


A Qualitative Study on Illness Perception and Coping Behaviors Among Patients with Chronic Obstructive Pulmonary Disease: Implications for Intervention

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Background: Understanding patients' perceptions of their illness may be more beneficial for healthcare providers in maintaining vigilance than merely focusing on the clinical status of patients. As patients' perceptions can significantly influence their behavior, it is possible that health care providers who are aware of patients' thoughts in advance may help improve their intervention programs, such as increased treatment adherence. However, current research offers limited insight into the subjective perceptions of disease among patients with Chronic Obstructive Pulmonary Disease (COPD). This study aims to deeply explore COPD patients' illness perception and coping behaviors.

Methods: A descriptive qualitative approach was used, conducting semi-structured in-depth interviews with 32 COPD patients, and verbatim data recording. Data analysis was based on thematic analysis methods proposed by Braun and Clarke.

Results: Through data analysis, we identified three themes to describe participants' perceptions and coping behaviors related to COPD: inadequate knowledge regarding the disease, improper self-management of the disease, and diverse impacts resulting from the disease.

Conclusion: Illness perception is crucial for COPD patients. Participants' descriptions underscored their perceptions of the disease as well as the various challenges and consequences they face when dealing with it. To enhance care for individuals with COPD, researchers and healthcare professionals should increase awareness about the disease among patients, understanding their coping strategies, beliefs, and recognizing its significant impacts.

Keywords: chronic obstructive pulmonary disease, illness perception, coping behaviors, qualitative research

Background

Chronic Obstructive Pulmonary Disease (COPD) is a chronic inflammatory disease characterized by primarily restricted airflow, which exhibits partial irreversibility and progressive nature.¹ In the context of rapid economic growth and lifestyle changes, both the incidence and mortality rates of COPD are on the rise.² Particularly in China, the prevalence of COPD among individuals aged 40 years and above reaches as high as 13.7%, estimated to account for approximately one-fourth of global COPD patients,³ with over 900,000 deaths annually attributed to this disease.⁴ Besides deteriorating respiratory function, COPD can also precipitate severe complications such as spontaneous pneumothorax, chronic respiratory failure, cor pulmonale, and right heart failure; thus posing a significant threat to patients' lives while imposing substantial socioeconomic burdens.⁵ Consequently, enhancing effective management strategies for COPD becomes imperative in order to mitigate the risk of complications and alleviate overall disease burden.

As an irreversible yet treatable chronic disease, adherence to treatment plays a pivotal role in optimizing outcomes for patients with COPD. Clinical research consistently demonstrates that consistent adherence to evidence-based treatment

plans, including continuous medication usage as recommended by medical guidelines, significantly enhances both the quality of life and survival rates of patients.⁶ Furthermore, it also effectively reduces hospitalizations,⁷ and mitigates medical costs.⁸ However, suboptimal treatment adherence remains a prevalent issue among individuals with COPD, which leads to frequent acute attacks and directly affects the management effect of the disease.^{9,10} Moreover, inadequate patient knowledge regarding COPD along with feelings of shame associated with the condition and the presence of negative emotions pose substantial barriers to effective COPD management.^{9,11,12} These barriers are intricately intertwined with patients' beliefs and perceptions concerning COPD.

Illness perception refers to patients' subjective views and experiences regarding their own health status and disease, originating from the Common Sense Model (CSM) of self-regulation proposed by Leventhal et al in 1980.¹³ This model emphasizes how patients' beliefs, emotions, and behaviors interact to shape their understanding of illness and coping strategies. The CSM provides a framework for understanding how individuals self-regulate cognitively and emotionally when faced with health challenges, contributing to a deeper insight into patients' illness perception and its influence on behavioral choices and self-management strategies.¹³ According to this model, when patients become aware of potential health risks, they activate physiological and psychological stress responses, leading to the formation of specific cognitions based on personal educational background, past experiences, and other factors. The focus of illness perception lies in patients' awareness of their bodily conditions and understanding of potential diseases, including the impact and consequences they may encounter. Therefore, illness perception represents an interactive process between patients and their disease that influences self-management behaviors and response strategies when facing health threats or diseases.^{14,15}

COPD is characterized by breathlessness, coughing, and phlegm production. However, these symptoms may not be apparent which often leads many patients to overlook them until it progresses into a more severe state. Therefore, the improvement of illness perception in COPD patients can help patients recognize their symptoms earlier, improving their coping behaviors needed for disease management,¹⁶ such as medication adherence or lifestyle adjustments.^{17,18} Consequently, illness perception significantly impacts both physical health outcomes for COPD patients as well as their treatment decisions; thus its importance cannot be underestimated.

