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Self-management dilemmas and influencing factors of patients during the waiting period for heart transplantation in China based on the social ecosystem: a qualitative study

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ABSTRACT

Objectives To investigate the self-management challenges and influencing factors faced by patients during the waiting period for heart transplantation through the lens of social ecology as well as to explore the family management needs of Chinese patients with end-stage heart disease during this critical waiting period.

Design During March 2023 to March 2024, purposive sampling was adopted to conduct in-depth interviews with 11 patients awaiting heart transplantation and their primary caregivers at a Class III Grade A hospital in Nanjing, China. A phenomenological research approach was adopted, and Colaizzi's method was applied to analyse the data and extract the key themes.

Setting The study involved face-to-face interviews at a Grade A hospital in Nanjing, China.

Participants During March 2023 to March 2024, face-to-face interviews were conducted with 11 patients and their primary caregivers.

Results The analysis identified the primary reasons for patients' limited self-management capacity, yielding 3 overarching themes with 12 subthemes. At the micro level, physical discomfort and inadequate self-management abilities were prominent, as patients experienced persistent physical discomfort, challenges in alleviating symptoms, insufficient knowledge about self-management, a lack or loss of belief in their ability to manage their health and prolonged periods of anxiety and depression. At the meso level, the study identified limited family support, inadequate professional medical assistance and insufficient social support. These issues manifested as limited caregiving capacity within families, increased financial burdens on households, insufficient educational resources and guidance provided by medical staff, a lack of continuity in care across different settings and the absence of supportive social networks. At the macro level, systemic challenges such as the unequal distribution of medical resources and the absence of a comprehensive long-term follow-up mechanism were identified as significant barriers to effective patient management.

Conclusion The dynamic interaction among the micro, meso and macro systems significantly influenced patients' motivation and capacity for self-management, thereby ultimately affecting the progression of their disease and their overall quality of life. To address these challenges, healthcare providers must prioritise comprehensive health guidance for patients during the heart transplantation waiting period. Emphasis should be placed on developing robust family-centred management plans tailored to the unique needs of these patients. In addition, there is a pressing need to establish a coordinated, three-tiered management system that integrates hospitals, families and community resources so as to provide holistic and continuous care for patients awaiting heart transplantation.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Semi-structured interviews were used to collect the insights of patients and their caregivers.

⇒ The social ecosystem model provides a framework for analysing the self-management factors of patients.

⇒ The economic and cultural background of patients waiting for heart transplantation and their primary caregivers may limit the transferability of the study results.

⇒ Interviews that did not involve the opinions of professionals such as doctors and nurses may affect the inference results.

The latest data indicate that the incidence of heart failure (HF) in China is 1.3%, indicating that it affects approximately 13.7 million individuals, including 1.3 million patients with end-stage HF.[1] Heart transplantation is considered the standard treatment for end-stage HF; however, its application is significantly limited by the scarcity of donor organs, with only 6000 transplants performed annually worldwide.[2] In recent years, advancements in medical technology have introduced ventricular assist devices as an alternative treatment option for patients with refractory HF. Despite their potential, the adoption of these devices is constrained by stringent pre-implantation evaluation requirements and high costs, making them inaccessible to many patients and inadequate to meet the growing demand for end-stage HF treatment.[3] Consequently, a substantial number of patients with end-stage HF remain in the waiting period for heart transplantation.

Previous studies on patients awaiting heart transplantation have predominantly focused on perioperative experiences, quality of life and psychological well-being, with limited exploration of their self-management practices. Effective self-management of HF can thus enhance patients' quality of life, reduce hospital readmissions, lower healthcare costs and decrease mortality rates.[4] HF self-management refers to the behavioural adaptations patients make when experiencing HF symptoms. It encompasses five key components: disease knowledge, seeking support, self-efficacy, behavioural performance and self-perception. These include medication adherence, symptom control, exercise management, lifestyle modifications and psychological adjustments.[5] For patients in the waiting period for heart transplantation, the complexity of their condition necessitates collaborative self-management between the patients and their primary caregiver.[6]

Social-ecological theory posits that individuals and systems interact and influence one another's development. This theory divides the social ecosystem into three levels: micro, meso and macro.[7] It has been widely applied to the analysis of risk factors for chronic diseases such as diabetes and chronic obstructive pulmonary disease, health promotion and the development of family management programmes.[8–10] Under the guidance of social ecological theory, this study aimed to examine the challenges and influencing factors of self-management among patients during the waiting period for heart transplantation. By understanding these dynamics from the perspectives of patients and their primary caregivers, the present study seeks to provide insights towards improving self-management strategies and developing comprehensive family management plans for this patient population.

