psychological Transition from Fear and Resistance to Acceptance	P12: "You can't expect to be young again—that's impossible. Just be content. That's enough." C12: "She's over seventy—going out shopping, that's fine. What more can you ask for?"
	Emotional Fluctuations Perceived as Triggers of Illness	P12: "Don't get angry, avoid anger, don't overwork... If you get angry, it hits fast. Physical exhaustion isn't good either." P7: "No use getting upset—can't change it. You just have to face it. Treat it, stay calm, don't get stuck in a loop. If you do, things only get worse."
	Striving to Maintain Dignity and Family Roles Amid Illness	C1: "Yes, since that time, I decided to spend more time caring for my dad. Before, he never wanted to bother me..." P15: "As long as I can move, I'll do it myself. Don't want to trouble others."
Craving Sustained Care Amid Fragmented Support	Discontinuity in Post-Discharge Guidance and Strong Demand for Information	C6: "For heart failure... it might trigger other diseases later. After discharge, many things need attention—no overexertion, manage emotions, diet too." P15: "I wish I could add the doctor's WeChat... For small issues, no need to come to hospital every time. Just ask quickly, get a reply..."
	Caregiver Resource Exhaustion and Role Conflict	P1: "He can't take care of me—his illness is worse. His legs hurt, can't move well. In the end, I'm the one taking care of him." P13: "During IV treatment, he had work, was in a hurry. A normal course is seven or ten days, but he stopped after three or four days to return to work. Slight improvement, then left. Didn't fully recover, so it kept recurring—years like this."
	Poor Healthcare Accessibility and Economic Pressure Intersect to Affect Treatment Continuity	C12: "Reimbursement here is different—us out-of-province patients get very little back." P12: "I'm from out of province." P8: "Not just this drug—others too... Since the abdominal aortic aneurysm in 2008, it's been like this—organs all involved." P8: "Sometimes when I feel another episode coming, I have to rush to get money ready. If I've earned it, fine. If not, I can't."

Theme 1: Cognitive Ambiguity in Understanding Illness

Relying on Intuitive Symptoms to Judge Disease Progression

Patients generally lack the ability to recognize early signs of disease progression, often initiating healthcare-seeking behavior only after significant functional impairment has occurred. The “visibility” and “unignorability” of symptoms become core criteria for judging whether their condition has worsened—such as obvious limb edema, dyspnea, difficulty walking, or marked loss of appetite. This decision-making pattern, triggered by functional disability, reflects a cognitive blind spot regarding the insidious nature of disease progression, and also exposes the real-world challenge of lacking systematic symptom monitoring guidance after hospital discharge.

- P1: It started with swelling, you know, leg pain. Then I could not even walk properly. That's when I came back to the hospital.
- C1: His belly was full of ascites—whole-body fluid retention. Could not pee it out. Press your finger in, and it left a dent.
- P2: First I had a fever, then the swelling started... could not catch my breath, walking made me gasp, every breath made the swelling worse—then I had to come to the hospital.
- P4: I lost 20 pounds in a month. Could not eat, no energy at all. Could not even get up onto the road.

With repeated hospitalizations, some patients begin to encounter and attempt to understand medical indicators such as ejection fraction and protein levels. However, their understanding remains heavily dependent on physicians' verbal explanations, lacking the ability to integrate this knowledge independently. Most interpret “transfer from ICU to general ward” or “being able to eat again” as signs of improvement, indicating that their judgment of disease status remains deeply rooted in the restoration of daily living functions. This perceptual logic—from “loss of bodily control” to “life can continue”—constitutes the fundamental path through which patients construct the meaning of illness amid fragmented information.

- P5: We were first in the intensive care unit, right? Then today I heard—maybe they are downgrading me from Level 1 to Level 2—so I can be moved to another ward.
- P3: Well, it means I am better, right? All the indicators are normal now, stronger than when I came in. That's why I will be discharged.
- P6: The doctor evaluates my overall condition—my ejection fraction has risen to nearly 40%, which is good, and my protein levels are replenished. Too much protein will not help anymore.

Limited Understanding of Disease Mechanisms and Treatment Principles

Although some participants can name medical terms such as “ejection fraction” or “enlarged heart,” they often struggle to explain their specific meanings or health implications. This fragmented knowledge accumulation stems from a lack of systematic health education and sustained doctor-patient communication. Many patients rely on daily observations and social media platforms like Douyin for scattered information, leading to incomplete understanding of their condition, which further affects self-management capacity and treatment adherence.

