Lived experiences of patients with idiopathic pulmonary fibrosis: navigating through the complex healthcare system

Yang Lyu (✉ lyyang_369@126.com)

Beijing Chaoyang Hospital

Yanrui Jia

Beijing Chaoyang Hospital

Fengli Gao

Beijing Chaoyang Hospital

Ya-ling Huang

Griffith University - Gold Coast Campus

Frances Lin

University of the Sunshine Coast

Research

Keywords: Experiences, Care needs, Qualitative study, Idiopathic pulmonary fibrosis

Posted Date: July 23rd, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-45620/v1>

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Abstract

Background: Over the last decade, idiopathic pulmonary fibrosis (IPF) has been attracting healthcare professionals' attention worldwide due to its impact on poor survival rate and quality of life, such as ongoing physical and emotional distress experienced by patients and their families. The diagnosis and management of IPF patients often remain a significant challenge for clinicians. Therefore, it is imperative to gain an in-depth understanding on experiences of IPF patients during their disease journey in order to improve the care delivered to this vulnerable group. We aimed to explore the lived experiences of disease journey and care needs of patients with IPF.

Methods: Semi-structured face-to-face interview were conducted with a purposive sampling of sixteen IPF patients admitted to the department of respiratory medicine in a tertiary hospital in China. The consolidated criteria for reporting qualitative research was followed.

Results: Four themes emerged from thematic analysis of the qualitative data included: the long and confusing journey to reach diagnosis, living with the disease, understanding the disease and treatment, and desire for continuity of care.

Conclusions: 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 to improve care models of healthcare systems, especially in the remote area in order to improve the continuity of care in the communities.

Background

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 increasing over the last decade [3]. In US, the prevalence 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]. In the UK, there are approximately 5,000 new cases being diagnosed with 15,000 prevalence cases annually [6].

In China, there has been an increased 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, while the case load 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 as 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]. As such, this group of patients often has poorer quality of life (QoL) compared to patients with other types of respiratory diseases [12]. It is evident that 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]. Current literature recommends that management of IPF patients should focus on slowing down the progression of lung fibrosis, which in turn helps to extend patients' life expectancy and improve their QoL [16].

There have been some studies describing patients' experiences of living with IPF in European countries [15, 17]. Still, there has been a paucity of research exploring the lived experience of IPF patient in Chinese population. Given the complex nature of IPF disease, there is a need to gain an in-depth understanding of the lived experiences regarding their disease journey and care needs.

Methods

Aim

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

Study design

A phenomenological approach with face-to-face interview was used [18]. Phenomenology seeks the narratives of the lived experiences of a certain phenomenon and it is considered the most appropriate methodology to explore the way people experience and interpret the world where they live in [19]. The reporting of this research followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Supplementary Material S1) [20].

[Insert Supplementary Material S1 about here]

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 ability to medical treatments, education and research. Patient acuity 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: i) patients with confirmed IPF diagnosis; ii) no psychiatric history; and iii) able to speak and understand Chinese. Purposive sampling approach was used. That is, prospective participants with IPF were identified and referred to the research team by respiratory physicians.

Data collection

Sixteen semi-structured interviews were conducted in Chinese between August 2018 and February 2019 by an experienced bilingual female researcher (YL) who had extensive knowledge in respiratory care with a master's degree and did not have therapeutic relationships with the participants. Interviews were audio-recorded (50–60 minutes) at the time and location convenient to the participants in the hospital. Prior to 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 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 story 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 can be stopped at any time, if required.

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 for immersion of 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 themes based on common threads throughout the data. Any disagreement or contested theme/subtheme was discussed within the team with all researchers (YL, YRJ, FLG, YLH, FL) until consensus was reached. Interview transcripts were returned back to participants for comments and further clarifications.

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 before 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 which can only be accessed by the research team. The interview records will be retained for five years from the publication date and then will be deleted from the computer.

