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Diagnostic delay among newly diagnosed pulmonary hypertension patients: A narrative study based on the social-ecological system theory Running title: Diagnostic delay in pulmonary hypertension: a narrative study

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Research Article

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Abstract

Background

Pulmonary hypertension is a progressive pulmonary vascular disease with a poor prognosis. Its early symptoms lack specificity, leading to widespread diagnostic delays.[1] Most patients are already in the moderate-to-severe stage at the time of diagnosis. Existing research has primarily focused on pathophysiological mechanisms and pharmacological treatment, while there is insufficient understanding of the socio-ecological barriers that contribute to diagnostic delays.

Methods

This study conducted a qualitative narrative inquiry within a socio-ecological framework. Using purposive sampling, 16 patients with newly diagnosed pulmonary hypertension were selected from a tertiary hospital in Guizhou. Through semi-structured narrative interviews, the study explored in depth their complete journey from symptom onset to diagnosis. Data were analyzed using three-dimensional narrative analysis combined with thematic coding, and mapped to the micro, meso, and macro system levels. The rigor of the study was ensured through triangulation, member validation, and independent coding by two researchers. This study was reported in accordance with the COREQ checklist.

Results

The median diagnostic delay was 6 months (range: 1 month–40 years). At diagnosis, 93.75% of patients presented with WHO functional class III–IV, and 87.5% were classified as having moderate-to-severe pulmonary hypertension. Notably, patients with lower education levels and from rural areas experienced more pronounced diagnostic delays.Three thematic levels emerged. At the micro level, patients exhibited gaps in disease knowledge and symptom misattribution (to aging or common colds), leading to passive healthcare-seeking behavior driven by economic concerns. At the meso level, fragmented referral pathways, poor clinician-patient communication, and lagging family support were identified as key barriers. At the macro level, systematic deficiencies in public pulmonary hypertension education and structural inadequacies in primary care diagnostic resources were pervasive.

Conclusions

Diagnostic delay in pulmonary hypertension represents not simply a deficit in patient awareness, but a systemic failure operating across multiple socio-ecological levels, which directly contributes to the presentation of advanced right heart failure at the time of diagnosis. There is an urgent need to implement multi-tiered intervention strategies: raising awareness among the public and primary care providers, optimizing resource allocation, and establishing standardized screening protocols. This study provides qualitative evidence for designing targeted interventions to shorten the diagnostic window and prevent irreversible pulmonary vascular damage.

Trial registration:

Not applicable. This study does not report results of a clinical trial involving human participants.

1 Background

Pulmonary hypertension (PH) is a malignant pulmonary vascular disease characterized by a progressive increase in pulmonary vascular resistance, ultimately leading to right heart failure and even death. Due to its poor prognosis and difficulty in achieving a cure, it is often referred to as the "cancer of the cardiovascular field" [1, 2]. The global incidence rate is approximately 1% [3], and the incidence rate increases significantly with age [4], with 80% of PH patients residing in developing countries [5]. Its early symptoms, such as shortness of breath after activity and fatigue, lack specificity and are easily confused with other cardiopulmonary diseases, leading to widespread diagnostic delay [3].

Diagnosis delay refers to the time interval from the onset of PH-related symptoms to the diagnosis of PH via right heart catheterization [6]. Currently, there is no unified international academic standard for the time threshold of "delay." Studies show that the time interval from symptom onset to confirmed diagnosis can be as long as months or even years [7]. Notably, approximately 80% of PH patients have already progressed to WHO functional class III or IV at the time of diagnosis [8]. A survey on the survival status of patients with pulmonary arterial hypertension in China revealed a median time of 183 days from symptom onset to diagnosis [9]. By the time of diagnosis, patients are often in an advanced stage, placing a heavy economic burden on their families [10].

From a pathophysiological perspective, a chronic increase in pulmonary vascular resistance drives progressive right ventricular hypertrophy and ischemia, ultimately leading to heart failure [11]. A delay in diagnosis is not merely a matter of time; it also means missing the critical window for protecting the right ventricle [7], causing patients to miss the opportunity for early treatment, which in turn leads to a decline in their ability to care for themselves, a deterioration in their quality of life, increased nursing challenges, and a heavier healthcare burden.

Existing research has primarily focused on the pathophysiological mechanisms and pharmacological treatment of PH [12], and has identified barriers to the diagnosis and treatment of PH from both patient and healthcare provider perspectives [13]. However, there has been insufficient exploration of the complex, multidimensional social factors underlying diagnostic delays. To systematically analyze this issue, this study introduces the social-ecological system theory. This theory was first proposed by Bronfenbrenner in 1979 [14] and later elaborated upon by Charles Zastrow; it emphasizes that an individual’s development is jointly influenced by the interactions among micro-, meso-, and macro-system environments [15]. This study aims to use narrative research methods to explore in depth the experiences of newly diagnosed pulmonary arterial hypertension patients who encounter diagnostic delays during their healthcare journey, and to reveal the underlying causes from a multidimensional social-ecological systems perspective, thereby providing a theoretical foundation for establishing a system of early detection and intervention.

