



A worker in the dusty tunnel construction site. Photo by Yijia Chen.

PAIN IN THE CHEST:

What are Responsible for the Dilemma of Pneumoconiosis Patients?

Inspired by “Life Matters”

Social Responsibility

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Introduction

Sitting in the shadow, Dexiang, a former coal miner in Shanxi Province, sighed when asked about his future expectations. This emaciated middle-aged man is a typical pneumoconiosis patient with painful, incurable disease in his lungs, heavy financial pressure on his shoulders, and thus great distress in his eyes.

Slowly, Dexiang told his stories about pneumoconiosis. Decades ago, he worked in coal mining and knew nothing about its risks. The air down in the mines was so dusty that the masks he and his colleagues used could not guard them from inhaling harmful particles. It was all too late when Dexiang found his lungs permanently damaged by the job he lived off of. Dexiang became paler and weaker everyday afterwards. He went to three local hospitals but was misdiagnosed as tuberculosis. Eventually he met Dr. Ping Wu, a conscientious doctor specialized in respiratory diseases. Thankfully, Dr. Ping Wu offered him medical advice and encouraged him to apply for industrial injury compensations from that coal mining enterprise.

However, the coal mine had closed for a long time, and Dexiang and his colleagues can never apply for compensations without essential documents from that company. Thus, Dexiang's life was further destroyed by the huge price of treatment of pneumoconiosis. Working hard to afford the cure potent drugs exhausted him, and

he had not seen his daughter for a year since he had to leave the young girl with her grandparents in rural town to save up some money.



Dexiang was sharing his story about pneumoconiosis.

Photo by Xizhi Huang.

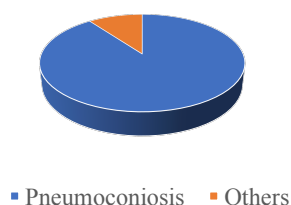
I. Overview: Facts about Pneumoconiosis

Pneumoconiosis is an occupational disease, mainly caused by diffuse fibrosis of lung tissue, due to long-term inhalation of productive mineral dusts and their retention in the lungs. The patients' lungs will gradually become hardened and petrified, retarding the patients' ability to breathe, move, work, and end up suffocating. Pneumoconiosis has a high death

rate of 22.04%.

Pneumoconiosis is now one of the most serious occupational diseases in China. As of 2017, over 850,000 cases of pneumoconiosis have been reported, accounting for 89.8% of occupational diseases in China. The reality is even worse than the data. For instance, in Yunxi county, in a total of 7,942 people who received physical examination, 4,367 of them were diagnosed with pneumoconiosis. However, the Center for Disease Control and Prevention in Yunxi county reported only 14 pneumoconiosis cases, which was 311 times less than the real number.

Occupational Disease in China in 2017



*The percentage of pneumoconiosis among occupational disease in China
Investigation report on the living status of migrant workers with
pneumoconiosis in China (2018)^[1]*

Pneumoconiosis patients live a dire life. Most of them live in poor families in the rural town and work in coal or stone processing to support livings for family. There is a vicious circle that to earn money, patients have to stick on their dusty jobs which deteriorate their illness, while in turn paying for expensive medical

treatments to sustain life.

Main causes of the desperate situations are the government's lack of advertising and supervision to pneumoconiosis; improperly strict policy for pneumoconiosis diagnosis; and inaccurate diagnosis in qualified institution. Nevertheless, this discouraging situation is improving with more attention from the society.

II. The Government: Lack of Supervision and Publicity

The government does not build strict supervision on potential pneumoconiosis-induced enterprises. Although there are certain requirements on the operational procedures for coal mining, building demolition, or jeans processing, the low level of regulation allowed those companies to evade the rules, for profits or just for convenience. According to Director Chen, a pneumoconiosis volunteer, "None of constructed workers in Guangzhou do wear qualified gauze masks and few of them conduct dust-related works, like cutting marble, with eligible sprinklers." For instance, on the subway construction site at the back of our school, the workers put on no mask at all, even in building demolition when dusts have covered the site.

The lack of publicity also causes the wide spread of pneumoconiosis. Most of these low-

skilled workers, especially workers living in decades ago, receive low-leveled education, so their knowledge about dusts, lungs and pneumoconiosis is very insufficient. It is the government's responsibility to educate the mass about the dangers of pneumoconiosis and proper ways to protect against them. But in these years, our government focused more on grassroots constructions rather than the risks taken by workers engaging in these constructions. According to Mr. Chen, at the end of last century, coal mining workers in Yongzhou county, knew nothing about pneumoconiosis. Most of them suffered from this disease but ignored it as simple tire, breathing pain or tuberculosis.

III. The Policy: Strict Application for Compensation

The diagnosis of pneumoconiosis is very complex based on the "The Law of PRC on Prevention and Control of Occupational Diseases" ^[2]. Patients can apply for occupational-disease diagnosis by professional occupational-disease diagnosis institution -- only when they can provide: their occupational history, inspection of pneumoconiosis-inductive factors in the workplace, and other relevant materials. If they were diagnosed as

occupational-disease, they can enjoy corresponding industrial injury compensations from their companies.

The problem is that when patients cannot provide sufficient evidence, the diagnosis institution will not accept their applications. However, many labors worked in pneumoconiosis-induced factory several years ago when the working contract system was imperfect, and after long incubation period of pneumoconiosis, either most evidence of employment was lost or previous companies were closed.

In June, a group of pneumoconiosis patients from Yongzhou county staged a hunger strike in front of the gate of the Guangzhou municipal government. They were pneumoconiosis patients who constructed roads, buildings and bridges in Guangzhou in the '90s,'00s. However, these people could find no written evidence of their dust-related works, so they could not get qualified diagnosis and corresponding compensations. The huge treatment price exhausted some of them since 2004 or 2005.

