

From Dust to the Margins: An Analysis of the Rights Protection Dilemma for Pneumoconiosis Patients

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ABSTRACT

As one of the largest groups of occupational disease sufferers in China, pneumoconiosis patients endure not only the physical agony of respiratory distress but also persistent social pressures, including those arising from the rights defense process itself. This study focuses on the challenges these patients face in asserting their rights, examines the underlying causes, and explores potential remedial measures. Through field investigations, interview-based research, and sustained literature review, it offers an in-depth portrayal of the difficulties and obstacles encountered in their pursuit of justice. The analysis delves into contributing factors at multiple levels-including the workers themselves, government bodies, liable enterprises, and broader social status and social status and public awareness. Building on this analysis, the paper puts forward constructive recommendations tailored to the identified causes, proposing future solutions aimed at transforming the roles of workers, corporations, and other stakeholders. Its purpose is twofold: to expose the realities of this social issue and to offer rationally grounded strategies that may help affected families overcome their current plight and pressures, regain normalcy in life, and provide an academic reference for future support work by advocates or charitable organizations assisting pneumoconiosis patients.

KEYWORDS

Pneumoconiosis Patients; Rights Protection; Dilemma.

1. INTRODUCTION

According to the description of occupational pneumoconiosis released by the Shenzhen Municipal Health Commission, it refers to a disease characterized primarily by diffuse fibrotic lesions in the lung tissue, caused by the long-term inhalation and retention of productive mineral dust during occupational activities. Regarding its clinical manifestations, in the early stages, the body can compensate, so patients may have no or only very mild subjective symptoms. As the lesions progress and complications arise, various symptoms and signs can appear. The primary clinical manifestations in pneumoconiosis patients are respiratory symptoms, notably the four major symptoms: cough, expectoration, chest pain, and dyspnea, along with others such as wheezing and hemoptysis. The presence of fever, hepatomegaly, and edema may indicate the onset of complications. [1] Pathologically, pneumoconiosis is irreversible; once contracted, it becomes a lifelong condition, and lack of attention can lead to further deterioration. In the initial stages, the symptoms are difficult to detect and can be easily mistaken for a common cold. In the advanced stages, patients often experience severe breathing difficulties, excessive sputum production, and further complications such as pneumothorax or cor pulmonale. They may completely lose their mobility, where even standing becomes a distant hope, and severe complications can very easily lead to death.

Today, as the largest known category of occupational diseases, occupations at risk of pneumoconiosis span various industries-including mining and renovation, where large amounts of visible dust are

easily generated. Particularly in regions with underdeveloped economies and a lack of large-scale factories or enterprises, the relatively high salaries for miners have attracted numerous migrant workers, who end up sacrificing their health or even their lives for this work. Yet, despite such severe hazards, a steady stream of workers is still drawn to this sector. By the end of 2021, the cumulative number of confirmed occupational pneumoconiosis patients across China had reached 915,000. Even though the incidence trend is on the decline, the annual number of new cases still remains as high as over 10,000. [2]

Such a high-risk and prevalent disease as pneumoconiosis has long drawn the attention of government authorities, which have rolled out a series of measures to minimize the number of pneumoconiosis cases and provide appropriate support for those affected. However, due to a variety of factors, these measures have been slow to be effectively implemented. Pneumoconiosis patients not only suffer physically, but also fail to obtain effective social security, attention, and assistance.

In January 2025, the author joined the Yuankexing Public Welfare Team on a one-week field research trip to P Township, J Province, focusing on pneumoconiosis. During this period, the author conducted face-to-face interviews with several pneumoconiosis patients and held in-person discussions with the head of the local charity foundation in P Township, the chief physician of the Respiratory Medicine Department at P Township Municipal Hospital of Traditional Chinese Medicine, the head nurse of P Township No. 3 Hospital, and the patients' family members. These interactions provided in-depth insights into the living predicaments of occupational pneumoconiosis patients and the support offered to them by civil society and non-profit organizations. In line with ethical and social research principles, all personal information of the research subjects has been anonymized in this paper. (At present, a large number of scholars have carried out social research on the group of pneumoconiosis patients, focusing on aspects such as the causes of their illness and the difficulties they face in society.)