2 Methods

2.1. Study design

This study employed a qualitative narrative inquiry design within the socio-ecological framework. Narrative research enables the deep exploration of patients' illness experiences and life stories, revealing elements that are instructive for nursing practice[16]. By collecting patients' complete narratives of the diagnostic process, we systematically examined how diagnostic delay is experienced and interpreted across personal, interpersonal, organisational, community, and policy levels.This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

2.2. Participants and setting

Purposeful sampling was used to recruit patients who were first diagnosed with PH at the Department of Cardiovascular Medicine of a tertiary hospital in Guizhou, China, from January to April 2026. Inclusion criteria: (1) met PH diagnostic criteria and received a first diagnosis; (2) age ≥ 18 years; (3) willing to participate and able to provide written informed consent; (4) conscious with normal communication ability; (5) able to fully narrate the entire process from symptom onset to diagnosis. Exclusion criteria: (1) severe organ failure, mental illness, or cognitive impairment; (2) incomplete clinical data; (3) withdrawal from the study. Sample size was determined by data saturation (no new themes emerged). Saturation was reached after 14 participants, and an additional two were included to confirm findings, resulting in a final sample of 16 patients. Ages ranged from 19 to 80 years (mean 57.0 ± 15.3 years). Diagnostic delay (from first symptom onset to diagnosis) ranged from 1 month to 40 years, with a median delay of 6 months (IQR: 4–24 months). Educational levels ranged from illiterate to bachelor's degree. Participants were from rural (n = 10), urban (n = 4), and township (n = 2) areas. The majority (14 participants (87.5%)) were covered by the Urban and Rural Resident Basic Medical Insurance. At diagnosis, 14 participants (87.5%) were classified as having moderate to severe PH, and 15 participants (93.75%) were at WHO functional class III or IV. Participants were coded N1 to N16 for anonymity. See Table 1 for participant characteristics. The study was approved by the ethics committee (approval number : 2025 Ethics (385)). All participants provided written informed consent prior to enrolment. The study was conducted in accordance with the Declaration of Helsinki.

Table 1
General characteristics of interview participants (N = 16)

No.	Gender	Age	Education level	Place of Residence	Health Insurance Type	PH severity	WHO functional class	Diagnostic delay
N1	Male	69	Middle school	Rural	Resident	Severe	IV	4 years
N2	Male	54	Primary school	Rural	Resident	Severe	IV	6 months
N3	Male	73	Undergraduate	Urban	Employee	Severe	IV	7 months
N4	Male	62	Illiterate	Rural	Resident	Severe	IV	3 years
N5	Female	19	Secondary vocational school	Urban	Resident	Severe	III	10 years
N6	Female	80	Illiterate	Rural	Resident	Severe	III	6 months
N7	Male	69	High school	Urban	Employee	Mild	II	4 months
N8	Male	63	Primary school	Rural	Resident	Moderate	III	4 months
N9	Female	50	Illiterate	Rural	Resident	Moderate	III	6 months
N10	Male	32	Middle school	Rural	Resident	Severe	III	2 years
N11	Female	60	Illiterate	Rural	Resident	Severe	III	40 years
N12	Male	70	Primary school	Rural	Resident	Mild	III	1 month
N13	Female	60	Illiterate	Urban	Resident	Severe	IV	2 years
N14	Male	58	Primary school	Urban	Resident	Severe	III	6 months
N15	Male	53	Primary school	Township	Resident	Moderate	III	3 months
N16	Male	40	Middle school	Rural	Resident	Severe	III	6 months

Employee = Basic Medical Insurance for Urban Employees;Resident = Basic Medical Insurance for Urban and Rural Residents

2.3. Interview guide

formulated through a systematic process: literature review and clinical experience generated an initial draft; two nursing experts and one senior PH specialist (associate professor level) were consulted; two pilot interviews were conducted to refine question wording and logic. The core narrative invitation was: “Please tell me your story from the first time you felt unwell to the final diagnosis of pulmonary hypertension. Please tell it as a complete story, starting from the beginning, including any details, feelings, and events that you think are important.” Follow-up probes were flexibly generated according to the socio-ecological levels, for example: at the micro level, “During the time when you did not know what the illness was, how did you yourself interpret these discomforts?”; at the meso level, “How did your family or close friends support you at that time? How did their

reactions affect you?" ; "When you visited different hospitals, did you feel that communication with the doctors was smooth?"; and at the macro level, "Which other healthcare facilities did you visit before the final diagnosing hospital? How smooth was the process of moving between different hospitals or departments?"

2.4. Data Collection and Quality Control

Semi-structured face-to-face narrative interviews were conducted at times and places convenient for participants (private, quiet, undisturbed) to create a relaxed narrative atmosphere. Each interview lasted 30–60 minutes. Interviews were audio-recorded with consent. The researcher acted as an active listener and co-constructor, engaging with empathy and timely probing. To ensure methodological rigour, several strategies were employed. Triangulation was achieved by combining in-depth interviews, researcher field notes, and medical records. Member checking was conducted by returning preliminary findings to several participants for validation. The researcher maintained a reflexive journal to document and examine potential biases. Finally, two trained researchers independently coded the data, and any disagreements were resolved through discussion or adjudication by a senior qualitative expert.

