

Socioeconomic Status and Family Structure: A Qualitative Investigation of Female Caregivers in Families Coping with Pneumoconiosis

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Abstract.

Pneumoconiosis is the most prevalent occupational illness in China. In Chinese scholarship and media discourse, migrant workers with occupational illness are almost uniformly described as helpless and vulnerable. While this is true in many cases, this study calls attention to the roles of socioeconomic status and family structure in shaping the differential experiences of workers with pneumoconiosis and their female caregivers. Using qualitative interviews with 19 Pneumoconiosis patients from the Fujian, Shaanxi, and Henan Province in China and their family members, I show that socioeconomic status affects not only the type of medical treatment the individual patients can receive but also their wives' coping strategies and attitudes towards the illness. Among pneumoconiosis patients with higher socioeconomic status, the patients optimistically await lung transplant surgeries, while their wives become bread-winners of the family and at the same time provide care for them. In families of less socioeconomic resources, however, husbands expect death and wives either remarry or become the only breadwinner. The latter group is also more likely to hold a pessimistic attitude toward death. This study extends the existing literature on occupational disease in China by highlighting the socioeconomic gradient in individual and family-level outcomes in the face of pneumoconiosis.

Keywords: Chinese workers; health outcomes; labour rights; occupational disease; Silicosis

1. Introduction

Pneumoconiosis is the most widespread occupational disease in China (Y X Liang, 2003). Specifically, it's a slowly progressive lung disease caused by inhalation and deposition of dust in the lungs. According to the 2018 National Occupational Diseases Report, there are 873000 Pneumoconiosis patients in China (Y X Liang, 2003). Focusing the research on patients with Pneumoconiosis in China, this article situates the study of pneumoconiosis patient experiences into a broader context, considering the aspects of socioeconomic status, health outcomes of occupational diseases, and social and cultural roles of women as caregivers for the patients. While current researches concentrate on political and economic aspects to analyse occupational disease, the impact of important factors like family structure, socioeconomic status, corresponding health outcomes, and attitude toward occupational disease have received less attention. My goal in this paper is to examine how socioeconomic status influences the family structure, especially the role of female caregivers in families coping with Pneumoconiosis in China, and their attitudes toward death.

The association between SES and health outcomes has been discussed over the years. Weber's concept of "life chances" (Weber, 1968) considers both the diversity of the biographical consequences of social standing and their probabilistic character, in other words, factors related to the probabilities of actually staying alive or dying. Lower socioeconomic status (SES) is generally associated with worse health and higher mortality rates (Chapin, 1924). In a broader context, Rothman (Rothman, 1986) states that social class is "causally related to few if any diseases but is a correlate of many causes of disease." SES is conceived as "access to resources . . . that help individuals avoid diseases and their negative consequences through a variety of mechanisms." When knowledge exists on how to prevent, treat, or manage the disease, then those with greater resources are better able to take advantage of this knowledge to attain lower likelihoods of adverse health outcomes (Karen Lutfey, 2005).

On the other hand, researches on workers with occupational diseases have also gained increasing attention. Agamben's concept of "bare life" describes people who are exposed and threatened on the threshold in which life and law, outside and inside, become indistinguishable (Mambrol, 2018). Wing-Chung Ho (Ho, 2014) uses Agamben's concept of "bare life" to portray the sick workers in China as "taboo people who are always vulnerable to policing and violence while simultaneously banished from society by a variety of formal and informal mechanisms of exclusion: legal, economic and social". While most researchers focus more on the economic burdens, biopolitics, cultural practices, and workers' rights, socioeconomic perspective and the role of caregivers have almost become the blind spot in researches, especially under the Chinese context. Workers with occupational diseases are often described as "vulnerable" in every aspect. While this is likely true for most cases, my interviews have shown that variations of higher or

2. Context

As a result of rapid industrialization in China, rural-urban migrant workers are increasingly susceptible to occupational diseases (Liu, 2015). In 2018, there were almost 76 million migrant workers in China who had left their homes to find work in another province (Han, 2019). Despite the various laws on occupational diseases, migrant workers are generally unable to receive legal compensation. Instead, they have to negotiate with employers informally for private compensation. In addition to suffering physically from occupational diseases, the poor enforcement of public laws creates new social risks for workers, that is, the disadvantaged encounter unjust treatment, judicial injustice and social exclusion (Liu, 2015).