Pneumoconiosis arises when patients inhale productive dust over the long term, leading to diffuse pulmonary fibrosis and a subsequent impairment of the lungs' gas exchange capacity. As the largest known category of occupational diseases, occupations at risk of pneumoconiosis span diverse sectors—including mining and renovation, where significant amounts of visible dust are readily generated. Beyond the pathological causes of the disease, however, social factors also play an indispensable role. This has thus drawn a large number of scholars to conduct in-depth research on the social determinants of pneumoconiosis.

2. CAUSES OF PNEUMOCONIOSIS

2.1. Severe Economic Pressure

According to Sun Jie's research, 90% of all pneumoconiosis patients are migrant workers [3], most of whom have strained family finances. The majority of these migrant workers are male, serving as the primary breadwinners of their families and shouldering the responsibility of supporting their households. As a result, most choose to work in the coal mining industry—where wages are relatively higher but the risk of contracting pneumoconiosis is significantly greater. Additionally, studies indicate that a large number of pneumoconiosis patients cannot afford the high medical costs due to insufficient medical compensation [4-5], causing them to miss the optimal window for diagnosis and treatment.

2.2. Lack of Educational Resources

In a sample survey of pneumoconiosis patients in Chongqing, among a total of 20 patients, only 2 had completed junior high school education—and most of them lived in rural areas [6]. This finding allows us to conclude that the majority of pneumoconiosis patients have not received adequate education, which leaves them with insufficient awareness of self-protection. When engaged in high-

risk work, they often prioritize immediate comfort over long-term risks, neglecting precautions that could prevent illness.

2.3. Inadequate Implementation of Support Policies

While there are now work-related injury insurance and subsistence allowance policies in place to provide institutional protection for eligible groups, a considerable number of people still fail to access such support, which undermines their access to treatment. The most prominent issue here is the lack of effective supervision over non-public enterprises. Most migrant workers are employed in such high-risk, labor-intensive jobs, making them more vulnerable to contracting pneumoconiosis—a work-related disease. According to research, within these non-public enterprises, most pneumoconiosis patients struggle to provide valid proof of employment, or the private employers in question no longer exist. This leaves the group unable to secure the compensation they are entitled to even after being diagnosed with the disease. Consequently, these migrant workers, unable to afford the high treatment costs, have no choice but to abandon treatment—allowing a condition that could have been managed without severely disrupting their lives to worsen progressively. [7]

While pneumoconiosis develops from well-defined pathological and social factors, patients living with the disease suffer from its torment and agony for the rest of their lives. This suffering stems not only from physical symptoms, but also from the intertwined hardships across economic, institutional, and psychological dimensions. The following sections of this paper will review existing research on the dilemmas that pneumoconiosis patients face in society after diagnosis.

3. SOCIAL DILEMMAS FACED BY PNEUMOCONIOSIS PATIENTS

3.1. Disruption of Sustainable Income Sources

Economic hardship stands as the most pressing challenge for pneumoconiosis patients. According to extensive research by scholars, pneumoconiosis patients suffer rapid deterioration of physical functions after diagnosis, which robs them of their ability to work and, consequently, their source of income. As mentioned earlier, most pneumoconiosis patients are male, who typically bear the primary responsibility of supporting their families. The shift from being the family's economic backbone to being homebound due to illness and losing all income places immense psychological pressure on both the patients and their family members. In particular, pneumoconiosis patients often fall into feelings of self-blame, and in severe cases, this situation may even lead to marital breakdown or family dissolution. [8]

3.2. Inadequate Protection of Rights and Interests

Furthermore, studies indicate that the failure to effectively safeguard the legitimate rights and interests of migrant workers with pneumoconiosis represents another severe challenge for these patients. As Li Han points out, those who have not signed labor contracts with their employers often become entangled in protracted legal battles—a consequence of the cumbersome first and second-instance proceedings required merely to prove their employment relationship with the employers. This not only hinders their ability to secure entitled compensation for occupational pneumoconiosis but also denies them access to workplace injury insurance, a situation exacerbated by insufficient government oversight of employers. [9] These gaps in the protective measures compound the plight of patients who have already lost their source of income, further trapping them in a predicament of profound financial hardship.