OBJECT AND METHOD

Study subjects

Patients with end-stage heart disease and their main caregivers admitted to the cardiovascular surgery department of a Grade A hospital in Nanjing from 19 March 2023 to 20 March 2024, were enrolled in this study. The subject inclusion criteria were as follows: (1) patients with end-stage HF eligible for transplant recipients according to[11] (the transplant waiting period); (2) age ≥18 years; (3) voluntary participation in the study; (4) conscious, good language communication skills and the ability to fully and accurately express their ideas; (5) patients with no serious damage to the liver, kidney, brain and other important organs. The subject exclusion criteria were as follows: (1) patients with serious diseases of other organ systems; (2) patients with serious mental diseases. The inclusion criteria for the primary caregivers were as follows: (1) patient care experience of ≥1 year; (2) age ≥18 years; (3) normal cognition and good communication skills. The sample size was based on the interview data, and new themes could not be analysed. 11 patients (aged 47–73 years) and 11 primary caregivers (aged 26–60 years) were finally included in this study. More information about patients and their main caregivers is presented in table 1. Informed consent was obtained from all patients and the primary caregivers in this study.

Research method and team

This study adopted a descriptive phenomenological method that advocates suspended personal bias, extracted the commonalities of phenomena from the experience of multiple participants and directly grasped things, while the researchers were allowed to objectively contact the essence of phenomena[12] based on the content and purpose of this study.

A research team of six people (including one chief superintendent nurse, two co-chief superintendent nurses and three intermediate professional title nurses) was established, all with >10 years of nursing experience in cardiac surgery. The study group was independent of the medical care team and did not participate in the medical care of the study subjects. The chief superintendent nurse and the co-chief superintendent nurses were responsible for the study design, interview outline and data analysis; the intermediate professional title nurses were in charge of interview data collection and data analysis.

Develop the interview outline

Based on the social-ecological theory, a preliminary interview outline was developed through a review of the literature, consultations with the chief nurse and integration of their insights. Data were collected using face-to-face semi-structured interviews. The final interview outline was refined after discussions with two patients and their primary caregivers.

The patient interview outline included the following questions:

1. How are you feeling right now (considering disease symptoms and psychological state)?
2. In what aspects do you manage your disease (eg, symptom monitoring, exercise, medication, diet, activities)?
3. What do you feel about your self-management?
4. What do you think are the factors that hinder your self-management (from social, family and personal perspectives)?
5. How do you address these barriers?
6. What support do you expect from the external world (family members, colleagues, friends, medical staff, etc)?

The key caregiver interview outline included the following questions:

1. How did you feel when you learnt your family member would need to wait for a heart transplant?
2. Do you consider the patient's self-management to be an individual or a family responsibility?

Table 1 Characteristics of participants

Patient characteristics (n=11)	n (%)	Main caregiver characteristics (n=11)	n (%)
Gender		Gender	
Male	2 (18.2)	Male	4 (36.4)
Female	9 (81.8)	Female	7 (63.6)
Age		Age	
40–50	1 (9.1)	20–40	2 (18.2)
51–60	9 (81.8)	41–60	9 (81.8)
>60	1 (9.1)	>60	0
Education background		Education background	
Illiteracy	1 (9.1)	Primary school	3 (27.2)
Primary school	2 (18.2)	Junior middle school	1 (9.1)
Junior middle school	3 (27.2)	Senior middle school	3 (27.2)
Senior middle school	2 (18.2)	Junior college	3 (27.2)
Junior college	2 (18.2)	Undergraduate course	1 (9.1)
Undergraduate course	1 (9.1)		
Occupation		Occupation	
Unemployed	3 (27.2)	Farmer	2 (18.2)
Farmer	1 (9.1)	Worker	8 (72.7)
Worker	6 (54.6)	Retire	1 (9.1)
Retire	1 (9.1)		
EF (%)		Relationship with patients	
15–25	5 (45.5)	Father and son	2 (18.2)
26–35	5 (45.5)	Father and daughter	1 (9.1)
36–40	1 (9.1)	Husband and wife	8 (72.7)