2.5. Data analysis

Transcription and anonymisation: Interviews were transcribed verbatim within 24 hours and anonymised (codes N1–N16).Three-dimensional narrative analysis and storyline integration: We first performed three-dimensional narrative analysis (temporal, interactional, situational dimensions) through immersive reading to grasp the overall narrative structure. Simultaneously, we applied the socio-ecological framework to identify and label content at micro-, meso-, and macro-levels, and integrated the narratives into coherent storylines chronologically. Thematic extraction and narrative reconstruction: Based on the storylines, we applied thematic analysis with systematic coding using Colaizzi's seven-step method. Two researchers coded independently and cross-checked. Core conflicts, individual interactions and struggles across system levels, and dynamic influences of systemic factors were identified. Finally, the extracted themes were organised into the three socio-ecological levels, and the storylines were reconstructed into a clearly structured "research narrative".

2.6 Theme Frequency and Between-Group Comparisons in Data Analysis

Following the thematic analysis, the researchers tallied the number and proportion of participants mentioned under each theme. Based on the median duration of diagnostic delay (6 months), the 16 participants were divided into a short-delay group (< 6 months, n = 6) and a long-delay group (≥ 6 months, n = 10) to compare differences in theme distribution between the two groups. This quantitative synthesis aimed to enhance the structured presentation of results; however, all statistical analyses were based solely on the frequency of theme occurrence within the qualitative data and did not involve inferential statistical testing.

3 Results

3.1 Basic Characteristics of Diagnostic Delay in PH Patients

Diagnostic delay among participants was characterised by universality, heterogeneity, and a convergent healthcare-seeking trajectory. Delay durations ranged from 1 month to over 40 years, with 12 patients experiencing delays of 6 months or more. The diagnostic journey could be summarised as a triple pattern:

prolonged neglect due to non-specific symptoms, repeated misdiagnosis and ineffective treatment at primary care facilities, and ultimate diagnosis dependent on provincial-level medical centres.

The lack of nursing services is particularly evident in this process—nurses failed to identify non-specific symptoms during triage and outpatient service, and did not provide health education to correct patients' cognitive biases. Core symptoms (fatigue, chest tightness, post-activity shortness of breath, cough) were long overlooked due to their non-specific nature, with patients often attributing them to aging or common colds. For example, the family member of N1 stated, "At that time, I thought the cough was just a common cold, so I didn't pay attention to it"; N2 sought medical attention only after "being tired for a year"; N11 had a symptom history of "30 to 40 years" and did not seek medical care when young, only going to the hospital "when old age made the body unable to bear it." Misdiagnosis and underdiagnosis were common in primary healthcare institutions—even when examination reports indicated abnormalities related to PH, they were not formally diagnosed or specifically addressed. All patients ultimately had to be referred to provincial medical centers for a definitive diagnosis, with the care pathway characterized by a multi-level passive referral pattern of "township/county hospital → municipal hospital → provincial hospital," lacking standardized guidance.

3.2 Distribution of Theme Frequencies and Diagnostic Delay Duration Across Groups

To enhance the structured presentation of results, Table 2 summarizes the mention frequencies of major themes and their distribution across different diagnostic delay duration groups. The results indicate that, at the micro level, all participants in both groups reported a lack of disease knowledge; long-delay group participants showed higher proportions of symptom perception bias and passive healthcare-seeking behavior compared to the short-delay group, suggesting that these individual-level perceptual and behavioral factors may be more prominent in cases of prolonged delay. At the meso level, gaps in referral continuity and poor follow-up compliance were more frequently reported in the long-delay group (90.0% vs. 83.3%), while family support lag and barriers in doctor-patient communication were reported by a approximately half of the short-delay group participants. At the macro level, lack of public education and insufficient primary care resources were mentioned by nearly all participants across both groups, indicating the pervasive impact of systemic issues on diagnostic delays regardless of delay duration.

Table 2
Mention Frequencies of Themes and Their Distribution by Diagnostic Delay Duration (n = 16)

Level	Theme	Total n (%)	Short-delay group (< 6 mo; n = 6)	Long-delay group (≥ 6 mo; n = 10)
Micro-system	Lack of disease knowledge and simplistic interpretation	16 (100%)	6 (100%)	10 (100%)
	Symptom perception bias and non-disease attribution	15 (93.8%)	5 (83.3%)	10 (100%)
	Passive healthcare-seeking behavior dominated by economic concerns	14 (87.5%)	4 (66.7%)	10 (100%)
	Mismanagement of underlying diseases and symptom overlap confusion	5 (31.3%)	1 (16.7%)	4 (40.0%)
Meso-system	Lag in family support and absence of caregiving functions	4 (25.0%)	1 (16.7%)	3 (30.0%)
	Poor clinician-patient communication and fragmentation of diagnostic information transfer	7 (43.8%)	3 (50.0%)	4 (40.0%)
	Differential guiding role of social networks	3 (18.8%)	1 (16.7%)	2 (20.0%)
	Referral continuity gaps and low follow-up compliance	14 (87.5%)	5 (83.3%)	9 (90.0%)
Macro-system	Systematic deficiency in rare disease public education and public awareness	16 (100%)	6 (100%)	10 (100%)
	Structural insufficiency of diagnostic resources and lagging primary care workforce development	14 (87.5%)	5 (83.3%)	9 (90.0%)
	Environmental triggers and disparities in healthcare accessibility	4 (25.0%)	1 (16.7%)	3 (30.0%)

3.3 Micro-system: Limitations of Individual Cognition, Perception, and Behaviour

3.3.1 Lack of disease knowledge and simplistic interpretation

All patients had no knowledge of PH before diagnosis and tended to confuse it with common diseases. Family member N1 stated, "I had no idea about PH at all. At first, I thought it was just lung inflammation caused by a common cold, so I bought some anti-inflammatory medicine or got an IV drip in town." Some patients even equated it with ordinary hypertension. N5 mentioned, "At diagnosis, I thought this disease could be controlled with medication, just like hypertension. I had no idea it was severe and irreversible." This cognitive gap is widespread. N3 said, "I only first heard of PH this September." Rural patients with low education levels still could not access disease knowledge through the internet after diagnosis. N8 stated, "Even after diagnosis, I didn't understand this disease. We don't know how to use phones to search, so we are unclear about the details." N12,

N13, and N15 had vague or complete lack of knowledge about the etiology and harm of pulmonary arterial hypertension, all representing typical cases of disease knowledge deficiency.

