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2. Leprosy welfare: entrenched stigma and policy formation

Shao-hua Liu

INTRODUCTION

This chapter examines how stigma shaped China's leprosy control and treatment programme during the collective era (1950s–1978) into the 1980s. Following the rise of socialist medicine, the 1950s witnessed China's first time in history that nearly all sufferers of leprosy received medical and material assistance from the State. This aid served as welfare at a time when the disease remained highly stigmatised in all arenas of life. In this chapter, I show how different kinds of stigma, which plagued both leprosy sufferers and the politically disadvantaged doctors who treated it,¹ underpinned the design and efficacy of this welfare programme. The chapter is thus a lens on the politics of China's socialist welfare programmes and the role of welfare in perpetuating and complicating an already stigmatised disease and those who treated it.

'Welfare stigma', understood as stigma caused by receiving social welfare, has been a key issue examined widely in welfare studies (e.g. Horan and Austin 1974; Mink and Solinger 2003; Rogers-Dillon 1995; Spicker 1984). Most have proposed reducing stigma as a goal of improving welfare programme design, such as keeping recipients anonymous or making welfare universal to avoid the consequences of labelling (e.g. Anttonen et al. 2012; Besley and Coate 1992; Titmuss 2006). Stigma, as Goffman (1963) explains, is by definition a socially constructed label which may signify disfavoured physical attributes or derogatory non-physical attributes. In other words, it is the social perspective at stake that determines the so-called normal and the stigmatised. The discussion of welfare design and stigma, however, has largely focused on the recipients and how welfare causes stigma, while the role of welfare providers in the politics of stigmatisation remains relatively under-examined.

This chapter provides a more comprehensive picture of China's leprosy control during the period under study. In addition to examining the stigma facing leprosy sufferers, it examines the role of both the State and the doctors associated with welfare stigma, and the impact of political environment on their work and on the disease. As I will discuss at length, the political background of doctors in China's collective era often became a hidden reason for them to be selected to work on leprosy control, orchestrated through a logic in which unfavourable political background led to undesirable job assignments such as leprosy care. Although leprosy was largely controlled during the collective period, an unfortunate by-product of China's welfare design was that it reinforced a vicious cycle of stigmatisation that gave rise to invisible social suffering, which continues through the current economic reform era.

To engage the relationship between leprosy, welfare and stigmatisation, I first discuss leprosy and political stigma in China during the 1950s to the early 1980s, when China's

disease control approach ran counter to the international norm at the time. More importantly, I illustrate how political stigma affected the allocation of jobs, including those of doctors, and how new kinds of political stigma were built on more established biological stigma within China's medical profession. Highlighting the principles by which all Chinese people were officially categorised in the collective era reveals how fundamental stigma is to understanding and evaluating China's leprosy control until today.

The current China case helps us reconsider the role of stigma in welfare programme design. It shows that adopting a universal mode of welfare may not reduce stigma, although such a mode of welfare provision has been considered to be conducive to that effect.

METHODS

The chapter employs a mixed-method approach of semi-structured and life-history interviews, participant observation and documentary collection and analysis. The data presented here is largely based on my research project between 2003 and 2014 concerning leprosy in China. The chapter draws on evidence such as official documents, medical journals, health reports and personal correspondence with leprosy doctors, as well as participant observation and interviews conducted in leper colonies. Using snowball sampling, I was able to locate and conduct in-depth interviews with 32 male and ten female doctors across China, who began their work on the control of leprosy during the collective era. The term 'leprosy doctor' refers to a wide range of health professionals or practitioners interviewed, from well-known leprologists in national and provincial hospitals and health offices, to doctors and health workers employed below the provincial level. These doctors, most of whom are now retired, lived and worked in the provinces of Sichuan, Yunnan, Guangdong, Zhejiang, Jiangsu and Shaanxi, and in Beijing. The location of leper colonies varied tremendously: high in the mountains, isolated by rivers and oceans or well confined in suburban areas or the surrounding countryside. My fieldwork in these colonies helped me understand the lives of the patients and the working conditions doctors had to cope with in the past, and how biological and political stigma were defining characteristics of their experiences of welfare.

Leprosy Stigma and Controversial Welfare Design

Leprosy is unique for its particularly distressing humanistic and medical implications across space, time and culture. Also known as Hansen's disease, leprosy has a history that dates to antiquity in many parts of the world. Biomedically, its cause is traced to chronic infections of *Mycobacterium leprae*, a pathogen discovered by the Norwegian physician G. H. Armauer Hansen in 1873. Hansen's breakthrough not only led to a scientific understanding of the disease; it also led to the international practice of segregating leprosy patients for quarantine and treatment, based on the then newly established theory of leprosy transmission (Vollset 2013).

Despite Hansen's bio-scientific findings, the unsolved mystery of leprosy's exact transmission pathway (White and Franco-Paredes 2015), the moral connotations of the disease (Leung 2009), the grim deformity its sufferers may present (Irgens et al. 2006) and

the portraits of lepers as the 'living dead' in literature (Prioleau 1983) all impacted on how leprosy came to be widely perceived in the West as a divine scourge that demanded either banishment or salvation of the afflicted (Douglas 1992; Kipp 1994). Although the transmission route of the disease remains scientifically unknown, it is believed to be transmitted via droplets from the nose and mouth during close and frequent contact with untreated patients. However, *Mycobacterium leprae* is not highly infectious; it multiplies slowly, with an incubation period of about five years, and symptoms may take as long as 20 years to appear (WHO 2016). In 1958, after a new medication regimen appeared to be effective in treating leprosy, a global appeal for ending the practice of compulsory segregation of patients was formally proposed at the 7th International Leprosy Congress in Tokyo (Baling and Valdez 1994). Still, while the stigma of leprosy has been ameliorated in countries where control of the disease has been largely successful, it continues to blight the lives of sufferers in some parts of the world.