Current research on illness perception among COPD patients has predominantly focused on quantitative studies, failing to fully capture patients' internal reflections and subjective experiences of the disease. Therefore, this study employs a qualitative research approach to explore patients' perceptions and coping behaviors regarding COPD. The aim is to provide a basis for developing more personalized COPD intervention strategies.

Methods

Study Design

This study employs a descriptive qualitative research design to comprehensively explore the cognition, experiences, and emotions of COPD patients regarding their illness, facilitating an in-depth expression of their personal viewpoints. The selection of a qualitative research design aligns with the research objectives as it enables a profound understanding of participants' perspectives and experiences related to the research questions.¹⁹ Despite existing extensive information from experts (researchers and clinical doctors) on COPD patients' perceptions of their illness,^{17,18,20} Our aim is to contribute new insights to this field by directly understanding patient perspectives and exploring potential new ideas. The reporting of this study adheres to the consolidated criteria for reporting qualitative research (COREQ), which ensures explicit and comprehensive reporting in qualitative studies.²¹

Ethical Issues

This study adheres to the principles outlined in the Helsinki Declaration. Ethical approval for the research was obtained from the Medical Ethics Committee of the University of South China (2023NHHL004). Prior to conducting interviews, written informed consent forms were signed by each participant. Participants were duly informed about their voluntary participation and had the option to withdraw at any time, with strict confidentiality measures in place.

Participants

The study employed a purposive sampling strategy and recruited patients with chronic obstructive pulmonary disease (COPD) from the respiratory outpatient department of a tertiary hospital in Hengyang City, Hunan Province, China, between January 2024 and March 2024. Inclusion criteria were: 1) diagnosis of COPD according to the GOLD guidelines confirmed by pulmonary function tests,²² ranging from GOLD1 (mild, FEV₁ \geq 80% predicted) to GOLD4 (severe, FEV₁ $<$ 30% predicted); 2) conscious and able to communicate effectively; 3) voluntary participation in the survey. Exclusion criteria were: 1) presence of other serious acute or chronic illnesses such as malignant tumors, acute myocardial infarction, acute heart failure, respiratory failure, hepatic encephalopathy, cerebral hemorrhage, or stroke; 2) participation in other clinical studies that could potentially affect the results of this study. This study deliberately recruited patients of different ages, genders, educational backgrounds, durations of illness, and clinical stages to maximize diversity and representativeness of the sample. A total of 32 patients participated in this study, identified by the pseudonyms P1 to P32 to protect their privacy.

Data Collection

The interviews were conducted by one researcher (HLM) in a lounge adjacent to the respiratory outpatient department, with another researcher (TCY) observing and recording. Prior to the interviews, an interview outline was drafted, and preliminary interviews were conducted with three patients. Based on these preliminary interviews, the interview outline was revised to create the formal interview guide. This comprehensive guide encompassed various topics including: Could you please elaborate on your comprehension of COPD? What challenges have you encountered during the treatment or management process? How has COPD impacted your daily life? What emotions did you experience following your diagnosis of COPD? In what areas do you primarily seek assistance?

Before each interview, the researcher briefly introduced themselves to establish rapport with the participants, providing a concise explanation of the study's purpose, significance, and methodology. Following participants' completion of an informed consent form and basic demographic questionnaire, the interviews officially commenced. During the interviews, questions were posed in accordance with the interview guide while adapting to participants' responses without employing leading questions. Participants were actively encouraged to express their emotions candidly. Concurrently, meticulous attention was paid to non-verbal cues such as facial expressions, body movements, and emotional fluctuations by documenting these observations meticulously. In instances where participant responses were unclear or ambiguous, prompt clarification and verification of opinions were sought from participants again. The interviews concluded once all topics had been exhaustively discussed and no further inquiries arose. Each interview lasted approximately 20 to 30 minutes per participant.