3.3.2 Symptom Perception Bias and Non-Disease Attribution

Patients commonly attribute the core symptoms of PH to non-disease factors, leading to long-term misjudgment. First, symptoms are insidious and atypical, with early manifestations including shortness of breath, Fatigue, Chest tightness, Cough, and Edema. Elderly patients attribute progressive worsening of post-exercise shortness of breath and fatigue to aging. N3 stated, "I felt tired one or two years ago, but I just thought it was due to old age and never considered PH." Second, respiratory symptoms such as chest tightness and cough are most often associated with self-limiting conditions like the "common cold" or "Bronchitis." N15 also attributed cough and sputum production to a common cold. N11 remarked, "I've had chest tightness and coughing for decades... and I've always been treated for bronchitis and COPD." Finally, some patients simply link symptoms to transient physiological states or temporary factors such as "overwork" or "menstruation." N13 attributed recurrent wheezing and shortness of breath to a cold or fatigue, only receiving anti-inflammatory treatment at a small clinic without investigating the underlying cause. N10 regarded persistent "tiredness" as a general condition to be ignored, and even after a county hospital diagnosed "Myocardial ischemia," chose to "do nothing about it," failing to recognize its connection to heart or lung pathology, completely overlooking the organic disease behind the symptoms, thereby interrupting the diagnostic pathway and missing early identification opportunities.

3.3.3 Passive Medical Seeking Behavior and Economic Concerns Dominate Decision-Making

Influenced by the traditional concept of "enduring pain" and economic pressure, patients generally adhere to the principle of "endure if possible, only seek medical attention when it becomes unbearable," actively delaying medical visits. Economic concerns are a core barrier, especially for rural, elderly, and low-education patients, where the delay in seeking medical care is more pronounced. Family member N1 stated, "From feeling unwell to going to the hospital, I delayed for more than ten days, thinking it was just a common cold and didn't pay attention." N2 described, "At first, I could still rest while climbing three floors, but later I felt short of breath even walking on flat ground or sitting, and only went to the hospital when I couldn't bear it anymore." N4 frankly said, "The first time I felt unwell, I delayed for more than three years before seeing a doctor. This time, I also delayed for over a month before coming to Guiyang. Rural people find it hard to earn money, and once you enter the hospital, you have to spend money. I'm even afraid to go to the hospital."

3.3.4 Mismanagement of Underlying Diseases and Symptom Overlap Confusion

Some patients have underlying diseases such as hypertension, chronic obstructive pulmonary disease (COPD), and hypothyroidism, and there is widespread mismanagement leading to exacerbation of symptoms. For instance, N1 had hypertension for over four years without standardized control, and N12, also hypertensive, "did not take medication daily, only when feeling unwell." Symptom overlap further confuses patients' judgment of their condition, becoming a major interference in early identification. For example, N9, with hypothyroidism, experienced fatigue from hypothyroidism intertwined with PH symptoms despite consistent medication. N3, N11, N13, and N14 all had COPD, where symptoms like cough and wheezing highly overlapped with core PH

symptoms. Grass-roots Doctors focused solely on COPD treatment without further investigating PH, thereby delaying identification.

3.4 Meso-system: Interactional Barriers in Family, Healthcare, and Social Networks

3.4.1 Lag in Family Support and Absence of Caregiving Functions

Family support shows significant cognitive homogeneity, delayed actions, and absence of financial support. First, cognitive homogeneity: family members often share the same disease cognitive biases as patients, failing to provide correct medical guidance or timely reminders. N14's family member also mentioned, "The county hospital's test report indicated pulmonary hypertension, but we didn't understand, and the doctor didn't elaborate, so we didn't take it seriously." Second, delayed actions and caregiving: some patients lack close care due to family members working away from home or living alone, making it impossible to seek timely medical attention even when obvious symptoms appear. For example, N2 stated, "My wife is working outside and can't manage much; I can't do heavy work either, so I have to take care of myself... There's no one at home to care for me, so I wanted to wait until my wife's holiday to come back for a follow-up." N5, Pu Xinyue, said, "At first, I felt unwell during my period, and I live alone, so I didn't tell my family. I endured it until I couldn't stand it anymore and went to the clinic." N15 lives in the countryside, and family members only took them to the hospital after symptoms worsened, without actively paying attention to their cough symptoms in the early stage, clearly indicating lagging family support. Finally, significant absence of financial support: the heavy economic burden directly exacerbates delayed medical treatment. Patients are mainly from rural families with low income and limited medical insurance coverage, facing high long-term treatment costs. N2 admitted, "From last year to now, I've spent 70,000 to 80,000 yuan on medical treatment. My wife's earnings aren't enough, and with my paralyzed mother and young child, the pressure is immense." N9 said, "My children support my treatment, but long-term medication and surgery put a heavy burden on the family." N13 mentioned, "One surgery costs over 40,000 yuan, and I've spent at least 100,000 yuan in total, relying entirely on subsistence allowances and medical insurance."

