

Breathing In and Shouting Back:

Black Lung Disease and Neo-liberalism in China

by

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Chapter One: Introduction to the Politics of Pneumoconiosis in China

“Hello, President Xi. My name is He Quangui. I am 41 years old this year. I was born in the mountains of southern Shanxi province. When I was a child, our family was very poor. We didn’t have enough to eat. I went to school for only a few years, then I stayed at home to help my parents farm. Until the year I turned 20, it was the time of China’s ‘reform and opening up’. Farmers no longer went hungry. Living standards improved. I also had a dream: I wished my family could have a prosperous life. So I went with other fellow villagers to Henan to work as a miner at one of the gold mines there. When we got to that mountain, we workers lived in dark, damp caves. There was no sunlight. No one taught us about the dangers of working there. We didn’t know how to protect ourselves.

I worked there for ten years. That was when I started to get sick. I had palpitations and shortness of breath. I went to hospital to have it checked out and I was told that I already had second-stage silicosis. The doctor told us that there was no effective treatment for this disease, that the only thing to do was leave this environment and take care of myself, that I would lead a normal life, that my life was not in danger. Then I traveled [with other workers from the mine] to hospitals all over China to see doctors and receive treatment. When we ran out of money for treatment, we went to see the boss at the mine [where we’d worked], but he wouldn’t even admit we worked there. We had no choice but to borrow money from friends and family, and to get loans from credit cooperatives. I believe that the country [referring to the state] has a good treatment.¹ Living gives us hope. But year

1. My own translation

after year, day by day, all day every day, it hurts to breathe/endure the pain that comes with breathing. The illness is getting worse. As time passed, I was in and out of the hospital. Now I can't even move. In order to live, I need oxygen 24 hours a day. We have met other miners who worked for state-run mines. They get a salary every month, they have access to high-quality treatment at hospitals, they can live into their 60s and 70s. But where I come from, people who get sick live for 3 to 5 years at most. They don't have money to get treated. Their families can't make ends meet. They give up, or they commit suicide. They leave behind their elderly parents (father) and their children. Their families are destroyed. It's so painful to think about. We weep for them in silence. I'm fearful that one day this will happen to my family, but I am an extremely tough man. I love my family very much. My family treats me so well. They take care of me, and never abandon me.

[pause to breathe]

I have a notebook at home. Every time I lose a friend, I make a notation. In the past few years, I've written down more and more names. I am so scared. [pause for breaths] I wish, President Xi, you would love the people as you love your own child. We are [also] China's children. We would like to request that the country [please] take care of us. Please help (save) us, and our sons and daughters. This is my Chinese dream. Thank you!"

He Quanguai's account of his experience with pneumoconiosis in a five-minute video, filmed by award-winning Singaporean journalist Sim Chi Yin, first introduced me to the plight of

Chinese miners with pneumoconiosis.² Pneumoconiosis is an occupational lung disease caused by the inhalation of fine dust, produced mostly in mining processes. In the video, He Quangui sits on a log of wood by his brick house, breathing through a ventilator and constantly pauses his words to catch his breath. The video is made as if it were a letter to the country's president, Xi Jinping. Indeed, He addresses Xi directly in his monologue. He speaks slowly, but with a clear logic situating his disease etiology and illness experience in the context of China's economic reform. He speaks with pride and dignity. But in those few moments of silence forced by his shortness of breath, a sense of despair and pain becomes palpable. In the short introduction Sim Chi Yin wrote for the video, I found out that He was indeed more haunted by the fear of a suffocating death and leaving his family behind than he allowed himself to show:

“Over the four years I have known him, He Quangui, a gold miner from Shanxi, has told me many times he wants to travel with me back to Beijing. It's not just me he wants to visit. He dreams of going to the Chinese leadership's compound, Zhongnanhai, for an audience with Chinese President Xi Jinping. He wants to tell Xi about the plight of migrant worker-miners like himself, who heeded the government's call and left the land to work as migrant labourers to bring prosperity to their families—and fueling China's great growth. Failing that, he told me, he wanted to go to Tiananmen Square and unfurl a red banner to scream for help for migrant-miners like him who are now dying from silicosis...

One night in February 2013, as we sat chatting in his bedroom in his Spartan farmhouse

2. He used the term silicosis. Silicosis is a specific type of pneumoconiosis that specifies the kind of dust, silica dust, that causes the lung disease.

in Shaanxi's mountains, He told me of his dream again, and said if all that failed, he would blow himself up with dynamite on Tiananmen Square. I strongly dissuaded him and briefly chided him for not being more thoughtful, less desperate. I should have understood more deeply that at that time, when he was particularly ill, he was despairing. He really was at the end of his rope. He tried to suffocate himself at 4:30am the following day, with his wife, son, and I sleeping in or next to his room. We found him and he recovered.

About half a year later he miraculously fought off severe tuberculosis. On a trip back to visit him, I asked him: "If you really went to Beijing and met President Xi, what would you say to him?" I set up my camera for him and left him on his own to speak into it. He invoked the "China Dream" slogan that has been key in Mr. Xi's rhetoric, and chose to address the Chinese president in Shaanxi dialect, speaking as one Shaanxi man to another" (Yin 2015).

He and Yin's accounts, read in conjunction to each other, allow one a glimpse into the lives of Chinese black lung patients in the context of China's present political economic landscape. In this thesis, I try to make clear the connection between China's great economic growth, made possible partly by its adoption of neoliberalist policies since the 1980s, and the prevalence of black lung disease amongst Chinese miners. The turn towards neoliberalism is made evident by China's growingly market-driven economy, gradual privatization of public goods such as health care and higher education, and rising individualist sentiments amongst ordinary citizens. This has had life-altering and deterministic impacts on black lung patients' illness experiences, which as medical anthropologist Arthur Kleinman pointed out, are social by nature (Kleinman 1988). The state's

retreat from providing public goods to its most vulnerable citizens has created an empty space for China's emerging civil society to fill, but has also engendered a reaction from patients who are using the state's own laws and regulations to assert and defend their rights in a growingly neoliberal state. I divulge in the following pages how individuals and their families, through various ways, are trying to cope with a radically changing regime and life circumstances. The patient community, consisted of six million black lung patients and their immediate families, are in no way homogenous (Ho et al. 2016). My aim is, hence, to paint a heterogeneous picture of the black lung epidemic in China even knowing it may never be a complete one.

Contingent Illness Experience:

Reflecting on his experiences with seeking medical assistance, He Quangui compares and contrasts his experiences with others he has met at the hospital, "*We have met other miners who worked for state-run mines. They get a salary every month, they have access to high-quality treatment at hospitals, they can live into their 60s and 70s. But where I come from, people who get sick live for 3 to 5 years at most...They give up or they commit suicide*" (Yin 2015). He's statements show that while people may be affected by the same disease, they do not always share similar illness experiences and indeed often bear contrasting fates. His testament speaks to a literature within the field of medical anthropology which holds that despite the proclaimed universality of biological processes and biomedical knowledge across bodies, *biology* is also *localized*, and *illness experiences* are often contingent upon the political, social and economic context within which the patient is situated (Lock 2001; Roberts 2012).

My own understandings of illness experiences and biomedical knowledge as localized, contingent and indeed fluid are informed by scholars such as Arthur Kleinman, Duana Fullwiley and Elizabeth Roberts, although they are by no means the only ones who have

contributed to this insight. Arthur Kleinman, in his influential work *The Illness Narratives*, distinguishes amongst what he calls *disease*, *illness* and *sickness*. He highlights a gap between what patients experience (*illness*), and what the doctors treat (*disease*) in the Western mode of healing, namely biomedicine. *Illness* is defined by Kleinman as “the innately human experience of symptoms and suffering” (1988: 3). That is to say, illness includes not only the bodily experiences of pain and discomfort, but also the ways with which “the sick person and the members of the family or the wider social network perceive, live with, and respond to symptoms and disability” (1988: 3). *Disease*, on the other hand, is how illness is perceived by the practitioner of biomedicine. It is considered strictly technical by the doctor, where “an alternation in biological structure or functioning” has taken place in the physical body (1988: 5). Lastly, Kleinman introduces the term *sickness* to “complete the picture”, defining it as, “the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces” (1988: 6). Throughout this work, I treat pneumoconiosis as a disease, illness as well as sickness, and through these three analytics, attempt to paint a relatively complete picture of the pneumoconiosis experience in China. Specifically, pneumoconiosis as a sickness makes intelligible to connection between a miner’s body and macroeconomic development, and as an illness opens up possibilities for an analysis of the changing Chinese family.

In his work, Kleinman is mainly interested in the gap between biomedical perceptions of disease, and the sick person’s personal, social experiences with illness. Kleinman holds that illness experiences are culturally situated, “local cultural orientations organize our conventional common sense about how to understand and treat illness thus we can say of illness experience that it is always culturally shaped”, but seems to suggest that, at least within the confines of biomedicine, diseases are understood as universal across bodies (1988: 5). While I concur with

Kleinman that illness experiences are culturally shaped, I join authors such as Roberts and Lock in demonstrating that even biomedical knowledge of disease may be subject to political and social interpretations.

Anthropologist of medicine and science Margret Lock coined the term *local biologies* to “reflect the very social and physical conditions of women’s lives from one society” (2001:494). Through comparative studies of menopause in Japan, Canada and the United States, Lock challenges “the notion of a universal menopause and the post-menopause disease profiles vary from one study population to the next” (2001: 494). “Women from these different nations literally possessed different biologies, brought about through different local material and cultural conditions” (Roberts 2012: 2). Specifically, she makes clear that even practitioners of biomedicine, when operating in different societies, have varying understandings of the same general biological process. Elizabeth Roberts, in her study of assisted reproduction in Ecuador, also argues that people experience “biology and bodies as contingent”, “there is no universal body and no normative experience of embodiment...material conditions vary” (2012:2-5).

I build my understandings of the black lung experience in China on these works, and argue in chapter two of this work that Chinese worker/patients experience pneumoconiosis differently from their American counterparts, but also from each other.³ As He Quanguai’s words make clear, patients who have worked for private mines have a drastically different life-expectancy to those who have worked for state-owned companies, and have adequate health insurances. The way with which health insurance is organized in China has meant that even though two people may suffer from the same affliction, their illness experiences may be completely different. It also means that families of the sick person experience pneumoconiosis

3. Specifically, Lock’s work has contributed to my conceptualization of comparisons between local vs global, and Roberts’ work to local vs local.

differently from each other. As Kleinman correctly points out, illness experience not only includes how the physical discomfort of the patient, but also how his/her family responds to and lives with the illness.

Through a close examination of the process of pneumoconiosis diagnoses, I also try to make clear that the causal relationship between one's occupational history and his/her being affected by pneumoconiosis is not taken for granted in China. More specifically, I argue that the diagnostic process is somewhat reversed in China as compared to the United States: while in the U.S., the patient's condition is established first, and the occupational history is used to corroborate what doctors find clinically; in China, a miner suspected to be suffering from pneumoconiosis must prove their occupational history on which a formal diagnosis is predicated. This is a case in which the political and economic interest of the state become entangled with biomedical knowledge, and it has profound impact over the illness experience of patients.

Development, embodied

As I learned more about Chinese miners' experiences with pneumoconiosis, I began to start viewing it as a malady of development. In defining *sickness* as a macro-social experience and its relationship to the more personal experience of *illness*, Kleinman suggests that "not just researchers but patients, families, and healers, too, may extrapolate from illness to sickness, adding another wrinkle to the experience of disorder, seeing it as a reflection of political oppression, economic deprivation, and other social sources of human misery" (Kleinman 1988: 7). Underlying this statement is the important understanding, that the experience of a physical disorder is often times reflective of political and economic processes if not oppression. He Quanguai, by suggesting that he "heeded the government's call and left the land to work as migrant labourers" because he wished his family to have a prosperous life and his subsequent

description of working conditions in Henan, “*When we got to that mountain, we workers lived in dark, damp caves. There was no sunlight. No one taught us about the dangers of working there*”, was doing precisely this work (Yin 2015). He places the etiology of his sickness not just in the work that he had done, but the state’s call for rural farmers to become migrant workers, and its subsequent failure to properly regulate the extraction of GDP boosting natural gases, minerals to protect the labourers. In this sense, development becomes embodied.

My conceptualization of pneumoconiosis as a manifestation of economic development on the body is influenced by Hannah Landecker and Harris Solomon’s works on *metabolism*. In her work *Post-Industrial Metabolism*, Landecker demonstrates metabolism’s significance as an analytic to allow one to theorize the relationship between the environment and the human body. She argues that just as “knowledge is a product of its times”, *metabolism* as a way of knowing is also shaped by its particular temporality. Namely, metabolism has shifted from industrial to post-industrial in our times, “knowledge of metabolism in the industrial period was framed by manufacturing and energy; knowledge of metabolism in the postindustrial period is suffused with environmental rise, regulation, and information (2013: 497). Importantly, however, Landecker notes that these two modes of understanding through metabolism should not be viewed as completely separate: “postindustrial metabolism both comes after and is very materially and literally produced by industrial metabolism” (2003: 495). Solomon in his *Metabolic Living: Food, Fat, and the Absorption of Illness in India* builds on Landecker’s work to demonstrate “the possibility for bodies, substances, and environments to mingle, draw attention to each other, and even shift definitional parameters in the process”, suggesting that bodies and the environments in which they operate are mutually porous (2016:5).

It is through their lenses that I began to theorize black lung as an extension of the process of minerals and natural gas extraction even though I do realize breathing is not necessarily

considered as a part of the metabolic process. Pneumoconiosis is caused by the inhalation, and subsequent settlement of dust in a miner's lung. Dust is produced as a waste product of the extraction process. As dust from the mines settles in the lung of a miner, it effectively renders the lung as a site of waste disposal. In this sense, the body is indeed porous, and the inner, organic and the external, industrial environment become inter-exchanging. This process also enacts Landecker's claim that postindustrial metabolism is a product of industrial metabolism - I will argue in chapter two that while Chinese miners live in a time defined mostly by post-industrial metabolic knowledge, their bodies are, to a degree, stuck in the temporality that views metabolism as industrial.

The family under neoliberalism

Neoliberalism, as its name suggests, is the twentieth century twist on nineteenth century *laissez-faire* economic liberalism that began to gain force in the 1970s globally. The United Kingdom and United States as advanced capitalist societies at the time lead the global march into neoliberalism, with Margaret Thatcher and Ronald Reagan as chief advocates for neoliberalism "as a new economic orthodoxy regulating public policy at the state level" (Harvey 22). Half a century has passed, and neoliberalist capitalism has arguably been adopted, although to varying degrees, by most nations in the world. China, while dubbed by David Harvey as a strange case of neoliberalization, is no exception.

There is little contestation amongst scholars now over the polyvalence of neoliberalism as concept. It is taken by some as a developmental model that emphasizes market de-regulation, privatization of public goods, and little or no trade barriers (Boas et al. 2009). While for others, it is taken as more than simply a way to organize the economy but rather a form of governance, in

the Foucauldian sense.⁴ For the purpose of my work, I take neoliberalism as both of those things: neoliberalism has manifested itself most clearly in China as a set of economic policies through which the market was created, but it is also very much a mode of governmentality employed by the state. Last but not least, it is also the dissemination of neoliberal ideas and beliefs into the society to the point when they become so entrenched in each individual that it becomes the unproblematic, underlying logic of the society.

Aihwa Ong in her *Neoliberalism as Exception* provides an excellent analytic for understanding neoliberalism and its impacts in China. She resolves Harvey's conceptual difficulty that views China as the strange case by suggesting that we view neoliberalism as "exceptions in emerging countries where neoliberalism itself is not the general characteristic of technologies of governing" (Ong 2006: 3). Indeed, in my research I have found that while China took a turn towards more neoliberal governance and economic policies since the 1980s, the transition is no way complete. The day-to-day lives of Chinese rural dwellers, specifically, continue to be jointly influenced by both the remnants of socialist policies and newly formed neoliberal logics.

Chinese miners/patients' lives were profoundly changed by China's turn toward neoliberalist capitalism. In chapter three of this work, I hone in on one particular aspect of life that I believe has been under significant change: the Chinese family. In He Quanguai's short monologue, he mentions that he has a supportive, loving family and substantiates this claim by saying, "*My family treats me so well. They take care of me, and never abandon me*". Indeed, He has a lot to be appreciative for in this regard. As my research will show, consistent and unrelenting care from the patient's family should not be taken for granted. There have been many

4. "'Governmentality' as the array of knowledges and techniques that are concerned with the systematic and pragmatic guidance and regulation of everyday conduct. As Foucault puts it, governmentality covers a range of practices that 'constitute, define, organize and instrumentalize the strategies that individuals in their freedom can use in dealing with each other' " (Ong 2006: 4).

cases in which family members, under enormous financial and emotional pressure, have chosen to not support the patient.

Anthropology as a discipline has a long tradition of using the family and kinship structures as analytics into understanding the larger society. Following this tradition, I try to interpret what I observed as changing expectations between parents and children, henceforth, perceptions of filial piety as reflective of the social forces and changes individual families are experiencing. Unsurprisingly, there is a rich literature written on familial structures, and its changes during the socialist era in China. My understanding of the topic is informed largely by anthropologist Yan Yunxiang's *Private Life under Socialism* in which he discusses more than simply family life under socialism, but also how it is transformed as the socialist era came to an end. Yan conducted extensive research in a small village in Northeast China, the Xiajia village, between 1971 and 1978, and returned more between 1989 and 1999. During this expansive period of time, he witnessed first-handily the emergence of individualism and private spaces within the family amongst people he shared deep personal connections with (Litzinger 2005). I find Yan's account of the private family in China particularly compelling and useful for my own analysis because it does not draw a clear distinction between socialist/collective and the reform/post-collective era, rather, Yan situates the shifts he witnessed into evolving, dynamic historical moments: making clear that changes in the private domain are prolonged and gradual responses to structural shifts. Indeed, almost two decades have passed since Yan completed his fieldwork research, but the process that he witnessed is still unfolding. I engage with his discussions by demonstrating that the Chinese family, whilst undergoing significant changes as a result of China's partial adoption of neoliberalism, continues to be affected by socialist ethics. My work affirms many of Yan's findings but furthers his theorizations by suggesting that the changes in

family structures were experienced as painful and contentious by his informants have become increasingly internalized and even embraced by my interlocutors.

Beyond the Suffering Subject: Toward an Anthropology of the Good

In his namesake article that gives title to this section, Joel Robbins traces the history of the shifting primary object/subject in anthropological studies: from the savage-other to the suffering. He argues, or more accurately, observes that “over the last twenty years or so, it has often been the suffering subject who has replaced the savage one as a privileged object” of anthropologists’ attention (2013:450). The appeal of writing about the suffering is that it seems to transcend culture and makes clear to readers “the shared humanity that links us to others who suffer, how profoundly human beings can fail one another, and sometimes we gain insight into ways we might be complicit in this failure” (2013:456). Influential works have been produced that exemplify the kind of ethnography Robbins calls anthropology of suffering, one of which is Joao Biehl’s *Vita*. While Robbins commends the work’s achievement in affirming the humanity of Catarina, whose life-story is the central narrative of the book, he suggests that it did not develop in “great ethnographic depth about how neoliberal states and their citizens come to abandon those who cannot productively regulate themselves” (2013:455). Biehl’s work has in many ways shaped my approach to black lung patients’ life experiences: I attempted to demonstrate how China’s turn towards a neoliberal state has rendered many of its citizens as non-citizens, or secondary citizens, and left on their own for survival through the stories of individuals, so I cannot wholeheartedly concur with Robbins in his critique of Biehl’s literary approach.⁵

5. A neoliberal state, per its definition, is a government that adopts neoliberal policies, and upholds liberal values, such as market economy and individualism. I should note that a neoliberal state is not an anarchist state, rather it is one that designates the role of the state to safeguarding the free market, private property and the rule of law. The imagination of a neoliberal state is for most theorists

However, I think Robbins makes a significant and valuable argument in his proposal to moving beyond the suffering subject.