Existing discussion of occupational disease in China’s media focuses on the negative sides of patients, including economic shortage and treatment limitations, and few investigates the role of female caregivers. Workers with a relatively higher socioeconomic status have more resources, thus becoming less vulnerable when coping with economic and social burdens triggered by diseases.

The media reported that the limited ways of receiving information in rural areas make patients unable to know authoritative hospitals with advanced technologies. Conservative treatments, however, make patients rely on ventilators waiting for the moment of suffocation and lose the ability to work. Thus, patients with lower socioeconomic status experience a lower possibility of survival. For example, Mi Shixiu is the wife of a famous pneumoconiosis patient He Quanguai who has miraculously survived over ten years relying on ventilators and has been reported online. She says,

“The nearest hospital is a three to four-hour drive over mountains so I give him an injection myself. I am now his wife, best friend, and nurse.”

With almost no income, Mi has to do all the work alone to maintain the family while other couples do the work together. The bundles of firewood she carries are even heavier than others’. Her husband who relies on ventilators is too weak to even walk, so she has to carry him over mountains. She says,

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“I always finish all the work before my husband wakes up so I can focus on taking care of him. I never expect he can recover and be able to work in the fields. The only thing I hope is to see him every day.”

Second, according to the media report, economic conditions limit the possibility of treatment and thus survival. Another patient reported by the media is He Kaihong, a pneumoconiosis patient from Shaanxi Province who died 20 hours before his son’s wedding. His wife, Zhang Hong, had to take his son who was under 15 years old to the city to earn money since her husband was sick. She said,

“In Jiangsu, Guangdong and Shanxi provinces, I worked in small restaurants, on construction sites, on assembly lines in private enterprises, and stayed at home for only a few days a year.”

In 2015, He’s health conditions worsened because he could not afford the treatment. He transferred from the local hospital to an authoritative hospital but was told by the doctor to go home and prepare for his funeral. The couple travelled more than 200 miles on the mountain road in the long-distance bus. His wife said,

“We even could not afford to rent a car to send my dying husband home. We owed more than 200,000 yuan for the medical treatment these years.”

He Kaihong died 20 hours before his son’s wedding, without finishing his dying wish of seeing his daughter-in-law. His wife said, “I borrowed a ventilator from another dead pneumoconiosis patient’s family in our village to help my husband breathe. He died at last while I have to pay the debt and support my son’s family.”

3. Methodology

3.1 Overview

In the existing study, the life of patients living with caregivers, I chose an ethnographic approach to data collection. Although I did have certain expectations for what I would find based on a review of the literature and media reports, I found the real results quite different after interviewing with those patients. To help generate a more clear and well-rounded understanding of this experience, I chose a great variety of data sources and interviewed with different groups, including patients, caregivers, and chief physicians.

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3.2 Participants

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The participants for this study included Pneumoconiosis patients aged between 20 and 40 years old, female caregivers in families coping with Pneumoconiosis, and chief physicians in the lung transplantation centre. I investigated 19 coal workers and jade caving workers with different

socioeconomic statuses from the Fujian, Shaanxi, Henan Province, and 1 chief physician from one of the most authoritative lung transplant centres in China.

3.3 Data Collection

Preliminary interviews were conducted with chief physicians, who have experience with lung transplantation patients, in the lung transplantation centre. These interviews examined perceptions of health, treatment expenses, causes of occupational disease, changes in attitudes, and issues of social support. The purpose of including these data was to provide the primary researcher with entrance into this population of Pneumoconiosis patients and to prepare with background knowledge and understanding of these patients' experiences.