3.4.2 Poor doctor-patient communication and fragmentation of diagnostic and treatment information transfer

Primary care physicians merely inform patients of treatment failure with a simple "cannot be cured", without clarifying diagnostic doubts to patients and their families, suggesting further investigation directions, or clearly indicating referral indications. Due to a lack of professional knowledge, patients are unable to proactively inquire, leading to a breakdown in the transfer of critical diagnostic and treatment information, making referral a passive and blind choice for family members. Family member N1 stated, "After three days of treatment at the city hospital with no effect, they didn't tell us it might be other heart or lung diseases, only said it couldn't be cured and to transfer." N7 mentioned, "The provincial hospital performed a coronary CT angiography, only saying there was mild vascular blockage, and kept treating it as a common heart issue." N14's experience was particularly typical; the family member said, "The county hospital report mentioned pulmonary arterial hypertension, but we didn't understand, and the doctor didn't elaborate, so we didn't take it seriously. Later, when feeling unwell, we went to a traditional Chinese medicine hospital, which diagnosed it as COPD and treated it for over a week."

3.4.3 Differential guiding role of social networks

Against the backdrop of poor formal referral channels, social networks composed of medical professionals or informed individuals among relatives serve as a critical bridge for some patients to break through primary care difficulties and directly reach advanced medical centers. Family member N11 explicitly stated, "Because my sister-in-law works at the hospital, she told me to come to Guiyang Medical University, so I came." This social network resource directly and efficiently guided the patient to an advanced medical center with diagnostic capabilities. N12, due to their children working in Guiyang, leveraged regional resources from relatives to transfer to a provincial hospital in Guiyang. After ineffective treatment at the primary level, N14's family decided to transfer to Guiyang after discussion, with relatives' social resources becoming crucial support for some patients to receive effective diagnosis and treatment.

3.4.4 Diagnostic and Treatment Continuity Gaps and Low Follow-up Compliance

There is a lack of standardized PH referral mechanisms between primary hospitals and higher-level hospitals, leading patients to undergo multiple ineffective transfers, generally following the tortuous path of "township clinic → county hospital → city hospital → provincial hospital." N1 described: "First, I went to the town clinic for IV fluids, then the city hospital's treatment was ineffective, and finally I came to the provincial hospital." N2 said: "The Bijie City Hospital couldn't treat me, so they sent me to Guiyang, and it took several months back and forth." Patient compliance with follow-up is poor; many patients do not monitor their condition as required after discharge, resulting in continuous disease progression without timely detection. N14 was diagnosed with pulmonary arterial hypertension at the county hospital but was not informed of the importance of follow-up, only seeking medical attention again after a cold worsened the condition. N2 delayed the doctor's recommended follow-up time due to family members being away and unable to provide care. N12 missed regular follow-ups and the opportunity for early diagnosis due to the long distance between their hometown and the provincial hospital. N4, under financial pressure, always delayed coming to the hospital until the body could no longer bear it.

3.5 Macro-system: Deep Structural Barriers in the Healthcare System

3.5.1 Systematic Deficiency in Rare Disease Public Education and Public Awareness Gap

There is a severe lack of public education about PH at the societal level, resulting in extremely low public awareness. This systematic deficiency in public education is an important sociocultural factor leading to misdiagnosis, missed diagnosis, and delay in medical treatment. Family member N1 stated, "I have undergone various examinations before, but no doctor ever mentioned pulmonary hypertension, and none of my relatives or friends had heard of it." N5 said, "I had never heard of pulmonary hypertension until this time when I experienced chest tightness and edema and was diagnosed at a provincial hospital." N9 expressed, "After being diagnosed with pulmonary hypertension, I still didn't understand the disease. No one around me had it, and apart from the doctor saying I need to take medication long-term and cannot stop, I had no other way to know what to do." The lack of community nursing health promotion activities further exacerbates this gap—no participants reported receiving any PH-related information from community nurses or primary care nurses, reflecting a critical missed opportunity for early awareness.