Trustworthiness

Trustworthiness were ensured by evaluating credibility, dependability, confirmability and transferability [22]. To strengthen credibility, regular meetings within the research team (YL, YRJ, FLG, YLH, FL) were held to discuss the emerging codes, subthemes and themes. 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 collection of interview data. Transferability was ensured by providing a detailed description of the healthcare context in China and characteristics of participants. As for confirmability, a paper trail was kept recording significant ideas or incidents emerging from the conversation with the participants. The interviewer (YL) also asked participants to provide their feedbacks on the transcripts for further clarifications.

Results

There were 16 participants with 13 males (81.3%) and 3 females (18.7%). Participants' age ranged from 35 to 72 years old with mean age 59 years). 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 3 participants had university education. Table 1 shows the characteristics of participants with IPF.

Table 1
Characteristics of participants with IPF

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

*Primary school: 1–6 education years; Secondary school: 7–9 education years; High school: 10–12 education years; University level: >12 education years

No.	Gender	Age	Education level*	Occupation	Long-term residence	City/Countryside	Length from initial symptom to diagnoses
14	M	56	High school	Officer	Hebei Province	City	2.5 years
15	F	62	Secondary school	Worker	Beijing	Countryside	3 years
16	M	58	University level	Officer	Liaoning Province	City	2.5 years
*Primary school: 1–6 education years; Secondary school: 7–9 education years; High school: 10–12 education years; University level: >12 education years							

Thematic analysis of the participant narratives uncovered four themes representing the lived experiences of patients with IPF. These included: the long and confusing journey to reach diagnosis, living with the disease, understanding the disease and treatment, and desire for continuity of care. Table 2 shows the themes and associated sub-themes.

Table 2
Themes and associated sub-themes

Themes	Sub-themes
The long and confusing journal to reach diagnosis	<ul style="list-style-type: none"> • Uncertainty of diagnosis • Delaying process
Living with the disease	<ul style="list-style-type: none"> • Living with physical symptoms • Living with emotional distress • Loss of independence • Uncertainty with the prognosis
Understanding the disease and treatment	<ul style="list-style-type: none"> • Questioning the cause of the disease • Concerning the side effects of treatments
Desire for continuity of care	<ul style="list-style-type: none"> • Lacking continuity of care • Wanting better quality of healthcare in community hospitals

The long and confusing journey to reach 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.

Majority of the participants (n = 14, 87.5%) 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. For those with cardiac disease, they seek for treatment with a cardiologist in a specialized hospital, 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 3 to 4 years delay of confirmation of IPF diagnosis for many participants. Two participants from the countryside had more than 5 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 5 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)

Living with the disease

Participants described their lived experiences with the disease as: i) living with physical symptoms; ii) living with emotional distress; iii) loss of independence; and iv) 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 the daily activities. They also experienced the symptoms 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 very tired with energy." (P6)

Participants also experienced emotional distress i.e. feeling anxious, frustrated and depressed due to the long 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 regards to basic activities from their families on the daily basis.

"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)

In addition, uncertainty with the prognosis emerged from the interview data. Many participants expressed a strong feeling of uncertainty regarding the prognosis of the disease and its impact on their life. They often wondered if they could go back to their normal lives, especially young participants who were 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)

Understanding the disease and treatment

Most participants stated that they had "never heard of ILD or IPF" and that they 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 may reduce the smoke inhaling. Maybe, I would not get the disease." (P8)

In addition, immunosuppressant 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 medications used for the IPF treatment. As one participant stated,

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

Desire for continuity of care

Participants described their experience in care needs from health professionals as: i) lacking continuity of care; and ii) wanting 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 how to self-manage 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 that are closer to home and are more accessible than the specialized hospitals, which often require them to travel long distance. They reported having low confidence on the healthcare quality in the community hospitals.

"Doctors in community hospitals only prescribed some medications and drips. You really can't trust them. Pulmonary rehabilitation program (during my stay in the specialized hospital) made me feel better to breath, but I don't think the doctors and nurses in the community hospitals are properly trained for this [pulmonary rehabilitation]." (P5)

Discussion

To our knowledge, this study was the first study exploring the lived experience of the diagnosis journey and the care needs of the 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 most overwhelming issue expressed by the participants is their long journey (on average 2–3 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 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 as patients often present with the initial symptoms of breathlessness and cough, which are common symptoms of other respiratory diseases. While some regard breathlessness is related to the aging process, others often attribute the symptoms to the cardiac disease [23].