Data Analysis

During the design phase of the study, the investigators ensured adequate time for data collection and analysis, with the interview phase lasting two months and the analysis phase also reserved for two months to allow for in-depth exploration of the data. After each interview, we transcribed the audio recordings and notes into textual data within 24 hours, and verified any discrepancies with the participants. Two researchers (HLM and TCY) followed the principles of Braun and Clarke's thematic analysis method and used NVivo (version 12, QSR International[®]) software to conduct content thematic analysis. The process involved familiarization with the data, generating initial code, searching for topics, reviewing topics, defining and naming topics, and identifying topics, and ultimately generating a report.²³ First, team members repeatedly read the interview transcripts to identify and record potential themes, and then an initial code was formed through discussion. To increase transparency, team members recorded the definition of each code and the corresponding text fragment in detail to ensure the traceability of the analysis process. The topic definition phase included open coding, axial coding, and review. Open coding was used to analyze the interview transcripts paragraph-by-paragraph to mark important concepts. Axis coding classified the open coding results and identified the main themes and sub-themes. During the review phase, team members reviewed the coding and themes again to ensure that each theme was fully supported by text, and recorded the process of theme formation and specific definitions, including

representative examples, to improve reproducibility. To ensure consistency in the theme definition process, the analysis team maintained regular meetings to discuss progress in coding and theme formation. After each meeting, team members updated the documentation to record the latest progress and changes to the theme definition. For disagreements during the analysis process, the research team used a dual coding approach. Two researchers coded the data and compared the results in a group discussion to resolve disagreements. For apparent disagreements, the team further discussed specific text segments to reach consensus. Another researcher (CX) was also involved in the analysis to assess similarities and differences in the interviewees' analyses and to ensure that the analysis was comprehensive.

Results

A total of 32 patients with COPD were interviewed, comprising 13 females and 19 males. The age range of the participants was between 49 and 87 years, with a mean age of 69.78 years. Clinical data can be found in [Table 1](#), while detailed demographic information is provided in [Table 2](#). Through participant interviews, three key themes emerged to elucidate their perceptions of the disease and coping behaviors: inadequate knowledge regarding the disease, improper self-management of the disease, and diverse impacts resulting from the disease. For a more comprehensive understanding of the interrelationships among these themes, please refer to [Figure 1](#).

Theme I: Inadequate Knowledge Regarding the Disease

Despite the predominant reliance on personal experiences among most participants for comprehending COPD, including its etiology, symptoms, and progression, their understanding often remains incomplete or erroneous, thereby hindering effective disease management.

Table 1 Participant Characteristics (n=32)

Characteristic	Count/Mean (\pm SD)
Gender	
Male	19
Female	13
Age	69.78 \pm 9.07
Education Level	
None	4
Primary School	10
Junior High School	7
High School	6
University	5
Smoking Status	
Yes	24
No	8
Smoking Duration (years)	40 \pm 10.77
COPD History (years)	6.66 \pm 5.53
COPD Stage	
Stable	11
Acute	21
COPD Severity	
GOLD 1	2
GOLD 2	6
GOLD 3	9
GOLD 4	15
Insurance Type	
Urban Resident Basic Medical Insurance	22
Employee Basic Medical Insurance	10

Abbreviations: COPD, Chronic Obstructive Pulmonary Disease; n, number; SD, standard deviation; y, years.