Follow-up interviews were conducted with Pneumoconiosis patients and their female caregivers. These interviews focused specifically on issues related to coping with Pneumoconiosis within the context of family roles and responsibilities and family functioning. 3 Pneumoconiosis survivors aged between 20 and 40 years old and their wives were interviewed. The purpose of these interviews was to utilize the first-hand professional knowledge these individuals have regarding the everyday challenges and treatment of Pneumoconiosis as it relates to the lives of Pneumoconiosis patients and their families. This experience allowed for observation of the discussions these patients shared about their experiences, including those related to treatments and family.

4. Results and discussion

From the preceding interviews and qualitative data analysis, two specific findings related to family functioning and female caregivers were generated. These findings address issues of coping strategies and families' perceptions of death. While media describes those patients as "vulnerable", based on my fieldwork, I found variations in coping strategy, which is how patients mobilize resources to cope with occupational diseases. Patients with relatively higher socioeconomic status still exist even in this often considered "vulnerable" social group, based on my observation. Though patients still suffer from occupational diseases and following treatments, they use different coping strategies related to their SES, thus leading to different outcomes.

4.1 Impact on family structure

The role that women play within the traditional families in rural China is often caregiver, housekeeper, and cook, while men work as the only bread-winner to support his family. One might speculate that, by and large, how can pneumoconiosis families cope with the economic burden during and after treatment. In general, wives change their roles from only

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“housekeepers” to both “breadwinners” and “housekeepers” altering their responsibility from doing housework to earn money. While the family structure changes similarly in all pneumoconiosis families, the extent still differs due to different socioeconomic statuses. There

are several possible reasons why socioeconomic status is related to different outcomes in changes in family structure.

First, education levels and sources of information restrict access to treatment. Some pneumoconiosis patients in rural China didn't know they have pneumoconiosis until late-stage either due to lack of awareness or misdiagnosis from rural hospitals. For example, as mentioned previously in the context section, the Pneumoconiosis patient called He Quanguai in the news suffered from limited access to local hospitals and therefore treatments. Thus, his wife had to be the role of both a breadwinner and his nurse. Another 28-year-old patient I interviewed in the local lung transplantation centre, however, had totally different treatment and health outcomes. Though he experienced the same suffering caused by Pneumoconiosis, as his parents said,

“My son was panting like a dog before receiving treatments. He was breathing with the help of the ventilator in the car on our way and his nose was bleeding.”

He is one of the very few Pneumoconiosis survivors who successfully completed the lung transplantation with matched lung. With access to updated information, his family had been to different places in China seeking treatments. He said,

“We rented a car to come here, more than 900 kilometres away from my hometown Fujian province. I heard the lung transplantation centre here can treat Pneumoconiosis.”

Though his wife and his parents quit their jobs to take care of the patient and his wife had to work to support the whole family afterward, the situation of this family structure wouldn't last long. Due to the success of lung transplantation, the patient I interviewed didn't lose his ability to work and would find a job soon after his recovery. His wife told us,

“I will soon go back to work to help my family pay the debt. I'm worried if I could find a job, though.”

Second, according to the media report, economic conditions limit the possibility of treatment and thus survival. Though the treatment of lung transplantation gives patients two-third of the possibility to survive, it costs 600,000-800,000 RMB, not to mention the cost of constant reexamination afterward. Pneumoconiosis families in rural even can't afford conservative treatments, thus waiting for death with a ventilator. For example, as mentioned in the context

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section, He Kaihong's health conditions worsened because he could not afford the treatment and he died at the end. The patient I interviewed, a father of 3 children, experienced the same suffering but could not survive without the strong economic support from his family. Without any social welfare and medical insurance for his occupational disease, all the treatment expenses

are at his own expense. What made the economic burden even heavier was the failure of the first lung transplantation. His wife said,

“After the failure of the first lung transplantation, he spent 2 months in ICU and then received the second try. It costs us over 1 million yuan.”

Due to the economic burden, his wife, who used to be a housewife, had to be the only breadwinner in the whole family to pay back the debt.