- P1: What does heart failure really mean? It's about the heart's pumping—ejection fraction, an index. Last year my EF was around 31 or 32—the attending doctor said that's shock-level, dangerous. Now, after a year, it's over 50. That's normal.
- C1: Look, your left atrium is enlarged, and now your left ventricle too.
- P2: I feel like I have learned a lot now... there's a dead spot at the heart's apex, plus emphysema—bad for the airways. Some common medications, I can even buy them myself now.
- C3: I watch these things on the app—Douyin. Mostly, it's doctors explaining stuff. Otherwise, I would not know much about heart and lung issues. Who'd think he'd get this disease?

Delayed Cognitive Recognition Due to Twisted Diagnostic Pathways

Patients' understanding of their illness often lags behind disease progression. Some individuals experience delayed recognition of heart disease due to the insidious onset of symptoms or misattribution to other chronic conditions. This “misattribution” not only prolongs the diagnostic journey but also weakens their alertness to symptom severity. Meanwhile, uncertainty about treatment effectiveness and social stigma associated with public help-seeking behaviors (eg, calling an ambulance) further delay timely medical care. Cognitive awareness often emerges only after therapeutic effects are observed or family support is mobilized, reflecting a passive, “retrospective confirmation” pattern.

- C7: Back in spring, he just did not feel well—weak all over, short of breath... and digestive problems. We treated the gut first. Only after finishing that did we discover the heart issue.
- P11: At first, how could I know if this disease could even be cured? But it actually got better. At first, yes, I felt a lot of pressure.
- P7: I have never called an ambulance. I try not to. If you call one, everyone sees it—Who's dying now?—feels kind of awkward.
- C7: Last year, around 10 p.m., he could not breathe, felt suffocated... I called my kid, and he drove over.
- C7: Calling an ambulance feels scary. Like something terrible is happening.

Theme 2: Seeking Balance Amid Psychological Struggles

Psychological Transition from Fear and Resistance to Acceptance

Patients often experience fear and a sense of loss of control upon initial diagnosis. However, as their condition stabilizes and treatment feedback accumulates, they gradually shift toward calm acceptance. This process reflects a re-evaluation of life status—individuals no longer cling to cure, but adjust expectations, learning to coexist with illness, and developing adaptive psychological coping strategies. An internal shift from resistance to realistic adaptation is thus completed.

- P3: At first, I was nervous—knowing this is heart failure, which is dangerous. But now I feel much calmer. The psychological pressure is not as heavy. I know how to manage it now.
- P12: You cannot expect to be young again—that’s impossible. Just be content. That’s enough.
- C12: She’s over seventy—going out shopping, that’s fine. What more can you ask for?
- C4: When you go home, just take your meds on time. And if—let us say, it flares up again—you come back to the hospital.
- P13: Now I do not care about dying. One more day alive is a bonus. I have never felt stressed. Unlike others who sigh all day, I have never done that.

Emotional Fluctuations Perceived as Triggers of Illness

Patients and caregivers commonly construct a “emotion-symptom” linkage framework, viewing irritability, anger, and anxiety as direct triggers of cardiac decompensation. This cognition arises not only from daily observations of symptom recurrence but also reflects individuals’ active identification of controllable risk factors in chronic disease management. By avoiding emotional states such as “getting heated” or “overexerting mentally,” patients attempt to establish a self-management strategy centered on emotional regulation—embodying an embodied understanding of the mind-body connection in illness experience.

- C13: If he gets upset or angry—something does not suit him, or someone does something wrong—he immediately loses his temper. He clutches his chest, it comes right up. His temper’s really bad. It easily triggers an episode.
- P12: Do not get angry, avoid anger, do not overwork... If you get angry, it hits fast. Physical exhaustion is not good either.
- P7: No use getting upset—cannot change it. You just have to face it. Treat it, stay calm, do not get stuck in a loop. If you do, things only get worse.
- P14: After discharge, the doctor gave us some supportive meds. We take them regularly—they work well. But if he gets anxious or heated up, it flares up again.
- C14: We follow the doctor’s orders strictly—take the prescribed meds consistently, do occasional check-ups. But if he gets anxious or heated up, it flares. Otherwise, it would not. Now, we take meds regularly and keep his mindset calm. I think emotional state affects him. At our age, any sudden event can make him “heat up”—but otherwise, things are going well. Just watch out for colds.

Striving to Maintain Dignity and Family Roles Amid Illness

Patients attempt to maintain a sense of control over life by limiting reliance on others’ support. Even with physical limitations, they persist in independently completing daily tasks. This behavior is not only resistance to the passive dependency caused by illness but also an effort to sustain self-worth within family relationships—an embodied practice of reconstructing dignity and a manifestation of chronic patients’ persistence in autonomy.

