Patient Preference and Adherence

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Dilemmas of Self-Management in Patients with Pulmonary Arterial Hypertension: A Descriptive Phenomenological Study

Jianping Cai[1], Na Zhao[2], Yang Gao[1], Lanxia Pan[3], Qiaofang Yang[4]

[1]Structural Heart Disease Ward 2, Fuwai Central China Cardiovascular Hospital, Zhengzhou, Peoples Republic of China; [2]Coronary Heart Disease Ward 1, Fuwai Central China Cardiovascular Hospital, Zhengzhou, Peoples Republic of China; [3]College of Nursing, Henan University of Traditional Chinese Medicine, Zhengzhou, Peoples Republic of China; [4]Nursing Department, Fuwai Central China Cardiovascular Hospital, Zhengzhou, Peoples Republic of China

Correspondence: Qiaofang Yang, Nursing Department, Fuwai Central China Cardiovascular Hospital, Zhengzhou, Peoples Republic of China, Email eaam68@163.com

Objective: To explore how patients with PAH experience self-management challenges.

Methods: A descriptive phenomenological research was applied to conduct face-to-face, semi-structured, in-depth interviews with 12 patients diagnosed with PAH recruited from Fuwai Central China Cardiovascular Hospital in Henan Province, from January to June 2025. The collected data were analyzed using Colaizzi's phenomenological analysis method.

Results: Analysis revealed two overarching themes: (1) Individual-level barrier, comprising lack of awareness,insufficient knowledge about medications and disease management, and heavy financial burden; and (2) Contextual challenges, comprising uncertainty about the disease progression, lack of family and social support, poor accessibility to medications, and disruptions due to public health emergencies.

Conclusion: Patients with PAH face significant multi-faceted barriers to effective self-management. Interventions should be multi-faceted, involving structured patient education, psychological support, family involvement, and policy-level changes to improve drug accessibility and financial support.

Plain Language Summary: Why was this study done? We wanted to understand the daily challenges faced by people in China living with Pulmonary Arterial Hypertension (PAH), a serious heart and lung condition, when they try to manage their health outside of the hospital.

What did the researchers do? We conducted in-depth interviews with 12 PAH patients from one hospital in China. We asked them about their experiences, struggles, and needs in managing their condition.

What did the researchers find? Patients faced challenges from within themselves (like not fully understanding their disease and the heavy cost of treatment) and from their environment (like difficulty getting medicines and a lack of support from family or society, especially during events like the COVID-19 pandemic).

What do the results mean? The results show that PAH patients need better support. Healthcare providers should offer clear, ongoing education and psychological help. Families should be more involved in care. The government and insurers could help by making medicines easier to get and more affordable. This study helps us understand how to better support PAH patients in their daily lives.

Keywords: self-management, pulmonary arterial hypertension, psychological distress, qualitative study, phenomenology

Introduction

Pulmonary arterial hypertension (PAH) is an abnormal hemodynamic state and physiopathological syndrome characterized by elevated pulmonary artery pressure,[1,2] which is highly lethal and disabling. Research showed that approximately 1% of adults worldwide suffer from PAH and that the prevalence of PAH can be as high as 10% in populations older than

https://doi.org/10.2147/PPA.S563550
Received: 27 August 2025
Accepted: 13 January 2026
Published: 17 January 2026

65 years.[3] The clinical categorization of PAH distinguishes five groups: 1) PAH linked to left heart disease (PAH-LHD) ; 2) pulmonary arterial hypertension (PAH); 3) PAH linked to hypoxia and/or lung disorders (PAH-LD); 4) PAH linked to pulmonary artery blockages (mostly chronic thromboembolic PAH; CTEPAH); 5) PAH with ambiguous and/or complex processes.[4]

Although there is a great deal of variation within each group, they all have pulmonary arterial remodeling and functional changes in common. These changes can result in syncope, exhaustion, tightness in the chest, chest pain, and laborious dyspnea, which can further lead to disability, high mortality, and a poor prognosis.[5] The median survival rates at one and five years after diagnosis are 86 and 61%, respectively.[6,7]