I read his work as suggesting not that we forfeit the important task of identifying the structural violence and oppression which ordinary people from every society are subjected to on daily bases, but in addition to that work, to aim to realize “the promise suffering lot anthropology always at least implicitly makes: that there must be better ways to live than the ones it documents” (2013:458). This is what I have tried to achieve in chapter four of this thesis. I contrast two narratives constructed around black lung patients in China: one of charity and the other of rights, to demonstrate patients’ rejection of a singular, suffering image often imposed on them. I argue that the narrative of charity, employed by NGO Love Save Pneumoconiosis, is constructed around suffering, compassion and volunteerism. It operates within the affect economy: non-governmental organizations appeal to the empathy of the public by circulating images of suffering, and this exercise is in many ways inherently oppressive. In doing so, I demonstrate what patients imagine as the “good” life: one in which they do not have to fight for medical care that is rightly owned to them, and they do not have to live off the empathy of others, but rather as dignified citizens.

Methodology

Shortly after I saw the He Quanguai video, I was given the opportunity to do independent research on pneumoconiosis, specifically coal miner’s pneumoconiosis (black lung disease), with

not one completely without state sponsored welfare, albeit to it should be reduced to the minimum (Gray 2010).

Dr. Ralph Litzinger.⁶ Coal miner’s pneumoconiosis, just like silicosis, is a specific type of pneumoconiosis common to coal miners as its name suggests. During this time, most of my research were mediated by social media. I conducted phone and Wechat interviews (video/audio) with patients, volunteers and scholars. I also relied heavily on social media discourse analysis with most of my data from Wechat and Weibo.

Social media has become growingly present in ethnographic works. Indeed, as noted by Tom Boellstorf in his *Rethinking Digital Anthropology*, “technology is now ubiquitous worldwide, and few, if any, future fieldwork project could ever constitute ‘ethnography unplugged’” (2013: 39). However, as anthropological research gradually embraces the online, how should we understand the relationship between the digital world and the physical world? The online world is often referred to as virtual, while the offline as real, implying that however close to reality the online world is, it is not. Others consider the online world as an extension of the physical, offline world, and suggest that the two are collapsing into each other. Boellstorf argues, however, that “the gap between online and offline is culturally constitutive” and that we treat “the digital not as an object of study, but as a methodological approach, founded in participant observation, for investigating the virtual and its relationship to the actual” (2013: 40). Indeed, throughout my research, social media platforms have served as “real” sites for participant observations.

WeChat and Weibo are two China’s most used social media platforms, and can best be understood by a Western reader as the Chinese version of WhatsApp and Twitter (Tu 2016).⁷ WeChat distinguishes itself from WhatsApp with its diverse features, as it is put by an online commentator, WeChat is a “better WhatsApp crossed with social features of Facebook, and

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7. In 2015, Tencent reported as having 600 million active monthly users. In the same year, Weibo reported 198 million active monthly users (Tu 2016: 344).

Instagram, mixed with Skype and a walkie-talkie” (Svensson 2013). “Distinctive features on WeChat include group chat, public account platform, and moments” (Tu 2016: 344). Moments, a feature similar to Facebook timeline, is where many of my informants share with their WeChat friends both their private life moments, such as a nice dinner out or a vacation trip to Southeast Asia, as well as their public opinions. WeChat Moments is comparatively more private than other similar platforms such as Facebook timelines, or Twitter tweets as no posts on one’s moments are completely “public”. You must become friends on WeChat with someone to view their moments. It is also nearly impossible to search a private user by their real first and last name as one often can with Facebook or Twitter. To add someone, one must be given his/her specific username, phone number or scan a QR code specific to that account (similar to snapchat).

Both Wechat and Weibo are important public sites for debates, mobilization and protests at times. Indeed, as I will discuss in greater details in chapter four, Weibo is an important site which charitable organizations employ to raise awareness and fundraise for specific causes. Throughout my research, however, I found Wechat to be a better source for more personal and politicized opinions from ordinary people than Weibo, as the latter has growingly been under stricter censorship by the state since President Xi’s reign. Following the crack-down of opinion leaders on Weibo in 2013, tough regulations also ensued, “if a rumor is retweeted 500 times or been viewed 5000 times, the creator is liable to be sentenced to three years in jail” (Kaiman 2013; Tu 2016). The tightening of Weibo has compelled many to move their discussions to WeChat, a more private and secure space. While WeChat is also subjected to censorship, its technical features renders censoring harder and slower. Most censorship that takes place toward WeChat is targeted at public accounts rather than personal. Indeed, WeChat has emerged over the last few years as an “eco-system of closely connected alternative spheres, in which a plurality of interests can be represented and coexist” (Tu 2016: 345).

This thesis is based on the result of a little over a year of research that started since February 2016. My initial contacts took me to the province of Hunan, but eventually lead me to Chengdu, Sichuan. Chengdu is the capital of Sichuan province. Located in Southwest China, Sichuan is one of China's largest provinces, and a major industrial center (The China Perspective 2017). Spanning 485,000 square kilometers, the province has a population of 80,418,200 and has a GDP of 1718.5 billion RMB (~250 billion USD) as of 2017.⁸ In the mid-1990s, the time during which many of my interlocutors worked, Sichuan ranked second “in terms of output from township and village coal mines” (Wright 2000: 113- 130; Ho et al. 2016).

In Chengdu, most of my fieldwork took place in Huaxi Fourth Hospital. Huaxi Fourth Hospital is a subsidiary teaching medical center of Sichuan University, located at the outskirts of the university campus. It is also a provincial centre for occupational disease treatment, hence most pneumoconiosis patients in Sichuan who can afford professional care seek medical assistance there. I also spent some of my time in patients' homes, sharing meals with them in restaurants and their previous work sites. “Playing” (a literal translation of the Chinese word “shua”, meaning to have fun/hanging out) and dining as I discovered are integral to the Sichuanese culture, and even as these patients endured both physical pain and emotional stress every day, they never forgot to enjoy life whether it is playing poker, going to karaoke at night or having a nice lunch out. I was fortunate enough to have shared some of those moments, and through which I was able to gain a more nuanced, and multi-faceted insight into the lives of pneumoconiosis patients.

In total, I spoke to around thirty patients and their families; some of whom I conducted formal interviews with, while others were more casual encounters. I also interviewed around fifteen people who were not patients themselves, most of them were volunteers/activists, while

8. See Appendix for a map of China.

others were journalist and donors to the cause. My notes were stored in my iPhone, a Moleskine notebook and my small audio recorder that has been turning itself on at random moments since my return to the United States as I have kept the habit of carrying it with me everywhere.

Since there was little gap time between the writing of this thesis and my research, I chose to write about the themes that I intuitively found most prominent. But as Max Weber has reminded us of, “regardless of the position one takes on the possibility of separating empirical observations from value judgments in the course of social-scientific analysis, one has to acknowledge that the choices social scientists make about what to study in the first place, and the way they define clear objects of study out of the ever-shifting reality of social life, are always driven by the values they hold to be important”, my choices undoubtedly have reflected my own intellectual curiosity (Robbins 2013:448; Weber 1949). There remains much more to be further explored and examined, and it is my hope that my work so far would stimulate the interests of others.

Chapter Progression

In chapter two of this thesis, I trace the processes through which a patient contracts the disease, obtains a diagnosis and receives (or not) treatment. I argue that the prevalence of black lung disease in China makes visible the inextricable connection between sick bodies of Chinese miners and the society’s hasty economic development. The state’s negligence to provide adequate regulations, protection for miners have directly contributed to the high incidences of this occupational disease in China. I conceptualize the blackened lungs of patients as an reification of the cost of development, and suggest that through the inhalation of dust particles, miners embody the very processes of development. Using Margaret Lock’s theory of *local biologies* to understand the difficulties Chinese black lung patients encounter in obtaining an occupational

disease diagnosis, I contribute to the existing literature that argues the cause, symptoms and the consequences of a disease are contingent upon social and political contexts, and varies from body to body.

Chapter three outlines China's adoption of neoliberal policies since the 1980s and divulge its impact on the Chinese family. Namely, I argue that the moral norms governing familial dynamics and intergenerational reciprocity have been undergoing a significant change in response to the changing political economic landscape in China. The traditionally uncontested belief that it is the young's obligation to provide for their parents in their old age is no longer taken for granted. The private family is on the rise, and the extended family as a mutual support network is shrinking. However, despite the lowering expectations of children to support their parents, black lung patients with children continue to express the sentiment that to provide and care for their children is sometimes the strongest motivating factor allowing them to endure through a suffocating everyday life. I suggest that such can be read as an expression of socialist ethics that the Chinese Communist Party continues to uphold. Hence, chapter two argues that a duality of ideologies is at work in today's China to govern the family: neoliberalism work concurrently with socialism in the creation of self-reliant subjects, who in their illnesses are at once abandoned by the state but still held responsible for the rearing of their children.

Chapter four compares and contrasts two existing narratives around and approaches toward providing relief for black lung patients in China. Namely, the narrative of charity and the narrative of rights. I argue that the narrative of charity, employed by the NGO Love Save Pneumoconiosis, is one constructed through depicting patients as the suffering subject, and operates within an affect economy. Patient-activists, on the other hand, implore a narrative of rights, which in many ways stand in direct contradiction to that of charity. They assert their places in the patient-state relationship as citizens with rights, and demand the state to fulfill its

responsibility to effectively provide a safety net for all that is under their jurisdiction. In doing so, they have employed tactics that qualify as what Kevin O'Brien may consider as "rightful resistance" (O'Brien 2013). I further the chapter in suggesting that the work of patient-activists in the field of black lung disease relief may have long-lasting impact on a larger labour movement that is gaining force in China.

Chapter Two - Development, Embodied

*“Not all the organs, you must realize
Are equally important nor does health
Depend on all alike, but there are some –
The seeds of breathing, warm vitality –
Whereby we are kept alive; when these are gone
Life leaves our dying members”*

————— Lucretius, *The Way Things Are*



Figure 1 A Lung with Black Lung Disease from MedSpace

This is what a black lung, affected by the disease of its namesake, black lung disease, appears to the naked eye when removed from the body, though many also know it as coal miner’s pneumoconiosis. It is not what a thriving, functioning lung would look like. A healthy lung is a lively, fibrous and pink organ, pulsing with the massive amount of blood that it pumps through to

support the rest of the body. It is a muscle constantly pumping and delivering fresh oxygen to the body with its every pulse. A black lung is hardened by the dust inhaled by the lung's host through the process of working in mines and dust-intensive environments. The organ loses its ability to pump effectively, and causes its host great pain as the body experiences a constant lack of oxygen. This is the lung that more than six million Chinese miners now possess as they live permanently in a state of fatigue, weakness, breath shortages, even suffocation.

Clinically, *pneumoconiosis* refers to any of several types of interstitial lung diseases that are caused by the inhalation of dust, and the lung tissue's subsequent reaction to the dust (National Institute for Occupational Safety and Health Respiratory Health Division 2012). The specific kinds of pneumoconiosis are distinguished by the kinds of dusts inhaled. For instance, asbestosis is caused by the inhalation of asbestos fibers, and silicosis by silica dust. Black Lung Disease, or coal workers' pneumoconiosis, as the name suggests, is caused by the inhalation of coal mine dust.

In Chinese, all inorganic pneumoconioses are referred to as *Chenfei Bing* (尘肺病), literally translated as the lung sickness of dust and powder. The people with whom my research is concerned, by the nature of their occupations, are mostly inflicted with what in English is called black lung disease or coal miner's pneumoconiosis. However, the distinction between the two is not present in their native Chinese. My informants never specified their "type" of pneumoconiosis from which they suffer, although most of them are most likely suffering from black lung disease. This may simply be the result of linguistic differences. It may also be because sometimes one patient's pneumoconiosis is caused by exposure to a multitude of dusts as a result of having worked temporary jobs in various industries. This is not uncommon in China amongst rural labourers, as many of these workers are hired on temporary terms and move from job to job rather

frequently. Hence, throughout this thesis I use the terms black lung disease and pneumoconiosis interchangeably to account for the variety of patient experiences I consider.

In many ways, I think of the blackened lung as reifying the cost China's development has taken on the bodies of its population during the last thirty years. The lung becomes sick because the dusts inhaled cannot be destroyed by nor removed from the body. Instead, these foreign particles become engulfed by the pulmonary macrophage, form a dust macule and take up residence in the tissue of the lung (Castronova 2000).⁹ In other words, the dust become a permanent part of the lung. After settling in the lung's tissues, the dust macule then becomes inflamed and causes the development of fibrosis. Aggregations of carbon-laden macrophages are visible under a microscope, where they appear as granular, black areas (Becklake et al. 2015). In serious cases, nodular lesions will be formed, and the centre of which may become necrotic (Vanhee et al. 1995). As the respirational units of the lung become blocked, and part of the lung experience tissue death, it becomes increasingly difficult for the host body to properly breath and obtain sufficient oxygen to undergo the mundane activities of daily life, let alone perform arduous labour.

This is the medical story of how a lively, healthy lung turns into one that is blackened and hard. But it is not the full story. In this chapter, I explore the macro socio-economic processes that fall outside the gaze of a narrow medical microscope through which a healthy lung becomes sick. Arthur Kleinman, in his book *The Illness Narratives* distinguishes among the terms *disease*, *illness* and *sickness*. For Kleinman, *disease* is the pathological understanding of bodily problems, "an alteration of in [one's] biological structure or functioning" (1988: 5). Disease is what the doctor sees in a patient - strictly physical and confined within the boundaries of biomedicine.

9. Macrophage are a type of white blood cell. It is present in all essential tissues, and one of role is to engulf and digest foreign objects (Ovchinnikov 2008: 447-462). Pulmonary alveoli are the basic units of respiration.

Illness, on the other hand, is defined as the “innately human experiences of symptoms and suffering” (1988: 3). That is to say, illness includes not only the bodily experiences of pain and discomfort, but also the ways with which “the sick person and the members of the family or the wider social network perceive, live with, and respond to symptoms and disability” (1988: 3).

Sickness, lastly, is the understanding of a disorder across a population in relation to macro-social forces.

Furthering the works of medical anthropologists before me, this chapter considers the possibilities black lung disease opens up for unsettling the often-assumed boundary between the social and political on the one hand, and the biological and medical on the other. Following Kleinman, I consider black lung disease through the analytic of *sickness* to trace the processes through which a miner contracts the disease, attempts to gain medical diagnosis and lastly, treatment. I begin with conceptualizing the micro-macro connection between a blackened lung and China’s economic growth realized through the mining industry to argue that development is embodied by miner-patients’ sickness. I then proceed to introducing readers to the arduous tasks of obtaining a diagnosis, which every patient must undertake in order to have a chance at receiving compensated medical care. The knowledge of and patients’ experiences with a particular disease are almost always contingent upon the social, political environment in which they are situated. Unsurprisingly then, the diagnostic processes of black lung disease are also dissimilar across national boundaries, resulting in the disease’s differential manifestation in different bodies. I show how the causes and meanings of a widely recognized and accepted occupational disease in Western nations, such as the United States and Australia, are contested in China, and hence, produce life-altering effects for the sick person. I end the chapter with introducing the hospital as a site of fieldwork research, and the diverse array of patients present in

the hospital to suggest that even within country, patients of the same disease do not share similar fates.

Development, Embodied

He Bing's story began in the early 1990s. He was thirteen years old. After graduating from primary school, he took up a job at a small, privately owned mine in a neighbouring town near Leshan along with his father and three brothers. This transition from school to work, Bing recalled with a sense of lament and regret. He couldn't continue with his education because his family didn't have the money. Due to his young age when he first arrived at the mine, he worked only as a chef for the first three years. But he wasted no time. During breaks between meals, he always tried to observe the "masters" work. The masters are those who occupy the highest position on the working hierarchy - they possessed the skills and knowledge of drilling and blasting, their works were less labour intensive, and they were paid much better. Indeed, while he was paid 150 RMB per month, the masters were paid three times as much - "almost as much as the public servants were paid" in He's words.¹⁰

He started really working inside the mine at the age of 16, after spending three years around it, and in a year's time became a master himself. He would have continued working in the mines if it was not for the provincial reform and subsequent closing of most private mines in Sichuan in 2001. When he left the mines, he did not know that all the dust he inhaled during the past decade was already taking hold of his lung. His biggest concern then was making sure he received all the salary that was owed to him. As he would later find out, however, he took home

10. ¥150 ~ \$25.

with him more than the money he had earned, but also a lungful of coal dust. In this sense, he was never really to leave the mines. He will carry a part of it with him for the rest of his life.

Money was a constant theme in our conversations and influenced his every life decision. Indeed, the mining industry was an important source of income for him and million others, but the biggest beneficiary of the mining industry's boom? The state. The story of China's miraculous economic take-off hinges on its mining industry, which was instrumental to China's astounding economic growth in the twentieth century. Today, China is the world's largest producer and consumer of coal, as well as the largest user of coal-derived electricity (Puko 2017). The mining industry is hailed as one of the industries that most contributed to the processes of urbanization, poverty reduction and the overall economic development in China. In 1999, the mining cities and townships produced 37.3% of the country's overall GDP. In 2007, China exported \$474 billion worth of mining products (World Trade Organization 2015). It is not an exaggeration to say that the mining industries have fueled China's economic boom since the 1970s. Analyzing this phenomenon through the neoclassical model of growth, it becomes clear that the mining industry's boom is made possible by two factors: discovery of energy (coal) and extremely cheap, and abundant labour even though the latter is often rendered invisible in the discourses of development as if energy all of a sudden, through some invisible magic previously unknown to mankind made itself available for consumption (Allen 2009).

Thus, the prevalence of black lung disease in China is intricately linked to this process of economic development. He Bing started working, as a young teenager, when China was transitioning from the socialist period of collective production and economy to a market-driven industrial one. His father was among the first generation of farmers in rural China who gave up their traditional farming roles to work better-paid industrial jobs. There was a simultaneous proliferation of private mines which were owned by ambitious entrepreneurs who utilized new

economic policies in China as an opportunity to “get rich first” (Deng 1984). However, as the market was still in its nascent stages, so too were the regulations of industries. While the Coal Mountains Safety Law was passed, and put into effect by mid-1993, it was rarely enforced.¹¹ Most of the private mines had extremely poor working conditions with few safety measures in place; many of the processes that were becoming mechanized in the West by then were continued to be done by human labourers, “There was no separate bathrooms for men and women”, and while some miners were given cotton masks before working others had little protection before they entered the highly hazardous working environments. “The employers took deaths as a necessary externality of the work, on every mine there were a few miners who died from blasting. It was normal. If the employers were nice, they paid the families a few thousand RMB in compensation”, He Bing told me.

It is important to understand that while black lung is irreversible, it is preventable to a large extent. “Prevention involves managing exposure by monitoring dust levels, and actively taking steps to reduce coal dust exposure in miners”, such as providing miners with proper masks, having a good ventilation system (Gibson 2016). Hence, when high incidences of black lung break out, it is not due to technical barriers but rather willful negligence of miners’ safety by both the state and the capital. As a matter of fact, Chinese state officials have expressed their beliefs that “high accident and death rates is necessary as a cost of economic growth”, let alone occupational disease (Homer 2015: 427). The extremely high rate of black lung amongst Chinese miners is rooted in the hasty economic development process that took place in the early 1990s, which allowed for rapid economic growth and yet failed to protect those who fueled the development. Indeed, a comparative study on coal mine safety regulations in China and the US showed that China had a “disproportionate number of coal mining fatalities”, and “the crisis in

11. My Translation

Chinese coal mine safety” has been considered by some as “the nation’s ‘lesser-known human rights tragedy’” (Lambrecht 2005: 5; Homer 2009: 425).