This strict policy was developed because, in the 70's and 80's, in state-owned enterprises, the state gave huge compensations to a pneumoconiosis patient: this patient could receive high subsidy and educational priorities for his children. Since then, the diagnosis of the

disease has been very cautious to ensure the accuracy of these compensations. However, currently, more dust-related works were held by private enterprises, which cannot afford previous benefits for patients. “The policy today is unnecessarily strict,” said Dr. Ping Wu.

IV. Medical System: The Trend of Inaccurate Diagnosis

Not only the patients’ evidence but also the diagnosis process in medical system are required strictly in the policy: collective diagnosis by 3 to 5 experts and full responsibility of the result for each of them. Common respiratory doctors like Dr. Ping Wu have no qualification to give written diagnosis for pneumoconiosis.

This strict requirement caused many troubles to the diagnosis qualified doctors and unfair treatments to patients. In 2016, three pneumoconiosis diagnosis doctors in Guizhou diagnosed seven workers as pneumoconiosis, but then they were sued by these workers’ company as having misdiagnosed the workers to help them get more compensations. These doctors were arrested for seven months. Although eventually they were exculpated, this event supported an atmosphere in doctors -- to avoid responsibility, they try to give milder

results when diagnosing.

According to Dr. Ping Wu, she met Mr. Zhang last year, a pneumoconiosis patient who once worked in fodder processing factory. The factory added large percent of stone powder to the fodder to increase its weight, which induced pneumoconiosis in Mr. Zhang. However, in Guangdong occupational-disease diagnosis institution, he wasn’t diagnosed as second stage stone pneumoconiosis. The diagnosis doctors worried that the fodder mill would bother them because normal fodder processing did not contain pneumoconiosis-induced factors like stone. After this “misdiagnosis”, Mr. Zhang could get no compensation from his company and suffer from intense financial pressure. Also, Dr. Ping Wu, who kept defending Mr. Zhang against this injustice, was excluded by that institution indirectly.



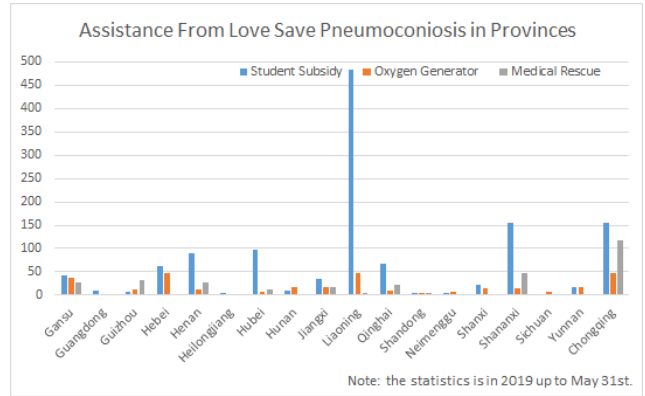
Dr. Ping Wu was talking about the diagnosis process.

Photo by Xizhi Huang.

V. Society is Bringing Hope

In 2018, our group members watched a documentary, “Life Matters”, which described stories of several pneumoconiosis patients. We were shocked by their depressed situations and great needs of social assistance. Although our strength was meager, our team determined to investigate the problems they faced and catch more people’s attention on pneumoconiosis through this research. Bringing pneumoconiosis patients hope is always our primary motivation.

Besides us, there are far more people giving a hand to pneumoconiosis patients voluntarily. An influential NGO in China “Love Save Pneumoconiosis” is an inspiring example. To investigate the progress of this organization, we interviewed Director Chen, the local coordinator of “Love Save Pneumoconiosis” in Guangdong Province. Established on 15th of June in 2011, so far, “Love Save Pneumoconiosis” has offered 3680 oxygen generators, 3463 critical medical opportunities, and 9812 pieces of student subsidies to the family with pneumoconiosis patients. What’s more, the organization popularize pneumoconiosis through media like WeChat, Weibo, and promote government’s actions on pneumoconiosis. Currently, “Love Save Pneumoconiosis” promotes the inclusion of pneumoconiosis to health insurance.



Note: the statistics is in 2019 up to May 31st.
In 2019, up to May 31st, Love Save Pneumoconiosis had subsidized 1267 students, offered 323 oxygen generators, and provided medical rescue to 294 patients in different provinces. Source: The May issue of Love Save Pneumoconiosis ^[3]

In the next stage, the goal of “Love Save Pneumoconiosis” is to prompt government to completely support pneumoconiosis patients. “It’s hard, but we do hard things all the time. Getting the health insurance seemed impossible previously but was accomplished by us after eight-year persistence.” Director Chen told us in the end of the interview, “You see, keeping on one thing always brings good result.”



We were interviewing Director Chen.

Photo by Xizhi Huang.

Focusing on the bright side, Dexiang is one of the patients who are now aware of their

difficulties and actively seeking aids from the society. Thankfully, there are doctors and volunteers willing to reach out to these victims of pneumoconiosis. Although there are indeed much more to work on, at least Dexiang and many patients like him are starting to see light in their future.

“No matter how long night, the arrival of daylight Association.”^[4]

References

- [1] “Investigation report on the living status of migrant workers with pneumoconiosis in China” (2018).
- [2] “The Law of PRC on Prevention and Control of Occupational Diseases” (2018).
- [3] “The May issue of Love Save Pneumoconiosis Journal” (2019).
- [4] Shakespeare, William. *Macbeth*.