Note: all patients were graded IV for cardiac function.
EF, left ventricular ejection fractions.

3. What difficulties have you encountered in caring for the patient, and how have you addressed them?
4. What additional guidance or support would you find helpful in caring for the patient?
5. How do you and your family cope with the progression of the disease (in terms of daily life changes and psychological adjustments)?

Data collection method

The selected participants were patients admitted to the cardiovascular surgery ward, along with their primary caregivers, who were screened based on the inclusion and exclusion criteria. Face-to-face semi-structured interviews were conducted after obtaining informed consent. Interviews were held in the ward conference room, ensuring a quiet and undisturbed environment (11 patients and their primary caregivers were interviewed in different rooms and at different times, different spaces and times to ensure that interfering factors were avoided). At the start of each interview, the interviewer introduced themselves and explained the purpose, method and content of the study. During the interview, one researcher interviewed while another recorded the audio. The participants were encouraged to express themselves freely without leading or suggestive questioning. Non-verbal behaviours of patients and caregivers were observed throughout. The interviews lasted between 30 and 60 min.

Data collation and analysis methods

Within 24 hours of each interview, the recorded data were transcribed and verified for accuracy. Two researchers then imported the text data into NVivo V.12.0 software. According to the Colaizzi phenomenology 7-step analysis method for analysis, coding and integration, the process included the following steps:

1. Careful reading of the raw data processes .
2. Extracting statements related to the self-management challenges of patients and caregivers.
3. Categorising micro, meso and macro-level factors based on the social ecological theory.
4. Summarising and extracting common concepts to form themes and theme groups, followed by iterative comparison and refinement.
5. Identifying and grouping similar themes.
6. Conducting comparative analyses, summarising final themes and discussing findings in team meetings.
7. Validating the research results with responses.

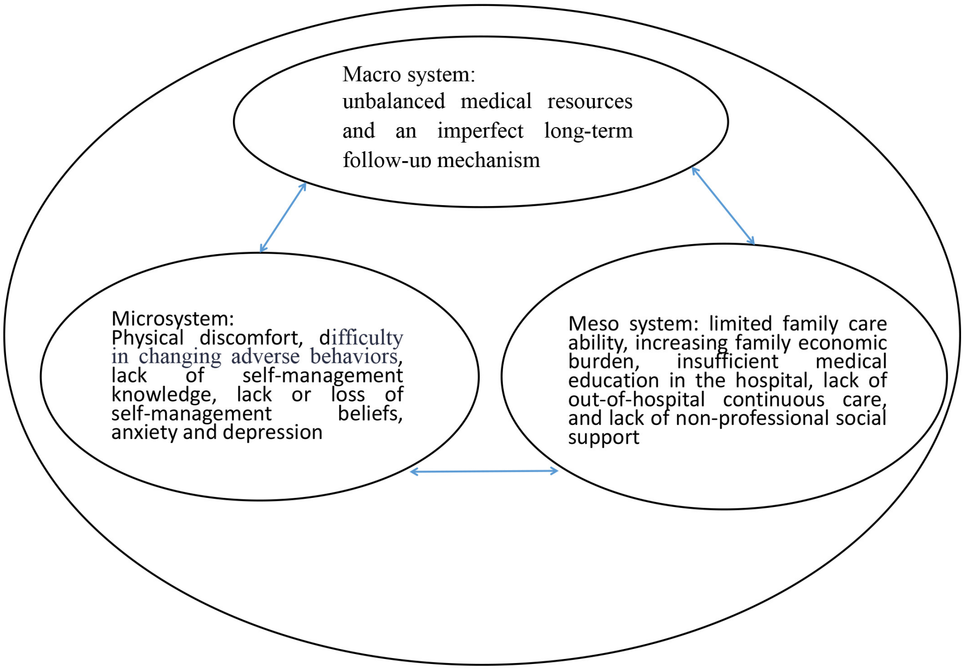

Figure 1 Factors of self-management dilemma.