The blackened lungs of former miners represent an extension of development process as well as an embodiment of development’s costs in material, bodily form. Forty-three-year-old Li Zhi began working as a ventilation worker on a gold mine in He’nan province in November 2008. This job paid well compared to others at the mine, with a salary at 3,000 RMB per month.¹² The high salary was compensation for the very immediate and detrimental physical effects it had on his body. The job had a high turnover rate because people were constantly quitting after a short period of time. Li, too, noticed the job’s effect was having on him after a few months and requested to be re-assigned. “The boss kept on telling me that he could not find someone else to replace me, so I ended up working the job for about a year” (Phoenix Television 2015). Li’s shifts lasted twenty-four hours and his responsibilities quite literally rendered him an extension of mine’s ventilation process itself: “Once the cannon fires on the other end, I must run into the heavy smoke to connect the ventilation machine with the pipe that is working so that the ventilation could begin, and fresh air could be let in. After the smoke is ventilated out, the other workers can start working, or else it was common for some workers to faint under the heavy pollution. I was given a dampened cloth to cover my mouth and nose during this process” (Phoenix Television 2015). Without himself knowing, Li facilitated the illegal and unsafe operation of the mine – which was subverting the regulation that required mines to have two ventilators for operations (The National People’s Congress 1992). While his work of connecting the ventilator helped to suck the polluting air out for other miners, he was hurt himself by acting as a part of the ventilator. He was quite literally absorbing the mines stale air, except he could not

12. ~ \$450.

release that dust into the air like the ventilator could. He sucked it into his lungs. In essence, Li's job was that of a human ventilation machine.

As the dust that he inhaled through working as the “ventilator” settled permanently in his lung, his body was also rendered a site of waste disposal. The wastes/excesses created by mining processes — processes that produced the minerals which fueled, both figuratively and literally, China's economic development— now reside in the lungs of the miners who produced them. Their lungs in many ways have become an extension of the mines and factories, hence, blurring the boundary between the body and the external environments. They are avenues of ventilation, sites of production and at last, waste disposal.

My thinking of the relation between the black lung and China's development processes as intimately connected and indeed, mutually constituent is informed in part by Harris Solomon's work on obesity in India, and the notion of “metabolic living”. In his *Metabolic Living: Food, Fat, And the Absorption of Illness in India*, he poses the following questions: “what is body and what is environment? Where does one end and the other begin?” (2016: 9). The boundary between the two is indeed not fixed. He employs the term of “absorption” as an analytic to understand “the possibility for bodies, substances, and environments to mingle, draw attention to each other, and even shift definitional parameters in the process” and suggests that bodies and the environments in which they operate are mutually porous (2016:5). I am interested here in “absorption” as an analytic, and its applicability to black lung vis-à-vis the mining process. What is different about the case of black lung is, while dust produced in mining processes can be inhaled, they cannot exactly be absorbed, rather they sit in the patient's lungs permanently as foreign objects. They become engulfed at the cost of tissue death, but never absorbed – to be absorbed implies in one way or another to become a part of one's body, and to contribute in some way to the internal workings of the body. The way I see it, just as a patient's lung becomes a site

of waste disposal for development processes, the physical part of the lung in which dust particles sit also become dispensable to its host. It becomes neurotic tissue that no longer serves a purpose to the body. In this regard, then, dust render the lung as waste for both the body and the mining process. It connects the body and the environment, and hence, unsettles the often-assumed natural boundary between the two.

While coal has fueled China's development for the past few decades, in the past ten years, the health and environmental hazards posed by its extraction and combustion has ironically emerged as one of the most imminent challenges facing China's continued economic development. This is due in large part to the urban middle class's growing wary over worsening air pollution and subsequent high incidences of lung cancer. The public's increasing concern is reflected by popular media reports, such as Chai Jing's *Under the Dome* (Chai 2015). In a film that would remind any of its Western audience of Al Gore's *An Inconvenient Truth*, Chai recounts her investigation of smog production and its health hazards. In illustrating the significances of controlling smog production, she tells the story of her newborn daughter — inciting the society's empathy for the most vulnerable to appeal to their humanity. She shows an image of her toddler standing by the window looking out to the city covered under smog, and tells her audiences that she must “cage” her child from the outside environment to make sure she does not breathe in the polluted, toxic air. She asks her audiences to do their part to curtail the pollution problem for her child, as well as their own children.

What she fails to mention, however, is that six million miners and their families have already been suffering the costs of development for the past two decades, the fruits of which were enjoyed almost exclusively by her targeted audiences: urban, middle-class people. Today public narratives are increasingly scrutinizing the mining industries for its contribution to the smog problem. Although tightening the regulations of operations in mines is often discussed, they are

considered mostly with regards to waste management. The overwhelming requests have been to relocate the mines away from suburbs that are in the approximation of big cities. In this sense, just as Chai is concerned that her child would breathe in the “bad” air from the outside environment, the public is concerned with the wastes of production contaminating their living environments. The miners, whose lungs - inner environments have already been contaminated by dusts and rendered a site of waste disposal, are not included in the heated public debate.

Through the inhalation of dust particles, miners internalize and embody the very processes of development, as well as its costs. Yet, when the cost of development is invoked by the public today referring to the smog that they can breathe in, they do not consider the dust that has already been inhaled, and resides permanently in miners’ lungs, slowly taking away their abilities to breathe and chances to live and labour. Because as the dust took up residence inside the miners’ bodies, it was removed from the environment and thus became “harmless” to the public. What cannot harm the public, or at least the members of the societies whose voices matter, does not exist, nor does the site of which it is deposited. When miners are turned from productive labourers to unproductive, and patients who only add to the burdens of the society, they indeed also become negligible. Therefore, as the dust is removed from the air shared and breathed by all, both the dust and the bodies in which it resides is rendered invisible. For the miners, then, the very acts of breathing become the process that renders them invisible.

In her *Postindustrial Metabolism: Fat Knowledge*, Hannah Landecker writes about *metabolism* as an analytical concept situated in particular temporalities, and observes a transition in the language of metabolism from that of industrial to postindustrial in our times: “knowledge of metabolism in the industrial period was framed by manufacturing and energy; knowledge of metabolism in the postindustrial period is suffused with environmental risk, regulation, and information (2013: 496-497). She points out that knowledge of metabolism does not exist above

time, “the material of the bodies fed by an industrialized agriculture and food-processing system built with knowledge of (industrial) metabolism subtends these conceptual shifts” (2013: 497; Guthman 2011; Wells 2012). Hence, “postindustrial metabolism both comes after and is itself produced by industrial metabolism” (Landecker 2013: 497).

If I understand her correctly, Landecker is trying to point to the connection between the knowledge of metabolism, and the temporality within which it is constructed and exists. Inflecting on her theory, and extending the useful conceptualization of metabolism to the respiratory system, I want to suggest that Chinese black lung patients, unlike their urban middle class counterparts, may be living in dual temporalities: both industrial as well as postindustrial. While urban dwellers understand the relationship between their constantly respiring bodies and the city through “environmental risk (air pollution), regulation (of coal combustion) and information (of pollution levels, sources of pollution)”; black lung patients, while also affected by those processes, are still experiencing their bodies and the environment in industrial time. After all, the very work that made them sick, and henceforth becomes an almost defining aspect of their lives, is the extraction of energy sources that are in part used to fuel China’s manufacturing industry. In light of this, I was reminded that the job of the anthropologist, becomes to reveal “the relationship between capitalist production and the failure to protect workers and others from its effects”, which hopefully is what I have accomplished so far (Rhodes 1990: 171)



Figure 2 Zhang Haichao showing journalists the scar from his open-chest surgery

Zhang Haichao from Henan province was “diagnosed” by doctors from multiple hospitals with pneumoconiosis in August of 2007, after having worked for three years in several dust-related industry jobs. He visited many different hospitals, not just ones in Henan but also hospitals in Beijing, which arguably represent the most advanced level of medical knowledge in China, and should have the most authority in terms of issuing diagnoses. The doctors’ opinions were unanimous and conclusive: What had been making Zhang feeling tired, causing him trouble to breathe, was black lung disease. Ironically, however, the doctors’ medical opinions mattered

little. Per state regulations, hospitals were not legally recognized occupational disease-diagnosis centres. And only occupational disease diagnosis centres were authorized and qualified to make diagnosis on diseases that are considered occupational by nature (Occupational Disease Diagnoses Regulation 2013). After having been told by multiple doctors in various hospitals that they believe he was affected by black lung disease, Zhang went to the occupational disease prevention and treatment center of Zheng Zhou, hoping to obtain an “official” diagnosis that would allow him to subsequently make insurance claims, he received an official diagnosis of “zero stage of black lung/no signs of black lung”. He was instead told that he had tuberculosis.

In 2009, after three years of trying to obtain a “legal” diagnosis that would warrant insurance coverage, Zhang requested to have an exploratory open chest/lung surgery at Zhengzhou University Hospital. He thought if he could have his lung opened up and the blackened part of it shown to the naked eye, the truth would speak for itself. Before falling asleep under anaesthesia, he asked his surgeons to pay extra attention of exactly what was in his lung. The finding of the surgery was again conclusive; his attending surgeon told him right after he woke up from the anaesthesia. It was third-stage pneumoconiosis. This meant that he had been under extremely severe exposure to industrial dust, and that the masses in his lungs were visible through scans. In fact, the doctors told Zhang that the masses created by the dust were so big that they can be seen through the scans, so opening up his chest was completely unnecessary. With the result of the surgical exploration, Zhang called the occupational disease prevention and treatment centre to tell them that they had misdiagnosed him. To his disappointment, however, the diagnosis centre responded with little interest and care, saying, “The hospital did not have the ‘qualifications’ to diagnose occupational disease”, rendering Zhang’s life-risking effort vain (Phoenix Television 2015).

Although eventually Zhang was able to obtain an official diagnosis, receiving not only insurance coverage on the medical bills but also additional compensation from his former employer, it took more than simply proving what he considered to be the incontestable truth. In fact, the sad truth is all of his efforts and unnecessary suffering would have been in vain if it was not for “luck”.¹³ The extraordinary measures to which Zhang resorted to gain recognition of his medical condition was picked up by a local news agency, and the story quickly gained traction in the public. The story eventually received so much attention and public scrutiny that the provincial government intervened to contain the situation. They first tried to do so by penalizing the hospital that performed the exploratory surgery, accusing it of being unprofessional for conducting the procedure. This further aggravated the public, which was growing increasingly emotionally invested in the outcome of the event. Eventually, the provincial government had little choice left but to recognize Zhang’s diagnosis, and ensured that he received the necessary compensation and recognition. Almost eight years have passed since Zhang’s diagnosis, and black lung patients in China continue to face the same challenges that he once did. Some are misdiagnosed with tuberculosis while others, because of their inability to produce employment proofs, are not even given the opportunity to have a diagnostic test. Without an official diagnosis, patients cannot receive any form of compensation for the costly medical treatments that are essential to sustain their lives.

Diagnosis

While black lung may not be the first disease to come to mind when one first starts experiencing discomfort with breathing, diagnosis itself is relatively straightforward. Upon inspection, a doctor can reach conclusive diagnosis through a physical examination, pulmonary

13. The irony of using this word here is not lost on me.

function test, chest x-ray and patient history, where they might recount symptoms and exposures. Physicians can also perform biopsies if they deem it necessary (American Lung Association 2016). According to the American Lung Association, “pneumoconiosis does not generally occur from environmental (non-workplace) exposures since dust levels in the environment are much lower (ibid), categorizing black lung as an occupational disease. Once diagnosed with pneumoconiosis, patients “may be referred to an occupational medicine provider to find out more about past exposures and to evaluate you further” (ibid). In the U.S. and other Western developed nations, then, the causal relationship between work history and black lung diseases is taken as default today. Symptoms and evidences of the condition are prioritized and taken as the determining factor of whether a patient is suffering from black lung. This is not the case in China.

In my interviews with both activists and patients, as well as from what can be identified from Zhang Haichao’s experience, one of the biggest challenge that black lung patients in China face, is the difficulty of obtaining a diagnosis. Diagnosis (诊断), in this specific context refers not to the confirmation of the presence of the disease by a medical professional. As it was evident in Zhang’s experience: general practitioners or even pulmonary specialists are not “qualified” ironically to make definitive diagnosis for black lung at all unless they work for an occupational disease diagnosis centre. What patients are talking about, therefore, is diagnosis issued by authorized occupational disease diagnosis centres. The diagnosis, an official and recognized piece of document, which confirms one’s disease as the result of one’s occupation is crucial because it determines whether the costs of their medical bills will be covered by insurance.

Just as the Chinese economy was making the transition from a socialist model towards a more neoliberal capitalistic framework, healthcare in China was also being radically reorganized and privatized.

Prior to 2003, those stipulated by the *hukou* system as rural residents in China were covered by what was called the Rural Cooperative Medical System (CMS). However, beginning in the late 1970s, as China began to de-collectivize its rural economy, the CMS that covered 90% of all villages started to collapse and brought about the privatization of health care (Dutta et al. 2017: 1619). As a result, 96% of the rural households in China were not covered by medical insurance by 2003 (Dutta et al. 2017: 1619). The lack of access to health care, and medical insurance meant that many rural households fell into poverty as one of the family members became ill (Liu et al. 1995: 1089).

In response to the widespread lack of access to health care, the New Rural Cooperative Medical Care System (NRCMCS/新农合) was introduced in 2003. The NRCMCS, contrasted to its previous version, is funded through flat-rate household contributions and government subsidies and designed to prevent illness-induced poverty (You et al. 2009). While NRCMCS places an emphasis on covering catastrophic illnesses (大病), it does not cover the treatment costs of occupational diseases, which fall under Work-Related Injury Insurance (工伤保险). To make claims on the Work-Related Injury Insurance, one is required to provide both a diagnosis confirming the occupational nature of the disease/injury as well as a letter from one's employer confirming that the concerned patient contracted the disease while working there (Occupational Disease Diagnoses Regulation 2013).

Obtaining both of these documents is one of the hardest fights a black lung disease patient in China faces. For many, this process alone would take years to complete, and that is if they are lucky. Incidences of patients passing away while still going through this process are tragically common. The prolonged process, and challenging nature are caused by many obstacles. First, as mentioned, doctors do not have the ability to make diagnoses on work-related injuries and diseases. Diagnoses for occupational diseases are issued by approved "occupational disease

prevention and treatment centers”. In order for one to obtain an occupational disease diagnosis there must be a letter from the patient’s employer accounting for the period of employment, hence, proving the patient’s occupational history. By providing the letter, however, the employer is essentially admitting to be responsible for the patient’s illness. Without undermining the integrity of individual employers, this voluntary, self-committing behaviour that is stipulated seems highly counterintuitive, and indeed proves to be unlikely in reality. In addition, most patients, just like Zhang, have worked at various different mines before realizing that they had developed black lung, and therefore, find it difficult to pinpoint a specific period of time, or employer as being responsible for their conditions. And yet without the proof of employment, patients are denied even the chance at a diagnostic test.

If a patient is lucky or resilient enough to have obtained an employment proof, there is still no guarantee that he would be correctly diagnosed. I use the phrase “correctly diagnose” to suggest the relative certainty that most patients who try to obtain a diagnosis are indeed affected by black lung because patients are often referred to diagnostic centres by medical professionals, who often despite their confidences in what they identify as being black lung, cannot “diagnose” the patient after having consulted the patient’s past occupations. Indeed, as the case of Zhang has made clear, the incidences of diagnostic centres would contradict the consensus of multiple medical professionals are not few. Under these circumstances, a patient can choose to appeal to a diagnostic centre with a higher administrative authority and obtain a second diagnosis. For instance, if a patient received his initial diagnosis at a municipal level centre, he can request for an “appraisal” (鉴定) by a provincial centre. The odds of a provincial centre overturning the decision of the municipal centre, however, are not optimistic. A document issued by the ministry of health in 2013 regarding the diagnosis and treatment of occupational disease states that the processes and conclusions of any centers should be *objective and independent* (Occupational

Disease Diagnoses Regulation 2013). But in reality, this is far from the case. These diagnoses centers are authorized by the provincial Ministry of Health, and their licenses are renewed every five years. This effectively means that the local government has the power to use negative incentives to ensure that the diagnosis organizations act in accordance with their instructions. It also explains why in the case of Zhang Haichao, the provincial government, as a political institution rather than a medical one, ultimately had the final say over his medical condition. Local (provincial, municipal and county) governments are motivated by financial reasons to keep the number of black lung patients in their jurisdictions as minimal as possible because of the way revenue and insurance costs are shared between local and central governments (Lu et al 2014). Medical bills of black lung patients are costly as it is a chronic illness and a patient's care could cost anywhere between a few thousand to a million Chinese RMB in one single year, and the majority of this cost comes from local revenue.

The difficulties with which patients encounter in proving they are indeed ill and require medical attention can perhaps be understood through Elizabeth Roberts' notion of *nuestra realidad*. In her book *God's Laboratory*, Elizabeth Roberts argues that Ecuadorians experience what they call *nuestra realidad* (our reality) when participating in assisted reproduction processes (Roberts 2012). Ecuadorians accept that in *nuestra realidad*, biomedical processes overlap and are often determined by economic, racial and religious factors. *Nuestra realidad* denotes non-universality of biological experiences but also refers to lack of infrastructure, "that project won't work in *nuestra realidad*" - because the economic development and the slow process of receiving medical materials in Ecuador. In one particular scene, Roberts raises an example of *nuestra realidad*: immediately after a volcano eruption in Quito, the dust and ashes from the volcano seeped into every corner of laboratories where the embryos, fertilized eggs were stored and rendered them useless. This would not have been the case in developed countries where

laboratories had air-infiltration systems.

Roberts' concept of *nuestra realidad* speaks to the notion of *local biologies*, first coined by Margaret Lock, when she argues that biological experiences and knowledge, contrary to what is often believed of biomedicine, are not universal. She makes her point through her findings on North American and Japanese women's varying experiences with menopause (Lock 2001). Menopause, which is often assumed to be a universal experience, was proved to illicit different reactions and symptoms in North America and Japan. Lock and Roberts' arguments speak to a wider literature in the field of medical anthropology that constantly tries to problematize the clear boundaries between the biomedical and the social, political. Indeed, the biomedical and the social are constantly engaging with and defining each other. For Ecuadorians who wish to have children through assisted reproduction, the chances of their pregnancy, the survival of embryos are contingent upon the economic and social context that they live in (Roberts 2012).

The stories of Chinese miners with black lung diseases reify the concepts of *local biologies* and *nuestra realidad*. What may be considered as objective truths of biomedicine: the cause, symptoms and the consequences of a disease, operate within a larger social and political context, and varies from body to body. In the realities of Chinese pneumoconioses patients, what is taken for granted in developed nations – the causal relationship between their work history and an occupational disease – is contested to serve a political purpose. The reality of one's physical conditions become contingent upon the material resources that they have, and the political contexts that they operate within. To be clear, however, it is not so much that Chinese doctors deny the occupational nature of pneumoconiosis; rather, it is that their knowledge is superseded by bureaucratic regulations. The burden of proof/diagnosis is shifted from medical professionals to the patients.

Heterogeneity Amongst Patients

My first interactions with patients took place in the Huaxi Fourth Hospital (华西第四医院), a provincial centre for occupational disease diagnosis and treatments that became my most frequent point of in-person contact with black lung sufferers. It is located on South Renmin road, on the outskirts of the campus of Sichuan University. The occupational department is in a building tucked behind the main building of the hospital, on the fourth floor. He Bing, who became my main entry point into the patient community, was staying there at the time that I visited for a cold caused by the transition of seasons that was also exacerbated by the severe air pollution during the winter. While a common cold is often not even cause for taking medications amongst the healthy population, it can be life-threatening for patients with late-stage pneumoconiosis. Constant coughing caused by a cold adds strain to an already half-functioning and burdened lung, and makes breathing more difficult than it already is for a black lung patient. Most patients who can hardly afford medical assistance for their pneumoconiosis condition do not even dare to dream of coming into the hospital for a cold. He Bing, however, having secured himself full coverage on his medical expenses through an arduous decade-long fight with his local county government now feels unrestrained to seek medical attention when he feels the need.