- P1: At first, I came to the hospital by myself—tried not to trouble anyone. (head down, voice weak) But as my condition worsened... every episode was unbearable. Like last time—got angry, heart attack, could not manage at all.
- C1: Yes, since that time, I decided to spend more time caring for my dad. Before, he never wanted to bother me...
- P15: As long as I can move, I will do it myself. Do not want to trouble others.

Some patients, due to introverted personalities or financial concerns, tend to hide discomfort and avoid expressing needs. While this silence maintains surface family harmony, it intensifies inner loneliness and guilt. As physical function declines, the conflict between “getting breathless with minimal movement” and the desire “not to become a burden” traps individuals in self-deprecating psychological distress.

- C2: My dad’s quite introverted—he does not like to talk. Older people, afraid of cost, afraid of trouble, just stay quiet. Otherwise, we’d have come earlier.
- P9: Of course there’s pressure... Just walking to the toilet is hard. Do not even want to go... Stand a bit, have to sit down... Get anxious, start gasping. You feel like a burden (sighs). How could there be no pressure?

Theme 3: Craving Sustained Care Amid Fragmented Support Discontinuity in Post-Discharge Guidance and Strong Demand for Information

Although patients receive basic medical instructions at discharge, they lack systematic follow-up guidance, facing significant challenges in adjusting lifestyle behaviors such as diet, emotion, and activity. Despite recognizing the importance of healthy behaviors, individuals are often constrained by real-life conditions, adopting only limited changes through gradual, experimental adjustment strategies—seeking feasible balance between ideal recommendations and daily reality.

- C6: For heart failure... it might trigger other diseases later. After discharge, many things need attention—no over-exertion, manage emotions, diet too.
- P1: Managing the illness at home means less anger, no heavy work, go for walks... Mainly, I do not smoke, drink less—just one drink a day.
- P7: Healthy eating—100% compliance is hard, but getting closer helps.

Faced with uncertainties in daily management, patients and caregivers universally desire ongoing communication channels post-discharge. They hope to use instant messaging tools like WeChat to enable informal, low-threshold communication with doctors—resolving non-emergency but concerning issues such as medication adjustments or symptom changes—thereby reducing anxiety and unnecessary hospital visits.

- P15: I wish I could add the doctor's WeChat... For small issues, no need to come to hospital every time. Just ask quickly, get a reply...
- C12: We have been in touch with Dr. Lin on WeChat since discharge. This time, I messaged: "My stomach's a bit bloated—not heart-related." We chatted, and he said I should probably get checked.

Caregiver Resource Exhaustion and Role Conflict

Many patients and caregivers face profound role conflicts when confronting illness. On one side is their own health limitation; on the other, family responsibilities and economic pressures. With limited caregiving resources, individuals often adopt minimal coping strategies—suppressing personal needs to maintain family functioning—revealing a survival logic of difficult balancing between health, work, and family.

- P1: He cannot take care of me—his illness is worse. His legs hurt, cannot move well. In the end, I am the one taking care of him.
- C11: As long as it does not get worse.
- P11: I can still go to work when I am better. But if the illness affects work, how can I survive? Cannot afford to quit. (voice low, with resignation)

When sudden or long-term caregiving demands arise, family members often face a dilemma between work and caregiving. Some caregivers immediately interrupt work to return home, reflecting the priority of family responsibility; while some patients, due to job pressure, shorten treatment courses, leading to recurrence. This structural dilemma reveals the reality where individuals sacrifice health or career due to lack of social support.

- C6: I was working out of town. Heard Mom was hospitalized on the 20th, flew back to my hometown on the 21st at noon. Was at work, heard the news, immediately explained to my boss (speaking fast), and he agreed—Go back and see her. I have been caregiving ever since.
- P13: During IV treatment, he had work, was in a hurry. A normal course is seven or ten days, but he stopped after three or four days to return to work. Slight improvement, then left. Did not fully recover, so it kept recurring—years like this.

Poor Healthcare Accessibility and Economic Pressure Intersect to Affect Treatment Continuity

Patients face systemic and structural barriers when seeking care, including low reimbursement rates for out-of-province care and limited treatment effectiveness at primary care facilities. On one hand, insurance policies strictly limit reimbursement for out-of-province care, resulting in high out-of-pocket costs; on the other, limited diagnostic and treatment capacity at grassroots facilities forces patients to seek higher-level hospitals. Although transfer improves outcomes, it also brings higher economic and caregiving costs—exposing deep contradictions in uneven healthcare resource distribution.