Table 2 Detailed Participant Demographics

ID	Gender	Age	Education	Smoking Status	Smoking Duration (years)	COPD History (years)	Stage	GOLD Grade	Medical Insurance
P1	Male	73	Primary School	Yes	36	7	Stable	GOLD 3	Resident Medical Insurance
P2	Male	79	High School	Yes	57	13	Acute	GOLD 4	Employee Medical Insurance
P3	Male	68	None	Yes	43	10	Stable	GOLD 4	Resident Medical Insurance
P4	Female	73	University	No	0	6	Acute	GOLD 4	Employee Medical Insurance
P5	Male	66	Junior	No	0	3	Stable	GOLD 3	Resident Medical Insurance
P6	Male	78	Junior	Yes	49	1	Stable	GOLD2	Resident Medical Insurance
P7	Female	49	University	No	0	1	Stable	GOLD1	Employee Medical Insurance
P8	Male	83	Primary School	Yes	63	22	Acute	GOLD4	Resident Medical Insurance
P9	Female	69	High School	Yes	39	11	Acute	GOLD4	Employee Medical Insurance
P10	Male	79	Primary School	Yes	47	5	Stable	GOLD3	Resident Medical Insurance
P11	Male	67	None	Yes	10	1	Acute	GOLD2	Resident Medical Insurance
P12	Female	58	University	No	0	2	Stable	GOLD4	Resident Medical Insurance
P13	Female	78	Primary School	Yes	33	9	Stable	GOLD4	Resident Medical Insurance
P14	Male	68	High School	Yes	38	6	Acute	GOLD3	Employee Medical Insurance
P15	Male	74	Junior	Yes	46	3	Stable	GOLD2	Resident Medical Insurance
P16	Female	72	Primary School	Yes	40	8	Stable	GOLD4	Resident Medical Insurance
P17	Female	57	Junior	No	0	3	Stable	GOLD2	Resident Medical Insurance
P18	Male	74	High School	Yes	50	16	Acute	GOLD4	Employee Medical Insurance
P19	Male	70	Primary School	Yes	45	6	Stable	GOLD3	Resident Medical Insurance
P20	Female	79	University	Yes	57	14	Acute	GOLD4	Resident Medical Insurance
P21	Female	61	None	No	0	1	Stable	GOLD2	Resident Medical Insurance
P22	Male	61	Junior	Yes	25	2	Acute	GOLD3	Employee Medical Insurance
P23	Male	74	Primary School	Yes	41	1	Stable	GOLD1	Resident Medical Insurance
P24	Female	76	Primary School	Yes	32	5	Stable	GOLD4	Employee Medical Insurance
P25	Male	68	Primary School	Yes	44	4	Stable	GOLD3	Resident Medical Insurance
P26	Female	68	High School	No	0	7	Stable	GOLD4	Resident Medical Insurance
P27	Male	87	High School	Yes	54	20	Acute	GOLD4	Employee Medical Insurance
P28	Male	57	University	No	0	2	Stable	GOLD3	Resident Medical Insurance
P29	Male	76	Junior	Yes	36	8	Acute	GOLD3	Resident Medical Insurance
P30	Female	49	Primary School	Yes	27	1	Stable	GOLD2	Resident Medical Insurance
P31	Male	73	None	Yes	47	9	Stable	GOLD4	Resident Medical Insurance
P32	Female	69	Junior	Yes	37	6	Stable	GOLD4	Employee Medical Insurance

Abbreviation: COPD, Chronic Obstructive Pulmonary Disease.

Lack of Awareness of Risk Factors

Risk factors such as smoking, air pollution, occupational exposure to dust and smoke, and a low body mass index (BMI) are all associated with COPD. However, participants tend to focus solely on one risk factor—smoking—while disregarding the management of other risk factors. Conversely, some participants who do not perceive themselves as having evident risk factors may dismiss the relevance of these factors in relation to COPD.

I previously believed that I contracted this disease only due to my smoking habit. Later, my doctor explained that my work in the coal mine dust inhalation was also related to this disease. This made me realize that wearing a dust mask is as important as giving up smoking. (P16)

One of my neighbors had been smoking his whole life and he lived to 81 years old. I never smoked and yet I got this disease. I feel that smoking has nothing to do with this illness. (P7)

Lack of Understanding About Complications

As chronic obstructive pulmonary disease (COPD) advances, patients may encounter complications such as spontaneous pneumothorax, chronic respiratory failure, pulmonary heart disease, and right-sided heart failure. However, limited