Quality control

All researchers involved in this study have qualitative research experience of 5–20 years. Two graduate students on the research team returned the findings to the interviewees to enhance the credibility and reliability of the results.

INTERVIEW RESULTS

Based on the social ecosystem theory, the self-management dilemmas and influencing factors of patients and caregivers during the waiting period for heart transplantation can be categorised into 3 overarching themes and 12 subthemes, as illustrated in figure 1.

Microsystem: coexistence of physical discomfort and inadequate self-management

For patients with end-stage HF, the management of complications, medication adherence, symptom control, volume management, exercise, lifestyle adjustments and self-regulation of cardiac health are essential to sustain life and ensure safe passage through the waiting period for heart transplantation.

Physical discomfort: patients with end-stage HF frequently experience symptoms such as chest tightness, shortness of breath, arrhythmia and oedema. These symptoms are often persistent and intensify as the disease progresses, leading to chronic discomfort. One patient (P2) shared: 'I often feel chest tightness all night and can't sleep. Even slight activity during the day leaves me breathless'. Another participant (P6) noted: 'I often feel dizzy and flustered. I can't take care of myself—my family helps me with eating and taking medication'.

Difficulty in changing adverse behaviours: self-management behaviours for patients with HF include maintaining a stable condition (eg, taking prescribed medications, engaging in appropriate exercise), self-monitoring (eg, regular weight checks) and responding effectively to symptom changes (eg, adjusting diuretic doses as needed).[13] However, during the heart transplantation waiting period, patients often exhibit adverse behaviours that hinder effective self-management. For instance, one caregiver (C6) said: 'My husband has been sick for so many years but still hasn't quit smoking. He smokes in secret, and I can't always keep track'. Another caregiver (C8) reported: 'We have to supervise my husband every time he takes his medication. If we don't, he'll miss doses'. Similarly, another caregiver (C10) mentioned: 'He likes eating fatty, salty foods and still smokes occasionally'.

Lack of self-management knowledge: most patients and caregivers in the study had a limited understanding of the symptoms of end-stage HF and heart transplantation, leading to gaps in overall disease management. Many patients also demonstrated poor medication adherence and inadequate knowledge of volume management. One caregiver (C2) remarked: 'My husband came to the hospital for an examination this time because his legs were more swollen than six months ago. But we ignored it two months ago and never sought medical attention'. A patient (P7) admitted: 'I take medications like antihypertensive drugs, furosemide, and spironolactone. The doctor told me to monitor my blood pressure daily, but I often forget'. Another caregiver (C5) stated: 'My husband sweats easily and feels thirsty often. Every time I tell him to drink less water, he doesn't listen'. Additionally, a patient (P6) shared: 'I knew I needed a heart transplant, so I looked up some information about rehabilitation online, but no one explained it to me, and I didn't understand some of it'.

Lack or loss of self-management beliefs: some patients experience a lack or loss of confidence in their ability to manage their condition effectively. This is primarily attributed to the recurring symptoms of discomfort associated with end-stage HF and the uncertainty surrounding the waiting period for transplant donors. One patient (P5) expressed: 'The doctor said there's nothing else that can be done, just to wait for a heart transplant. What else can I do?' Another patient (P8) shared: 'When I was first diagnosed, I thought there was still hope. But now, after waiting for more than a year without any updates, I feel disheartened. I searched for information online and realized it all depends on luck'.