3.3. Limited Social Attention

Beyond economic factors, research conducted by Xu Mengxian based on first-hand survey data shows that pneumoconiosis patients hold a relatively low status in society, particularly due to the general public's weak awareness of pneumoconiosis. [10] Today, Yu Zhilin's studies indicate that while some local governments have implemented measures to strengthen protection for pneumoconiosis patients—such as increasing reimbursement rates and establishing designated hospitals—the sustainability and replicability of these protection initiatives remain less than optimistic. As a result, most migrant worker patients with pneumoconiosis still cannot access timely and adequate medical subsidies or living assistance. Moreover, due to low social attention, pneumoconiosis patients have not received sufficient public concern, which in turn leads to insufficient support efforts from the government for this group.

In summary, substantial scholarly work has examined the social determinants of pneumoconiosis and the challenges patients face, covering areas such as economic hardship, educational resources, and institutional safeguards, thereby providing a solid theoretical foundation for subsequent research. However, studies remain scarce on how patients can effectively advocate for their rights and on measures to raise public awareness of the disease, representing a significant gap worthy of further investigation.

This study focuses on the challenges faced by pneumoconiosis patients in society, particularly their difficulties in defending rights. It aims to analyze the social factors contributing to these challenges and explore potential countermeasures to help alleviate their plight. The research seeks to provide effective support for safeguarding the rights of pneumoconiosis patients.

To achieve this objective, the primary research methods employed include literature review, in-depth interviews, and observational study. The integrated use of these multiple approaches is designed to gather diverse research materials from different perspectives and to ensure the robustness of the findings.

4. INVESTIGATION INTO CHALLENGES IN RIGHTS PROTECTION FOR PNEUMOCONIOSIS PATIENTS

4.1. Current Situation/problems

Based on the author's field research and a synthesis of existing literature, two key challenges regarding the rights protection of pneumoconiosis patients in society have been identified.

Firstly, the most significant obstacle they face is the inability to access legally entitled workplace injury insurance. According to State Council Decree No. 375, the Regulations on Work-Related Injury Insurance were enacted to ensure that employees who suffer work-related accidents or occupational diseases receive medical treatment and financial compensation, to promote the prevention of workplace injuries and vocational rehabilitation, and to distribute the risk of such injuries among employers [11]. However, due to the interplay of multiple social factors, many pneumoconiosis patients fail to receive the work injury compensation they are entitled to, even when their occupational disease is severe and meets the criteria for filing a claim. Since basic medical insurance does not specifically cover pneumoconiosis as a distinct occupational condition, these patients are forced to bear the high costs of treatment themselves, placing immense strain on their lives and financial circumstances. As recounted to the author by a certain Mr. L from P Township:

“None of us have work injury insurance now. We never thought about it back when we were working. The basic health insurance is just about the only thing that helps a little.”

Secondly, the problem extends beyond the lack of work injury insurance. Some pneumoconiosis patients, despite being impoverished and having spent their life savings on medical care, still fail to

qualify for the subsistence allowance. As of 2023, while China had 220 million people with a monthly income below 500 RMB [12], only 4.024 million households nationwide were receiving subsistence allowance benefits by the end of November 2023 [13]. This figure, covering both urban and rural areas, is significantly lower than the low-income population, indicating that a vast number of financially struggling individuals cannot access this legally mandated government support. The national subsistence allowance is a social assistance system designed to provide a minimum standard of living for households whose per capita income falls below the local minimum standard and who meet local asset conditions [14]. Consequently, being excluded from the subsistence allowance means these patients with occupational pneumoconiosis are stripped of this fundamental safety net. For patients who have already lost their earning capacity, the inability to receive this modest monthly subsidy makes it even more difficult for them to afford necessary treatments. As another resident from P Township, Mr. L, told the author:

“I saved some money from working before, but now I can’t even get the subsistence allowance. Every year, just a few hospital stays cost me nearly ten thousand yuan-I really can’t afford it.”