He Bing came to pick me up after dinner on Jan. 1st, 2017 for my first visit to the hospital – although I was able to find my way to the main body of the hospital, I was unsuccessful in navigating through the compound and finding his specific ward. He was much shorter than I had anticipated, which was characteristic of men from the Sichuan region and its surrounding southern provinces of China, despite the fact that I already expected him to not be very tall – I am 167cm, and he barely reached my shoulder while standing. I was surprised when I saw He was not wearing patient uniforms, rather, he was dressed in all red, a leather jacket, and corduroy

pants. Rather fashionable, I thought to myself. He appeared to be in good health, and well-nourished contrary to the stereotypical image of many Chinese black lung patients, giving me a firm handshake, and speaking in a steady and clear voice.

We turned a few corners, and passed several alleyways until finally arriving at the right building. Prior to my visit, I had imagined the hospital as resembling an American hospital: sterile, quiet and each room separated from the other. Before the elevator door opened itself, I had already begun to speak in hushed voice in anticipation of patients resting at night. However, it was nothing like I anticipated. The floor was buzzing with patients, and even though it was already quite late, there were still many visitors hanging around. The nurses and doctors appeared to be off work, and there was no one on call at the nurse station. I was reminded, strangely, of a scene in the A Night at the Museum when all patients come to life after the administrative staff are off work - the hospital became their kingdom.

The rooms were separated by walls that didn't reach the ceiling, with little glass-less windows through which people walking in the hallways can see inside. As I later found out, patients often used the small windows to communicate with each other. At lunch time, a patient called the others who are inside their respective rooms from the hall to go eat. He's room was the first from the elevator. I walked into the room and was immediately overwhelmed by the number of people there. The room was about four hundred feet, with eight beds in the room, four on each side, and a TV hanging on the wall next to the door. A Sino-Japanese war drama was capturing the attention of most in the room. Between each bed, there is only enough room for one person to stand. He's bed was stuck in the corner, and a woman was sitting on it when we walked in. He said quickly that she was his "friend", implying she was his girlfriend. I greeted her by calling her "auntie", but she did not respond and quickly shied away by sitting on another bed. A few minutes after my settling in on the sick bed across from He's, I realized that He Bing had

“prepared” for my visit. He told his patient friends that I was coming, and a few readily came to his ward to hang out and introduce themselves.

During that one night, I met what He Bing considers the three general types of black lung patients in the hospital, but also in the country. They are differentiated by the types of employment they had before getting sick: those who worked for state-owned enterprises (SOE) or state construction projects, private mines and those who have owned their own small mining operations. Patients can also be categorized by the sources of their funding, and these two categories although are indicative of each other do not align perfectly.

Patients who have previously, or are still working for SOEs are considered to be receiving the best compensation. One example is Uncle Liao, the first patient I spoke with that night besides He Bing. He was tall, well-built and spoke with a clear and piercing voice that distinguished him from other patients. He wore a clean plaid shirt, dark-brown corduroy trousers and a shining pair of leather shoes that night. He Bing joked that Uncle Liao did not have to “fight with the government” the same way as he did. Indeed, this patient seemed particularly animated, and although he displayed signs of shyness, he was laughing the whole time we spoke.

With a sense of light-heartedness, he told me his story. He initially went to the hospital for a check-up because he had thought he got a cold. He went to the hospital, and the next day went out and “played” (耍). Then he received a phone call from his company saying that something was up, and that he should go to the hospital as soon as possible. At the hospital, he walked into a room full of doctors and realized something was wrong. He said that the doctors asked him “exactly what he does for a job”, and he asked what does it matter. He was then informed that he might have contracted pneumoconiosis at his work. Liao was unique in the sense that the industry his company is in is not one typically considered as one among dust industries. In fact, of the 30,000 workers at his company, he was the first and only one with pneumoconiosis. This is

because he worked for a high industry (weaponry), and his work was to carve out stones. Only five people in his company specialized in this job. Due to the uniqueness of his condition in the context of his company, even though he was able to earn a satisfactory compensation package, as I soon learned, it was not an easy process. He went through an arduous process of negotiation with his company, and had to go through the diagnosis process three times until the company agreed to pay for all of his medical expenditures. In addition, while he no longer works on a regular basis, he continues to receive his monthly salary from the company. When I asked in confusion why this was the case, he laughed and explained that while the company could still “force” him to work at a less physically consuming post, he would cause a problem by pretending to faint at work and then stay at the hospital for an extended period of time, which further costs the company. After a few times of similar incidents, they told him that he did not have to go to work and would still receive his monthly salary. He Bing and other patients who did not work for SOEs and hence did not enjoy similar levels of compensation enviously teased Liao in a joking manner that he was “lucky”. Indeed, compared to the many other patients, Uncle Liao and his fellow patients who also worked for SOEs, were relatively lucky.

The second group of patients are those who worked for private mines, and within this group there are patients who are paying for their own medical expenses, and those like He Bing, who through labourious struggles with their local governments are receiving varying levels of assistances from the state. While there may be cases in which patients actually receive compensations from their private employers, I did not personally encounter any. Whether a patient is receiving money from his local government, I find, to be largely dependent on the patient’s conception of his relationship with the state; while how much he may be able to receive is a function of many other factors. Some patients believe that regardless of whether they worked for privately or publicly owned enterprises, their contraction of the disease can be traced back to

the lack of regulatory agencies and policies – in their opinion, a key responsibility of the state. Others, however, embrace what I believe to be a form of neoliberal conscience in understanding their predicament: They believe it was their fault, or their employer’s fault but do not trace the responsibility to the state. Similarly, the last group of patients, are exclusively “self-funded” (自费). What differs them from those who worked for private employers and are self-funded is that these patients were often mine owners themselves before their illnesses pulled them back to poverty. They often owned small-scale mines that only employed five or six people. Most if not all of the labourers who worked on their mines would also be co-owners of the property. Therefore, even though there is no doubt that these patients were financially advantaged compared to most others, they were not mine owners in the conventional sense. He Qishu, a Tibetan patient who previously owned a small operation himself, told me that he spent all his savings and the money that he got from selling his mine, on his treatment. Their family now has around 10,000 to 20,000 RMB in income each year from his wife’s caterpillar fungus business, and this money is used to cover his medical expenses, the day-to-day lives of the family and his youngest daughter’s education.¹⁴

My purpose in this section is to contextualize black lung disease by describing the hospital as a site of fieldwork, and introducing the various kinds of patients who are present there. But more importantly, I wish to use this introduction to make clear the heterogeneity within the black lung community. I argued in the previous section that illness experiences with black lung disease are not uniform across geo-political boundaries, and are contingent upon political and social

14. Caterpillar fungus (Yartsa Gunbu) is an entomopathogenic fungus that is native to the mountains of Nepal and Tibet. It is valued as a valuable herb in traditional Chinese medicine, hence sold for lofty prices in mainland China. He Qishu’s wife has a small business as a middle-person: she buys fresh caterpillar fungus from Tibetans who did the labour of harvesting, and sells them to wholesale retailers from mainland China.

environments. But they are not uniform even within the premises of one hospital. Here, it is once again useful to think through Roberts' analysis of assisted reproduction in Ecuador (Roberts 2012). In her book, she makes clear that while the notion of *nuestra realidad* is one construed to understand transnational differences in experiences, amongst Ecuadorian women, experiences are also contingent upon race, class and financial abilities within the country. External, structural factors contribute to patients' disparate experiences, such as the kind of jobs a patient-miner held before getting sick, his original financial statuses. There are, however, also variables that were dependent on each individual. As aforementioned, one crucial factor that determine, to a certain extent, whether a patient receives monetary assistance from the state is their conception of the state, and its responsibilities. That is not the only determining factor of course, often times the tactics patients employ in their negotiations with the state, also play an important role in deciding their struggle's outcome. I elaborate in greater details on this topic in chapter four. In all, what I try to demonstrate through the case of black lung disease is that illness experiences are varying and contingent locally as well as globally.

Conclusion

Frederich Engels correctly pointed out that, "disease is construed as the embodiment of the symbolic network linking body, self, and society" (Kleinmen 1988:6; Engels: 1977). As I have demonstrated in the previous pages, the prevalence of black lung disease in China embodies the link between bodies of Chinese miners and the society's hasty economic development in ways beyond the symbolic. In treating black lung as a *sickness*, my aim has been to make intelligible this connection between the state's negligence in providing adequate regulations, and protections for the labourers, and also to make visible those who were, arguably, harmed the most by the process of development. The privatization of health care, which was a reflection of China's

growing neoliberal economic policies, further exacerbates the despair of many patient-miners. This understanding, while not shared by all, has also been enunciated by patients themselves from time to time. He Bing, for instance, believe that regardless of the kind of jobs a patient held before, whether it was state-owned or private, the contraction of black lung at work warrants him/her compensation from the state, because it is the various branches of the state's responsibility to regulate and ensure the safety of productions.

Nancy Scheper-Hughes in her book *Death Without Weeping* questions the role Brazilian doctors play in facilitating the imposition of structural violence upon the impoverished and hungry poor of Brazil, whether consciously or not, she suggests that “medicine, the hospital, and the clinic can be isolated, closed off, from the external world and from the experiential world of patients, but they can [also] provide a space where new ways of addressing and responding to human misery are worked out (Scheper-Huges 1993). The truth is, the clinic, and biomedical processes rarely, if not never, lie outside of the socio-political world in which it is situated. Understanding that biomedicine and its knowledge do not exist outside of socio-political spheres, however, does not mean the tacit acceptance of this fact. I propose that we ask what is the implication of the entanglement of medical knowledge with politics, with the reminder that while politics can do work to medicine, so can the agents of medicine contribute to changes in political and social spheres.

Chapter Three – The Chinese Family, Neoliberalist State, Socialist Ethics

I started noticing a “peculiar” yet repetitive pattern in the makeup of family members as care givers in Huaxi Fourth hospital, my main fieldwork site as introduced in the previous chapter, after my third or fourth visit there. The only people visiting the patients I was spending all my days with were women - as either wives or lovers. It made sense to me that there were no parents visiting –most of the patients I worked with were in their early or late forties and fifties, which means that their parents were either too old to care for them, sick themselves, or perhaps have already passed away. But why weren’t there any children, whom I would imagine to be around my age or slightly older? Puzzled by what I had observed, or more precisely what I did not see, I started to ask questions about children when interviewing new patients. The answers I received hence lead me to believe that the norms governing familial relationships and expectations in China are undergoing a slow but steady change. The responsibility of adult-children to provide for their parents in old-age, which for centuries have been seen as uncontested, is no longer taken for granted to say the least.

He Minjun and Zhang Yingkui were staying in neighbouring sick beds: bed 43 and 42. They were both what the others called “self-funded” (自费) patients, that is, they were paying for their own medical expenses. These patients pay around 55% of their total medical expenses. As urban residents, the NRUCI covers around 45% of the rest. He Minjun was in the final stage of pneumoconiosis when I met him, and had worked temporary jobs on different coal mines for the decade prior to coming down with the sickness. In the worst physical state amongst all the patients I had met, he was pale, hollow cheeked and could barely speak without coughing phlegm mixed with blood into a plastic cup by his bed. While I was initially “arranged” to speak with him that afternoon, he seemed neither too eager nor in the physical state to speak with me after I was

introduced to him by another patient I had gotten to know. When he did speak, he spoke in an extreme low and husky voice, and for the most part of the time that I was there, he stared aimlessly at the TV or out the window. If it was not for the wife of his next-bed-neighbour, Zhang Yingkui, I would probably have fled the room in awkwardness much sooner. Zhang's wife, however, was keen to see a new face and immediately invited me to sit on her husband's crowded twin-size bed with the two of them.

Without me asking any questions, Zhang's wife started telling me their story. Indeed, it is "their" story rather than only her husband's. They experience the disease, though in different ways, together. Natives of Sichuan, Zhang and his wife lived in Henan province where they owned a small gold mine together until he started feeling sick in 2009. Zhang was not the first patient I visited who actually had been a mine owner. However, these were extremely small-scale operations, unregulated by the state, and usually with only five or six employees. In such cases, the owner is almost always also a labourer himself in the mine. Upon realizing he was sick, Zhang and his wife sold the operation to pay for his treatments, and told me they have almost spent all of their savings during the past seven years. He has been in the hospital for around three months this time, and this visit alone has cost them ¥100,000.¹⁵ Zhang's wife teared up as she spoke and told me that they no longer had any money left. When I asked why they did not try to seek compensation from the state like some of the other patients on same floor did – all of their medical expenses are paid for by their county government—the wife responded that they were different. The other patients worked for national projects or state-owned enterprises. He's wife jumped in to corroborate, and said with a sense of resignation that the other patients were "luckier", "our lives/fates are different". He and Zhang as well as their wives believed that they

15. ~\$14,524

were solely responsible for their illnesses because they were “ignorant” and “reckless” when working, and as a result now are not entitled to seek support from the government.¹⁶

Zhang’s wife was curious as to who I was. She said that she had seen me on the elevator up the fourth floor where the occupational disease department is located that morning speaking on the phone in English, “I could not understand a thing you were saying, but thought I should call my daughter-in-law. She teaches English in another city, she would understand what you were saying!” I learned that Zhang and his wife have two children, an older son and a younger daughter. The son and his wife, who teaches English at a private institute for students who are preparing for the TOEFL exam, live in another city in Si’chuan province, while the young one is still in university. From Zhang’s description, the older son and his wife sound like they are doing rather well for themselves economically, so I asked if they are supporting their parents financially, especially given Zhang’s illnesses. The answer took me by surprise: “Oh no, they don’t really. My son only just bought a new car and a new house. They are also expecting a baby. He has his own family now, and he cannot afford to support us anyways”. I was initially taken aback by her answer but decided to not press further as to risk being impolite. Knowing that the city where the older son lives is around 2 hours away, I then asked if they visit often and learned that while they do occasionally, for the most part they are too occupied with work and family life to come visit. Similar to Zhang, He and his wife also have two children: a son and a daughter.

16. I later asked He Bing what he thought He and Zhang could do - whether he believed that they had no legitimate claims against the state. He Bing disagreed that these two patients could not, and suggested that they were “lazy” because they wanted to rely on public donations, and their past savings. He also pointed out that although these two patient families described their financial situations as dire, there was an element of exaggeration - “the truly impoverished families do not dare to dream of staying in the hospital for three months”. He Bing’s rationale is deeply rooted in his understanding of the responsibilities of the state to its citizens, but this sentiment is clearly not universal. While He Minjun, Zhang Yingkui and their wives’ beliefs reflect, in my opinion, a neoliberal consciousness that rid the state of its responsibilities to care for them. By providing his “alternative” view, I do not wish to undermine the validity of any side’s account, but merely to offer a diversity of opinions for readers’ own interpretations.

While they do receive financial support from their children, they expressed a similar sentiment as the other couple, namely that their children are starting their own families, and they do not expect much from the children.

By saying “*they have their own family now*”, Zhang’s wife speaks to what I observed as changing understandings of familial dynamics, and intergenerational reciprocity in China. These two families are not alone in sharing this sentiment. During my short stay at Huaxi hospital, I did not encounter a single case of a patient accompanied by their children. Patients were either there alone, or attended to by their wives, and in some cases, their girlfriends. That is not to say, of course, none of these patients was receiving financial support from their children; however, it is true most relied on themselves or other sources of finance. There is no doubt that this represents a break, even if it’s in no way definitive, from traditional conception of the Chinese “family” as an extended network of mutual support. It signals a development away from the uncontested belief in the young’s obligation to provide for their parents as observed by anthropologists before me (Yan 2003). I believe this change in the moral norms governing familial relationships and expectations is a response to the changing political economic landscape in China, including but not limited to China’s turn towards a neoliberal capitalist market economy.

Historical Context

The relevance of understanding contemporary Chinese political economy within the framework of neoliberalism and its critiques is worthy of brief discussion. David Harvey, when writing about neoliberalism and its force in China, noted the analytical difficulty in “reconciling the coexistence of Chinese socialist reformation with feverish capitalist activity” (Ong 2006: 12; Harvey 2007). I found myself facing similar predicaments as Harvey did in reconciling what I observed as neoliberal forms of family dynamics and kinship relationships among black lung

patient families that are nonetheless not rid of seemingly contradictory socialist sentiments. To resolve this conceptual challenge, I employ Aihwa Ong's useful analysis of *neoliberalism as exception* to understand this transnational political economic ideology's work in China.

Ong proposes that we see neoliberalism “not as a ‘culture’ or ‘structure’ that is singular in its application and manifestation but as mobile calculative techniques of governing that can be decontextualized from their original sources and re-contextualized in constellations of mutually constitutive and contingent relationships” (2006:9). This analytic of neoliberalism as exception is advantageous because, as noted by Ong, “neoliberalism itself is not the general characteristic of technologies of governing” in China, rather, it is introduced in specific spheres to generate economic growth and perhaps increasingly “impose market criteria on citizenship” (2006: 1-3). Indeed, even though socialist realities exist but only in the older generation's memory, the ideology itself continues to be upheld by the state. Ong's analysis is echoed by Wang Hui's work on Chinese neoliberalism, “It does not make sense to refuse to recognize the hegemonic status of neoliberalism because of the existence of state intervention” (Wang 2003: 4). Indeed, amongst black lung families in Sichuan China, I witnessed concurrent forces of neoliberalism and socialism as modes of governmentality (Foucault 2003).¹⁷ This understanding has significant implications to my interpretations of family dynamics amongst black lung families.

China emerged from the social trauma and economic shock of the Great Leap Forward and Cultural Revolution in 1978 as a state-directed, closed, and underdeveloped economy that did not have much of a capitalist market (Wang 2013). The state placed high priority on heavy industry. And while people were extremely and constantly overworked, there was no money, time nor cultural context for private consumption. It is against this historical background that the

17. I use this term in the Foucauldian sense to refer to the diffused power/control the state exerts over its population.

leadership under Deng Xiaoping initiated a series of reform effort that marked the beginning of China's turn towards a market economy albeit maintaining socialist ideologies. The new brand of thinking's essentials commenced by Deng are best summarized by its slogans, "socialism with Chinese characteristics" and "let a few people get rich first" (Deng 1984).¹⁸

The first phase of economic reform lasted from 1978 to 1990. Barry Naughton characterized this historical period as one devoted to the endogenous creation of the market (Naughton 2007). Agriculture was decollectivized, foreign investments were allowed to selectively enter "the market" and entrepreneurs were permitted to start businesses, but most industry remained state-owned. During this time, there was an increase in output as well as in income and efficiency. Households started to diversify their income portfolios, meaning that more and more people were leaving their agricultural lands at home to work in the industrial sector. Another important change was the introduction of private savings, predicated on the collapse of the private and public sector. The growing economy and the introduction of private savings provided strong incentives for individuals to work in industries that they perceived as high-income sectors (Naughton 2017). However, it was not until the second wave of the reform during which private gold, coal and other mineral mines where many of my informants worked at really proliferated.

The Tiananmen incident, as a result of political relaxation and economic stagnation, triggered a second wave of reform, which consisted of a combination of tightening political control and the continued opening up of the market. During this time, more industries became privatized, and the economy increasingly market-driven while the political environment returned

18. Indeed, Deng saw no conceptual inconsistency with China's earnest industrial capitalist production, and its socialist ideals. In fact, he believed that, "Marxism attaches utmost importance to developing the productive forces...at the advanced stage the principle of from each according to his ability and to each according to his needs will be applied...Socialism means eliminating poverty. Pauperism is not socialism, still less communism" (Deng 1984).

to one that is strictly controlled and monitored by the party. A capitalist yet non-democratic institution was being developed to support the expansion of the market (Naughton 2017). A few specific changes during this period affected the current system in which black lung disease patients operate, including the privatization of the healthcare system and the reform of the fiscal revenue sharing system.