Anxiety and depression: during the transplant waiting period, patients often face unpredictable waiting times, high medical costs and significant psychological, familial and social pressures. These factors frequently lead to anxiety, depression and other negative emotions.[14] A survey of Chinese scholars found that 19.4% of patients in the waiting period for heart transplants showed moderate depressive symptoms, and 47.4% had moderate-to-severe anxiety symptoms.[15] A Spanish study showed that the proportion of patients waiting for a heart transplant with depression was as high as 56.1%.[16] Persistent physical symptoms are also significant contributors to psychological distress in these patients.[17] For instance, a patient (P5) remarked: 'I'm only in my 50s. Since I learned about my illness, I can't stop thinking about when I might die'. A caregiver (C6) added: 'When my father was diagnosed with terminal heart disease, he became unhappy all the time. We rarely see him smile, so we avoid telling him anything that might upset him'.

Meso system: limited family support, insufficient medical professional support and lack of non-professional social support

The knowledge level of primary caregivers of patients with HF is generally low. Contributing factors include the caregivers' educational background, the time required for daily patient care, their physical condition and their ability to provide effective care.[18] In addition, only 40.8% of patients with HF reportedly receive adequate medical education from healthcare professionals.[19]

Limited family caregiving capacity: most caregivers in this study exhibited limited caregiving knowledge and skills, coupled with insufficient time to dedicate to patient care. One caregiver (C2) shared: 'I usually have to work and also take care of children in school, so I have no time to look after him. He takes care of himself most of the time'. Another caregiver (C6) stated: 'I often look up information about heart disease on my phone, but I'm not sure if it applies to my husband, and I forget most of what I read'. A patient (P10) added: 'My wife is retired, but she also looks after our grandchildren. Sometimes I end up cooking and washing clothes all day by myself'.

Increasing family economic burden: patients in this study often faced repeated hospitalisations, which imposed significant financial strain. Hospitalisation and medical expenses were described as burdensome, particularly for families reliant on limited income sources. One patient (P1) said: 'Rural medical insurance doesn't cover much, so we end up spending a lot. My husband does odd jobs to earn some money, and we rely on financial help from our children. The economic pressure is overwhelming'. Another caregiver (C4) noted: 'After my husband fell ill, our household income dropped by more than half. We have a child in college, and two elderly family members in poor health'.

Insufficient education in hospital care: five patients in this study reported limited communication from healthcare providers during their hospital stays. One patient (P1) shared: 'Every time I was hospitalized, it was to adjust my heart function due to chest tightness and palpitations. I stayed for 10 days each time. The doctors and nurses were very busy every day and only communicated more on the day of admission and the day before discharge'. Another patient (P8) said: 'I've been hospitalized three times, and no nurse has explained heart transplant surgery or postoperative rehabilitation to me. Maybe they're too busy, but I want to know about these things. One day, I might get a donor and need the surgery'. A third patient (P9) mentioned: 'Only the doctor doing the rounds reminds me of precautions and tells me to come in for regular check-ups'.

Lack of out-of-hospital continuity care: the American Medical Center describes continuity care as a process extending from hospital to home, involving long-term disease care education for patients and their families. This approach aimed to support effective medication management, self-health monitoring, recognition of deterioration signs and appropriate responses.[20] However, the patients in this study reported insufficient continuity of care. For instance, one patient (P3) stated: 'After I was discharged, I got a call from the hospital asking if I was satisfied with the doctors and nurses during my stay. When I said I was satisfied, they didn't ask me anything else'. Similarly, a caregiver (C5) explained: 'Once, we were unsure about the medication dosage and called the hospital. They told us the doctor was in surgery. The next day, we had to go to the outpatient clinic for a consultation. It's always a hassle, and we're constantly running around'.

Lack of non-professional social support: patients also reported diminished interactions with family, relatives, friends and colleagues. For example, one patient (P3) remarked: 'I've been in the hospital for over 20 days. I want to go home to see my grandson, but few relatives have come to visit me. At my age, what's the point of seeing a doctor?' Another patient (P9) shared: 'I used to plan annual trips with my colleagues after retirement, and we were very close. Since I got sick, I've had less contact with them. Now I just lie in my hospital bed, looking at their travel photos. Retirement hasn't been what I expected'.