- C12: Reimbursement here is different—us out-of-province patients get very little back.
 P12: I am from out of province.
 C12: Spent over 3300 yuan, only got 400 reimbursed... basically nothing. (sighs)
 C6: Hospitalized in my hometown for half a month—results were not good. So I requested a transfer. Treatment here has been very effective.

Faced with long-term medication, expensive out-of-pocket drugs, and multimorbidity, families bear enormous financial pressure. Although doctors consider patients' financial conditions when prescribing, some treatments remain self-paid, with daily costs reaching hundreds of yuan. Individuals are forced to weigh treatment necessity against household affordability, attempting dietary substitutes or interrupting therapy—forming a vicious cycle of “remission–relapse,” reflecting survival compromises under limited resources.

- P2: Medication costs are huge. You cannot stop taking them all year...
 P15: The doctor considers our financial situation... two vials a day, nearly 800 yuan out-of-pocket.
 P11: Five boxes of human albumin a day, 450 each... My daughter said, “What can we do? Just buy it.” (shakes head)
 C11: This has been going on for years. If you do not take it, you cannot survive—so you take it.
 P8: Not just this drug—others too... Since the abdominal aortic aneurysm in 2008, it's been like this—organs all involved.
 P8: Sometimes when I feel another episode coming, I have to rush to get money ready. If I have earned it, fine. If not, I cannot.

Discussion

This study reveals that discharge preparedness in chronic heart failure extends far beyond the transfer of medical information. It is a complex process shaped by patients' and caregivers' struggles to make sense of an unpredictable illness, manage emotional turbulence, and navigate fragmented support systems after hospitalization.

These challenges highlight critical gaps in current transitional care practices. Addressing them requires not only patient education but also the integration of psychological support and the establishment of continuous care models that sustain patients and caregivers beyond the hospital walls.¹⁸

Provide Structured Illness Education at Discharge

Patients in this study relied heavily on intuitive symptoms—such as breathlessness or fatigue—to interpret their condition, rather than understanding the underlying pathophysiology of heart failure. This reliance reflects an underdeveloped illness representation, a central construct in the Common-Sense Model of Self-Regulation, wherein individuals lacking coherent cognitive schemas about their disease default to somatic cues to guide behavior.¹⁹ This mirrors Anderson et al's (2022) concept of “symptom-based illness logic” among older heart failure patients, wherein bodily sensations—not pathophysiological knowledge—serve as the primary basis for self-monitoring and decision-making.²⁰ This symptom-based cognition may lead to delayed help-seeking or inappropriate self-management decisions, particularly when symptoms are subtle or atypical.²¹ Without clear explanations of disease mechanisms and treatment rationale, patients remain passive recipients of care rather than active participants in self-management.²² Evidence shows that structured, theory-informed education programs—particularly those based on the Common-Sense Model of Self-Regulation—can improve illness understanding and adherence to treatment regimens in chronic conditions.^{19,23} To be effective, education should begin early during hospitalization, use plain language and incorporate interactive methods such as the “teach-back” technique to confirm comprehension and reinforce learning.²⁴

Furthermore, education should actively involve family caregivers, who often assume responsibility for monitoring symptoms and supporting daily self-care. Programs that include both patients and caregivers have been shown to improve confidence in managing heart failure and reduce caregiver burden.^{4,25} Educational materials should be provided in multiple formats (eg, written, audio, digital) to accommodate varying health literacy levels and learning preferences.²⁶ Crucially, teaching should be standardized, documented, and delivered by trained staff as part of a formal discharge protocol. By ensuring that patients and caregivers receive consistent, accessible, and actionable knowledge before leaving the hospital, healthcare teams can lay the foundation for effective self-management—setting the stage for later support systems to build upon.

Integrate Psychological Support into Transitional Care

Participants described significant emotional strain during the transition period, including fear of recurrence, anxiety about independence, and feelings of burdening family members. These psychosocial challenges are not merely secondary to physical symptoms but are central to patients' ability to adapt to life with a chronic illness. This pattern is consistent with Liu et al's identification of "relational burden" as a key psychosocial barrier to adaptation among Chinese heart failure patients post-discharge.²⁷ The stress of managing uncertainty and role changes can overwhelm coping resources, particularly among older adults and spousal caregivers.²⁸ According to recent studies,²⁹ depression affects up to 21.5% of heart failure patients post-discharge, and anxiety symptoms are reported in 38% to 70% of patients. These conditions are independently associated with poor adherence, reduced quality of life, and higher readmission rates. Despite this, psychological needs are often overlooked in transitional care programs that prioritize physiological stability¹⁵. Integrating routine screening using validated tools—such as the Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7)—can help identify at-risk individuals early.³⁰ The Transitional Care Model (TCM), which assigns advanced practice nurses to coordinate care across settings, explicitly includes emotional well-being as a core domain, demonstrating improved mental health outcomes and lower 30-day hospitalization rates.³¹