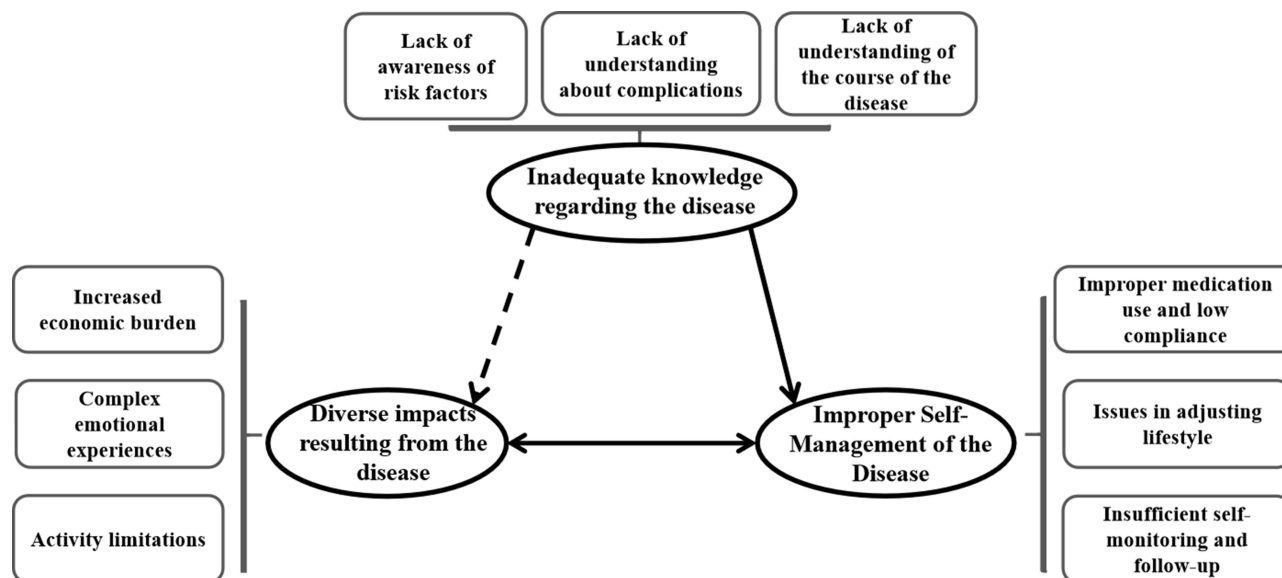


Figure 1 The relationship between themes. Note. The solid line represents a relatively direct relationship and the dotted line represents an indirect relationship between the theme.

participant comprehension of these complications contributes to a lack of awareness regarding the severity of the condition and potential treatment delays.

I only had symptoms like coughing, phlegm, and wheezing, so I didn't think this disease was serious. It wasn't until I saw someone in the same ward die from heart complications related to COPD that I realized its complications also need attention. (P1)

I've had the disease for many years, and one day my feet suddenly swelled up. At first, I didn't pay much attention. Looking back now, if I had gone for a check-up promptly, maybe my illness wouldn't have been so severe. (P13)

Lack of Understanding of the Disease Course

As a chronic illness, COPD can have acute exacerbations within a short period. However, some participants perceive it as a curable acute illness and do not emphasize long-term treatment and management.

I feel like this disease (COPD) is more like an acute illness. Because its exacerbations are very acute and sudden, like a cold, once treated, it's fine. (P15)

If I also had cancer besides this disease, I think cancer would be more worrying. Because the symptoms of this disease (COPD) can be quickly controlled, so it doesn't need excessive attention. (P8)

Theme 2: Improper Self-Management of the Disease

After gaining a comprehensive understanding of the distinctive features associated with COPD, nearly all participants endeavored to manage and control the ailment through diverse interventions. Nevertheless, they encountered numerous practical challenges that impeded their effective disease management.

Improper Medication Use and Low Compliance

Adhering to medication guidelines is crucial for the control and management of COPD. However, many participants encounter challenges related to improper medication use and low compliance, particularly during stable periods of the disease. Some participants lack comprehension regarding inhaler techniques, operation of inhalation devices, or have uncertainties about precautions and drug interactions associated with oral medications, resulting in inappropriate utilization.

When I use the nebulizer, I don't hold my breath. But I've always had a question: should I hold my breath while inhaling? If so, for how long should I hold my breath? (P25)

I used to drink tea to relieve throat discomfort when taking cough syrup, but then I realized that it didn't work for my treatment. (P19)

Regarding patient medication adherence, interviews revealed that some participants do not realize the importance of consistent medication usage and therefore fail to adhere to their prescribed schedules. Some participants are hesitant to take medication due to concerns about side effects. Additionally, many elderly participants find it easy to forget their medication schedule due to memory loss and interruptions in daily life.

I only think about taking medicine when I have shortness of breath. Now that my condition has improved, I don't feel like taking medicine anymore. It seems like it doesn't make a difference whether I take it or not. (P10)

The doctor prescribed a lot of medications for me, including inhalers and oral medications. Some of them upset my stomach, so I stopped taking them. (P3)

I'm getting old and my memory isn't as good. I think about taking my medicine right after getting up, but then forget as soon as I turn around. (P8)

Issues in Adjusting Lifestyle

When managing COPD, the majority of participants attempted to enhance their condition through lifestyle adjustments; however, they exhibited a general lack of awareness and consistency in modifying unhealthy habits. Occasionally, effective lifestyle adjustments were avoided due to acute exacerbations or deteriorating conditions, resulting in an inability to achieve long-term outcomes. Furthermore, inadequate knowledge and guidance led some participants to feel perplexed about suitable lifestyle modifications for themselves, thereby impeding the implementation of effective adjustments.