Despite advances in the treatment of PAH with the advent of floating catheterization and the emergence of new therapeutically targeted drugs, PAH remains an inherently malignant and fatal disease. Benza et al (2012) have described its prognostic severity as comparable to that of many cancers, sometimes referred to as the "cancer of the cardiopulmonary vascular system,[8] which has become a serious threat to human health. However, PAH has remained an incurable disease with a median survival of 7 years despite advancements in treatment.[8] The White Paper on the Survival Status of Patients with Pulmonary Hypertension in China points out that the promotion and implementation of China's PAH health insurance policy has begun to bear fruit in recent years;[9] however, there are still some areas with high PAH prevalence and dense potential high-risk populations where outpatient reimbursement has not yet been realized, and patients are facing a huge burden of treatment and disease. Medical professionals should pay attention to the physical and mental health of PAH patients, understand their needs and self-management confusion, and develop targeted intervention strategies. Hughes et al[10] suggested that patient experience was one of the most important indicators of healthcare quality and that focusing on patients' treatment experience and health needs was important to promote their recovery and satisfaction. However, much of the current research related to PAH patients focuses on diagnosis and treatments, with little exploration of the disease experience and self-management challenges of PAH patients, particularly within the Chinese healthcare and cultural context. Given these gaps, this study employs a qualitative descriptive phenomenological approach to explore how patients with PAH in China experience and navigate challenges in self-managing their condition.

Methods

Note: A completed COREQ checklist should be submitted as Supplementary Material and referenced here.

Study Design

This study used the descriptive phenomenological design within the qualitative research tradition. In-depth, semi-structured interviews were employed to explore participants' lived experiences of self-management with PAH. The data collection was conducted from January to June 2025.

Participants and Sampling

A purposive sampling method with maximum variation strategy was used to select PAH patients who attended a cardiac center of Fuwai Central China Cardiovascular Hospital in Zhengzhou City. All study participants met the following inclusion criteria: ① aged 18 years or older; ②diagnosis of PAH according to Chinese Guidelines for the Diagnosis and Treatment of Pulmonary Arterial Hypertension (2021 Edition);[11] ③able to speak and under-stand Chinese. The exclusion criteria were: ①impaired cognition, difficulty to get comprehension and consent for research;②known other chronic diseases. Justification: This criterion was applied to minimize the potential confounding impact of complex multimorbidity on the specific experience of PAH self-management, thereby sharpening the focus on PAH-related challenges. However, it may limit the transferability of findings to PAH patients with significant comorbidities; ③patients in the terminal stages of disease. All recruited patients were conscious and had no auditory impairments; each provided written agreement informed consent to participate in the interviews. The sample size is determined by the information saturation principle, which states that no new themes will emerge from the data analysis as the interview data are repeated.[12] Two preliminary interviews were conducted to refine the interview guide and were included in the final analysis. Recruitment continued until informational saturation was reached, defined as the point where analysis of three consecutive interviews

yielded no new themes or insights relevant to the research question. This occurred after the 12th interview. No eligible patients refused participation.

Data Collection

The final interview guide should be provided as an appendix included open-ended questions such as: ①What symptoms do you have, and what were your feelings?②What impact, if any at all, would you say your PAH has had on your life, job, and family? ③What's your current treatment? ④How do you self-manage your PAH outside of the hospital? ⑤What kind of help would you like from the medical staff?

The interviews were conducted by two researchers (J P.C. and N.Z.) who had received training in qualitative interview techniques and had no prior relationship with the participants. The researchers acknowledged their clinical backgrounds in cardiology nursing, which informed their understanding of PAH but also necessitated conscious bracketing of assumptions to prioritize the patients' perspectives during interviews and analysis. Interviews took place in a private room at the hospital, ensuring privacy and confidentiality. They lasted 30–40 minutes,were audio recorded, and researchers took field notes on non-verbal cues. Transcripts were not returned to participants for member checking due to logistical constraints; instead, analyst triangulation and peer debriefing were used to enhance credibility. Interviews were conducted in Chinese. Quotes presented in this manuscript were translated into English by a bilingual researcher and back-translated by an independent translator to ensure conceptual and semantic equivalence.