3.5.2 Structural Insufficiency of Diagnostic and Treatment Resources and Lagging Grassroots Talent Development

Medical resources exhibit a distribution pattern of "concentration at the provincial level and scarcity at the grassroots level," making PH diagnosis highly dependent on regional medical centers. Township and county-level primary hospitals generally face a dual shortage of equipment and talent. On one hand, key diagnostic equipment is lacking. Primary hospitals rely mainly on chest radiography, CT, and routine electrocardiogram, but do not routinely perform cardiac ultrasound to assess right heart function, let alone the right heart catheterization essential for PH diagnosis. Patients N14 and N15, among others, reported that their county-level hospitals lacked the above diagnostic equipment. On the other hand, the diagnostic capabilities of primary care physicians are weak. Due to a lack of standardized PH training, they are extremely unfamiliar with the diagnostic criteria, differential diagnosis points, and referral indications for the disease. A typical example is N14's experience: although the ultrasound report at their primary hospital already suggested PH, the doctor did not make a formal diagnosis or provide targeted treatment or referral advice. Later, at a traditional Chinese medicine hospital, the patient was still treated only for "chronic obstructive pulmonary disease (COPD)." Family member N1 recalled that the CT at the city hospital only indicated "emphysema," and treatment was ineffective without considering PH. N3 was hospitalized multiple times but only underwent lung function tests and electrocardiogram, without targeted examinations, and remained undiagnosed. N4 visited multiple hospitals but only received symptomatic medication without ever identifying the underlying cause. N10 was diagnosed with "myocardial ischemia" at a county hospital but no other issues were found. N11 pointed out that although the primary hospital suspected PH, treatment was ineffective, and the patient was later misdiagnosed with "COPD," leading to a delay of up to 3 years. These cases fully demonstrate the fundamental deficiencies in equipment and talent at primary hospitals, constituting a key link in diagnostic delay. The absence of primary care nurses trained in PH recognition means that even when patients present suggestive symptoms or abnormal ultrasound findings, nursing staff lack the knowledge to alert physicians or initiate appropriate patient education and referral discussions.

3.5.3 Environmental Triggers and Disparities in Healthcare Accessibility

Unstable temperatures and poor living conditions in rural areas easily induce colds, which directly exacerbate PH symptoms and become an important trigger for disease progression. Patients in rural and remote areas also face issues such as low healthcare accessibility and inconvenient transportation, making geographical distance an objective barrier to seeking medical care and referral. N15 stated, "In our rural area, temperatures fluctuate between hot and cold... bathing also makes it easy to catch a cold." However, the symptoms of a cold, such as cough and shortness of breath, are highly similar to the early symptoms of pulmonary hypertension (PH), making it difficult for patients to recognize the specificity of the condition. They mistakenly interpret it as a common cold and only seek medical attention when symptoms significantly worsen, further exacerbating diagnostic delay. N15 also mentioned that while working in Jiangsu, they "never got sick" because the stable temperature reduced disease triggers, indirectly reflecting the adverse impact of geographical environment on the disease. Additionally, inconvenient transportation increases the difficulty of referral, worsening diagnostic delay. In contrast, patients in city-level areas, such as N3 and N7, despite having higher healthcare accessibility, still experienced mild diagnostic delay due to insufficient disease awareness. The disparity in healthcare

accessibility across different regions further amplifies the geographical differences in diagnostic delay, with patients in rural and remote areas becoming the most affected group. The lack of rural community nursing outreach services means that basic pathways such as home visits and community-based symptom screening, which could identify high-risk individuals, remain absent. This structural deficiency constitutes an indispensable grassroots link in the chain of diagnostic delay.

4 Discussion

4.1 The Pervasiveness and Direct Harm of Diagnostic Delay: From Clinical Deterioration to Hemodynamic Cost

Our study found that the time from symptom onset to diagnosis varied widely (1 month to 40 years; median delay 6 months), with 93.75% of patients already in WHO functional class III–IV at diagnosis, indicating advanced functional impairment, with 87.5% classified as moderate-to-severe PH. This finding aligns with previous reports and underscores the pervasive and severe nature of diagnostic delay[17]. Notably, the median delay of 6 months in our cohort is consistent with the 183 days reported in the Chinese survey of survival in patients with pulmonary arterial hypertension, suggesting that diagnostic delay may be even more pronounced in underdeveloped western regions such as Guizhou Province.

Diagnostic delay itself constitutes an independent and significant clinical hazard. From a hemodynamic perspective, the chronic elevation of pulmonary vascular resistance (PVR) during the undiagnosed period drives progressive right ventricular (RV) hypertrophy, ischemia, and ultimately failure. A Japanese study has clearly demonstrated that diagnostic delay is significantly associated with worsening RV function, and that patients in the delayed-diagnosis group have significantly lower event-free survival compared to those diagnosed early[18]. This study found that patients with delays exceeding 24 months all had severe PH, suggesting a “hemodynamic tipping point”: while early-stage PH (WHO class I–II) may present with subtle symptoms, the disease can progress to an advanced stage where right ventricular function becomes irreversibly impaired. Qualitative data indicated that patients with delays longer than 3 years (e.g., N4, N11) presented with severe PH at diagnosis, likely reflecting the transition from adaptive RV remodeling to maladaptive dilation. We propose that socio-ecological barriers (e.g., lack of referral, symptom discounting) act as “effect modifiers” that accelerate biological deterioration by depriving patients of the opportunity for early vasodilator therapy during the reversible phase of RV adaptation.

Furthermore, diagnostic delay imposes a substantial economic burden. DuBrock et al. found that patients with diagnostic delays of > 12–24 months and > 24 months incurred monthly per-patient medical costs approximately $3,986 and $5,366 higher, respectively[19], in the first year after diagnosis compared to those with delays ≤ 12 months. A large UK survey also reported that 63% of patients experienced financial worries, and employed patients saw a 13%–33% reduction in monthly income[20]. Collectively, these findings indicate that diagnostic delay not only compromises clinical outcomes but also imposes a heavy burden on families and healthcare systems.