The second phase of the reform marked China's official turn towards neoliberalism. *Neoliberalism* is in its most basic form the resurgence of a set of nineteenth-century political economic beliefs associated with *laissez-faire* economic liberalism, which emphasized the privatization of public services, fiscal austerity, opening up of market and free trade (Haynes 2014; Harvey 2007). In recent years, there has been debate amongst scholars over the relevance of neoliberalism to understanding social processes, as the term has become used so widely that some argue it has lost its argumentative power (Harvey 2016). In what follows, I use neoliberalism to describe a political strategy, a mode of governmentality employed by the state as well as the dissemination of its key ideas into the society to the point when they become so entrenched in each individual that it becomes the unproblematic, underlying logic of the society (Harvey 2007, 2016). The sub-conscious embrace of neoliberal ideas at the individual level is key to the neoliberal project. Dubbed by some scholars as neoliberal subjectivity, it concerns the "government of the individual, [which demands] a particular way of living" (Read 2009: 27). An ideal neoliberal subject, is one that is rational, self-interested and self-reliant.

This turn towards capitalist neoliberalism at the end of the 1980s had significant implications on the day to day lives of every Chinese person, from the ways they were born to the ways they die and everything in between (Wang 2003: 3). There is no doubt that some of these changes have been beneficial, my own family is an example of those whose qualities of life have been improved tremendously by the opening up of the market, but the benefits were felt

unevenly; and some had more negative impacts than they did otherwise. The kinds of food people consumed, the jobs that are available to them, and the kind of medical care one can afford all underwent dramatic changes. But beyond the material changes, I find the most significant of all changes took place in how people viewed and formed social relationships.

In this chapter, I will focus specifically on the family as a unit, and how perceptions of family and familial obligations have changed. While kinship relations did not appeal to me initially as particularly pertaining to my larger research interest, as my research continued, it became clear to me that just as Arthur Kleinman has noted – patients' illness experiences are deeply situated in the family, and family members often experience the illness with the sick person albeit in different ways – studying black lung experience gave me a unique entry point to understand the changing Chinese family. I argue that the ways with which black lung patients perceive themselves as members of society and the family unit have taken a turn towards neoliberal beliefs. People are beginning to envision themselves, whether it is consciously or subconsciously, as neoliberal subjects, who place individuality and self-interest above collective interests. Hence, this chapter concerns itself specifically with consanguine relationships amongst black lung disease patients and their families in an attempt to understand the effects of changing governing modalities on family life, especially family lives of chronically ill patients. In doing so, this chapter engages with scholarships on the dominance of global neoliberalism, and its encounters with the local (Ong 2006). It forwards the argument that the modern Chinese state employs both neoliberal modes of governmentality as well as socialist ideologies in the government of its populace. The duality of ideologies at work places Chinese miner-patients at particularly precarious positions, as they are not only left to care for themselves alone but continue to bear the burdens of caring for their young.

Changing norms of familial relationships and expectations

百善孝为先 (*Filial piety is the most important of all virtues*)

父母在，不远游 (*The Master said, “While his parents are alive, the son may not go abroad to a distance. If he does go abroad, he must have a fixed place to which he goes”*)

养儿防老 (*Raise a son so he will provide for you at old age*)

A rich ethnographic literature exists on the changing moral economy in contemporary China, and many scholars have written on or argued for a pattern of “declining morality” vis-a-vis the recent economic boom (Lora-Wainwright 2013). For instance, Richard Madsen in his study of the Chen village observed that there was a constant reconstruction of moral discourse vis-a-vis the larger political changes since the 1950s (Madsen 1984). Since the 1970s, he argues, there was a rise of a new moral order “dominated by a utilitarian individualistic paradigm” amongst the young generation that elicited complaints from the older generation (1984: 28). The older generation “complained of a ‘spirit of lethargy’ among the young generation...and had become demoralized” (Madsen 1984: 240; Lora-Wainwright 2013: 46). Yunxiang Yan in his book *Private Life Under Socialism* argues that the economic reform and the previous period of collectivization concurrently generated a “social vacuum of moral values and behavioural norms” that gave room to the emergence of individualism which “tends to emphasize individual rights and personal interests while downplaying a person’s obligations to the community and other individuals” (2003:16). He suggests that traditional Chinese familial dynamics were upheld for centuries, in part, because parents were able to bequeath their children (mostly sons) land, properties and money upon their passing. This tradition, however, was rendered impossible by the socialist collectivization movement, which appropriated private lands and properties from the individuals into the collective. The weakening of the traditional family was also further

exacerbated by the CCP's ideological movement to undermine Confucianist ideals, such as filial piety, which were considered as backward and feudalistic during the socialist era. Hence, as China embarked on the economic reform in the 1970-80s, the older generation of parents readily lost the ability to promise any properties to their children. In turn, the children who did not enjoy any financial support from their parents were accumulating wealth and tasked with both providing for their children and their parents. This dramatically changed the power dynamics between old-aged parents and their adult-children.

Yan further argues that since the 1970s, the private family which places emphasis on the husband-wife relationship over cross-generational, extended familial relationships has been on the rise. This gave wives of the younger generation, who traditionally occupied the lowest strata within familial hierarchy, more power. In fact, as Yan's ethnographic accounts make clear, wives as daughter-in-laws often played a central role in marginalizing or disempowering parents. Together, Yan considers these phenomena as "the crisis of filial piety" and calls for a redefinition of filial piety. Yan, as his word choice of "crisis" suggests, views this shift with a sense of distaste, and indeed, considers many of the adult-children as "uncivil individuals" (Yan 2003; Litzinger 2005). Yan's observations of changing intergenerational dynamics were affirmed by Anna Lora-Wainwright in her book *Fighting for Breath*. She proposes, however, an alternative interpretation to the phenomenon that is perhaps less morally charged. Writing in the early 2010s, Lora-Wainwright argues that the changing moral beliefs amongst the younger generation "is not immoral or uncivil but rather embodies their own attempts at refashioning the boundaries and parameters of morality in radically different contexts" (2013: 49). I concur with Lora-Wainwright by suggesting that the retreat to nuclear families not as a decline in morality but rather, an individualistic level response to structural changes.

I want to take a moment to elaborate on the idea of filial piety and its significance to the Chinese family as well as society as a whole. An understanding of its ideological centrality in the Chinese moral and historically, political landscape, is crucial to grasping the pervasive force with which neoliberal and the market-driven policies have influenced the day-to-day lives of peasants in China. Filial piety, as demonstrated by the various proverbs from different historical periods above, is embedded and upheld in almost all schools of Chinese philosophies and folk cultural traditions. Earliest tales of filial piety goes back to the mythical Shun emperor, making it difficult to identify the precise moment when filial piety became central to Chinese moral philosophies. What is clear, however, is that the teachings of Confucius (551–479 BCE), which informed the governing principles of emperors for at least a thousand years after him, took filial piety as one of the most important virtues of (wo)men.

Throughout history, filial piety was not only prescribed by “religious” beliefs and philosophical teachings, but also reinforced through imperial law as it was regarded as “a fundamental ethical and social norm” (Yan 2003: 182). Parents had the power of going to local governments and ask for a son to be prosecuted on the ground of un-filiality, and no further evidence would be stipulated because there are no wrong parents in the world (Yan 2003: 183). “And if a parent or grandparent should commit suicide in a fit of anger at a son’s behavior, the latter would be decapitated for causing the death” (Yan 2003; Baker 1979: 115).

Since the demise of the Qing dynasty, Confucianism ceased to be the dominant philosophy governing life in China, so the expectations of “filial” have significantly changed. Yet it remains one of the most important personal character with which one is judged. To be considered unfilial, even in today’s China, is to risk being thought of as untrustworthy for business partnership, friendship, and unsuitable for marriage. In Yan’s book, he tells the story of a couple who suffered serious public scrutiny for not treating their old-aged father well. Indeed,

“the villagers were outraged by the death of this old man; [...] and some threatened to report it as a case of parent abuse to the local court. The pressure of public opinion forced the couple to avoid public life for a while” (2003: 163). So, what does it mean to be filial? Yan argues that there are competing expectations and interpretations across generations, however, what is not contested is the responsibility of the young to take care, emotionally and materially, for their aging parents. Yan’s did most of his work during the 1980-90s when the reform was only starting to take place, twenty years have passed since then. Some things have changed since he made these observations.

I build my analysis of black lung families on Yan and Lora-Wainwright’s observations and suggest that the process through which the private family gained import and parents losing their power and secure position at home that was “full of confusion, anger, despair and suffering in both emotional and material terms” has further progressed since Yan completed his work. The younger generations in Yan’s book have grown to become the old-aged parents in my research who unlike their parents have substantially lower expectations of their children. I interpret what I have seen at the hospital, wives sharing their husband’s bed to support them while their grown children are not only pardoned but also *expected* to start their “own family” as an embrace of a new moral order, which emerged alongside the neoliberal shift.

As the story of Zhang and He that opened this chapter demonstrates, parents no longer *expect* their children to provide for them in their old-age or at their sick beds, nor do their children, I speculate, feel the compelling sense of obligation to do so. Reflecting on my late realization of this changing familial dynamic, I recalled my first meeting with He Bing. I had just arrived in Chengdu, and settled in my temporary apartment. Knowing I did not know anyone in the city, He asked if I wanted to join “them” for dinner. In hindsight, I know he was probably referring to his girlfriend and fellow patients, but at the time, that was not my speculation. Having

known that he had a son, my instinctual guess was that his son must be in the hospital with him. As we got to know each other better, He started telling me more about his son. Around 18 years old, he lives in He Bing's home in Meishan, but no longer attends school. "He did not do well in high school, and being a rather liberal parent, I did not want to force him to do something he didn't enjoy. He likes media and is quite good at it actually, so now I try to help him with starting a media company", He Bing told me with a sense of parental pride. He Bing's son leads a small team consisting of three other friends from his high school times, and they make comedy content that are distributed on WeChat and Youku.

Noticing his son's daily videos actually get a good amount of views, I asked if he helps with any of the black lung activist works He Bing does. It could be a great way to promote awareness amongst the public, I proposed. But He Bing readily dismissed this idea, "no, no, I don't talk to him about this very much. He is too young, and has his own ambitions. I do not want to get him involved in this". But *this* was no small matter. Black lung disease, and indeed the treatments of black lung patients, are what He Bing has devoted most of his time and energy to. It would not be too far of a stretch to say that his experience with the disease has defined the last decade of his life. The suggestion that his son ought not to be involved in any of his work can almost be equated as to saying that his son does not need to be involved in his private life. Indeed, this would seem to be the case. He Bing lives in Chengdu with his girlfriend, who attends to him when he is in the hospital; while his son is starting to establish his own life in a city a few hours of drive away. There is a clear boundary drawn between the two men's private lives – and He's son is excused from experiencing He's *illness* (per Kleinman's definition of illness). While He Bing and his son are in many ways unique, the dynamics between them are representational of the other families that are present (or not) on the fourth floor of Huaxi Fourth hospital. The husband-

wife duo, or the patient himself, views enduring and overcoming the disease exclusively their own responsibilities.

I want to make clear that I am not interpreting what I have seen at the hospital as a decline in morality as Yan suggested, but rather, I am pointing to a change in understandings of what people consider to be filial and hence “moral”. For many of the patients I have spoken with, they endured the hardship of backbreaking labour and worked hard to provide for their children in the hopes that their children would live a better life than themselves. To now burden their children with their illness would render their previous work and hopes vain. And for the children of these patients, as sons and daughters of miners and farmers, they work and struggle hard to maintain their new lives in cities whether as teachers, entrepreneurs or factory workers. The new urban life style is costly: housing, transportation and education for their children, which are all privatized now, would most likely cost them most of their earnings if not more. These kids are just barely holding onto the middle-class lifestyles their parents allowed and made possible for them to achieve. To provide for their parents may mean to risk losing the possibility of making a “good” life for themselves and their nascent families. And through this logic, it could be argued that, to give up working or education to care for one’s parents through a chronic disease may be more unfilial than it would be otherwise. An important distinction between intentional neglect and a political structure that makes the support network of the extended family impossible, henceforth leaving it atomized must be made.

I do not wish to, however, deny that I initially shared Yan’s distaste for what he considered the “uncivil individuals” when I discovered that adult-children, such as Zhang’s, who were “perfectly capable” of supporting their parents, did not. Although having lived in North America for a significant portion of my life, my parents ingrained in me their traditional values of filial piety. Perhaps through a naïve act of romanticizing my own morality, I imagined if I were in

the position where these black lung patient's children, I would give up everything to care for my parents. Yet, in a closer examination of my positionality as an anthropologist and outsider to their life circumstances, it dawned on me the privileged position from where I attempted to pass value judgments on my informants and their families. This revelation hence is coupled with the speculation that the changing familial norms and intergenerational reciprocity does not take place evenly across social classes. As a member of the urban, upper middle-class Chinese society, I, in many ways, have continued to experience the traditional family portrayed by Yan. Unlike my rural counterparts, I have not contributed much to my family financially at the age of 22, and are not expected to do so by my parents anytime soon. My parents, like those in the traditional Chinese society, not only continue to support me financially, but also, through forms of real estate properties, promise future "gifts" that, perhaps in the most cynical way, qualifies their insistence of my performance of filial duties. There is no doubt that my experience resembles nothing like those of black lung patients' children, most of whom started paying for themselves at teenage ages. To assert that there has been a decline in moral principles is to ignore structural forces that render many rural families with little choice but to prioritize nuclear families over extended families.¹⁹

19. Due to the scope of this work, I have not been able to explore the role of the women as much as I would like to. They are indeed a crucial aspect of the rise of the private family. I briefly elaborate on the topic here for readers who are interested in the topic. Women whose husbands are black lung patients also face an overwhelming amount of "responsibilities": she must be by his side to care for him physically, to provide for the family materially, and also, must care for their elders if they have any. The wives and mothers of dying miners also face the same reality as their husbands, namely that children will not provide for them as they grow old. Therefore, incidences where women choose to divorce, or simply leave their husbands to either pursue a new life altogether or work elsewhere but send back remittances are not rare. During my visit in Chengdu, I discovered that one of the patients in a Wechat patient group's wife had recently left home without leaving as much as a note explaining her plans. No one seemed to know if she would ever return. He Bing told me of the heated debate and perhaps condemnation that took place in the chat group as we drove to his house to see some of the old documents he used for petitions. I asked him what he thought of it – whether he thought it "wrong" or "bad" that a wife would leave her husband in his illness.

Socialist Ethics, Neoliberal State

While parents have significantly lowered their expectations for their children in terms of reciprocating material support in their old age, I have not observed a similar decline in parental love or financial support for their children. Rather, patients with younger children repeatedly told me that to provide and care for their children is sometimes the strongest motivation pushing them to endure the reality of a suffocating life. In the following section, I explore and demonstrate how this may be read as an expression of persisting socialist ethics in a growingly neoliberal state.

Jiang Pengcheng is forty-four years old now and was diagnosed with last-stage pneumoconiosis in 2010. He worked in coal mines in Shaoguan, Guangdong since he was sixteen years old. There he worked for fourteen years until constant coughing, fatigue and difficulty to breathe caused by black lung forced him to give up the job in 2005. He has not received formal compensation from either his local government, or his former employers since. The only financial

“But you never know, maybe she would send money back after finding work in the city”.

“What if she does not? Does that make a difference to you?”.

“Well, then maybe she is trying to make sure her children get a better material life”.

“But what if she is not, she is not going to come back, nor is she sending money back or bringing her children with her”, I pushed.

“That’s still her choice then, I don’t think there is a right or wrong – she is not obligated to stay with her husband. Some of my fellow patients thinks it bad but I don’t think so”.

Again in this exchange, I find an instantiation of what I interpret as a neoliberal individualism within the domain of the family. As Yan argued, not only was there a rise of the private family vis-a-vis the extended interfamilial network, within the nuclear family, the previously underprivileged members such as the women and the children are also gaining growing economic power, and thus can pursue lives individuality. The ultimate expression of individuality for a woman, one could argue, is the freedom to leave a family when it is no longer beneficial to her, economically or otherwise. There are also plenty of women who choose to stay by their husbands side, care for them while also working part-time jobs or making handicrafts to support the family. This gesture, too can be interpreted as an expression of the women’s choice and agency.

assistance that he is receiving now is a meager monthly welfare, designated for low income family. Even though it is not much money, Jiang had to fight hard for it. He protested at the city hall twice and even went to the provincial capital to petition. During his first conversation with me, he repeatedly told me that he had more than once considered ending his life. Life was not pleasurable anymore. He was always weak, and constantly experienced difficulties breathing. Indeed, when speaking to me, he was often forced to pause the conversation by coughs that he seemed to have little control over.

A few years after he was diagnosed and lost his job, Jiang's wife divorced him. It was simply too much for her: the financial and emotional burden of caring for a chronically ill husband, all whilst also providing for their two children. Jiang was devastated by his wife's departure. More than once, he confessed to me, he had wanted to end his life believing that it would not only relieve him of his pain, but also allow his family to be better off. Jiang spoke of suicidal ideas, and the separation with his wife with a daunting sense of normalcy that I later understood as a reflection of the prevalence of similar incidences amongst black lung families. Every patient I have spoken with has a personal friend who has committed suicide, experienced divorce, or is divorced themselves as a result of their ailment.

The divorce left Jiang as the sole provider for his teenage twins, whom he loves dearly. Like most proud parents, Jiang loved talking about his children. He told me that they were both smart and beautiful. He readily showed me pictures of them, since they were away at school when we chatted, and explained that unlike him, his children had fair skin. With a sense of pride, he bragged that they are constantly praised by neighbours as looking like Westerners. Both of them do well in school, even though the girl performs slightly better than the son. Knowing that I attend a "prestigious" university in the United States, he asked me if I could speak to his daughter online to help her get into a good university. "My children, to provide for them, are my

motivations for not only to continue living but to live well”. With the help of an NGO (Love Save Pneumoconiosis), he now keeps a herd of sheep which requires minimal physical work, and gives him a meager income that is enough to sustain his three-person family. Resonant in his narrative is an incredible expression of fatherly love that is unremitting even in the face of extremely difficult circumstances.

At the same time, I came to see this as perhaps a way Jiang tries to situate himself as a productive member in the family, and in the larger society. Joao Biehl in his 1998 ethnography, *Vita*, tells the illness story of Catarina, a young woman proclaimed to be mad living out her time in Vita – what Biehl considers a zone of social abandonment, the residents of which are no longer considered full humans or citizens of the state. Biehl’s narrative is as much as the story of one human being as it is the story of how an impoverished family is forced to react to a radically neoliberal state. The “complex network of family, medicine, state and economy in which Catarina’s abandonment and pathology took form” at once reveals the powerful truths that love, even within the family may not always be unconditional (2013: 8). To become completely unproductive is perhaps to risk being abandoned, and deemed unworthy of care. Brazil and China in many ways underwent similar processes of neoliberalization through which the family has growingly become sites of economic transactions, both literally and figuratively. Familial relationships are strengthened and maintained through “material exchanges of care” (Roberts 2012). Without undermining the expression of true parental love, I argue that Jiang’s act could also be interpreted as a gesture to reconstruct himself as a productive citizen and re-position/re-insert himself into the society as someone who can contribute meaningfully to his family. Through the recognition from his children as their provider and guardian he also gains a sense of purpose and meaning in life.