Lastly, pneumoconiosis patients also find themselves trapped in a deep sense of helplessness when it comes to fighting for their rights. As former miners with pneumoconiosis who have not received senior high school education or above, these patients may not even be able to understand relevant legal provisions, leaving them completely clueless about how to protect their rights. During the author’s interview with Director L of the Pulmonology Department at a hospital in P Township, Director L stated:

“These patients’ families were extremely poor in the past. Most of them only finished primary or junior high school before going out to work-because that’s where the money was. All they thought about was making life a bit easier for their families; they saw going to school as a waste of time.” Additionally, President X of a local public welfare organization for pneumoconiosis patients also told the author: “Many of them can barely use a mobile phone, and a lot are illiterate. They can only make calls and check messages at most.”

Therefore, when faced with situations that require them to protect their own rights, these patients often feel at a loss and confused about the process itself. Some even fail to realize they are entitled to such rights in the first place. Even if they make active efforts to defend their rights-such as reporting their issues or putting pressure on relevant authorities or former employers-their insufficient understanding of rights protection and low social status usually leave them with no choice but to give up, silently bearing the adverse impacts pneumoconiosis has brought to their lives.

Collectively, these twin economic forces have trapped pneumoconiosis patients deep in the quagmire of their illness with little means of escape. Gradually, this group of people-who could still realize their own value through treatment and a positive approach to life-has been reduced to consumers of social resources. They have lost the ability to contribute to sustained social progress and are gradually being cast aside by society. Pneumoconiosis patients already lack sufficient education to enable them to make rational analyses; they are even unclear about what legal rights and interests they are entitled to, let alone whether they can independently safeguard those rights through legal means.

4.2. Causes of the Dilemmas in Pneumoconiosis Patients’ Rights Protection

First, regarding the lack of work-related injury insurance, the author has summarized three causes based on literature review and interviews with patients and pneumoconiosis-related staff conducted during field research.

The most prominent cause is the irregular operation and management of some enterprises. Apart from state-owned enterprises, there are countless small private enterprises in society-particularly in the township-level mining industry covered by the author’s research. As the name suggests, private enterprises are not directly controlled or owned by the government. This gives rise to a problem: to

determine whether such an enterprise has violated regulations, the government cannot obtain information directly and must conduct on-site investigations before regulating any irregular practices. However, the number of private enterprises in China far exceeds the scope of the government's ability to conduct comprehensive investigations and precise supervision. Statistics show that among industrial enterprise legal entities, domestic private enterprises account for 84.4% of all domestic-funded enterprises [15]. This high proportion further underscores the large number of private enterprises. Therefore, inadequate supervision is not uncommon, which directly leads to the failure of many private enterprises to provide adequate protection for their employees. During the author's interview with Mr. H, a confirmed pneumoconiosis patient (and former coal miner) from P Township, Mr. H mentioned:

“We weren't educated back then. The mine paid 300 yuan a day, which was pretty high in this small area. We just wanted to make money, so we didn't care about things like insurance—anyway, we got paid. It wasn't until we got sick that we realized the boss never bought us any insurance at all.”

From this authentic interview excerpt, it is clear that many workers were only drawn to the high daily wages when they joined the workforce, overlooking the work-related injury insurance they were entitled to. Therefore, for these patients, since the company failed to pay insurance premiums from the very beginning, they naturally cannot receive the protection provided by work-related injury insurance—even if they realize they have the right to such insurance after falling ill.

