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## Lived experiences of the disease journey among patients with idiopathic pulmonary fibrosis

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**CRedit authorship contribution statement**

**Yang Lyu:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing-original draft. **Yan-Rui Jia:** Validation, Formal analysis, Investigation, Resource. **Feng-Li Gao:** Supervision, Writing-reviewing and editing. **Ya-Ling Huang:** Validation, Formal analysis, Supervision, Writing-reviewing and editing. **Frances Lin:** Validation, Formal analysis, Supervision, Writing-reviewing and editing.

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**Declaration of competing interest**

The authors declare that there are no conflicts of interest regarding the publication of this paper.

## **Lived experiences of the disease journey among patients with idiopathic pulmonary fibrosis**

### **Abstract**

*Objective:* This study aimed to explore the lived experiences of the disease journey and patients' care needs with idiopathic pulmonary fibrosis (IPF).

*Methods:* Face-to-face semi-structured interviews were conducted with a purposive sampling of IPF patients admitted to the department of respiratory medicine in a tertiary hospital in Beijing. Interview data were analyzed using the thematic analysis method. In the end, 16 patients were interviewed.

*Results:* Four themes emerged from the qualitative data included the long and confusing journey to reach a diagnosis, living with the disease, understanding the disease and treatment and desire for continuity of care. A series of subthemes were also identified, including uncertainty of diagnosis, delaying the process, living with physical symptoms, living with emotional distress, loss of independence, uncertainty with the prognosis, questioning the cause of the disease, concerning the side effects of treatments, lacking continuity of care, and wanting a better quality of healthcare in community hospitals.

*Conclusions:* Based on the findings, there is an urgent need to improve the care delivery to this vulnerable population in China. To meet their health needs, it is of paramount importance to develop effective education programs for health professionals and IPF patients and improve care models of healthcare systems, especially in remote areas, to enhance care continuity in the communities.

### **Keywords**

Health services needs and demand

Idiopathic pulmonary fibrosis

Patients

Qualitative research

Journal Pre-proof

**What is known?**

- Patients with idiopathic pulmonary fibrosis (IPF) have a low survival rate and poor life quality.
- The optimal management for IPF patients is suggested to improve outcomes by slowing down the progression of lung fibrosis, which helps extend the life expectancy and improve the quality of life.
- Studies exploring the lived experience and care needs of patients with IPF in European countries show that patients commonly experience protracted delays in receiving an accurate diagnosis and need further improvement in disease management and patient education.

**What is new?**

- Patients with IPF in the Chinese context felt “disconnected with the healthcare system,” a systems approach to provide integrated care is needed in China.
- There is a need to improve healthcare systems’ care models to enhance the principle of continuity of care for IPF patients in the communities in China’s remote areas.
- Education and support programs tailored to this vulnerable group of people to improve their disease journey experience and quality of life are needed.

## 1. Introduction

Idiopathic pulmonary fibrosis (IPF) is defined as a progressive, incurable, fibrotic interstitial lung disease (ILD) of unknown cause [1], characterized by impaired gas exchange, progressive decline in lung function, and increased symptoms that limit physical activities [2]. Worldwide, the prevalence of patients diagnosed with IPF has been rising over the last decade [3]. In the US, the majority has been steadily increasing from 13.4 cases in 2005 to 18.2 cases in 2010 per 100,000 person-years [4]. In Europe, the IPF case rose from 1.25 to 23.4 per 100,000 populations in Belgium, the Czech Republic, Finland, Greece, and Italy [5]. There are approximately 5,000 new cases being diagnosed in the UK, with 15,000 prevalence cases annually [6].

In China, there has been an increase in the incidence of ILD (including IPF). ILD Group of the Chinese Thoracic Society (2004) revealed that 56 ILD cases were admitted to 10 hospitals in Beijing in 1990, accounting for 1.98% of yearly hospitalized cases. The caseload reached 485 in 2003, accounting for 4.66% of yearly hospitalized cases [7]. A survey conducted in ten hospitals in Tianjin province in China showed that hospitalized ILD cases accounted for 4.5% of all hospitalized cases in 2003. This rate rose to 39.5 % in 2009 [8].