Data Analysis

Demographic data were analyzed descriptively. Interview data were analyzed using Colaizzi's (1978) seven-step method:[13] (1) Transcribing interviews and reading transcripts repeatedly to acquire a general sense of the data; (2) Extracting significant statements relevant to the phenomenon; (3) Formulating meanings from these significant statements; (4) Aggregating formulated meanings into theme clusters; (5) Developing an exhaustive description of the phenomenon; (6) Producing a fundamental structure statement capturing the essence of the experience; (7) Validating the findings by returning to participants or, as done here, through peer debriefing and searching for disconfirming evidence. Two researchers independently coded the first three transcripts, and discrepancies were resolved through discussion until consensus was reached, establishing a preliminary coding framework. Subsequent transcripts were coded by one researcher and reviewed by another. The qualitative research analysis software NVivo 12.0 was used for data management. An audit trail of analytical decisions was maintained.

Ethics Considerations

This study was approved by the Research Ethics committee of FuWai Central China Cardiovascular Hospital (Number: 2025–42). The study complies with the Declaration of Helsinki.All study participants were provided with verbal and written information regarding the study's objectives and their participation.Written consent was obtained, which included consent for the publication of anonymized responses and direct quotes. The funder had no role in the study design, data collection, analysis, orreporting.

Data Availability Statement

The datasets generated and analyzed during the current study are not publicly available to protect participant confidentiality but de-identified data (eg, anonymized quotes) are available from the corresponding author on reasonable request.

Results

A total of 12 patients (aged 18–75; 8 male, 4 female) were interviewed, which were numbered A~L. Demographic characteristics are presented in Table 1. Analysis identified two overarching themes and seven sub-themes related to self-management challenges, summarized in Table 2 alongside representative quotes.

Participants' descriptions of the dilemma of self-management with PAH are presented in in 2 themes and 7 subthemes.Themes and Subtopics are presented in Table 2.

Table 1 Demographic and Clinical Characteristics of Participants (n=12)

ID	Age	Gender	Marriage	Education	Medical Payment	Career	Science Diagnosis	Functional Class
A	18	Male	Unmarried	Senior middle school	Resident medical insurance	Student	1 months	3
B	27	Male	Married	Bachelor's degree	Remote medical insurance	Teacher	3 years	2
C	45	Female	Married	Primary School	Resident medical insurance	Farmer	10 years	3
D	25	Male	Married	Associate diploma	Employee medical insurance	Teacher	1 years	2
E	31	Female	Married	Primary School	Resident medical insurance	Farmer	2 years	2
F	28	Male	Married	Bachelor's degree	Employee medical insurance	Staff	10 years	2
G	37	Male	Married	Junior middle school	Resident medical insurance	Farmer	3 years	3
H	35	Female	Unmarried	Junior middle school	Self-funded	Manager	2 years	2
I	29	Male	Unmarried	Senior middle school	Resident medical insurance	Manager	5 years	2
J	33	Male	Married	Junior middle school	Remote medical insurance	Unemployed	2 years	2
K	75	Male	Married	Illiterate	Resident medical insurance	Farmer	10 years	4
L	33	Male	Married	Primary School	Resident medical insurance	Farmer	5 years	3

Table 2 Themes and Subtopics

Themes	Subtopics	Representative
1. Individual-level Barriers	1.1 Lack of disease awareness and initial attention	A: "I suddenly fainted. I didn't pay much attention when feeling weak earlier."
	1.2 Insufficient knowledge about medications and disease management	F: "I joined a PAH patient group. We communicate. I find it really helpful."
	1.3 Heavy financial burden	F: "Treprostinil costs over 8,000 yuan per bottle. My monthly drug expenses exceed 20,000 yuan."
2: Contextual challenges	2.1 Uncertainty about the disease progression	E: "This illness can worsen at any moment."
	2.2 Lacking of family and social support	K: "I'm from a rural area. Never heard of any welfare organizations."
	2.3 Poor accessibility to medications	H: "I couldn't buy pulmonary pressure-lowering medications locally."
	2.4 Disruptions due to public health emergencies	L: "During the pandemic. Making it extremely difficult to get medications."

Theme 1: Individual-Level Barriers

Lack of Disease Awareness and Initial Attention

Patients with PAH should be vigilant about symptoms related to their condition in daily life to prevent the occurrence of pulmonary hypertensive crises. In the early stage, patients with PAH often experience a decline in physical strength, fatigue, shortness of breath during activities, abdominal distension, and other symptoms that can easily be overlooked or confused with other diseases.[14] *Participants described how initial, non-specific symptoms were often overlooked, delaying diagnosis and early management*.

Participant A: "I suddenly fainted at school and that's when I discovered this illness. I did not pay much attention when feeling weak earlier."