“My parents are taking care of my children. As I had to go to work and look after my husband, I had no time for my children.”

Though the patient survived after the second lung transplantation, he still needs time for recovery and his health condition is too weak to support any work. Compared with He Kaihong, who died due to the lack of financial support, the patient I interviewed in the lung transplantation centre had a better health outcome after receiving treatments.

4.2 Impact of Socioeconomic Status on attitudes toward death

While patients reported by the media, for example, He Quangui, always prepare their own coffins in their house, the patients I interviewed in the lung transplantation centre hold a much more positive view. The chief physician in the centre said,

“Patients who do not have a wife or family to support them can hardly afford to come to the lung transplantation centre, so there is a little possibility to meet those patients described in the media.”

Most patients and their caregivers in the lung transplantation centre had enough financial support and knew their diseases have a higher possibility to be cured, thus all the female caregivers have a positive attitude toward the disease.

One of the patients I interviewed used to be a stone carving worker in Fujian Province. Aged 40 years old, he is the father of three kids. His chief physician told me the cause of his occupational disease,

“Producers replace hand-carving with machines simply to increase productivity, leaving those workers in dusty factories.”

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8 He had spent over a million RMB in Guangdong and Hebei Province but treatments didn't work.
10 November 2019 After he took the lung transplantation surgery in the current hospital, the transplanted lung failed to do normal pulmonary function, which made him unable to breathe without a ventilator.

During the 2 months in ICU, he had a tracheostomy and his weight decreased from 70 kilograms to only 49 kilograms. His wife told me,

“We were told by the chief physician that there was no possibility of surviving if my husband doesn't do his second lung transplantation.”

Luckily, though, his second lung transplantation was successful but a weekly blood concentration monitoring was still required. The wife of the patient who received two lung transplantations said,

“Though it was a hard time, I never thought of giving up. We were desperate and heavily indebted, but I had to make the decision to save my husband. We came a long way to find this centre and could not give up any possibility of treatment.”

Similarly, the wife of the 28-year-old patient I interviewed also showed a positive attitude. His special blood type made it even harder for him to find a matched lung source. His wife said,

“We had been to Beijing for lung transplantation but was told no matched lung available. We were so lucky that we heard a matched lung is available in this lung transplantation centre, so we came. It was extremely hard for us to find a matched lung for transplantation. We would do the transplantation at any expense and we are waiting for the day he recovers.”

My fieldwork suggests that in patients' families with higher socioeconomic status, husbands survive but need time to recover the ability to work and earn money while wives are positive and hopeful, waiting for the day their husbands can shoulder the responsibility. Instead, in those with lower socioeconomic status: husbands died and wives always hold a pessimistic attitude and are ready for funerals at any time.

5. Conclusion

This study offers a new perspective of investigating occupational diseases in China, one that has emphasized the importance of patients' socioeconomic status on health outcomes and female caregivers. While the media always describes all occupational disease patients as “vulnerable”, my fieldwork finds out the variation of health outcomes and indicates that it is time to rethink the SES-based coping strategies of patients. Patients with relatively higher socioeconomic status are able to better mobilize resources to cope with economic burden and social pressure caused by occupational diseases, which is different from media reports. Lower

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socioeconomic status is associated with fewer possibilities of treatment and higher mortality rates in virtually every case we interviewed. In analysing how families cope with occupational diseases in China, this study suggests that economic burden changes the family structure and family functioning. In all cases interviewed, wives change their role from housewives to the only bread-winner in the family to pay the expensive treatment costs. By focusing primarily on

their attitudes toward death and employment after treatments, my study indicates that in families with higher socioeconomic status, husbands survive and still are able to work after recovery while wives turn to be the bread-winner. Family members are more likely to hold a positive attitude toward survival due to the availability of advanced treatment. In families with lower socioeconomic status, however, husbands die and wives either remarry or become the only bread-winner. They are more likely to hold a pessimistic attitude toward death.

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