I know I should quit smoking, but I just can't stick to it. I'm used to having a cigarette in my hand, and every time I try to quit, I end up smoking again. (P29)

I already have a tendency to be short of breath, and when I do Tai Chi, my breathlessness gets worse, so I dare not continue. If things get worse, what should I do? Maybe I'll wait until I feel a little better. (P4)

I'm not sure what kind of exercise I can do, and I don't know how long I should be active. Once, I tried riding a bike, but I got breathless after a while. After that, I didn't dare to attempt any strenuous exercise. (P12)

Insufficient Self-Monitoring and Follow-Up

During stable periods, many participants face challenges associated with inadequate self-monitoring and follow-up procedures. The absence of professional guidance further contributes to participant confusion regarding the proper execution of self-monitoring and follow-up activities. Additionally, there is a tendency for participants to overlook recording symptoms and medication usage, which hinders the effective evaluation of disease progression and treatment efficacy.

I have an oxygen concentrator at home to help me breathe, but sometimes I set it to 1 and other times to 5. I'm not sure if it affects anything. Also, I haven't filled the water in the bottle completely. Is that important? (P15)

My doctor said I should have regular follow-ups, but I always forget to make appointments, and I don't think it's necessary to go to the hospital all the time. (P6)

My daughter bought me a fingertip pulse oximeter to monitor my blood oxygen levels. However, I only remember to use it when I feel short of breath or my cough worsens. (P23)

Theme 3: Diverse Impacts Resulting from the Disease

The constellation of symptoms resulting from exacerbations of COPD significantly impact the participants' daily activities, socioeconomic status, and emotional well-being, thereby exerting a profound influence on their overall quality of life.

Increased Economic Burden

COPD is a chronic condition characterized by frequent acute exacerbations necessitating recurrent hospitalizations and long-term therapeutic interventions, thereby resulting in diminished occupational capacity and protracted financial strain for affected families. Moreover, the existing diagnostic-related group (DRG) payment mechanism within health insurance amplifies their burden of treatment costs.

This year, I've been hospitalized for the fourth time. Each hospital stay costs a lot of money. This disease feels like a bottomless pit. (P5)

Nowadays, I struggle to breathe even just getting out of bed. Working to earn money is out of the question for me now, so I feel like a burden at home. (P19)

Despite the new DRG payment system under health insurance reducing the cost of each hospitalization, my out-of-pocket expenses have increased. (P27)

Complex Emotional Experience

The complex and dynamic physical conditions observed among the participants indicate a wide spectrum of emotional experiences, characterized by an elevated incidence of negative emotions. In instances of acute exacerbation, a substantial number of patients undergo considerable distress attributed to aggravated respiratory symptoms including heightened breathlessness and intensified coughing, thereby manifesting deep-seated concerns regarding their own mortality.

I feel like every breath is difficult, as if there's a stone pressing on my chest, causing me intense pain. (P20)

I cough up phlegm every day now, but it won't come out. The mucus blocks my throat and makes it hard for me to breathe, like my mouth and nose are sealed in a plastic bag. Sometimes I feel like I'm suffocating, it's really painful. I feel like one day I might suffocate because I can't cough out the phlegm. (P4)

COPD is a complex and frequently recurring disease, making it difficult for participants to predict its progression and feeling limited in their control over it. Consequently, almost all participants experience psychological tension and anxiety.

What makes me most anxious is whenever I cough in public, a wave of mucus surges up. The feeling of being uncontrollable is really scary and disgusting, you're never fully prepared. (P2)

Yesterday, I opened the window for ventilation to get fresh air, but afterward I became extremely nervous, feeling restless, worrying that I might catch a cold and worsen my condition acutely. I really don't want to go through that again. (P24)

Despite COPD being caused by various factors, most participants tend to blame themselves, believing their own faults led to their illness. Some participants also feel guilty about burdening their families and friends.

It's all my fault, if I hadn't smoked or exercised more in the past, maybe I wouldn't have gotten this disease! (P17)

There are so many things I can't do, I even need my wife's help just to undress. I'm always going to the hospital for check-ups and treatments, constantly spending money. I feel like I'm a burden dragging down my family. (P28)

Activity Limitations

Participants frequently experience the distress of dyspnea and hypoxia, akin to being afflicted by imperceptible constraints that significantly impede their capacity to perform daily activities and engage in social interactions normally. This constraint becomes particularly severe during acute exacerbations.

I feel restrained, unable to do what I want to do. Even in my bedroom, I can't walk around easily, let alone go out to work or exercise. (P9)

Once, I attended a gathering with old friends. When we took a walk together, I couldn't keep up with their pace due to breathlessness. I fell behind slowly, drifting away from them. It felt like my friendships—our connection was lost, and I couldn't truly enjoy the gathering. (P21)

Discussion

This qualitative study explores the illness perception and coping behaviors of patients with chronic obstructive pulmonary disease (COPD) to provide valuable insights for effective intervention strategies aimed at enhancing disease management and overall patient outcomes. Participants contributed to a comprehensive dataset, yielding a wealth of perspectives. The study revealed a pervasive lack of disease-related knowledge among individuals with COPD, which poses significant challenges in managing the condition and profoundly impacts various aspects of their lives.