Participant B: Some were diagnosed incidentally: "I was discovered during the company's entrance medical examination after graduating from university; I used to be very healthy before."

Participant C: "I worked on the construction site and always felt tired and short of breath. I was diagnosed with PAH as my coworkers took me to the hospital."

Insufficient Knowledge About Medications and Disease Management

Gaining knowledge about the disease through professional sources enables patients to identify symptoms early, gain experience with medication administration, and improve their ability to manage their condition on their own.[15] While some participants actively sought information, many relied on peer support and self-exploration due to a perceived lack of structured professional guidance. During the interviews, some patients stated that they could acquire and benefit from disease-related knowledge through networks and health lectures in the ward.

Participant J: Initially, I knew very little about this disease. It wasn't until I was diagnosed that I learned what pulmonary hypertension is. After that, I started looking up information on my own using my smartphone.

Participant A: During my hospital stay, I attended health lectures organized by the department. After returning home, I knew what to pay attention to, and how to take my medication, and I kept the doctors' contact information. If I had any questions, I would call them, and they would help adjust my medication.

Participant G: When I first started taking the medication (Treprostinil), I had a really hard time adjusting to it—I experienced headaches and arm pain. But over time, I figured out that I shouldn't change the injection site too frequently. After about ten days, I got used to it.

Participant F: I joined a PAH patient group with hundreds of members. We communicate in the group when we have questions and learn from others' experiences. I find it really helpful.

Participant D: I've been living with this disease for 16 years. I don't dare to stop taking my medication, and when I have trouble breathing, I use oxygen at home immediately.

Heavy Financial Burden

According to the "White Paper on the Survival Status of PAH Patients in China",[16] China has made significant progress in developing and enforcing medical insurance rules relating to PAH. Nonetheless, outpatient reimbursement has not yet been achieved in many areas with dense populations at potentially high risk. Additionally, the reimbursement rate for outpatient expenses is relatively low, with only 22% of outpatient patients able to claim reimbursement for more than 70% of their treatment costs. Research by Jiang Ying et al[17] indicated that nearly 90% of patients suspended their treatment or discontinued medication due to personal financial reasons. The high cost of PAH-specific medications was a predominant and frequently cited barrier, leading to non-adherence and significant psychological stress.

Participant F: Treprostinil costs over 8,000 yuan per bottle—it's too expensive! I need two bottles a month, and even with 65% reimbursement, combined with other pulmonary pressure-lowering medications, my monthly drug expenses exceed 20,000 yuan.

Participant H: I can't work now. There was a time I went out to take a job, worked for seven days, and ended up hospitalized for nine days. The money I earned wasn't even enough to cover the medical expenses. I have no source of income.

Participant C: I often take my medication irregularly at home because I feel it's not very helpful and the cost is too high. The financial burden is heavy, especially with my two daughters needing to pay tuition fees and other expenses. My wife is the one earning money, and I feel particularly guilty towards them.

Participant L: I usually just take some diuretics and potassium supplements. The pulmonary pressure-lowering medications are too expensive—over 3,000 yuan a month. As an ordinary person, I can't afford that.

Theme 2: Contextual Challenges

Uncertainty About Disease Progression

Some patients report that the occurrence and progression of pulmonary hypertension symptoms are highly unpredictable In daily life, the worsening of symptoms or the simultaneous appearance of multiple symptoms severely impacts their work and life. This unpredictability leaves patients feeling a deep sense of helplessness and frustration in managing their disease.

Participant E: What troubles me the most is that as soon as I engage in any activity, I feel exhausted, short of breath, and struggle to catch my breath. Sometimes, I can't even manage household chores. This illness can worsen at any moment.

Participant H: "This time, I caught a cold and experienced difficulty breathing and extreme fatigue, which led to the discovery of this disease."

Participant B: "I could not accurately judge the severity of my condition. I was coughing up blood at home and thought it might get better by the next day, but unexpectedly, it got worse. I had to rush here overnight from out of town."

Lacking of Family and Social Support

Social welfare organizations and family support are crucial for the management of idiopathic PAH. In China, there are also social welfare organizations related to PAH patients, guiding patients and their families in disease management, emotional and psychological support, and social activities, from which many patients benefit. However, some patients still report that they cannot obtain sufficient family and social support.