Macrosystem: unbalanced medical resources and an imperfect long-term follow-up mechanism

Data indicate that the demand for heart transplant donors far exceeds the supply, with an average waiting period of over 9 months.[21] In this study, the waiting time for patients ranged from 5 to 52 months. During this period, patients underwent regular check-ups, medication adjustments and hospitalisations during severe episodes. Furthermore, a hospital-community-family triad model of continuous care can significantly enhance the self-care abilities of patients with HF.[22] However, gaps in resource allocation and follow-up mechanisms remain challenges for ensuring optimal care during the transplant waiting period.

Unbalanced medical resources: the population waiting for heart transplantation in this study comes from various regions, and the development of medical resources varies significantly between these regions. Both patients and their primary caregivers experienced a complex and challenging process of seeking medical treatment. Many patients reported considerable financial strain during their search for treatment, with limited financial assistance available. One patient (P2) shared: 'When the doctor at our county hospital said they couldn't help me, they directly recommended that I go to a provincial hospital. Now, whenever I need to be hospitalized, I go to the provincial hospital'. Another patient (C11) mentioned: 'I visited many hospitals, including those in the northeast, Beijing, and Shanghai, before finally coming to this hospital for treatment'. A third patient (P9) noted: 'I come from another province, and the reimbursement from my out-of-province medical insurance is minimal. I have been hospitalized several times a year, and my pension is limited. The financial pressure on my family is quite significant'.

Imperfect long-term follow-up mechanism: a study suggests that using a hospital-community-family linkage model of continuous care improves the self-care ability and health behaviour of patients with chronic HF, as well as enhances their quality of life.[23] However, in this study, several patients reported challenges with long-term follow-up. One patient (P1) said: 'The hospital in my hometown can only prescribe medication. Every time I need a medication adjustment, I have to travel to a major hospital, which is very troublesome. The ride takes half a day, and after each visit, it takes a few days for my body to recover'. Another patient (C9) added: 'I hope there is a convenient and reliable platform where we can consult, so we can save a lot of time and energy'.

DISCUSSION

Complexity of self-management challenges during the heart transplantation waiting period

The findings of this study highlight the complexity and diversity of factors influencing the self-management of patients awaiting heart transplantation. The uncertainty surrounding donor availability, the particularities of end-stage HF and the challenges associated with self-management—both physical and mental—create significant barriers to self-care. Additionally, the limited care ability of family caregivers, the heavy economic burden, insufficient health education and continuity care from hospitals and the unequal distribution of medical resources and long-term follow-up mechanisms all interact to impact patients' self-management capabilities. These factors emphasise the importance of addressing these challenges to improve the self-management outcomes of patients in the waiting period for heart transplantation.

Family-centred empowerment, mental health support and building self-management confidence

Heart transplant patients often experience preoperative depression and nutritional issues, with depression being significantly more prevalent than anxiety. Preoperative depression is associated with poorer nutritional status in these patients.[24] In this study, the anxiety and depression reported by patients were often linked to physical discomfort, such as chest tightness, oedema and poor appetite, along with concerns about the heavy economic burden, uncertainty about transplant wait times and fears about post-transplant complications. Based on these findings, it is crucial for nurses to regularly screen for anxiety and depression during hospital visits. Using relevant assessment scales, healthcare providers can identify the severity of these conditions. By offering patients information about successful transplant cases and providing targeted interventions, nurses can help alleviate anxiety and depression, fostering better mental health and improving self-management confidence.

To reduce the pressure on patients managing their disease, it is essential to fully engage family members, encouraging them to actively participate in patient care. In addition, patients should be encouraged to maintain communication with friends and colleagues, who can listen to their concerns, monitor their psychological well-being and provide additional support. By strengthening the social network of patients—comprising personal, family and medical support systems—we can help alleviate the emotional burden on patients and foster better overall well-being.

Providing professional, personalised and comprehensive health guidance

Patients with end-stage heart disease face the constant risk of deterioration or death while waiting for a transplant. Moreover, the progression of HF is closely related to the patient's ability to self-manage. Patients who engage in self-management tend to have higher self-efficacy, a more optimistic outlook and improved quality of life.[25] Therefore, it is crucial to provide heart transplant waiting patients with clear, targeted health education, which addresses the specific challenges they face and promotes their self-management abilities.