A key finding of this research is the prevalent lack of disease-related knowledge among participants with COPD. Participants' lack of knowledge about the disease, including the factors affecting COPD, its complications, and its course, could affect their ability to effectively implement disease management. The early asymptomatic stages and slow progression of the disease, combined with low levels of awareness about COPD, contribute to patients underestimating its severity and the importance of proactive management.^{24,25} Consequently, there is a reluctance among patients to seek relevant information or appropriate treatments, thereby limiting their overall understanding and awareness of COPD.²⁶ Furthermore, deficiencies in China's healthcare system exacerbate patients' lack of knowledge about COPD. Most hospitals lack specialized outpatient services for COPD and expert consultations while providing limited access to educational materials on COPD which further hinder targeted health education efforts.²⁷ Based on these findings, many individuals with COPD neglect the severity of their condition as well as the significance of proactive management due to insufficient external scientific information.

In interviews, it was observed that participants actively pursued treatment and management strategies following their diagnosis. However, they encountered various challenges and difficulties during this process, including improper medication usage, non-compliance issues, lifestyle adjustment problems, and inadequate self-monitoring practices; all of which impeded effective disease management.²⁸ Although pharmacotherapy remains the primary approach for COPD patients' treatment, a significant proportion of patients struggle to adhere to long-term medication regimens.²⁹ Wu's study reported that up to 61.3% of patients experienced inhaler misuse at least once,³⁰ with most demonstrating poor adherence to inhaler therapy.^{30,31} The reasons for non-adherence among participants in this study included insufficient knowledge about medications, resistance towards taking them regularly, and concerns regarding potential side effects – findings consistent with previous research.³² Therefore, it is crucial to enhance patient education on medication methods and effects in order to improve compliance for better control and management of COPD. For example, regular lectures and personalized counseling on medication use are conducted to enhance patients' medication knowledge and confidence. In addition, Electronic monitoring devices are considered a promising intervention as they can track medication use and enhance patient compliance.³³ Consequently, combining patient health education with electronic monitoring devices and regular checking of inhaler devices and other treatments is expected to significantly improve treatment outcomes and quality of life.

According to the CSM theory, patients' cognition and beliefs directly influence their behavior.¹³ Patients' lack of knowledge related to COPD may affect their coping behaviors towards the disease, which may be detrimental to their disease management.²⁸ In addition, the Transition Theory of Afaf Meleis also points out that patients' health knowledge, beliefs and behaviors are closely related, and strengthening patients' health knowledge can promote them to take more effective coping measures, so as to improve disease management.³⁴ Thus, it is essential to implement effective health education programs. Nurse-led education model is considered to be an effective health education method, which can help patients improve their self-management ability and thereby improve their quality of life.^{35,36} Therefore, in medical institutions, COPD health education rooms can be set up and run by full-time nurses. In the education room, nurses can regularly hold patient education workshops, covering pathology knowledge, symptom management, medication guidance

and lifestyle adjustment. At the same time, personalized consultation services can also be provided to help patients develop feasible management plans according to their actual conditions.

It is noteworthy that participants exhibited distinct disease management behaviors during acute exacerbations compared to stable periods. For instance, during stable periods, participants demonstrated a higher propensity for medication errors and compliance issues, whereas during acute exacerbations, they tended to overlook lifestyle adjustments. This disparity may be attributed to COPD patients receiving treatment and medication guidance in hospitals during acute exacerbations, thereby enhancing medication adherence. Patients may prioritize treatment during acute phases, potentially neglecting lifestyle changes or fearing exacerbation if they alter their habits.⁷ Hence, hospitals can implement personalized drug management programs, provide detailed medication education for patients in the acute attack period, and follow up regularly in the stable period to ensure the medication compliance of patients. Regarding lifestyle modifications, smoking cessation plays a pivotal role in COPD management. Despite the majority of participants acknowledging this fact, successful quitters remain scarce due to persistent exposure to smoking environments and strong nicotine dependency.³⁷ Emphasizing the imperative nature of smoking cessation is crucial for effective COPD control and management. Cessation support groups that combine behavioral therapy with nicotine-replacement therapy can be organized to help patients successfully quit smoking. Additionally, educational advocacy campaigns will help patients and the public understand the benefits of smoking cessation, thereby breaking the entrenched social customs of smoking and further increasing the success rate of smoking cessation.