Second, there remains a disconnect between the provisions of the subsistence allowance policy and the actual circumstances of some pneumoconiosis patients, leaving some families with genuine needs unable to be covered. Regarding the issue of some pneumoconiosis patients failing to access the subsistence allowance smoothly, the author identified a hidden yet crucial cause through in-depth conversations with patients and analysis of their backgrounds: the incompleteness stemming from the strict assessment system for the subsistence allowance. The criteria for determining eligibility for the subsistence allowance are as follows: residents in a jurisdiction can apply if their family's per capita income is below the local subsistence allowance standard and their property status (including savings and housing) meets the specified requirements. However, the key concept of “family per capita income” fails to fully reflect the living conditions of individual family members. During the author's on-site research and interviews, it was found that before losing their ability to work, coal miners earned relatively high salaries. As a result, most patients could afford to send their children to school and even built houses in rural areas during periods when their financial conditions were more stable. Consequently, their family's per capita income exceeds the standard for qualifying for the subsistence allowance. Nevertheless, most of their children work in other cities—even major metropolises like Beijing, Shanghai, and Guangzhou—where they have also settled down and started families. However, the cost of living varies significantly across regions: the salaries these children earn in big cities may seem like a large sum when converted to the local currency of their parents' hometown, but in reality, they can barely cover their own basic living expenses and are also burdened with various loans, leaving them with little extra money to send to their parents. During the author's interview with another pneumoconiosis patient, Mr. D, he said:

“I have a son and a daughter, both working in Shenzhen now. They're married, and only come back to see us once or twice a year. Life is hard enough for them there, so they can't send us much money. Now I can barely move and can't go out to work—all the household chores fall on my wife. I also have to go to the hospital from time to time, and I don't get the subsistence allowance. We really have no money.”

The plight of Mr. D, as revealed in the interview above—trapped in dire circumstances yet ineligible for subsistence allowances—epitomizes the harsh reality faced by many pneumoconiosis patients.

Lastly, pneumoconiosis patients and their families suffer from insufficient personal capabilities and lack of capital accumulation. Trapped in high-pressure lives due to financial straits, these patients and their families are often caught up in the struggle to make ends meet, pouring all their energy into

sustaining their current livelihoods. They end up depleting their family savings and lack the means to effectively fight for their rights. For some patients, having only a junior high school or even primary school education leaves them unable to understand the legal provisions related to rights protection. As a result, they lack awareness of how to safeguard their legal rights and interests, which in turn means they take no relevant action to defend those rights-such as pressing claims or applying pressure on relevant authorities and companies. Even for patients who do recognize that they are entitled to protections like work-related injury insurance or subsistence allowance, they may face other barriers: some are too drained from juggling treatment and daily life to fully engage in filing complaints with authorities; others find that individual appeals fail to attract sufficient attention from relevant departments or the involved enterprises, leaving them unable to change the broader situation where pneumoconiosis patients lack adequate protection; still others see their rights protection efforts fizzle out due to some enterprises' inaction. In short, pneumoconiosis patients encounter numerous obstacles and difficulties on their path to rights protection, leading to the failure of many such attempts. The author also interviewed Ms. M, the wife of a pneumoconiosis patient, who said:

“Now my husband can only lie in bed at home all day. I have to work in the fields, take care of him, and do all the housework-when would I have time to deal with applying for the subsistence allowance? Right now, just having enough to eat is a blessing.”

4.3. Approaches for Pneumoconiosis Patients to Overcome Rights Protection Dilemmas

The analysis in this section-focused on countermeasures for occupational pneumoconiosis patients to effectively safeguard their rights-builds on the previous analysis of the causes behind these patients' lack of access to legal rights and interests. By integrating the insights from the three causal factors outlined above, the author has summarized three countermeasures that are deemed effective in addressing the issue of insufficient legal rights protection for these patients.