While it may be a product of and reaction to the increasingly neoliberal political economic landscape in China, Jiang's move also reveals the persistence of socialist ethics in the country, one which evaluates the value of the individual vis-a-vis his/her contribution to the larger society. Children and teenagers are often viewed in the socialist narrative as the future of the society (the socialist machine), and in raising his children, Jiang perhaps is sub-consciously fulfilling a perceived duty to the state. As China readily marched into a more economically capitalist state since the 1970s, CCP (Chinese Communist Party) leaders remained committed to upholding socialist ideologies to maintain political and social stability. In 1982, the 12th Party Congress found it necessary that economic reform be accompanied by socialist spiritual civilization to "police and control the cultural accompaniments of the economic turn to capitalism", and launched a "Socialist Ethics and Courtesy Month" (Wang et al. 2012: 26). The campaign publicized activities of public services, such as "learn from Lei Feng", who was a soldier of the People's Liberation Army. After his death, he became portrayed as the nation's role model, and characterized as a selfless person devoted to the people, and the party. While this particular campaign was, in hindsight viewed by scholars as having achieved little of its original goal, its significance perhaps lies in demonstrating that the CCP's employment of neoliberal governmentalities was always accompanied by concurrent socialist ideologies (Wang et al. 2012: 27). Since 1982, campaigns that promoted socialist ethics were consistently re-ignited by each subsequent leadership, such as Hu/Wen's Eight Honours and Eight Shames, which listed both "serving the people" and "be united, and help each other" as socialist honours (The State Council 2006).

It is against this backdrop that I propose the possibility of reading black lung patients' continued devotion to raising their children as, in part, an instantiation of deeply entrenched socialist ethics. Children are viewed by the socialist state as the rising sun, the future upon whom

furthering of the great socialist agenda will rely. As I am writing this chapter, Jiang, who I have not spoken with in a few weeks, posted in a group chat proclaiming that, “my body does not belong to me, it belongs to the state” (my translation). When fellow group members asked him to elaborate the statement, he simply responded that, “I endure so much bitterness in life, but cannot speak of it to anyone else. The only way is for me to swallow it down” (my translation 2017). In this daunting declaration, Jiang speaks clearly to a socialist perception of his relationship to the state. Though I dared not intrude further into his sorrows, I speculated that part of his vision entails the burden of raising his children, out of his love for them, and again out of his duty to the state.

Conclusion

The dynamics described so far amongst black lung families are, I suspect, not unique to this particular community. While as I have suggested, the changing norms of intergenerational reciprocity, and understandings of filial piety are most likely not evenly experienced across socioeconomic classes, I believe that what I have observed are true of the larger rural, migrant population. Further studies may be needed to affirm my speculation.

My aim in this chapter has been to demonstrate that a duality of ideologies is at work in governing the Chinese family: neoliberalism work concurrently with socialism in the creation of self-reliant subjects, who in their illnesses are at once abandoned by the state but still held responsible for the rearing of their children. It has, therefore, left the society’s most vulnerable abandoned politically as well as socially. It has created immense psychological/emotional burden for the patients, whom in their illnesses continue to feel obliged to be productive members of the society. While there has been a significant amount of literature written on neoliberalism’s unique work in China, none has focused on its impact on the six million people who are relegated to a

space of abandonment/exception as their bodies become dis-abled and unproductive, and the subsequent effects it has on their families.

Furthermore, in showing the changes that have undergone within the Chinese family, I am not suggesting that there has been a decline in consanguine love. Rather, the atomized families reveal China's changing political economic landscape's effects at individual levels. If anything, the sacrifices made by patient-parents to both provide for their children and pardoning them of the burden to reciprocate materially, should be read as an incredible expression of parental love.

Chapter Four: Competing Narratives

Introduction:

On June 6th, 2016 He Bing posted an open letter entitled “Who is Black Lung Labourers Harming by Defending Their Rights?” on his social media responding to a doctoral dissertation written by Zhejiang University PhD candidate Liu Jing, “The Mobilization Mechanism of Public Welfare, Organizations in the New Media Context - A Case Study of Love Save Pneumoconiosis” (He 2016; Liu 2015). In this work, founder of Love Save Pneumoconiosis (LSP), Wang Keqin is quoted calling grass-roots patient-activists (specifically He Bing) as advocating for Black Lung patients through a “scoundrel-like manner” (流氓的方式). In addition to publishing this well-articulated letter rebutting and questioning the factuality of the claims made in the doctoral dissertation; He Bing also threatened to pursue legal actions against Liu unless she forfeited the recording of the meeting during which Wang was recorded calling him “scoundrel-like”. Liu was unable to deliver the recordings as she claimed to have destroyed all recordings at the conclusion of her research. She was forced to retract and revise her dissertation under the pressure of potential law suits against her.

Even though the letter was directed at Liu and her writing, He Bing admitted to me that he was not interested in going after the doctoral candidate herself. The purpose of his letter, and open gesture were to challenge the claims that were being made by Wang Keqin, and his depictions of patient-activists. The evident, mutual animosity between the two parties reveals a fundamental, and indeed ongoing conflict between patient-activists and China’s largest black lung NGO, Love Save Pneumoconiosis. There are currently six million black lung patients in China,

and this number is increasing by 20,000 annually (Ho et al. 2016). A black lung patient, in the most ideal scenario, can live for decades after getting black lung. Indeed, black lung disease is not considered to be a life-shortening disease. How can this ideal be made a reality for all six million patients? This is, I submit a question of *sustainability*, and people have opposing opinions over how to best achieve it. On the one hand, there is the grass-root labour/patient activists represented by He Bing and his fellow villagers; and on the other, there are those who support Wang Keqin in his claim that the approach He is taking is uncivilized and counter-productive. Wang in his criticisms of patient/labour activists, evokes a common sentiment amongst the Chinese urban population that views rural peasants as uneducated and irrational. This in many ways demonizes labourers/patients as subversive and neglect the fact that they were in fact victims of structural violence. It serves to undermine the legitimacy of patient-labour's claims.

When suggesting that He Bing's approach to activism was "counter-productive and uncivilized", Wang was specifically referring to an incident when He Bing engaged in physical conflict with local government officials. Wang believed that such behaviours would agitate government officials, aggravate the conflicts between citizens and the state, and discourage local bureaucrats' willingness to help – counter-productive. Underlying his rationale, then, is the conviction that patients like He Bing do not "deserve" assistance from the state per se. They should plead for help rather than demand it, as a right-holding citizen would. This assertion renders patients marginal and as secondary-citizens. It also marks a categorical departure from patient-activists' conception of their relationship with the state. They view government officials as public servants, and are there to serve the interests of the people. While He Bing admitted to me in private that he did not think physical assault against the official was the best way of approaching a conflict, he insisted that the bureaucrats were there to serve the people's interests, and he had a right to be angry when they were not doing their jobs.

My aim in this chapter is to lay out the two sides of this debate to allow readers to draw their own conclusions, though I do not pretend to be un-biased in my presentations. Furthermore, it must be noted that the boundary between these two sides is not clearly drawn, people have diverse opinions over what the best approach is to realizing a sustainable future for patients. If He and Wang represent the two extreme ends of a spectrum in terms of their beliefs, most volunteers, patients and activists fall within that spectrum.

I divulge the narratives each side employs to argue that while the intentions of volunteers and the organization they comprise of should not be questioned, the consequences and efficacy of their work requires critical inquiry. Specifically, I forward the suggestion that the modus operandi of the NGO in question depicts patients as the suffering other, who must rely on the compassion and empathy of the public for their survival, enables the state's inaction in providing a social safety net for the society's vulnerable, and undermines patient-activists' claim to their rights as citizens.

Narratives of Charity:

“Love Save Pneumoconiosis” is China’s largest and only non-profit organization dedicated to the sole cause of black lung disease. Most other charitable organizations, such as the Red Cross often organize collaborative fundraisers on different causes, but their works are not limited to one particular cause. LSP was founded in June, 2011 by journalist Wang Keqin as a subsidiary public foundation group of China Social Assistance Foundation. Their mission statement found on the official website says that “Love Save Pneumoconiosis” was created to achieve the mid-term goal of pushing the government to fully take over the caring for all BLD patients through the introduction of policies and regulations by 2035, and the long-term goal of eradicating black lung diseases (presumably as an occupational disease) in China in 100 years’

time. In achieving these rather ambitious goals, they outline three types of strategies: “rescuing those in urgent need”, “raising public awareness”, and “policy advocacy”

That LSP is the only organization working on this cause should not go unexamined. There is an active effort made on the part of the senior leaders of the organization in making this the reality. As the dispute between He Bing and Wang demonstrates, Wang Keqin has concerted try to undermine and exclude patient-activists from sharing any perceived progress and success in the state’s policies on treating black lung diseases. In addition, the organization is devoted to making sure no new organizations committed to providing relief for black lung patients ever stands a chance against itself.

As the founder of LSP, Wang is considered by popular media as the most important public figure and the spokesperson for pneumoconiosis in China. That an activist, rather than a patient, is the voice and face for a disease is itself worthy of addressing, but before doing so it is worth understanding who Wang Keqin is and how he perceives himself in relation to his work as an advocate for black lung patients. Before he founded LSP, Wang was already widely recognized as one of China’s “most well-known investigative journalist” (Baidu 2012). He has 680,638 followers on Weibo and is hailed by some as China’s Lincoln Steffens for his work as the chief reporter of *China Economic Times* and the assistant to the editor-in-chief at *The Economic Observer* (Baidu 2012).²⁰ He first won public recognition as an investigative journalist by reporting on the monopoly of Beijing’s taxi industry in 2002. Subsequently, he reported on the AIDS epidemic in Xingtai, and corruption problems in his native province Gansu. Wang undertook significant risks to investigate and report these stories: a five-hundred-million RMB bounty was placed for his head in the early 2000s; his apartment was under police protection for

20. Weibo is roughly China’s equivalent of Twitter, and this number is retrieved on 12/02/2017.

months (Baidu 2017). These works won him several awards, wide public recognition, and the reputation as one who is deeply committed to social justice. Of the people I have spoken with, most refer to him as Professor Wang (王老师), an honorary title granted to him as is a common cultural practice in China, to show respect and acknowledge someone's authority and experience.

Wang first heard about black lung disease in mid-1990s when he met a superintendent on a mine in Gansu, a man whom he referred to as Lao Huang.

“When I was with him, he constantly struggled to breathe. I later found out that he caught an occupational disease as a result of working in coal mines, and excessive exposure to coal dusts for years – what we now call black lung disease. A few years later, a fellow miner of Huang called me to tell me that Huang passed away. Black lung disease smothered him. For a while after the call, the image of Huang's smile was stuck in my head. A person I personally knew and interviewed literally suffocated to death – anyone who has shared my experience would have the same kind of inexpressible feelings as I did. I never forgot about black lung disease after that” (Wang 2011).

After Huang's death, Wang continued his work as a journalist until another black lung patient caught his attention: the famous open-chest case of Zhang Haichao. The same year, he received a call from a reporter in Gansu. In the call, the reporter told him that there were over one hundred farmers in Gulang county, Gansu province who were suffering from black lung and a few had already been killed by the disease. These patients sought out help from the local media, but the local media was banned from reporting. “He asked me to please help them”.

After this phone conversation, Wang headed to Gansu to start an investigation, and subsequently published a report entitled “Gansu, black lung village, investigation” on January, 20th of 2010.

“Soon after that, I learned that these villagers in Gansu were granted welfare and through their county, received medical examinations etc. [...] On December 20th of 2010, three black lung patients from Gansu came to my office to bring an appreciation pennant to me to show their gratitude.²¹ After saying their thanks, they kept on asking me to please help them more – three more people passed away in the past year. I initially thought I would send more reporters back to Gansu, but on a second thought, the platform and voice of one medium is far from enough. Therefore, I called my colleagues in other media for help in order to generate support. Even then, I felt that this was not enough. Hence, I thought of an even stronger social mobilization platform - Weibo. That same day, I posted three similar posts on my Weibo asking the public to help. These posts received a lot of attention from netizens, and was reposted 2598 times. The next day, there were people who reached out to these patients, and gifted them cellphones. Other people helped them to start a Weibo account. [...] Weibo soon became the largest platform for rescuing and supporting black lung farmers” (Wang 2011).

Wang sent me this account of how he started LSP when I visited his office in January of 2017. It was published by LSP and titled, “Love is Satisfied Through Love” (Wang 2011). Following his initial social media campaign, he recounted that he was approached by Sohu Gongyi (Sohu Charity is a subsidiary group of Chinese internet company Sohu. Inc), which later connected him with the China Social Assistance Foundation marking the beginning of Love Save Pneumoconiosis.

This piece of writing is a useful entry point to understanding some of the narratives that are being constructed as well as strategies implored by Wang and LSP as a charitable organization. In addition to criticisms of him as attempting to glorify his self-image, which is

21. Similar to a certificate of appreciation

clearly present in the piece: Wang draws a clear causal relationship between the patients' receiving of welfare and his reporting, it also depicts patients as helpless individuals who begs for and must rely on the efforts of NGOs, and the public's donations to survive. It constructs a falsified reality in which patients had no agency and no access to help prior to the intervention of Wang, and subsequently LSP. What he fails to mention, however, is that these patients were granted social welfare not because the state recognized that these patients due to their experiences with an occupational disease, deserve compensation from the publically funded work injury insurance but rather for their states of impoverishments. In other words, even though Wang's reporting was able to bring pressure to the local government to react, they responded by granting the patients pity money. This narrative that distracts the public's attention from the obligations of the state, and instead pats both Wang himself as well as the local government of Gulang on the back for doing the bare minimum, is perceived by patient-activist such as He Bing as being extremely problematic. He Bing believes that it undermines the collective effort of patients by giving them incentives to give up the bigger cause, and demoralizes patients by rendering them as welfare/charity recipients. LSP exemplifies an increasing trend in China, where "social welfare [is] being carried out by the society" (Chu 1996: 63). In the next section, I illustrate the construction of this narrative of charity through images of suffering patients.

Images of Suffering in the Affect Economy

Arthur and Joan Kleinman in their 1996 work *The Appeal of Experience: The Dismay of Images* note that “images of suffering are appropriated to appeal emotionally and morally both to global audiences and to local populations” (Kleinman et al. 1996: 1). They warned us of the dangers of the commodification and over-saturation of unexamined representations of suffering – whilst images of suffering may continue to evoke empathy in the viewer, an over-abundance in the media may also risks it becoming a form of entertainment to be consumed (Kleinman et al. 1996) Indeed, as explained by Susan Sontag “It seems that the appetite for pictures showing bodies in pain is almost as keen as the desire for ones that show bodies naked” (Sontag 2002). Over-representation of pain and suffering allows ordinary audiences to have the illusion that they in fact “understand, and even feel” the pains of the other. And the most detrimental effect of all is that under the constant bombardment of the global exchanges of images of pain, viewers despite experiencing an initial moment of shock become emotionally immune. Yet, despite these well-articulated concerns against the un-examined use of such images, photographs of victims of diseases, natural disasters continue to persist today as a go-to campaign strategy for NGOs, and governmental organizations alike.



Figure 3

Photographs are central to LSP's online campaigns in two ways. First, it is used to ensure a constant flow of public donations, which now constitutes the sole source of finance for the organization. Second, it is used to recruit new volunteers. There are, therefore, different images that are used to evoke different kinds of emotional responses in the eyes of the viewer. Having followed LSP's official account on both Weibo and WeChat, as well as the accounts of many LSP volunteers, my feeds are bombarded daily with images of patients, as well as photographic documentations of LSP events. The above picture is what one sees when she/he visits the official website of LSP, where it bears the caption "LSP has helped tens of thousands of black lung patients restore their faiths in life" (Love Save Pneumoconiosis 2017). Indeed, that is what this image conveys: a clearly sick man connected to a ventilation tube, laying on a hospital bed yet his eyes are wide open. The lights reflected on his face and in his eyes, suggest a sense of hope. It allows the visitor to the site to instantly connect the work of LSP to providing hope to black lung patients. Directly below this image are two links: "apply for rescue" or "join us [as volunteers]".



Figure 4

In contrast, another image that is also widely used by LSP is one of pain and despair. In this picture, we see a scraggly man whose calves are so skinny that one could easily mistake them for his arms. He is sitting on his bed, but leaning forward against a pillow that is placed on a suspended wood-board over his bed. This is how this man sleeps every night because lying down would place too much pressure on his lungs to the point that he would not be able to breathe. This image, as described to me by one of the volunteers, is one of the most “iconic” images of black lung patients, used in many of LSP’s publicity materials. It was taken during one of the first field visits conducted by LSP volunteers in Sichuan province, during which volunteers go to villages and visit black lung families. They record patients’ basic household information, medical records and take extensive photographs of the patient himself as well as their family and living conditions. Following the visits, these images get uploaded onto the organization’s official Weibo and WeChat accounts with a short text describing the impoverished state of the family. Although it is not always made explicit in the contents of the post, there is no doubt that these posts serve both fundraising and publicity purposes.

LSP relies heavily on small-scale, social media campaigns for fundraising. They are as simple as consisting of a few images of a field visit, such as the one shown above, and a short but emotionally charged description of the despairing state the patient family is in. And they are often very effective, partly due to the simplicity of online donations on Chinese social media. Online transactions on social media platforms of Weibo, WeChat are made extremely expedient by the prevalence of Alipay as well as WeChat Wallet. Alipay is a third-party online payment platform launched by Alibaba Group in 2004 (Waitling 2014).²² WeChat encourages users to send Red

22. Alipay started off as a platform similar to PayPal, but has quickly broadened its services both online and offline. In the specific context of online donations, if one links their Alipay account to their Weibo, donations can be made with the click of a button. WeChat Wallet is a result of WeChat’s attempt to become an all-encompassing social media platform as opposed to being limited to a

Pockets with Lucky Money between users, and the money one receives from another user is directly saved in the wallet. This practice is used quite commonly in patient chat groups.²³ In a WeChat group consisted of patients from Hunan, patients and volunteers frequently send a Red Pocket to the rest of the group accompanied by some words of encouragement, such as “wishing everyone good health” or “live positively”. In addition, there are options such as “transfer”, “quick pay” and notably “Tencent charity”.²⁴ These options connect individuals, as well as businesses and makes online monetary exchanges extremely convenient. The ease with which one can donate to a cause they see online no doubt contributes to LSP’s choice of fundraising method. There is no barrier between seeing a story online, and making a donation to the family in the story. All it takes is a few clicks on one’s smart phone or computer and the donation is made.²⁵

In one particular LSP post from December, 2016, an orphaned pair of brothers are featured. The title of the post notes, “Parents Passed Away Due to Illnesses, Orphaned Brothers are Left with 15 Potatoes”. The post mostly consists of pictures of the two children and their home, which are all watermarked with LSP logo. Below each picture there are a few lines of captions. The boys featured in the story, Zhang Hairong and Chen Guangxin, lost their then 34-year-old father to black lung disease. Their parents had divorced before the father’s death. And

conventional communicational application. WeChat Wallet acts as a “savings account” for Wechat users and store all of the inflow of money from the various functions of WeChat. For instance, while some people link their bank accounts to the wallet, one does not have to have money in their account.

23. Red pockets, and lucky money are part of a cultural tradition in which the elders gift children, and young people in the family money and wish them good luck during the celebration of Chinese New Year. The money is wrapped inside of a red pocket. WeChat has appropriated this cultural tradition, and brought it online.

24. If one clicks the option of “Tencent charity”, the user is directed into the page of Tencent Charity where there are many online fundraiser campaigns, and the user can easily donate to these causes with the money in their Wechat wallet.

25. According to Tencent, as of December 2015, more than 48 million users donated through their platform and made donations over ¥0.76 billion (\$100 million).

their mother remarried another black lung patient, but also later passed away due to cancer. Impoverished and out of options, their step-father returned to the gold mine he had contracted black lung from despite his illness. The two brothers were left on their own. Although the post does not directly elicit donations, the effectiveness of these social media campaigns is reflected by the responses of online readers below the post. Just in the first thirty replies, there were five replies indicating that they have donated, or asking how they can help more, such as adopting the children. At the end of the post, there is also a small icon saying “reward this post” which links the user to a donation page powered by Alipay. Viewers of the post can donate with a mere two clicks, and the whole process takes less than two minutes.