The lung function of patients with COPD continues to deteriorate, and its symptoms are difficult to predict and recur, impacting various aspects of patients' lives.³⁸ Inadequate treatment and management of COPD may increase the frequency and duration of acute exacerbations, further burdening patients.³⁹ For instance, economically, both direct and indirect costs for patients are high. Research indicates that the median annual direct medical costs for COPD patients in China range from \$150 to \$2014 per capita, with median annual indirect costs ranging from \$0 to \$184 per capita.⁴⁰ Through interviews, it was found that participants generally bear a heavy economic burden, consistent with findings by Pham et al.⁴¹ Health insurance systems effectively protect residents' health and enhance their utilization of health services.⁴² Despite significant improvements in China's basic medical insurance system, there remains a considerable gap between overall supply and actual demand. This is particularly burdensome for low-income patients with severe illnesses as it makes medical care difficult and costly. Thus highlighting shortcomings in China's health security system.⁴³ In this context, the formulation of medical insurance reform policy is particularly important. It is necessary to re-evaluate the current medical policy and improve the cost structure, so as to bring the prevention and treatment of COPD into the priority range of national public health policy and reduce the economic pressure of patients. Such policy reforms aimed at COPD management will help to improve the quality of life of patients and have a positive impact on the actual work of healthcare professionals.

COPD not only impacts patients' physical health but also significantly affects their mental well-being. Research has demonstrated that during acute exacerbations, patients experience considerable distress due to symptoms such as breathlessness and coughing, often expressing fears of mortality.⁴⁴ The unpredictable nature of COPD symptoms contributes to anxiety, depression, and other psychological states, severely impacting mental health and potentially leading to suicidal ideation.⁴⁵ Moreover, the reduced ability of patients to care for themselves can result in feelings of guilt and self-blame among family members.⁴⁶ This study revealed through comprehensive interviews that participants underwent negative psychological experiences including pain, fear, tension, anxiety, and guilt which had a profound impact on their mental health. Therefore, in the management of COPD, it is crucial to prioritize not only physiological treatments but also provide appropriate psychological support and assistance. Medical staff can implement personalized psychological intervention measures, such as regular psychological counseling and group support activities, to effectively improve the emotional state of patients.⁴⁷ Moreover, medical staff should carefully evaluate the emotional distress of patients, formulate targeted intervention plans, meet the psychological needs of patients, and provide professional psychological support and guidance.

Limitations

Although this study provides insights into the illness perception and coping behaviors of COPD patients, there are several limitations to consider. Firstly, despite the maximum variation sampling approach to improve sample representation, the majority of participants suffered from severe COPD, while patients with mild and moderate disease were underrepresented, which may affect the generalising of the study across different disease stages, especially when discussing early perception. Secondly, participants were recruited primarily from one hospital, which may have limited the generalizability of the results to other Settings. Additionally, as participants were interviewed regarding disease causes and triggers, their illness experiences and perceptions might have been influenced by recall bias. Therefore, future studies should consider achieving a more balanced allocation of participants in terms of disease severity to strengthen the generalizations of the results.

Conclusions

This study used qualitative methods to thoroughly investigate the illness perception and coping behaviors of COPD patients, revealing the multiple challenges and difficulties they face in these areas. The results of the study showed that patients generally lack disease-related knowledge, which not only limits their comprehensive understanding of COPD but also hinders the implementation of their proactive coping behaviors. Furthermore, patients are often influenced by various factors during the disease management process, leading to a reduced effectiveness of coping strategies. In order to improve the health status of COPD patients, it is recommended to enhance patients' understanding of COPD in the early stages of the illness. This can be achieved by increasing the level of health education and providing systematic teaching of disease knowledge to help patients acquire the necessary coping skills. At the same time, healthcare personnel should pay more attention to the individual illness perceptions of patients and their specific symptoms, and develop personalized intervention plans tailored to the needs of the patients.

Data Sharing Statement

Due to privacy or ethical constraints, the raw data (interview records) of this study are not publicly available, but can be obtained from the corresponding author upon reasonable request.

Ethics Approval and Consent to Participate

This study obtained approval from the Medical Ethics Committee of the University South China (2023NHHL004), and written informed consent was obtained from each participant. The participants informed consent included publication of anonymized responses/direct quotes.

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Author Contributions

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

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Disclosure

The authors declare that they have no conflicts of interest.

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