Beyond screening, structured psychological interventions should be embedded into follow-up care. Cognitive Behavioral Therapy (CBT) has shown particular promise in reducing anxiety and depressive symptoms in heart failure patients. A study conducted by Altieri et al³² found that patients receiving telephone-delivered cognitive behavioral therapy (T-CBT) experienced significantly greater reductions in depression scores compared to those receiving usual care alone. In contrast, while general supportive counseling improves perceived emotional support, it often lacks the skill-building components necessary for long-term coping¹⁸. Mindfulness-Based Cognitive Therapy (MBCT) is another emerging approach that helps patients reframe distressing thoughts about illness and mortality, with pilot studies reporting improved emotion regulation and reduced rumination.^{33,34} Therefore, multidisciplinary teams should move beyond passive referrals and instead proactively deliver evidence-based, time-limited psychological therapies—preferably integrated within nurse-led transitional care models—to ensure accessibility and continuity. By treating emotional health as integral rather than optional, healthcare systems can foster resilience and improve overall self-management capacity.

Establish Continuous Post-Discharge Support Systems

Many patients and caregivers expressed a profound sense of abandonment after hospital discharge, describing a lack of follow-up and unclear responsibility for ongoing support.³⁵ This discontinuity of care undermines confidence in managing the illness at home and increases the risk of preventable readmissions. Participants' desire for sustained contact reflects a need for care continuity—not just in information transfer, but in relational and managerial coherence across settings. Telemonitoring,³⁶ nurse-led telephone follow-ups,³⁷ and early post-discharge home visits³⁸ have all demonstrated effectiveness in bridging the gap between hospital and community care. The Coleman Model of Care Transitions identifies "self-care support" and "communication across transitions" as key pillars for reducing readmission rates.³⁹ Therefore, healthcare systems should establish formalized post-discharge support pathways that ensure timely access to nursing advice, medication review, and care coordination.

Advantages and Limitations

Currently, research on patient-centered transitional care for heart failure in China is still limited, especially qualitative studies exploring patients' and caregivers' lived experiences after hospital discharge. This study used a phenomenological approach to explore the cognitive, emotional, and systemic challenges faced by patients and family caregivers during the transition from hospital to home, with a focus on illness understanding, psychological distress, and continuity of care. Findings provide preliminary insights into the need for structured education, integrated psychological support, and continuous follow-up in this population. However, this study only included patients and caregivers from a single medical center, which may affect the generalizability of the results. Moreover, all interviews were conducted by clinically trained researchers affiliated with the recruiting hospital, which, despite efforts to ensure neutrality, may have introduced social desirability bias—participants might have underreported negative experiences or overemphasized compliance. The sample also predominantly consisted of adult children as primary caregivers; spouses, siblings, or in-

laws may perceive and enact preparedness differently due to varying relational dynamics, caregiving expectations, and emotional investments. These factors limit the transferability of findings across diverse family structures and care contexts. In addition, future quantitative studies are needed to validate these qualitative findings and test the effectiveness of integrated interventions in improving self-management and reducing readmissions.

Conclusion

This study explored the lived experiences of older patients with heart failure and their family caregivers during the transition from hospital to home. It revealed three key challenges: inadequate illness understanding, emotional distress related to uncertainty and role changes, and a perceived lack of continuous support after discharge. These findings highlight the need for a multidimensional transitional care approach that directly addresses these gaps: structured education to clarify illness representations, psychological support tailored to dyadic emotional suppression and relational burden, and sustained, nurse-coordinated follow-up to bridge post-discharge care fragmentation. By capturing patient and caregiver perspectives, this study provides valuable insights for designing patient-centered interventions in the Chinese healthcare context. Future care models should actively involve both patients and families in care planning to improve self-management and reduce the risk of readmission. While these recommendations are grounded in urban Chinese experiences, their applicability to other settings warrants further investigation.

Abbreviations

CHF, chronic heart failure; PPI, Patient and Public Involvement.

Data Sharing Statement

Data are not publicly shared because the research is still in progress and the information contains private content that could compromise participant confidentiality.

Ethical Approval Statement

The study was reviewed and approved by the Institutional Review Board of the Second Affiliated Hospital of Qiqihar Medical University (Approval Number: [2025]04-013-01). This study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants, including for the publication of anonymized responses and direct quotes.

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Disclosure

All authors declare that they have no conflicts of interest in this work.

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