It is suggested that there is an increased financial cost of IPF treatment and poor prognosis with a median survival rate between 3–5 years from the time of diagnosis to the death [6, 9]. The diagnosis and management of IPF patients often remain a significant challenge for clinicians. The literature has suggested that patients with IPF often experience ongoing symptoms of dyspnea, dry coughs, sleep disturbance, and emotional distress [2, 10]. Such symptoms often result in loss of independence and restriction of daily activities [10, 11]. This group of patients usually has a poorer quality of life (QoL) than patients with other types of respiratory diseases [12]. IPF is often misdiagnosed and inappropriately managed [13]. For instance, a European study reported that it usually takes 2–5 years to reach a correct diagnosis for IPF patients



[14]. The delayed diagnosis often causes distress and frustration to patients and their families. Insufficient information and support for IPF patients are also reported in some studies [15, 16]. Studies suggested that to improve modern IPF care, and it is essential to provide the accurate and timely provision of information, to improve access to specialist care, to offer more support for managing the progression of lung fibrosis and treatment side effects, as well as better coordination of care [15-17].

It is argued that healthcare systems vary across countries and significantly impact the IPF patients' experiences and treatment journey. IPF patients reported a lack of healthcare support structures (i.e., cost, remote access to specialists) and regional IPF network as one of the barriers during their disease journey in Western studies [15, 16]. In China, IPF support in the primary, rural and regional healthcare systems is scarce. For example, patients often have to make the decision in which specialists they should see. This could lead to misdiagnosis and a long journey to reach a correct diagnosis. Therefore, to guide future tailored interventions on improving the care of IPF patients in China, it is essential to understand the lived experiences regarding this population's disease journey and care needs. To our knowledge, this was the first study exploring the lived experience of the diagnosis journey and the care needs of Chinese patients with IPF.

## **2. Methods**

### **2.1. Aim**

This study aimed to explore the lived experiences of the disease journey and Chinese patients' care needs with IPF.

### **2.2. Study design**

Husserl's descriptive phenomenological method with the face-to-face interview was used [18]. Husserl's descriptive phenomenology seeks the narratives of human

experiences, and it mainly focuses on the correlation of the noema of expertise (the “what”) and the noesis (the “how it is experienced”) [19]. The reporting of this research followed the Consolidated Criteria for Reporting Qualitative Research (COREQ)[20].

### **2.3. Setting and participants**

Hospitals are classified as a 3-tier system in China, including primary-level, secondary-level, and tertiary-level facilities. The 3-tier system recognizes a hospital’s bed capacity and medical treatments, education, and research ability. Patient understanding is higher at the tertiary-level facility as it offers care to patients with complex healthcare needs.

This study was conducted in a 44-bed department of respiratory medicine in a 1400-bed tertiary hospital in Beijing, China. Inclusion criteria were: 1) patients with confirmed IPF diagnosis; 2) can give informed consent; and 3) could speak and understand mandarin to take part in an interview. A purposive sampling approach was used. That is, prospective participants with IPF were identified and referred to the research team by respiratory physicians.

### **2.4. Data collection**

Face-to-face semi-structured interviews were conducted in Chinese between August 2018 and February 2019. The interviewer (YL), an experienced qualitative researcher. She is bilingual in English/Chinese; the female had extensive knowledge in respiratory care with a master’s degree in nursing science and did not provide care to the participants. Data collection continued until there was any evidence of no recurring themes from the data. As a result, 16 participants were interviewed. Interviews were audio-recorded (50–60 min) at the time. A quiet and safe room in the department was chosen to conduct interviews with participants. Before the study, a rapport was established with the team leader and patients by observing routine care on the ward. An explanatory statement was given, such as study nature, interview process,

benefits and risks, privacy and confidentiality, consent to participate, and concerns/complaints process. The interviewer obtained their informed consent before commencing with the interview.