First, the author argues that the government could intensify efforts to investigate and punish enterprises that fail to provide employees with legal work-related injury insurance. Subsequently, the fines collected should be stored in a centralized fund; when patients are denied the work-related injury insurance they are entitled to due to enterprise-related reasons, the corresponding amount can be drawn from this fund as a government subsidy to these patients. This approach can not only exert a certain deterrent effect on private enterprises, making them learn lessons from such penalties, but also safeguard the legal rights and interests of pneumoconiosis patients to the greatest extent and alleviate their financial pressure.

Second, regarding the subsistence allowance issue, starting from the allowance assessment system, relevant authorities could establish a dedicated support channel for pneumoconiosis patients when formulating subsistence allowance policies. Targeted compensation and support should be provided in response to the overall dilemmas faced by pneumoconiosis patients, striving to resolve the unfairness and irrationality encountered by patients with occupational diseases like pneumoconiosis during the subsistence allowance assessment process. Additionally, at the social level, more public welfare organizations for pneumoconiosis should be established to help patients pre-assess their eligibility for the subsistence allowance and assist them in filing lawsuits when they face unreasonable allowance assessment results-aiming to prevent pneumoconiosis patients from falling into dilemmas due to their lack of relevant knowledge.

Finally, the author believes that effectively improving the overall cognitive level of workers at risk of pneumoconiosis is particularly crucial to resolving the rights protection dilemmas faced by pneumoconiosis patients. Therefore, specific solutions can be outlined as follows: First, increase the number of primary and secondary schools established by the government in townships to provide residents with guaranteed access to education. Second, use multiple media channels-including social media, offline on-site promotions, and public lectures-to simultaneously convey the importance of

education, striving to enhance the general public's awareness of the value of education and thereby reduce potential cognitive risks in the future. Third, various public welfare and charitable organizations focused on pneumoconiosis (or, more generally, public welfare organizations for pneumoconiosis, or to be more precise, for occupational diseases in general, are now in operation across the country. Pneumoconiosis patients can thus seek assistance from these organizations, which also regularly provide patients with popularization of rights protection knowledge and relevant rehabilitation training. This helps patients maintain their quality of life without losing the energy or ability to protect their own rights.

5. CONCLUSION AND REFLECTIONS

5.1. Conclusion

To summarize, among the numerous dilemmas faced by pneumoconiosis patients, this paper identifies the primary challenges as the lack of social security (such as work-related injury insurance and subsistence allowances) and the confusion and failures experienced by patients in their efforts to protect their rights. The underlying causes include inadequate supervision stemming from the large number of private enterprises, insufficient flexibility in the prerequisites for certain social security benefits, and limitations in rights protection measures resulting from patients' own cognitive constraints. Pneumoconiosis is not merely a physical disease; it is a social disease and a structural social issue caused by the combined effects of financial pressure, flaws in the education system, insufficient social attention, and other factors. To address these problems, this paper analyzes potential countermeasures from the three perspectives corresponding to the identified causes—including expanding access to education and strengthening supervision and penalties for private enterprises—with the aim of helping pneumoconiosis-affected families overcome their difficulties and return to a normal life trajectory.

5.2. Research reflections

Nevertheless, this study still has certain limitations.

First, the on-site research samples of this study are limited to City P, Province J, and do not cover other provinces or cities. Therefore, due to significant differences in economy, cost of living, dominant industries, and other aspects across regions, the interviewees in this study cannot fully represent pneumoconiosis patients nationwide. Second, this study focuses on the rights protection of pneumoconiosis patients and does not conduct in-depth analysis from social, economic, or other perspectives; thus, its findings are only applicable for reference in the fields of rights protection and policy-making.

In light of this, future research will continue to focus on other dimensions of dilemmas faced by pneumoconiosis patients—including their low social attention, financial hardship, and severe psychological stress—exploring the suffering caused by pneumoconiosis, as well as the underlying causes of these dilemmas and corresponding solutions.

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