In addition, Qian (2012) stated that the public literacy of respiratory diseases is lower than other chronic diseases such as diabetes and hypertension among the public in China [24]. It is suggested that it is important to enhance people's knowledge on IPF [24], and also provide systematic education and training

to health professionals in community hospitals with early detection, timely and accurate diagnosis which in turn help to avoid unnecessary tests, treatments and to improve the outcomes [25].

The second theme 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 loss of independence. They also expressed their feelings of uncertainty with the prognosis and the future. Symptoms expressed by participants in this study are similar to what had been reported in 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 in recommending that people with IPF should have an ILD specialist nurse available from the diagnosis to the end of life [3]. ILD specialist nurse can conduct comprehensive assessment and make individual care plan throughout all stages of the disease, such as activity of daily livings, 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 numbers of trained specialist nurses in the areas of intensive care unit, operation theatre, emergency, diabetes, pressure injury, and intravenous therapy [27]. However, there is still no specialist nurse training available in the area of ILD (including IPF) in China. This gap needs to be addressed to provide effective and quality care for Chinese patients with IPF.

The third theme emerged from the data was understanding the disease and treatment. This finding was supported by Bajwah et al. (2013) 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 discussion 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 a shared decision-making with patients [29]. Such model can help to facilitate the decision-making process regarding the treatments and education on disease and symptom managements, which in turn improve the treatment outcomes and the QoL [16].

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 have been established working in collaboration and partnership with healthcare professionals, policy makers to improve quality of care for patients in the community [9]. Despite recommendation from the NICE, which states that the

pulmonary rehabilitation can improve exercise capacity and QoL [30], there is still unequal access to pulmonary rehabilitation in the community hospitals in China.

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

Limitations of the study

There are some study limitations. Firstly, all the participants came from northern regions of China. The findings should be interpreted with caution because patients' experiences in other parts of China may be different due to different healthcare 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 that there was an evidence of no recurring themes from the data but does not claim that the data saturation has occurred.

Conclusions

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

Abbreviations

COREQ: Consolidated criteria for reporting qualitative research; IPF: Idiopathic Pulmonary Fibrosis; ILD: Interstitial lung disease; NICE: National Institute for Health and Care Excellence

Declarations

Ethics approval and consent to participate

All participants were fully informed of the nature of this study, including the background, aims and benefit and harms prior to the commencement of this study. Written consents were obtained before the interviews. The Human Research and Ethics Committee of the hospital approved the study (ethics number: 2018-8-23-1).

Consent for publication

Not applicable.

Availability of data and materials

When receiving the consent received from the participants, the data are to be used only for the research purposes and are not to be disclosed to public without the approval of the study group. The datasets used and analyzed during current study are available from the corresponding author upon reasonable request.

Competing interests

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

Author details

¹Department of Respiratory and Critical Care Medicine, Beijing Chao-Yang Hospital, Beijing, China.

²Department of Nursing, Beijing Chao-Yang Hospital, Beijing, China. ³Department of Emergency Medicine, Gold Coast Hospital and Health Services, Queensland, Australia. ⁴Department of Respiratory Medicine, Gold Coast Hospital and Health Services, Queensland, Australia. ⁵School of Nursing, Midwifery, and Paramedicine; Sunshine Coast Health Institute, Queensland, Australia.

Funding

The study was supported by grants from Beijing Chao-Yang Hospital 1351 Talent Development Program Funding (HHXX-2017-02), Beijing, China and 2018 Beijing Municipal Hospital Research and Development Project (PG2018005), Beijing, China.

Author's contributions

Yang Lyu led all aspects of the project including conception and design of the study, acquisition of data, data analysis, interpretation of data, drafting, revising and finalizing the article. Yan-Rui Jia and Feng-Li Gao contributed to the conception and design of the study, made substantial contribution in data acquisition, interpretation of data and reviewing the manuscript. Ya-Ling Huang and Frances Lin made substantial contribution in conception and design of the study, data analysis, interpretation of data and reviewing the manuscript.

Acknowledgements

The authors would like to acknowledge all the participants for sharing their story and experience in our study.

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