Participant F: "The support from my parents and husband is incredibly important. With such high monthly expenses, it would not be possible without my family's support."

Participant K: "I'm from a rural area, illiterate, and have never heard of any welfare organizations or what they do."

Participant G: "I haven't received any help or support from organizations like these. I know there are many patient groups, and I often see them chatting inside."

Participant J: I hope there can be some welfare organizations, like the congenital heart disease assistance programs at our hospital, that can reduce some costs and provide more support in terms of medical insurance reimbursement and living security. This would help draw more attention from society and the government.

Poor Accessibility to Medications

The poor accessibility of targeted medications for PAH is a prevalent issue in grassroots regions, making the procurement of medications a significant challenge in disease management for patients. The difficulty of purchasing targeted PAH drugs varies across different regions. In some areas, due to economic conditions, healthcare, and medical insurance policies, patients face considerable challenges in obtaining these medications.

Participant H: For the past two years, I couldn't buy pulmonary pressure-lowering medications locally. I had to travel to several places, contacted the director of our county hospital, and went through several departments just to get them. It was too much trouble.

Participant J: "Currently, these medications are still not available where I live. I have to ask the manufacturer to send them to me. I hope this problem gets resolved soon."

Disruptions Due to Public Health Emergencies

The COVID-19 pandemic acutely exacerbated existing challenges, disrupting access to medications and healthcare.

Participant L: During the pandemic, we weren't allowed to go out, making it extremely difficult to get medications. Yet, my disease makes me heavily reliant on these drugs.

Participant I: During the pandemic, I was too afraid to go out, fearing infection, so my family had to go out and buy the medications for me. At that time, many pharmacies were also out of stock.

Participant K: We didn't have much money to begin with, and during the pandemic, we were all locked down at home. I stopped taking the pulmonary pressure-lowering medications and just took some diuretics and potassium supplements.

Discussion

To our knowledge, this is one of the first qualitative studies to explore self-management challenges specifically among patients diagnosed with PAH in China. Our findings illuminate the complex interplay of individual and contextual barriers that shape the self-management experiences of this population.

Consistent with the broader literature on chronic conditions, where approximately 50–60% of individuals exhibit poor treatment adherence,[18] our participants described significant challenges in maintaining consistent self-management routines.The symptoms they experienced, such as dyspnea and fatigue, align with those reported in other PAH studies,[19,20] contributing to activity limitation and psychological distress. The perceived unpredictability of the disease,

a key finding in our study, underscores the need for healthcare providers to equip patients with clear action plans for symptom worsening, potentially reducing this sense of helplessness.[21]

The role of social support emerged as crucial. The vulnerability to social isolation reported by our participants, linked to reduced physical capacity, resonates with international surveys.[22,23] Within the Chinese cultural context, where family interdependence is highly valued ("familism" or "jia ting guan nian"), the availability and quality of family support become paramount. However, stigma surrounding chronic illness and a cultural tendency to endure hardships silently ("ren nai") might also deter some patients from actively seeking help outside the family, potentially exacerbating isolation. Our findings suggest that proactively integrating family members into patient education and care plans is essential. Furthermore, facilitating connections with peer support groups, both online and offline, can provide validation and practical tips, as reported by some participants and supported by other research.[24,25]

The themes of heavy financial burden and poor drug accessibility highlight critical systemic barriers. The high cost of targeted PAH therapies and the complexities of China's medical insurance reimbursement system directly impacted treatment adherence, a finding consistent with PAH-specific research reporting non-adherence rates of 25–40%.[26]

This financial strain, coupled with the logistical difficulty of obtaining medications, especially in non-metropolitan areas, creates a significant dilemma for patients, forcing them to make trade-offs between financial stability and optimal health management.[27,28] These findings call for practical applications aimed at policymakers and insurers, such as advocating for the inclusion of more PAH drugs in the national reimbursement drug list, simplifying reimbursement procedures, and increasing outpatient reimbursement rates. Exploring the establishment of public welfare funds for PAH could also alleviate this burden.

The disruption caused by public health emergencies, notably the COVID-19 pandemic, exposed the fragility of care continuity for PAH patients. Our study adds a specific PAH perspective to the broader discourse on pandemic-related healthcare disruptions, emphasizing the need for resilient healthcare systems that ensure uninterrupted access to essential medications and consultations for vulnerable patient populations through strategies like "internet + healthcare" services and designated drug delivery channels.