The interview started with a broad question: “Could you please tell me your experiences regarding how you were diagnosed with IPF?” Participants were encouraged to use their own words and tell their own stories in an open and free manner. The topic covered but not limited to their understandings of IPF and their experiences regarding diagnosis, living with the disease, care needs, and treatment options. Prompt questions were used, such as “then, what happened?” “Could you please tell me how that affected you?” “What were your thoughts and feelings?” Meaningful facial and body expressions were also recorded. Participants were informed that the interview could be stopped at any time if required.

## **2.5. Data analysis**

Sixteen interview records were transcribed verbatim into Chinese and translated to English by the researcher (YL). Translated transcripts were reviewed by the all-bilingual (Chinese and English) team. Braun and Clarke’s (2006) six-step thematic data analysis guided the process: i) familiarizing with the data; ii) generating initial codes; iii) searching for themes; iv) reviewing themes; v) defining and naming themes; vi) producing the report [21]. Two researchers (YL, YRJ) independently read and reread all the transcripts to interpret the data. Key quotes were highlighted, and initial codes were developed based on participants’ verbatim statements. Codes were grouped according to similarity into subthemes and then themed based on common threads throughout the data. Any disagreement or contested theme/subtheme was discussed with all researchers (YL, YRJ, FLG, YLH, FL) until consensus was reached. Interview transcripts were returned to participants for comments, and further clarifications, their verbatim expressions of participants supported the subthemes.

## **2.6. Ethics**

The Human Research and Ethics Committee of the hospital approved the study (ethics number: 2018-8-23-1). All participants were fully informed and consented to the interview. Confidentiality, privacy, and anonymity of all participants were ensured. The interview records are stored as de-identified files (coded as P1, P2, P3, and so on) in a password-protected computer that the research team can only access. The interview records will be retained for five years from the publication date and deleted from the computer.

### **2.7. Trustworthiness**

Trustworthiness was ensured by evaluating credibility, dependability, confirmability, and transferability[22]. Credibility was achieved by in-depth interviews followed by peer debriefing. Two researchers (YL, YRJ) analyzed the transcripts independently by bracketing data on preconceived ideas and strictly following Braun and Clarke's (2006) six-step thematic data analysis described above. In terms of dependability, all researchers (YL, YRJ, FLG, YLH, FL) had open discussions for the similarities or differences of the interview contents, which may change during the interview data collection. The researcher (YL) asked follow-up questions, sought clarity from the responses, and briefly described the data collection process to ensure transferability. A paper trail was kept recording significant ideas or incidents emerging from the conversation with the participants for confirmability. The interviewer (YL) also asked participants to provide their feedback on the transcripts for further clarifications.

## **3. Results**

There were 16 participants with 13 males and three females. Participants' age ranged from 35 to 72 years old with a mean age of 59 years. The diagnosis journey (from initial symptoms to confirmed IPF diagnosis) was between 1.5–5 years with an average of 2.9 years. Around one-third of participants had high school education,

followed by primary and secondary schools. Only three participants had a university education. Table 1 shows the characteristics of participants with IPF.

Thematic analysis of the participant narratives uncovered four themes representing the lived experiences of patients with IPF. Data analysis revealed associated sub-themes under the main themes. Table 2 shows the themes and associated sub-themes.

### **3.1. The long and confusing journey to reach a diagnosis**

Participants described their long journey to get a correct diagnosis, including uncertainty of diagnosis and delaying process. Common initial symptoms experienced by participants were shortness of breath and cough. While some participants did not take it seriously, others looked for medical advice from their local community hospitals.