In this study, many patients and caregivers demonstrated poor health habits. In addition, 6 out of 11 patients and 4 out of 11 caregivers had educational backgrounds below high school, highlighting a significant lack of disease knowledge. Some patients and caregivers sourced information about HF from the internet, but they often found it to be of limited practical use. Moreover, the health knowledge possessed by patients was primarily related to medication and fluid management, with most education being delivered orally, which lacked comprehensiveness and diversity. The health education content for heart transplant waiting patients should include topics such as diet, lifestyle habits, fluid management, medication adherence, symptom management, exercise and emotional well-being. A particular emphasis should be placed on enhancing symptom management and fluid control education.

Furthermore, attention should be given to the methods used to deliver health education. The teach-back method is particularly effective for patients with low health literacy as it improves health literacy, increases disease knowledge and enhances self-care behaviours in patients with HF.[26] Additionally, patients with end-stage HF often experience multiple complications that interact with heart disease, creating a vicious cycle. Managing these complications is a crucial aspect of medical care.[24] Therefore, health education should also focus on chronic conditions such as hypertension, diabetes and chronic obstructive pulmonary disease.

Establishing a long-term follow-up mechanism and improving the social support system

Some studies[27] have highlighted significant challenges and deficiencies in standardising accurate diagnosis, treatment protocols and long-term monitoring for patients. The factors impacting patient self-management in this study included economic status, living environment and the availability of social and medical resources. Patients with end-stage HF face repeated hospitalisations, substantial family financial strain, prolonged physical discomfort, psychological stress and poor quality of life. These factors significantly influence treatment choices and patient confidence in their treatment plans.

To address these challenges, it is crucial to establish a three-tiered management system linking hospitals, communities and families. This system should include personnel training and the integration of medical resources to bring high-quality human resources and healthcare services into communities, particularly in remote or underdeveloped areas. Such a system will ensure long-term follow-up care for these patients. Additionally, organising charitable donations and connecting with foundations can help alleviate the economic burden on transplant-waiting patients, thereby boosting their treatment confidence. It is equally important to focus on discharge preparation. This involves contacting community healthcare services or local hospitals to establish a post-discharge follow-up plan, ensuring continuous care and support for the patients.

Conclusion and limitations

This study explores the following self-management challenges and influencing factors during the waiting period for heart transplantation:

1. Microsystem: the physical discomfort of patients coexists with a lack of self-management ability; meso system: limited family support, insufficient medical professional support and lack of non-professional social support; macrosystem: unbalanced medical resources and an imperfect long-term follow-up mechanism.
2. Interaction of systems: various systems interact and influence patients' self-management motivation and abilities, ultimately impacting their quality of life and the progression of their disease.
3. Recommendations for medical staff: healthcare providers should prioritise comprehensive health guidance throughout the transplant waiting period. This includes promoting the establishment of a three-level linkage system between medical institutions and encouraging family and societal support, leveraging modern internet-based technologies.

Notably, this study focused on heart transplant patients at a single Grade A hospital, which may limit the generalisability of the findings. Future studies should expand the sample to include patients from multiple institutions. Moreover, this study only interviewed patients and their primary caregivers and did not incorporate the opinions of doctors and nurses of the health system. In the future, more institutions and quantitative studies can be combined to comprehensively explore the self-management-related issues of this population.

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Contributors FL: Methodology, Conceptualization, Investigation, Data Curation, Formal analysis, Writing—Original Draft. ZX-M: Project administration, Supervision, Writing—Review and Editing. Y-HC: Formal analysis, Methodology. JC: Resources. S-YL: Visualisation. S-SL: Data Curation. The corresponding author, ZX-M, is the guarantor. All authors contributed to the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study has IRB approval at Nanjing First Hospital, Nanjing Medical University (IRB: KY20220425—05). Before the interviews, the researcher introduced the research content and obtained signed informed consent from all participants.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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