Based on our themes, we recommend several practical applications. For health professionals: Implement structured, ongoing patient education programs that address knowledge gaps and symptom management; conduct routine screening for anxiety and depression; and provide training for patients and families on recognizing warning signs. For hospital administrators and policymakers: Develop multidisciplinary PAH care models; advocate for policy reforms to improve drug accessibility and affordability; and support the creation and official recognition of patient support organizations.

Limitations

The study was limited to a small sample size of only 12 participants at a single Grade A hospital. This could potentially restrict the generalizability of the findings. Furthermore, as the majority of our study participants were hospitalized patients, their physical and mental problems might have been more severe. Patients from other institutions should be included in the sample in future research.

Conclusion

In conclusion, this study demonstrates that PAH places a significant burden on patients' physical, mental, and social well-being in China. Key barriers identified include a lack of disease awareness and knowledge, the substantial financial burden of treatment, the unpredictable nature of the disease, insufficient support systems, difficulties in accessing medication, and vulnerability to public health crises. Addressing these challenges requires a coordinated, multi-level response: clinicians must provide continuous, tailored education and psychosocial support; families should be actively engaged as partners in care; and health policy must prioritize improving the affordability and accessibility of PAH treatments to alleviate the significant burdens faced by patients.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This research was funded by the Henan Medical Science and Technology Research and Development Program (LHGJ20230151).

Disclosure

The authors declare no conflicts of interest in this article.