The majority of the participants (14/16) were initially misdiagnosed as having other types of respiratory diseases, such as asthma, Chronic Obstructive Pulmonary Disease (COPD), or pneumonia, and were consequently given symptom-relieving medication such as cough suppressants, inhalations, and oral antibiotics. They seek treatment with a cardiologist in a specialized hospital for cardiac disease patients, as they attributed exertional dyspnea to cardiac dysfunction. Most did not look for further medical advice until the condition deteriorated and significantly affected their daily living activities. As one participant stated:

*“I was just short of breath, and I coughed a lot. I went to the hospital, had a chest X-ray. The doctors said that I had chronic obstructive pulmonary disease. Then I went to another hospital, and I was told it was pneumonia. Anyway ... different diagnosis. Finally, I came to this hospital [specialized hospital in respiratory medicine] and was diagnosed with [IPF]” (P8)*

There was a 3 to 4 years delay of confirmation of IPF diagnosis for many participants. Two participants from the countryside had more than five years delay. They looked for further medical advice at several hospitals. Some participants underwent multiple and repeated diagnostic tests and procedures, such as blood, X-ray, and spirometry tests, before reaching IPF diagnosis. As participant two described:

*“It was nearly five years. [I] did all the examinations, chest function, blood sample, X rays. I went [to]nearly four to five hospitals to get the final diagnosis. Every time the prescribed medicines appeared to be working for a while, so it was delayed over and over again.” (P2)*

### **3.2. Living with the disease**

Participants described their lived experiences with the disease as living with physical symptoms, emotional distress, loss of independence, and uncertainty with the prognosis.

Most participants stated that the severity of the physical symptoms was associated with the progression of the disease. Breathlessness and persistent cough were the common symptoms, which significantly affected daily activities. They also experienced the signs of fatigue, sleep disturbance, and chest pain. As participant six stated:

*“... shortness of breath. [It is] like something was strangling my throat. Sometimes, I felt like choking, especially during physical activities. I cough all night, and my chest hurts. I can’t even sleep. I always feel exhausted with energy.” (P6)*

Participants also experienced emotional distress, i.e., feeling anxious, frustrated, and depressed due to the protracted disease journey, physical symptoms, and limitations to daily activities. The distress severity can be affected by the disease progression. Most participants often expressed feelings of guilt because they needed help with regard to necessary activities from their families daily.

*“Now even go to the toilet, I have to depend on [family members]. I cannot move freely. My daughter had to quit her job to take care of me. My wife was not in good health either. She has diabetes, but she takes care of me every day [and also] does housework. I feel that I am a burden to my family. I feel very frustrated.”(P8)*

Participants also expressed how the disease shaped their ordinary life and social function. As one participant stated,

*“I used to climb the mountain and ride a bicycle. It was fine. I can’ t do it now (sigh).” (P4)*

Also, uncertainty with the prognosis emerged from the interview data. Many participants expressed a strong feeling of uncertainty regarding the disease’s prognosis and its impact on their life. They often wondered if they could go back to their normal lives, especially young participants concerned about their careers. As stated by a 35 years old male participant,

*“Can this disease be cured? What will life be for me in the future? Will I have to depend on the oxygen for the rest of my life?” (P5)*

### 3.3. Understanding the disease and treatment

Questioning the cause of the disease and concerning the side effects of treatments were emerged from the interview data. Most participants stated that they had “never heard of ILD or IPF” and had insufficient knowledge regarding the cause, prognosis, and treatments of the disease. They often questioned the cause of the disease. As these quotes illustrated,

*“I always have the doubt why I get this pulmonary disease. I never smoked, and I have a very healthy lifestyle. I exercise regularly. I want doctors and nurses [to] tell me [more about] this disease, [helping] me [to] figure [it] out.” (P5)*

*“I don’t know if it is associated with the haze/smoke [in our environment]...I usually do not wear a mask when I go out. I regretted it. If I wore a mask, it might reduce the smoke inhaling. Maybe, I would not get the disease.” (P8)*

Also, immunosuppressants and anti-fibrotic drugs are commonly used for treating patients with IPF. Participants often expressed their concerns regarding the side effects, as they did not know much about the IPF treatment medications. As one participant stated,

*“I have taken immunosuppressant for a long time. I am worried about side effects, be addicted and cannot stop.” (P4)*



### 3.4. Desire for continuity of care

Participants described their experiences in care needs from health professionals as lacking continuity of care and further expressed the hopes of a better quality of healthcare in community hospitals.