Through the use of images, and different fundraising platforms, LSP participates in what is often referred to as the “affect economy”, in which “the role of the poor and needy [act] as both products and producers in an economy that relies on specific kinds of suffering” (Adams 2013:9). Through the generation of images of suffering, LSP “calls for the emotional response of the witnesses of suffering” and their material donations (Adams 2013:10). Scholars have scrutinized this process as it commodifies the human experiences of suffering, and turn them into profit-making businesses. Although I do not necessarily believe that LSP is guilty of using representations of black lung patients for profit-making, I concur with the existing literature in arguing that their participation in the affect economy contributes to reinforcing structural inequality and the precariousness of the social safety net which patients rely on because it “becomes a kind of affective choice, rather than a civil right protected by regulations that are enforced by strong public sector policies and juridical protections” (Adams 2013: 11).

The Making of Images

The makings of images employed by LSP require critical examination and scrutiny. During my conversation with Zhang Yingkui and his wife, the patient in bed 42, their interactions with LSP came up. They told me that they had been visited by LSP volunteers last month—something LSP volunteers do often, as they go to Huaxi Fourth Hospital to identify new patients, establish contact with them and record their information for archival purposes. During this visit, Zhang’s wife said, LSP volunteers recorded all of their information, including He’s medical records, personal identification number²⁶ and also took extensive pictures of her husband. As she spoke, she started unbuttoning her husband’s shirt and showing me the still-healing wound on his chest from the most recent surgery and said that “they took pictures of him like this”. He did not say anything while his wife talked to me, nor when she showed me his bare-chest that was still covered by medical gauzes, as if we were not actually talking about him. I felt extremely uncomfortable at that moment, and could not bear to look at Zhang without suspecting that I had participated in the process of objectifying his pain or worse himself.

For Zhang’s wife, however, that pictures were taken of her ill husband was not the point of outrage per se. Rather, she was upset because she and her husband didn’t receive what she thought was promised by the giving up of information and images. In her understanding, a “transaction” had taken place: in exchange for the pictures and information, the couple would receive a “donation” from the organization. So, in this sense, she and her husband were also active participants of the affect economy. In fact, they did receive ¥1000 from LSP, which the volunteer told them that they owe their gratitude to an international donor.²⁷ However, she did not think that was enough. She argued that the information they gave LSP should warrant more

26. Chinese equivalent to SSN in the U.S.

27. ~ \$200

money as well as an oxygen concentrator; moreover, they also recorded the information of He Minqun, Zhang's next-bed neighbour and did not give him anything in return. Jumping into the conversation, Zhang's wife said that LSP was just a big scam, "they are scamming 'our' money! They take our information to big companies, and foreign countries to ask for donations, but don't actually give us the money". Clearly instigated by our conversation, He's wife decided to call the volunteer they had met. "Yeah, ask them for an oxygen concentrator!" Zhang's wife encouraged. The call went through, and He's wife left the room to conduct the phone call. She came back into the room a few minutes later, outraged: the volunteer (whom I later found out was Lv Chao, one of the senior members of LSP, Sichuan) said that they do not have any more monetary allowance for her husband, and to qualify for an oxygen concentrator, a visit to their house must be paid so that their "impoverished state" can be verified. For the two wives, this only further confirmed their belief that LSP was a scam organization. I did not know at the moment, but two days later at LSP Sichuan's annual gala, I met both Lv Chao and the "international donor" that she had spoken of. It turned out that Lv was not exactly deceiving He and his wife. In terms of material help, LSP can, at most, supply each patient they identify with ¥10,000 equivalent of an in-patient hospital stay, an oxygen-concentrator and their children's school fees.²⁸ In order to receive these, the patient must satisfy four criterion: 1) the patient must be a labourer (工人); 2) the patient must be impoverished;²⁹ 3) the patient must not have received other forms of compensation; 4) and the

28. ~ \$1451

29. While China has made incredible progress on poverty reduction over the past decade – indeed, China's contributing rate to world poverty reduction is 166.9% (Hu et al. 2005: 2), but this number begs contextualization. China holds a poverty line that is more stringent than the World Bank's already minimum standard of \$1.25 a day. In 2011, the rural standard for poverty was raised to ¥2300 per year, which equates to less than \$1 a day (C. 2011). A 2008 paper published by the World Bank notes that China has one of the lowest poverty lines in the developing world (Chen et al. 2008). This is not to deny that China has made tremendous progress in poverty reduction, but simply to provide readers with the necessary context of what Lv Chao means by "impoverished". It would

recipient must be a black lung patient (although they do not have to have obtained formal diagnosis). Lv was not convinced that He fell within these categories, specifically, she did not believe that He and his family were as poor as they said they were.

It was a complete coincidence that Lv had brought He and his wife up. She was talking to Huiling Jiejie (sister Huiling), a Malaysian woman in her 50s living in Chengdu who joined us during our conversation, when He came up. Huiling has donated ¥100,000 and several oxygen concentrators to LSP. Because the donation amount is relatively high for an individual, and that the donor actually wished to be involved in the process of its distribution, Lv had been keeping an itemized expenditure sheet for her. It is an excel sheet that shows how each item was spent, accompanied by a small picture of the patient or the receipt at the end column as well as the remaining balance. Lv told Huiling that she spent the money very prudently this year so there was still ¥20,000 left. “Why?”, Huiling asked. Lv answered,

“I only give to those who really need it, and not those for whom it is not absolutely necessary. This is a must. Here is the situation, for instance, Bazhong county, each time patients from there come to Chengdu, there would be about 20-30 of them. If I give the your money to the first one that came, then the rest of them will all expect this. So now I can’t at all unless I verify with the local volunteers to know that they are actually very poor. It is not enough. You know, sometimes ten patients come at the same time, they would even fight over a medicated plaster/pain patch³⁰. For me, I must manage this so I

indeed seem that a black lung patient does not to be “impoverished” per state standard to be in real need of financial assistance.

30. 狗皮膏药. In Chinese language, this is used to suggest that a pain patch is something that is cheap and smelly, and normally not desirable. She uses this word metaphorically to suggest that patients may fight over the smallest thing.

am accountable to Huiling jiejie. Patients who come try to compare what they get to what others do. Sometimes, I spend my own money to buy patients who come for hospital stays gifts, or lunch if it is meal time. Look, I keep all the money that I spent on this little notebook.

This year we didn't receive that many patients coming to stay at the hospital, it is strange, many patients do not want to come to the hospital. The people who come to me don't necessarily need it. You see, these people, they are still contacting me now but LSP decided not to help them. Here is why, they have urban household registration, which means their health care covers slightly more than patients with rural household registration. I also asked volunteers from their local office, they are not as poor as they claim to be. When I was there, they asked me for money, and I only had 1,000 in my wallet so I gave it all to them. They also asked me for an oxygen-concentrator, I could give the ones you donated, but I didn't. They stayed in the hospital for over a month even with their own money, this means that they are still doing alright financially. Here is what is happening a lot. The patients who come to us are not necessarily those who are so poor that they can't even afford rice for dinner”.

Lv was not wrong in her assessment. After I spoke with those two patient families that afternoon, I was deeply troubled by the terrible financial situation they seemed to be in. I was also confused, however, as to why they would not try to seek governmental compensation, which according to He Bing was difficult but indeed possible. I asked He Bing why he thought that was, and his answer surprisingly agreed with that of Lv's, “sometimes you meet a patient, and they tell you that they are desperately poor because they know you are from the U.S., and that you might give them cash. Those who are really poor won't even be able to afford to come to the hospital.

The two patients you spoke with this afternoon have been paying for their own stay for the past month, which means they are not as poor as you think”.

For He Bing, patients who rely on public donations and the help of LSP, are lazy: they have chosen the easier road between receiving charity and fighting for their rights. “That’s their own choice. I tell them about the possibilities of getting compensation from the state; if they choose otherwise...”, He Bing shrugged nonchalantly and left me in perplex and a sense of outrage, unsure where to direct. I never stopped wondering why it was that patients must choose between receiving donations from the concerned public and also being able to claim that they deserve compensation/insurance from the state. I did not think that had to be the case. But there sure is a dichotomy for LSP volunteers, black lung patients and the donors. LSP and its modus operandi, I submit, contribute to the creation of this artificial dichotomy. I elaborate on them in the following pages.

The making of the images and the process of creating representations, as the Kleinmans have suggested, are exploitative ones: volunteers take pictures of patients in their most private and vulnerable moments, and use/disseminate these images without the full consent of patients. Patients have little control over how these images are used, and the kinds of rhetoric that are constructed around their pictures. Although it seems that some patients and their families are also actively participating in what they envision as an exchange process through which they hope to gain monetary reward, ultimately, they have little control over the outcome of this transaction.

Such images are then used to construct a narrative that is inherently oppressive. In order to evoke an emotional response from the viewers of these images, whom Vianne Adams calls the witnesses of suffering, a specific image of destitution and vulnerability must be constructed (Adams 2013). Photographs are often taken as an objective portrayal of truth, but it is hardly the case. As Susan Sontag correctly pointed out, “it is always the image that someone chose; to

photograph is to frame, and to frame is to exclude” (Sontag 2002). The point of focus for LSP in photographing black lung patients are their pain, vulnerability and passivity. This practice is violent and oppressive insofar as it has the ability to define what a black lung patient ought to be, and reduce/restricts them to “the suffering lot” (Robbins 2013).

Within this image, there is no place for a patient who is at once in need of help and also actively pursuing his self-interest. For instance, when Lv spoke negatively of the patients who “fought” over public donations, she was making intelligible the inherent logic of this narrative that patients ought not try to seek out resources for themselves. Rather, they should be the passive and grateful recipients of donations, and be content with however much they receive. This discourse operates within the affect economy in which empathy, money and specific narratives of suffering are exchanged (Adams 2013). In doing so, it renders patients at the mercy of the public’s compassion and undermines patients’ claims to public goods. It views patients who actively seek out to protect their rights, or maximize what they can gain from the affect economy to which they are the primary producer as “scoundrel-like”, greedy or ungrateful as evidenced by both Wang and Lv’s accounts.³¹

31. Admittedly, there is an argument to be made for the use of photographs. Areilla Azoulay in her *The Civil Contract of Photography* suggests that photography has the ability to create a “civil political space” that “puts photographers, viewers and the subjects of photography into a relationship each of them must acknowledge” (Azoulay 2008: 12; Smithson 2017). And in this sense, spectatorship can elicit more than sympathy but also moral action. Azoulay argues that rather than seeing subjects of images as part of a frozen, past moment, they should be viewed as “still there, struggles and people with agency” (Azoulay 2008: 16; Smithson 2017). While I do not necessarily disagree with Azoulay’s challenge to the assumption that photography of the suffering subject is always and ubiquitously oppressive, LSP’s processes of producing and subsequent uses of images do not do the empowering work she envisioned. Specifically, my contention lies with the intentionality underscored by the NGO’s production and dissemination of the images, and the rhetoric ever so carefully constructed around them. In the context of black lung disease in China, I propose that such expressions of agency through photography may be achieved by patients themselves. Indeed, many patients have smart phones and routinely post images of themselves in sick beds onto their social media.

Moreover, as mentioned above, although LSP itself is not a profit-making organization and hence not vulnerable to critiques of commodifying and profiteering from the suffering experience of black lung patients, they nonetheless operate in a corporate manner. Lv's conversation with Huiling makes clear that Lv feels accountable not to the patients whom she's trying to help, but rather the donor.

This encounter reveals an even more fundamental problem: the impossibility of a charitable organization like LSP, which is solely dependent on public donation for finances, to fund a black lung community of six million in China. Indeed, not only are they not able to support all the patients that there are, they can hardly sustain their support for the patients they do identify and establish connections with. While the organization acknowledges this, the way they operate does not reflect this understanding. In a recent post Wang Keqin posted on his WeChat, he wrote that "professionalization is what will ensure the sustained furthering of our work". In this post, he acknowledges the sheer size of patients but suggests that this is a problem that can be solved by the organization's professionalization and the institutionalization. However, not only is this assertion financially impossible, it also poses an unnecessary burden on the public. At present, the organization relies completely on the public's empathetic donations, elicited through the production and distribution of images of the suffering object on mass media. This emotional reservoir of the public is easily redirected or drained. As unfortunate as it may seem, there are simply too much "entertaining" pain circulated, and to be consumed on the internet. This process of emotional exhaustion has, in fact, already started. Many volunteers use personal connections, post on their accounts to elicit donations, but report that less and less of their friends are willing to donate as time goes on. Furthermore, LSP's approach is shifting the responsibility to care for the society's vulnerable from the state to the public - which begs the question whether civil

society, in this regard, is facilitating the inactivity of the state? Indeed, below the post of the orphaned brothers, readers ask, “aren’t there governmental policies for orphaned children?”.

Lastly, the moment Zhang’s wife shouted out, “they are scamming our money” embodies yet another danger of LSP’s modus operandi that He Bing was so wary of, and almost outraged by, albeit he tried to disguise it with an act of nonchalance. Zhang’s wife saw that money as “theirs” because it was donated to the organization with the intention of helping people like her husband and their families. The existence of potential to receive monetary support by posing for pictures and feeding into the public’s imagination of the suffering allow patients to imagine an alternative to making a claim against their governments when it is possible but challenging. As we have seen, this potential is not as promising and sustainable as it appears. In the end, the patients are, without an exception, left to struggle on their own. While He Bing may be justified in his almost despite of “lazy” behaviours as such, it is important that I point out LSP’s role in facilitating the state and fostering a shockingly neoliberal belief amongst patients – namely, the belief that they do not deserve state compensation, henceforth are left on their own, and at the mercy of the compassionate public.

Images of Compassion

LSP’s role in black lung communities speak to a larger social phenomenon in China, in which “provisioning has shifted from a more direct distribution of resources through the work unit and city government to a system that relies more heavily on social organizations and the ‘voluntary’ mobilization of citizens, and their time, labour and private assets” that emerged with the state’s neoliberalization (Hoffman 176). Volunteers are central to LSP’s operations and survival. Indeed, LSP now has around 4,000 volunteers across the country. Almost all people who “work” for LSP, even those who hold executive positions do so without pay. This is why I have

referred to everyone as volunteers, regardless of their specific post within the organization. While many of the volunteers are college students, who only stay with the organization for a short period of time, most of those considered to be the “core” members of the organization are people who are in their thirties or forties who work a full-time day job. This was surprising to me initially, as China does not have a mature culture of volunteerism that is institutionalized the same way it is in many Western societies. Hence, I asked almost every volunteer I spoke with why they decided to volunteer with LSP. A common answer I received is that volunteers believe they benefit emotionally from the work they do, as the title of Wang’s post from the beginning of the chapter: “love is satisfied through love.” Volunteers repeatedly told me that they view their interactions with patients and their families as an exchange of love, care and gratitude. While I found this narrative of mutual love and gratitude to be very emotionally appealing, I also realized, as time went by, of its potential danger.

This narrative is constructed around images of giving, compassion in concurrence with those of suffering and gratitude. It shifts a viewer’s attention from the struggles of patients to the altruistic gestures of volunteers, whom most viewers have an easier time relating to, and creates a belief that things are improving for black lung patients because there are people trying to help. In addition, as I have been arguing in this chapter, the narrative of compassion participates in the “affect economy” and reinforces the belief that black lung patients can only occupy a space of receiving charity, and empathy. Hence, when patients try to maximize what they could get out of a charity rather than being thankful for whatever they are given, they are viewed as ungrateful, and perhaps un-worthy of even public donations.

Lisa Hoffman in her *Serving and Providing for Those “In Need”*, note that “young people understood their participation as expressions of human caring, the development of a better self, and as work that helped to maintain social stability”, but also knew that their works were

completely voluntary (2016: 181). Her ethnographic research shows that volunteering organizations repeatedly emphasize to volunteers that they must prioritize their own lives over work, and help only to the extent that they are comfortable with (Hoffman 2016). I note here, again, the incredible neoliberal sentiment in this rhetoric that prioritizes the individual and his/her responsibility to the self, but there is, arguably, nothing wrong with it. What is problematic, however, is when this rhetoric is coupled with the reality that for some black lung patients, their only source of assistance is civil society and the public.

The discourses of the compassionate public consisting of both donors and volunteers, and the very survival of LSP predicate on the creation of a suffering object but also its secondary



Figure 5 Two volunteers explaining how to use a prevention mask

place in the narrative just as they are in the images. By attempting to help black lung patients, the organization inadvertently contributed to their marginalization, and render them as secondary citizens of the society.

Narratives of Rights

“The posture of the right-holder is not that of the supplicant” - Joel Feinberg

In writing about the nature of human rights, Joel Feinberg asserts that the posture of the right-holder should not be that of the supplicant. The right-holder does not beg by bowing or kneeling down, but rather, demands with his/her back straight. The right-holder does not try to appeal to another’s empathy, but instead invoke the rights that are *owed* to them (Feinberg 1970). This narrative of rights is one employed by He Bing, Rao Zhongwen and their fellow patient-activists and stands in direct contradiction to the narrative of charity employed by LSP. In this regard, these black lung patient-activists are engaging in what Kevin O’Brien called “rightful resistance”, through which Chinese peasants/villagers deploy “the policies, laws and commitments of the state to combat local officials who were ignoring those policies, laws and commitments” (O’Brien 2013: 1051). The course of actions, identified by O’Brien and Li follows that “the wronged peasants seek help through the formal and/or legal channels of adjudication; and when these channels fail, victims resort to petitioning to higher authorities, lobbying the media, or protesting to address higher authorities” (Ho et al 2016: 86; O’Brien 2013). Despite its important contributions to understanding notions of rights and citizenship in rural China, the work was not met without criticisms. Notably, Brandtstädter criticized the work for its overly rationalistic, and lacking of “ethnographic details of how peasants are turned into rightful resisters, including ‘who they are, and what they think’” (Brandtstädter 2006; O’Brien 2013:86). I hope to contribute to this discussion of resistive citizenry in rural China through ethnographic evidence, and argue that indeed, black lung patients in Sichuan are employing rightful resistance to defend their rights to life.

After his brother passed away in late 2006, He Bing decided that he was going to figure out what really was the disease that was bothering him, his father, brothers and fellow former

miners only. He, along with many other men who had worked with him, had been feeling sick in their lungs, and experiencing constant weakness ever since they returned home after their former workplace was closed. An overall reform of the mining industry directed by the local government in 2001 closed almost all private mines in Sichuan that year.

Many people had believed that it was just tuberculosis and bad luck, even though it seemed a little peculiar to He that the only people that were getting TB were those who worked on mines. After his elder brother's death, a few other fellow miners also subsequently passed away.

"In hindsight, we realized that this disease that was killing people was related to our past occupation on mines. So, we read up on regulations and laws online to understand the situation better. In 2007, we [patients in his village] officially came together to start working together to defend our rights. As we became more certain that our conditions were likely occupational, we started researching the treatments for occupational diseases and injuries. This diagnosis process took us three years: we started in 2010. This was the hardest first step. We went back and forth between the different provincial and county-level governmental departments. Everywhere you go, they direct you to a different department/ministry; in the end, we felt so lost as to where to go. We went to the Ministry of Labour of Ganle County; they told us to bring our occupational disease diagnosis, and they will pay us accordingly but really they were just trying to put us off. In order to receive a diagnosis, there was a requirement that one must obtain an employment proof from one's employers. The mine that we worked at was shut down temporarily by the state on the basis of improper work environment, but later the state just auctioned these mines off to other corporations to manage. None of our bosses was given any compensation for the expropriation of their mines; many of the previous owners went

broke themselves during this process. Retrospectively, the government classified the mines as illegal. But the problem is that when the reform of the mines was taking place in 2003, there were about two-hundred different mining companies on the coal mountain. With the exception of a few mines, all had legal papers granted to them by the Sichuan provincial Ministry of Land and Resources. Regardless of the conditions of operations within those mines, they were legal.