4.2 Micro system: Non-Specific Symptoms and Insufficient Disease Cognition as the Starting Point of Delay, and the Critical Importance of Moving Nursing Education Forward

Patients attributing symptoms such as fatigue and post-exertional dyspnea to aging, colds, or overwork is the primary factor leading to delayed medical consultation. Existing studies have consistently pointed out that the lack of specificity of PH symptoms is a key reason for their difficulty in recognition [21, 22]. In this study, patients generally had no awareness of PH, revealing a widespread gap in public health literacy. Although epidemiological data show that PH is more common in women [23], neither this study nor previous research indicates that female gender leads to earlier diagnosis; instead, symptoms may be delayed due to confusion with common conditions such as menstruation or anemia [24]. This suggests that nursing staff should develop targeted health education programs for female patients to help them identify cardiopulmonary symptoms unrelated to menstrual periods. Furthermore, patients with comorbidities such as COPD, chronic cardiac failure, and hypertension experience overlapping symptoms, and poor management further masks the early manifestations of PH. This finding aligns with the clinical complexity of PH often coexisting with other diseases, as noted in previous studies [25].

The study reveals a systemic absence of nursing education at the micro level: none of the 16 patients received any PH-related knowledge from nurses before diagnosis, indicating that nursing staff should act as the "first sentinels" for PH symptoms and transmitters of health knowledge. To address the issues of symptom non-specificity and public awareness gaps, nurses should maintain high vigilance for unexplained, progressively worsening dyspnea and fatigue during community health education, outpatient triage, and inpatient assessment, particularly focusing on patients with high-risk factors such as congenital heart disease, connective tissue disease, portal hypertension, and HIV infection [26–28], actively inquiring about relevant history and conducting preliminary risk screening. Nurse-led health education has been proven to improve patients' self-care abilities and treatment adherence [29]. Studies have shown that nurse-led multidisciplinary intensive management programs can significantly improve overall survival and event-free survival rates [30]. Therefore, shifting nursing education from post-diagnosis to community and outpatient settings is a key strategy for reducing diagnostic delay.

4.3 Mesosystem: Weak Primary Care Capacity and Fragmented Referral Mechanisms as Key Bottlenecks, and the Urgent Need to Establish a Nursing Navigation Function

This study found that primary healthcare institutions failed to play a "gatekeeper" role; even when imaging or ultrasound examinations indicated abnormalities, they often failed to make a formal diagnosis or provide correct referral guidance due to insufficient knowledge. Research indicates that echocardiography is a key screening tool [31], but primary care settings may lack equipment or interpretive capabilities, with diagnosis heavily reliant on specialized centers [32, 33], suggesting a severe deficiency in the dissemination of knowledge about rare diseases among non-specialist physicians. Secondly, poor doctor-patient communication, where physicians merely state "cannot be treated" without providing clear referral guidance, leads to a breakdown in the transmission of critical diagnostic information. Patients are forced to inefficiently and blindly navigate multiple levels of medical institutions, significantly prolonging the time to diagnosis. In contrast, patients with social networks of medical resources can reach advanced medical centers more quickly.

This study reveals the absence of a nursing referral navigation function: no patient received referral guidance, medical pathway planning, or healthcare system navigation services from nurses during their diagnostic journey. However, nursing serves as a key hub connecting patients with the complex healthcare system. Facing

fragmented referral mechanisms and chaotic patient pathways, nurses need to master clear hierarchical diagnosis and treatment guidelines and referral pathways, assist patients in understanding the diagnostic process, and coordinate information transmission and communication between different levels of medical institutions. Strengthening collaboration between navigators and community providers to enhance referral networks[34], nurses can play a core role as "patient navigators"—intervening from the onset of symptoms to help patients find the correct diagnostic path within the complex healthcare system, thereby reducing the time and energy wasted in ineffective referrals.

4.4 Macro System: Structural barriers are the root cause of delays, and nursing policies and resource allocation urgently need optimization

This study reveals the severe diagnostic delay faced by PH patients, where the medical resource pattern of "concentration at the provincial level and scarcity at the grassroots level" is a structural reason for the high dependence of PH diagnosis on regional centers, particularly prominent in Guizhou Province, a less developed western region. Existing studies have confirmed that in areas with scarce medical resources, the diagnosis of pulmonary hypertension is often delayed due to a lack of advanced facilities and resources [35]. Deviations in the interpretation of examination results such as echocardiography and the lack of management pathways at primary healthcare institutions in Guizhou may further amplify diagnostic delays. The fact that patients in this study were generally diagnosed at moderate to severe stages is a concentrated reflection of this challenge in resource-poor areas. Patients in rural Guizhou face a more pronounced gap in medical accessibility due to unfavorable geographical environments and weak social support networks. Furthermore, the systemic absence of PH public education across society [17], along with the lack of standardized screening systems for high-risk populations and norms for hierarchical diagnosis and treatment of rare diseases, means that early detection lacks institutional leverage [36, 37]. These macro-level structural factors collectively contribute to more severe diagnostic delays and disease burden.