In the interviews, participants expressed their desire for the continuity of care post-discharge from the specialized hospitals. They hoped that health professionals in the specialized hospital could provide more knowledge, especially on self-managing the disease at home. They wanted specific instructions or education about diet, oxygen use, medication, and daily activities. However, there was no support after being discharged home. As one participant stated,

*“When I need professionals to help in my hometown, I don’t know who I can ask. Obviously, I don’t think community hospital staff know how to treat such uncommon disease.” (P11)*

Participants often had to attend the follow-up appointments at the local primary care setting or community hospitals closer to home and are more accessible than the specialized hospitals, which often require them to travel long distances. They reported having low confidence in the healthcare quality in the community hospitals.

*“Doctors in community hospitals only prescribed some medications and drips. You really can’t trust them. The pulmonary rehabilitation program (during my stay in the specialized hospital) made me feel better to breathe. Still, I don’t think the doctors and nurses in the community hospitals are properly trained for this [pulmonary rehabilitation].” (P5)*

## 4. Discussion

To our knowledge, this study was the first study exploring the lived experience of the diagnosis journey and the care needs of Chinese patients with IPF. The interview data depicted a vivid picture of “being disconnected with the healthcare system” where IPF patients struggled throughout the disease journey.

Four main themes emerged from the data featured in IPF patients’ narratives of lived experiences. Firstly, the participants’ most overwhelming issue is their long journey (on average two to three years) from the initial symptoms to confirming the diagnosis. Participants were often “misdiagnosed” as asthma, COPD, recurrent pneumonia, or “undiagnosed”. This is consistent with the findings of Collard's study (2007) in the USA, which reported that 55% of patients reported delay at least one year from initial symptoms to a final diagnosis [14]. In a 2018 nationwide survey in the US, more than half of participants had to consult with more than three physicians to confirm the diagnosis of IPF [23]. This could be explained by the fact that diagnosing IPF is a challenging issue. Patients often present with the initial symptoms of breathlessness and cough, which are common symptoms of other respiratory diseases. While some regard breathlessness related to the aging process, others often attribute cardiac disease symptoms [23].

Also, Qian (2012) stated that respiratory diseases’ public literacy is lower than other chronic diseases such as diabetes and hypertension among the public in China [24]. It is suggested that it is essential to enhance people’s knowledge on IPF [24], and also provide systematic education and training to health professionals in community hospitals with early detection, a timely and accurate diagnosis which in turn help to avoid unnecessary tests, treatments and to improve the outcomes [25].

The second theme that emerged from the data reflects the lived experiences of patients living with IPF. Participants expressed the struggles of living with the physical symptoms and emotional distress and coping with independence loss. They

also expressed their feelings of uncertainty about the prognosis and the future. Participants' symptoms in this study are similar to what had been reported in the literature [26].

Current literature suggests that symptom management and palliative care are regarded as the cornerstones to improve QoL for IPF patients [3]. The National Institute for Health and Care Excellence (NICE) (2015) published a quality statement recommending that people with IPF should have an ILD specialist nurse available from the diagnosis to the end of life[3]. ILD specialist nurses can conduct a comprehensive assessment and make individual care plans throughout all stages of the disease, such as daily living activities, oxygen use, education on medication management, and emotional support[15]. Since the systematic training program of specialist nurses implemented in the year 2000 in China, there has been an increased number of trained specialist nurses in intensive care unit, operation theatre, emergency, diabetes, pressure injury, and intravenous therapy[27]. However, there is still no specialist nurse training available in ILD (including IPF) in China. This gap needs to be addressed to provide useful and quality care for Chinese patients with IPF.

The third theme that emerged from the data was understanding the disease and treatment. This finding was supported by Bajwah et al, who described that patients with IPF were not given accurate information about the progression and the prognosis of the disease [28]. Most participants in the present study asked why they had the disease, especially for the patients who had a healthy lifestyle. The present study suggests that inexperienced physicians may not know how to initiate the open discussion about the IPF with patients and their caregivers. Lack of open dialogue and information disclosure could lead to uncertainty, fear, doubt, and anxiety. There is a strong recommendation to establish a patient-centered care model, which focuses on collaboration and shared decision-making with patients[29]. Such a model can help facilitate the decision-making process regarding the treatments and education on disease and symptom management, improving the treatment outcomes and the QoL [17].