We managed to find our last employer, and he provided us with a written confirmation, confirming we had worked on his mine. But when we brought this confirmation back to the diagnosis center, no one would recognize that letter as legitimate. Why? Because when the mine he owned was expropriated in 2003, any record of this particular owner ever owning that mine was erased. We went to the company that was managing our mine since 2005, but they would not provide us with anything because we never worked on the mine after 2005. This really repulsed us. We have laboured hard since we were children just so we can have a good life, however, now that we are sick, our basic right to live or die seemed to rely on someone else's will. Because the right to getting a diagnosis was the right to live: without diagnosis, there is no way to get compensation and medical care, and if you don't have that, you will die within a year or two. Then it means that our life and death were held in someone's hands. This was not fair to the vulnerable people in the society. So, we decided to send documents to different governmental organizations, to petition for the regulations of obtaining an occupational disease diagnosis be changed. We requested that the right to obtain diagnosis not on the basis of someone else's agreement (such as the employer's). In addition, we also sent requests to the local police departments to be allowed to protest on the streets. In the end, this situation was reported

to the national level, and the National Ministry of Social Security sent a letter to us that was also copied to our local governments (liangshan) and the Ministry of Justice asking that our case be treated with consideration of its specificity (特事特办), essentially allowing us to obtain a medical diagnosis without the proof of our former employment. We prepared another set of documentations and our local village officials signed off on them, and we used that instead of an employer's letter at the diagnosis center. After our case, in 2011, the national regulations on obtaining occupational disease diagnosis (职业病管理办法) was revised to include this new possibility.

But as we finally got that piece of diagnosis and took it to the local Ministry of Labour, they still would not recognize our disease as occupational. Their justification was the same, because the mine we worked at no longer existed, and hence, we could not qualify for the occupational disease/injury insurance. We felt like we were pushed into a corner, so we started to collectively appeal/petition to higher levels of government (上访). We went everywhere in the province, and also threatened to go to Beijing. This effort effectively resulted in a special meeting between our provincial leaders and county officials. This meeting designated the responsibility of providing relief to patients to the local government with which the patients' hukou belonged to. This happened in early 2011, prior to that, our county government kept telling us to go to the county where we worked; now they could not say that. Soon, they told us that they would start reimbursing us for sixty-percent of our medical expenses. But even the remaining forty percent was impossible for us to pay. We did not have jobs left, how could we afford it? So, they

extended it to ninety percent. Still, we could not afford the 10% co-pay in addition to the traveling costs to the hospital every time.³² We went to them again, and this time they agreed to cover one-hundred percent the medical expenses. But, at that time, expenses incurred outside of the county must be paid for first, and reimbursed ex-post. For people who were really sick, each hospital visit would cost them hundreds of thousands RMB, and their savings were already exhausted over the years of being sick – they did not have the money to cover the cost themselves first, and wait for the reimbursement, which normally took months to be processed.

Coincidentally, Beijing introduced a new provision on the occupational injury/disease insurance regulations, which stated that if patients could not afford to pay ex-ante, there should be a fund established by the local government to help patients pay. With this document in hand, we went to our county government again, to ‘borrow’ money from them to go to the hospital. They refused to lend us money. We said, ‘ok, but you have to sign this document that we brought to confirm that you refuse to follow the new national policy’. They obviously were not going to do that, because that would put their jobs at risk. ‘But you can’t refuse to do both’, and we got into a bit of conflict that day. The Minister of Labour, I and another fellow patient became agitated and got physical. But they had a meeting after this incident, and decided to open an account at Huaxi Fourth Hospital as a fund to cover any patient from our county’s expenses there. This way they resolved our conflict, but also avoided giving patients cash. In addition to covering our medical costs, they are also now giving us, in various forms of welfare, roughly around

32. He Bing’s home village is half a day’s travel away from Huaxi Fourth Hospital in Chengdu by bus and train.

*20,000 RMB per year. Since these changes, our death rate is much lower. And we owe our success to our unity as a group of right-holders ”.*³³

What is evident in He’s account is that the tactics he and his fellow villagers employed in achieving their end goal were one of deploying “the policies, laws and commitments of the state to combat local officials who were ignoring those policies, laws and commitments” (O’Brien 2013: 1051). Indeed, He believed deeply that the realization of his rights lied within the boundary of the legal framework, and his battle with government bureaucrats was one over the execution of the law. Indeed, he told me on one occasion that, *“They are public servants, and should serve the interests of the people, but instead all they do is try to keep the peasants who do not know their rights at the door step. They do not even know the law themselves. If they do not know the law, they do not even deserve the job. Their jobs are paid for with my tax money. But whenever I interact with them, I have always been patient and forgiving. If you don’t know the law, it’s fine. I will teach you”*. It is true, He followed any tabling of new state policies closely, and held the local government accountable in their implementation, as it is evident in the case with the ex-ante payment. And as O’Brien observed, when the attempt to enforce local execution of central policies were failing, these Chinese black lung patients, by requesting the local minister to sign a document confirming his refusal to follow through state policies, covertly threatened to petition with higher authorities. He was rather proud of this particular tactic of his, as he told me that this gesture of threat was material enough that he did not actually need to follow through with it for the local officials to cave in.

33. A word on writing style: I understand that this is an extended prologue, that perhaps for most readers, are simply too long. However, the choice of transcribing and translating one monologue in which He told me his experiences with black lung and rights-defending movements was a conscious one. No one tells his story better than himself, and it is my hope that through the relaying of his own words, readers can gain a glimpse into this man’s articulation and intelligence.

Through the process of understanding and defending their rights, He and his fellow villagers have become incredibly educated and tactful. They understand the dynamics between various governmental bodies, and the incentives of individuals extremely well, and they employ these understandings to achieve their end goal. I submit that they, in many ways, have risen as what Gramsci may see as “organic intellectuals” amongst the working, migrant class of miners (Gramsci 1992). While he never pointed out the genealogy of his thinking, He clearly situates the struggle of black lung patient-miners within a structural imbalance between capital, labour and state in China. This reflects a larger trend within China’s labour rights movement to hold the state accountable as it continues to pursue a global capitalist and corporate mode of governance. Indeed, He now frequently participates in meetings with other labour rights activists, and envisions black lung patients’ cause as a part of a larger movement toward the democratization of the country.

In concurring with O’Brien and his observations, however, I do concede, and in this respect agree with one particular line of criticism posed against his theorization, namely, “rightful resistance” is not ubiquitous across the country. Wing-Chung Ho and Fen-Ling Chen in their study of “the perceived irrelevance of rightful resistance among peasant coal miners suffering from pneumoconiosis” have shown that there is a geographical divide in terms of peasant-patient’s employment of legal avenues in defense of their rights (Ho et al. 2016). In fact, as I have demonstrated, it is not even so across hospital rooms. He Bing and his fellow villagers’ story is undoubtedly one of success. As a patient group, they receive the highest level of financial compensation nation-wide from their local governments. Due to the way in which local politics is organized in China, however, their success with their particular local government cannot easily be replicated by patients from other parts of the country. It is important to understand, hence, that while their story is significant in showing the potential of a rights-based approach to

compensation, it is a rarity rather than a widespread reality for the majority of China's black lung patients, and requires a specific understanding of peasant-state relationship. Even He acknowledges that if a patient lacks knowledge of the laws governing black lung treatment, or if the patient is not persistent and resilient enough in the process, even with the existing provisions, it is highly unlikely for him/her to obtain the same kind of treatment. It is a thus part of the present reality that it requires immense labor and resilience from black lung patients if they wish to pursue the rights that are owed to them through China's existing legal frameworks. Ho and Chen are correct in this regard, to suggest that most patients, "were prepared to compromise their citizenship rights for a lesser amount of compensation" and hence contributed to the reproduction of "existing (corrupt) social structure" (Ho et al. 2016: 98). I depart from them, however, in that I am hopeful He and his fellow villagers' struggles do signify the start of something greater.

Conclusion

To this day, He Bing and his friends have not given up on their journey of "defending their rights." In his own words, "*our government never admitted that they did us wrong. What they are doing now is that they are occupying a moral high ground, and saying that, 'you guys are sick, and poor, and we are giving you welfare money out of kindness and charity'. We don't need charity! Even though our bodies are disabled, our minds are not. My people have worked hard for our livelihoods for generations, and never relied on welfare. The government imposed welfare on us, but we prefer to have occupational disease/injury compensation – what is owed to us*". He continues to appeal to the provincial levels of government, and file suits with the local court to have the compensation come from occupational injury insurance rather than from social welfare. I asked him why he bothers, because we both recognized in our conversations the near impossibility of this challenge. His answer that he did not wish to be receiving "charity" whether

it is from the government or the public when wrong was done to him by the state reveals, for him, the importance of insisting on rights over welfare.

His activist work now also expands beyond black lung related matters. Recently, he had filed a suit with the local court about the travel ban that has been placed on him. He also posts frequently on his social media about social issues. Rao Zhongwen, who is in the last stage of black lung and confesses that he believes he only has a few years to live, also still continues to engage in activist work even beyond black lung related causes. Their understandings of their work are centered around beliefs of rights as citizens, and the responsibility of the state to effectively provide a safety net for all that is under their jurisdiction. This marks a significant departure from both LSP's narrative and understanding of the role of patients vis-à-vis this kind of NGO as well as the state. While LSP's works provide relief for many patient families that are in desperate need of both emotional and financial support, their very existence contradicts the claims that patients are making: to receive charity from the public is to neglect the wrong that was done to them by the state. In addition, by placing the burden of caring for the society's vulnerable on the public, the NGO is inadvertently facilitating yet another process of negligence by the state.

Concluding Remarks: Body Multiple

We walked into a private room on the top floor with a big, round table that took up most of the space in the room. There was already food on the table, a lot of it: pork, fish, soup and red spices everywhere. But what captured my attention almost immediately was the amount of alcohol that was present. There were three bottles of baijiu and at least a dozen bottles of beer.³⁴ As the lunch began, so did the rapid consumption of alcohol. Soon, a cigarette was also lit in the room, albeit not by a patient...

During my time researching at Huaxi Fourth hospital, I got to tag along on He Bing and a few other patients' daily lunch expeditions. We went to a different restaurant each time, ranging from local eateries, tea houses to fish-head hotpot places. They were never fancy, expensive places; but they nonetheless had good food for affordable prices. Food is an important part of the Sichuan culture; indeed, Sichuanese is amongst one of the most popular Chinese cuisines both at home and abroad. Culinary culture also in many ways, define Chinese culture and sociality. A popular idiom that has its origin in the biography of Li Shiqi, an advisor to Han emperor Liu Bang, reads, "The people are the most important to the emperor, and food is the most important to the people" (the literal translation would be "people treat food as their god") (my translation).³⁵ Almost two-thousand years have passed since Li's time, but his insights remain true. Being able to enjoy food is crucial to Chinese people's perception of the good life (Lora-wainwright 2013). These black lung patients' determinations to having tasty food every day rather than eating the "tasteless" food, in their words, from the hospital makes clear that the challenges black lung disease posed to their lives have not curtailed their pursuit of the good life.

34. A Chinese variety of strong distilled spirits made from different kinds of grain, generally between forty- to sixty-percent alcohol by volume.

35. 《汉书·酈生陆贾列传》：“王者以民人为天，而民人以食为天。”

Not only are these lunches always guaranteed authentic Sichuanese food, they were also always an interesting time. The opening scene describes one of these lunch ventures. On January 3rd, Rao Zhongwen invited me and He Bing to celebrate his discharge from the hospital with a few others. We went to a local-styled tea house. There was a total of four storeys to the place: the first three floors were spaces where people could play poker and drink tea, and the top floor was a restaurant. Even on a weekday the first few floors were filled with people having a good time.

Having grown up in China, I was no stranger to social situations like this where drinking and smoking are just as integral to socializing as food is. Nonetheless, I was taken aback by what I was witnessing and indeed participating in. As a smoker myself, I had been restraining myself from smoking in front of any patients over the past few days because I knew how much even the thinning winter air and worsening smog affected their breathing. Even though the person who lit up the cigarette was not ill himself, how could he be so inconsiderate of Rao and He's conditions I thought? Rao Zhongwen, whom I refer to as Uncle Rao, was sitting next to me. With the fifth bottle of beer in his hand, he was telling me about the severity of his condition amidst a thick fog of tobacco infused smoke: Three fourths of his lungs are deemed necrotic, leaving him to breathe with only the rest of the one fourths. And he could hardly climb up a few stories of stairs without pausing to catch his breath, making it impossible for him to keep any job, not even as a janitor. The story only amplified my worries. Finally giving up on resisting my urge, I whispered to him, "But, Uncle Rao, does their smoking not make you feel uncomfortable or sick? Why don't you say something? Drinking is also not good for your health, has the doctor not said anything about it?"

Apparently amused by my concern, Rao burst into laughter, and told me that while he knew only too well of the health hazards smoking and drinking posed to his body, he did not care. He also told me that it would be impolite to ask the smokers in the room to stop because of his

condition. So, why keep protesting for better health care and compensation, if he did not even care about his health? I pushed further. Rao guzzled the glass of beer in his hand, and told me, “I don’t have much time left because the necrotic tissues in my lungs can never get better, a year or two at most, so I will not let it prevent me from enjoying life. I will die from drinking, eating and having fun but not from being sick”. For Rao, then, risking being jailed to defend his right to occupational injury insurance was not a matter of prolonging his life, but rather choosing how he wants to die. He refused to be killed by a job he worked for decades that only served to dis-ease and impoverish him, or a state that denies his chance at life by denying him health care.

This conversation with Uncle Rao, in many ways shaped my understanding of the black lung experience in China. In this thesis, I have argued that a black lung patient’s illness experience is one contingent upon the political, social and economic conditions within which she or he is situated. I have contrasted the diagnostic processes of pneumoconiosis in China and the United States to illustrate that biomedical knowledge is not unbiased and fixed as it is often assumed; rather, it is often reflective of cultural beliefs and telling of the state’s political interests. While in some cases, such contingency and fluidity are used to make clear patients’ capability to make claims over their bodily experiences, in China diagnosis has been used to undermine patients’ ability to gain proper health care.

Blackened lungs in China represent the process of neoliberal capitalist development that took place over the past thirty years. These economic changes have improved the lives of many, including my own, but they have also impoverished, diseased and killed many others whose plight is only now beginning to be made visible.³⁶ However, in depicting the lives of black lung patients, I have taken caution in not reducing them to only their sufferings. Just as Rao’s words and attitudes show, faced with challenges that at times seem unsurpassable, these resilient people

36. With the help of media, scholars and NGOs, but most importantly by patients themselves.

have not given up on relentlessly pursuing their visions of the good life, and perhaps also the dignified death.

The fight to making oneself visible, inserting oneself into the society and demanding from the state rights that one believes to be owed to him or her is not an easy one, as I discussed in chapter four. While civil society has emerged in an attempt to create a social safety net for black lung patients, their efforts have proved to be ineffective and counter-productive. The inefficiency, lies fundamentally in the narratives these NGOs employ. Working within an affect economy, NGOs rely on strategies that elicit the compassion and empathy of the public for funding, through constructing images of the suffering patients. In so doing, they render patients as incapable of defending their own rights, and even ineligible of state welfare. Black lung patients, however, have demonstrated through their ingenuity and unremitting efforts that they are indeed agentive citizens who are capable of articulating the etiology of their ailment as political and economic, and hence demanding rightful compensation. Their efforts are connected to and situated in a larger labour movement that has been gaining force in China.

Just as the cause of the disease can be traced back to China's economic reform, the sick person's illness experience has also come to be influenced by its turn toward a more neoliberalist state. Beyond the fact that the lack of proper medical care, and insurance, it also has consequences over their social experiences with the illness. The turn towards neoliberal modes of government, working in concurrent with a continued celebration of socialist ethics, deprives individuals of support from the traditional extended family network but continues to demand them of their labours.

The winter of 2016 and 2017, when I was doing my fieldwork research in Chengdu, China witnessed one of the worst episodes of smog in recent years all over the country. Walking in the city I constantly felt as if I was living the sci-fi post-apocalyptic life, everywhere I looked

there were impassive faces covered by big, white smog-prevention masks. One evening in the busy downtown area of Chengdu, I saw a couple kissing each other over their masks by the Tiffany store window, and was struck by its haunting resemblance to images from London before the devastating smog hit the city. I, too, compelled by what felt like the imminent threat of death, made my first purchase of smog-prevention masks. At the same time, my social media was exploding with heated debates. On the one side, there were people demanding that the state halt factory operations, and take environmental pollutions seriously; on the other, there were those who believed that to do so would violate the economic interests of the poor who did not yet get to enjoy the fruits of China's economic development. A friend of mine posted an emotionally charged post on his WeChat account arguing that demands for economic re-structuring towards greater environmental sustainability is "selfish". It represents the interest of the socio-economically privileged. He traced his argument directly back to Deng's vision of letting a few get rich first, "now that you got rich, you decide that your health is more important than the poor's opportunities at financial advancements?": to promote "environmental justice" for a few at the expense of "economic justice" for the majority of the society is morally questionable.

The back and forth I saw on my WeChat feed could in many ways be read as the microcosm of a much larger debate, with development on one side and its impact on the environment on the other, that is taking place nationally and globally. In a heated interview between investigative journalist Chai Jing, and Ding Zhongli, geologist and vice-president of the Chinese Academy of Sciences, Ding asked Chai, "Are Chinese people also humans?". This 2010 interview took place after the Copenhagen Summit. As a member of the Chinese delegation to the summit, Ding proclaimed that carbon emission cuts agreement proposed by IPCC at the conference, if ratified, would be yet another historical, unequal treaty signed between developed and developing nations and condemned it as "morally evil". He believed that carbon emission

rights equaled to development rights. To place a cap on a developing country's carbon emission is to deny its chance to develop. The rates of emission proposed by the IPCC allowed developed nations at least 2.3 times more emissions per person than developing nations. Despite China's large population, Ding argued, to ask that of China is to render Chinese people lesser humans compared to their Western counterparts.

While China has since committed itself to an eventual carbon-emission cap, Ding's words remain a true reflection of the dominant public discourse in China around the topic of climate change vis-à-vis economic development. Global carbon-emissions-cut mandates as compelled by clear evidences of climate change are viewed by a large portion of the Chinese public as an oppressive discursive device employed by developed nations to contain China's economic rise.

I do not challenge anyone's inherent right to pursue a good material life, nor do I disagree that developed nations do not deserve more emission allowances than their more populous developing counterparts. What I want to unsettle here, through my studies of black lung patients in China, is the assumption that the socioeconomically disadvantaged are somehow immune to the health hazards posed by environmentally unsustainable development. The worsening smog made breathing harder than it already had been and posed a serious threat to their survival. This winter, many patients had to admit themselves into the hospital simply because the "weather was not good". And these were the "lucky" ones who, in one way or another, could afford hospitalization. The fates of those who can't? The unthinkable. These same people are those who, through their hard work of extracting coal, literally fueled China's recent economic development, but have not enjoyed its fruits. They earned meager wage-labour salaries in mines, and just as their lives were improving, they were forced back into poverty by their illness. The heart-

breaking truth is that, as told to me by one LSP volunteer, those who were the most hard-working, are now the most ill.

This is what my friend and Dr. Ding failed to see. As the case of black lung miners made intelligible, the last twenty years of hasty development in China that largely ignored any environmental consequences placed society's most vulnerable and impoverished in the greatest harm. Continuing down this path will not result in the trickling down of wealth envisioned by Deng Xiaoping, but only exacerbate the present inequality amongst different strata of society. Ding tried to invoke the modern human rights discourse which holds the right to economic development as a fundamental human right to argue carbon emission rights are human rights. This is simply not true. Development and progress are not uniform nor linear; the booming global green energy industry has demonstrated to us that there are more sustainable ways to continue economic growth without causing grave environmental disasters and still, promote greater social equality. A just future for all should be one that does not view environmental and economic justices as conflicting. After all, the most fundamental human right is "the right to life", without which all else becomes meaningless.

Appendix One: Map of China



Figure 6 Map of China

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