References

1. Luo Q. Chinese clinical pathway for diagnosis and treatment of pulmonary hypertension. *Chin Circ J*. 2023;38(07):691–703.
2. Chinese government website. Notice of the national health commission on issuing commonly used clinical medical terms (2019 Edition). (2020-01-09)[2023-03-13].
3. Hoeper MM, Humbert M, Souza R, et al. A global view of pulmonary hypertension. *Lancet Respir Med*. 2016;4(4):306–322. doi:10.1016/S2213-2600(15)00543-3
4. Rosenkranz S, Delcroix M, Giannakoulas G, Hoeper MM, Kovacs G, Humbert M. The "Ten Commandments" of the 2022 ESC/ERS guidelines for the diagnosis and treatment of pulmonary hypertension. *Eur Heart J*. 2023;44(10):792–793. doi:10.1093/eurheartj/ehad018
5. Gelzinis TA. Pulmonary hypertension in 2021: part I-Definition, Classification, PathoPAHysiology, and presentation. *J Cardiothorac Vasc Anesth*. 2022;36(6):1552–1564. doi:10.1053/j.jvca.2021.06.036
6. Van Nuffel S, Quatredeniers M, Pirkl A, et al. Multimodal imaging mass spectrometry to identify markers of pulmonary arterial hypertension in human lung tissue using MALDI-ToF, ToF-SIMS, and hybrid SIMS. *Anal Chem*. 2020;92(17):12079–12087. doi:10.1021/acs.analchem.0c02815
7. Thenappan T, Ormiston ML, Ryan JJ, Archer SL. Pulmonary arterial hypertension: pathogenesis and clinical management. *BMJ*. 2018;360:j5492. doi:10.1136/bmj.j5492
8. Benza RL, Miller DP, Barst RJ, Badesch DB, Frost AE, McGoon MD. An evaluation of long-term survival from time of diagnosis in pulmonary arterial hypertension from the REVEAL Registry. *Chest*. 2012;142(2):448–456. doi:10.1378/chest.11-1460
9. Piette JD, Heisler M, Horne R, et al. A conceptually based approach to understanding chronically ill patients' responses to medication cost pressures. *Soc Sci Med*. 2006;62(4):846–857. doi:10.1016/j.socscimed.2005.06.045
10. Hughes JA, Alexander KE, Spencer L, et al. Factors associated with the experience of patients presenting in pain to the emergency department. *J Clin Nurs*. 2022;31(9/10):1273–1284. doi:10.1111/jocn.15983
11. Pulmonary Embolism and Pulmonary Vascular Disease Group of Respiratory Medicine Branch of Chinese Medical Association, Pulmonary Embolism and Pulmonary Vascular Disease Working Committee of Respiratory PAHysician Branch of Chinese Medical Doctor Association, National Cooperative Group for Prevention and Treatment of Pulmonary Embolism and Pulmonary Vascular Disease. Guidelines for diagnosis and treatment of pulmonary hypertension in China (2021 edition). *Natl Med J China*. 2021;101(1):11–51.
12. Li Z, Liu Y. *Nursing Research Methods*. 2nd ed. Beijing: People's Medical Publishing House; 2018:245–287.
13. Liu M. Using an example to illustrate Colaizzi's PAHenomenological data analysis method. *J Nurs Sci*. 2019;34(11):90–92.
14. Zhang Y, Li X, Li S, et al. Immunotherapy for pulmonary arterial hypertension: from the pathogenesis to clinical management. *Int J Mol Sci*. 2024;25(15).
15. Xu Y, Wang YY, Wang Y, et al. Self-management dilemma in patients with hemophilic arthropathy:a qualitative study. *Chin J Nurs*. 2021;56(04):534–539.
16. China News. 《White Book on Pulmonary Artery Hypertension Patients》 released:to reveal the status of diagnosis and treatment in patient groups [EB/OL]. 2021. Available from: https://baijiahao.baidu.com/s?id=1698478040776411284&wfr=spider&for=pc. Accessed January 8, 2023.
17. Ying JIANG, Minhong YU, Chunyan Zhang. Kang Xiaofeng. Investigation and analysis of influencing factors related to financial burden among pulmonary artery hypertension patients. *Chin J Nurs*. 2023;58(14):1733–1741.
18. Feng M, Zhu J, Fu XM, Chen L. Application research of mobile medical platform in self-management of pulmonary hypertension patients after discharge. *Chongqing Med J*. 2017;46(31):4455–4457.
19. McDonough A, Matura LA, Carroll DL. Symptom experience of pulmonary arterial hypertension patients. *Clin Nurs Res*. 2011;20(2):120–134. doi:10.1177/1054773810391249
20. Kingman M, Hinzmann B, Sweet O, Vachiéry JL. Living with pulmonary hypertension: unique insights from an international ethnograPAHic study. *BMJ Open*. 2014;4(5):e004735. doi:10.1136/bmjopen-2013-004735
21. Ivarsson B, Johansson A, Kjellström B. The odyssey from symptom to diagnosis of pulmonary hypertension from the patients and spouses perspective. *J Prim Care Community Health*. 2021;12:21501327211029240. doi:10.1177/21501327211029241
22. Zhang J, Zhang Y, Yin Y, et al. 'Fear, uncertain, tired….' psychological distress among pulmonary hypertension patients: a qualitative interview study. *BMC Psychiatry*. 2024;24(1):100. doi:10.1186/s12888-024-05539-z
23. Swetz KM, Shanafelt TD, Drozdowicz LB, et al. Symptom burden, quality of life, and attitudes toward palliative care in patients with pulmonary arterial hypertension: results from a cross-sectional patient survey. *J Heart Lung Transplant*. 2012;31(10):1102–1108. doi:10.1016/j.healun.2012.08.010

24. Matura LA, McDonough A, Aglietti LM, Herzog JL, Gallant KA. A virtual community: concerns of patients with pulmonary hypertension. *Clin Nurs Res*. 2013;22(2):155–171. doi:10.1177/1054773812462867
25. Carroll R, Antigua J, Taichman D, et al. Motivations of patients with pulmonary arterial hypertension to participate in randomized clinical trials. *Clin Trials*. 2012;9(3):348–357. doi:10.1177/1740774512438981
26. Kjellström B, Sandqvist A, Hjalmarsson C, Nisell M, Näsman P, Ivarsson B. Adherence to disease-specific drug treatment among patients with pulmonary arterial hypertension or chronic thromboembolic pulmonary hypertension. *ERJ Open Res*. 2020;6(4):00299–2020. doi:10.1183/23120541.00299-2020
27. Frantz RP, Hill JW, Lickert CA, et al. Medication adherence, hospitalization, and healthcare resource utilization and costs in patients with pulmonary arterial hypertension treated with endothelin receptor antagonists or PAHosPAHodiesterase type-5 inhibitors. *Pulm Circ*. 2020;10(1):2045894019880086. doi:10.1177/2045894019880086
28. Tsangaris I. Improving patient care in pulmonary arterial hypertension: addressing psychosocial issues. *J Clin Hypertens*. 2014;16(3):159–161. doi:10.1111/jch.12269