The desire for continuity of care also emerged from the data. Most study

participants were from northern regions of China, a remote area that is hundreds of kilometers away from specialized hospitals located in bigger cities. They often experienced a lack of continuity of care due to insufficient coordination between specialized hospitals and community hospitals after being discharged home. In the interviews, they described the uncertainty of the care quality provided by the community health professionals. In European countries, the local network for ILD (including IPF) specialist centers has been established, working in collaboration and partnership with healthcare professionals and policymakers to improve care quality for patients in the community[9]. Despite a recommendation from the NICE, which states that pulmonary rehabilitation can improve exercise capacity and QoL [30], there is still unequal access to pulmonary rehabilitation in China's community hospitals.

This study suggests that it is essential to increase public awareness of IPF, improve treatment outcomes and symptom management via collaboration with multidisciplinary teams, and provide a timely and accurate diagnosis. A care model with specialized ILD (including IPF) nurses must provide continuous care and improve care quality for patients with IPF.

## **5. Limitations**

There are some study limitations. Firstly, all the participants came from the northern region of China. The findings should be interpreted with caution because patients' experiences in other parts of China may be different due to different healthcare systems across China. However, the patients' experiences illustrated in this study may shed some light on how future improvements can be made to improve the quality and continuity of care for this vulnerable population. This study also acknowledges no evidence of no recurring themes from the data but does not claim that the data saturation has occurred.

## 6. Conclusions

The findings provide in-depth knowledge on the lived experience of Chinese patients with IPF. The themes that emerged from the interview data feature the lived experiences of IPF patients' narratives. The establishment of a comprehensive symptom management program and an integrated primary healthcare system is needed to provide continuous care post-discharge and improve the QoL of this vulnerable population in China.

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Table 1 Characteristics of participants with idiopathic pulmonary fibrosis

No.	Gender	Age ( years )	Education level	Occupation	Long-term residence	City/Countryside	Length from initial symptom to diagnoses ( years )
1	M	56	Primary school	Farmer	Hebei Province	Countryside	3
2	M	65	University level	Teacher	Inner Mongolia Autonomous Region	City	2
3	M	63	High school	Worker	Anhui Province	Countryside	3.5
4	M	58	Primary school	Farmer	Inner Mongolia Autonomous Region	Countryside	3
5	M	35	University level	White collar	Beijing	City	1.5
6	M	55	High school	White collar	Inner Mongolia Autonomous Region	City	1.5
7	M	59	Primary school	Farmer	Beijing	Countryside	3
8	F	66	High school	Officer	Heilongjiang Province	City	2.5
9	M	72	Secondary school	Worker	Beijing	City	2.5
10	F	70	Primary school	Farmer	Hebei Province	Countryside	5
11	M	52	High school	Teacher	Inner Mongolia Autonomous Region	Countryside	5
12	M	54	Secondary school	Worker	Heilongjiang Province	City	3.5
13	M	67	Secondary school	Worker	Liaoning Province	Countryside	2
14	M	56	High school	Officer	Hebei Province	City	2.5
15	F	62	Secondary	Worker	Beijing	Countryside	3

school

16	M	58	University level	Officer	Liaoning Province	City	2.5
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*Note:* Primary school: 1–6 education years; Secondary school: 7–9 education years; High school: 10–12 education years; University level: >12 education years.

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**Table 2** Themes and associated sub-themes

Themes	Sub-themes
The long and confusing journey to reach diagnosis	Uncertainty of diagnosis Delaying process
Living with the disease	Living with physical symptoms Living with emotional distress Loss of independence Uncertainty with the prognosis
Understanding the disease and treatment	Questioning the cause of the disease Concerning the side effects of treatments
Desire for continuity of care	Lacking continuity of care Wanting better quality of healthcare in community hospitals