Insufficient nursing resources in the western region, the lack of clinical nurse specialist deployment to grassroots levels, and an imperfect community nursing system are concrete manifestations of macro-structural barriers at the nursing level. All rural patients in this study had no contact with community or primary care nurses possessing basic PH knowledge during their medical visits, indicating that the nursing profession should promote and deeply engage in multidisciplinary team (MDT) collaboration. In a team composed of specialist physicians, nurses, pharmacists, rehabilitation therapists, nutritionists, and psychologists, nurses assume core functions such as coordinating care plans, implementing interventions, conducting long-term follow-ups, and dynamically assessing patients' overall conditions. Nurse-led multidisciplinary intensive management programs have been proven to significantly improve the long-term survival of PH patients[30]. Therefore, strengthening specialized PH knowledge training for nursing staff, promoting the downward deployment of specialized nursing resources to grassroots levels, and establishing a community-hospital linked nursing screening and education network are key steps to bridge the knowledge translation gap and build an efficient care system. At the same time, nursing managers should actively participate in macro-level policy advocacy, promoting the inclusion of PH in the coverage of chronic and special diseases, establishing guidelines for rare disease nursing and standards for primary care nursing training, thereby providing institutional safeguards to shorten diagnostic delays.

4.5 Strengths and Limitations

Strengths: This study is the first to apply the social-ecological system theory to systematically analyse diagnostic delay in PH patients from a nursing perspective, providing a comprehensive theoretical framework that captures the multidimensional nature of the problem. The narrative research method enabled rich, detailed accounts of patients' healthcare journeys, uncovering critical nursing intervention gaps that might not be identifiable through quantitative methods. The triangulation of data sources (interviews, observations, medical records) and dual independent coding enhanced the trustworthiness of the findings.

Limitations: This study has several limitations. First, as a single-centre study conducted at a tertiary hospital in Guizhou Province, the findings may not be transferable to other regions with different healthcare systems and resource distributions. Second, the sample comprised only patients who had eventually reached a tertiary centre for diagnosis, potentially missing the experiences of those who remained undiagnosed or diagnosed in other settings. Third, the study relied on retrospective patient narratives, which may be subject to recall bias. Fourth, the perspectives of healthcare providers—particularly nurses and primary care clinicians—were not included, which may have provided additional insights into systemic barriers.

4.6 Recommendations for Further Research

Future research should employ multi-centre designs across different regions and healthcare settings to enhance the generalisability of findings. Incorporating the perspectives of nurses, primary care clinicians, and family caregivers through triangulation would provide a more comprehensive understanding of diagnostic delay mechanisms. Interventional studies are needed to develop and validate nurse-led early screening protocols, patient navigation programmes, and comprehensive chronic disease management models for PH patients. Quantitative studies examining the association between specific nursing interventions and diagnostic delay duration would strengthen the evidence base for nursing practice. Additionally, research exploring the effectiveness of community-based PH education programmes and tele-nursing follow-up models in resource-limited settings is warranted.

5 Conclusion

Based on the social ecological system theory framework, this study systematically reveals the complex systemic causes of diagnostic delay in patients with newly diagnosed pulmonary arterial hypertension through narrative research on 16 patients. The study found that delay results from the interaction of multiple factors at the micro-individual cognition, meso-medical service, and macro-policy environment levels: the non-specificity of symptoms and the lack of public disease awareness constitute the starting point of healthcare-seeking delay; the weak screening and identification capabilities of primary healthcare institutions, broken referral pathways, and ineffective doctor-patient communication form the key bottlenecks in delayed diagnosis; while the high concentration of specialized medical resources, incomplete medical security system for rare diseases, and the systemic absence of disease science popularization across society build deep structural barriers hindering early diagnosis. These factors lead to patients being diagnosed at moderate to advanced stages and bearing dual burdens of health and economy. In view of this, breaking the dilemma requires building a full-chain intervention system. Nursing staffs should proactively move their role forward, becoming early disease warners and health knowledge disseminators, fully leveraging patient navigation functions to optimize referral processes, leading the implementation of comprehensive chronic disease management covering drug administration, symptom monitoring, rehabilitation guidance, and psychological support, and deeply integrating into multidisciplinary teams as the core of care coordination. As a qualitative exploration, this study has limitations such as a single

center and small sample size. Future research can adopt multi-center designs and include multiple perspectives such as medical staff and family members for triangulation, thereby developing and validating precise intervention models centered on "nursing navigation" targeting each stage of the diagnostic journey, to effectively shorten diagnostic delay and improve patient clinical outcomes.

Abbreviations

PH: Pulmonary hypertension

WHO: World Health Organization

RV: Right ventricle/right ventricular

PVR: Pulmonary vascular resistance

COPD: Chronic obstructive pulmonary disease

COREQ: Consolidated Criteria for Reporting Qualitative Research

IQR: Interquartile range

TRV: Tricuspid regurgitation velocity

MDT: Multidisciplinary team

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of Guizhou Medical University (approval number: 2025 Ethics (385)). All participants provided written informed consent prior to enrolment. The study was conducted in accordance with the Declaration of Helsinki.

Clinical trial number

Clinical trial number: not applicable.

Consent for publication

Not applicable. This manuscript contains no individual person's data in any form (including individual details, images, or videos).

Availability of data and materials

The qualitative data generated and analysed during this study are not publicly available due to the sensitive nature of patient narratives and the confidentiality agreement approved by the Ethics Committee (approval number: 2025 Ethics (385)). De-identified excerpts are presented within the manuscript to support the findings. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

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Authors' contributions

MC and WQY contributed to the study conception and design. MC conducted the interviews, performed the data analysis, and drafted the manuscript. WQY supervised the research process, contributed to data interpretation, and critically revised the manuscript for important intellectual content. All authors read and approved the final manuscript. WQY is the guarantor of this work, taking full responsibility for the integrity of the data and the accuracy of the data analysis.

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