China is one such example where leprosy sufferers continue to experience social stigma. Contrary to the international trend, China launched its programme of compulsory segregation of leprosy sufferers into colonies across the country in the late 1950s, at a time when other countries were beginning to abolish isolation as a treatment regimen. Compulsory segregation continued for two decades, ending in the 1980s; when China adopted the new international medication approach, sponsored by the World Health Organization (WHO). In 1981, WHO began to recommend multidrug therapy (MDT) consisting of two to three drugs to kill the pathogen and cure patients (WHO 1982). This new therapy treated 5.3 million patients in 1985 and 3.1 million in 1991 worldwide, and the hopeful outcomes inspired the World Health Assembly in 1991 to pass a resolution to 'eliminate' leprosy as a public health problem by the year 2000 (Smith et al. 2016). Elimination is defined as a registered prevalence rate of less than one case per 10 000 persons (WHO 2016). According to WHO's criterion, China achieved this goal in 1981 and openly announced its achievement in 1995 (Jiang 2006). This was a laudable achievement considering the disease's prevalence across the country before the mid-20th century (Maxwell 1937). There was no systematic national record in China prior to the 1950s, but estimates from the 1920s placed the number of leprosy sufferers at around one million (Wu 1927: 1). In 1956, it was estimated that there were 380,000–390,000 in the country (Jiang 2006).

Theorising Welfare

In general, the ideological spectrum of State welfare provision stretches from residualism to universalism. A residual model of welfare, at one extreme, is defined as a temporary social welfare programme that comes into play only when the private market and family support break down and cannot accommodate individual basic needs (Titmuss 1974). The correlation between residual welfare and the effects of labelling is that it perpetuates the social exclusion of the recipients, who are mainly socio-economically disadvantaged or marginalised (Horan and Austin 1974; Rogers-Dillon 1995; Spicker 1984). As for universalism, there is no broadly accepted definition of it in social policy, but the common assumption is that it implies a fair and just redistribution of resources or services to all members of society and has been considered ideal for social integration, equality and stigma reduction (Anttonen et al. 2012; Besley and Coate 1992; Titmuss 2006). Still, as China's case will remind us, without incorporating the prevention and reduction of stigma

into its treatment blueprint, a universal model of care cannot resolve the common correlation between stigma and welfare recipients.

SOCIALIST WELFARE AND THE CLASSIFICATION OF PEOPLE

China's comprehensive social security system as a universal form of welfare during the collective era was based on its socialist ideology and hailed as a symbol of socialism's superiority over capitalism (Chow 2000). The Soviet model of welfare had a great influence on China in the early 1950s, whereby the social security provided through work units underpinned the 'Soviet social contract' between the socialist State and the working class (Gu 2001). Although it was the working class that was considered the founding base of socialism in the Soviet Union, in China farmers were also a key part of the political strategy, and subsequently the nation-building imagery. The Chinese social security system during the collective era was categorised into two distinct segments – urban and rural – with associated work units (*danwei* 单位) and communes (*gongshe* 公社), respectively. In other words, work unit-based welfare targeted State employees and the commune-based welfare covered farmers.

Although welfare in the form of social security during the collective era was basically universal, following the socialist ideals of equality, its allocation remained stratified within and between work units. That is, who deserved welfare and how they received it were intrinsic to the State's identification and classification of its people – the recipients. In addition to the differentiation of welfare in terms of geography and the financial wealth of a work unit, some groups of people fell outside the scope of the State's welfare system under the official classification of individuals.

At the founding of the People's Republic of China (PRC) in 1949, political class divisions were the overarching principle by which people were identified as deserving or not deserving social security. Those designated as class enemies – landlords (*di* 地), rich farmers (*fu* 富), political reactionaries (*fan* 反), people who had committed bad deeds (*huai* 坏) and political rightists (*you* 右) – commonly faced exclusion. These people deserved no security unless they repented their (or their families') past errors, underwent thought-reform education and regained the acceptance of the people – or, more precisely, of the Party-State (Huang 1998).

Under the same classification system, the Party-State had a particular strategy to mobilise its workers to fulfil its welfare goals. Since the nationalist and warfare period of State-formation (1935–1949), as well as during the collective era, the Chinese Communist Party (CCP) conceptualised its support for the elderly, the disabled and the abandoned, as well as all public services, as 'social services' (*shehui fuwu* 社会服务), rather than 'social welfare' (*shehui fuli* 社会福利) (Croll 1999). The discourse of 'serving the people' was often embodied in the State's acknowledgement of cadres as moral paragons for their sacrifice and dedication to ordinary and vulnerable people. For instance, in memorialising Norman Bethune and Zhang Side, two dedicated communists in China,² Chairman Mao Zedong glorified their 'selflessness' (*hao bu li ji* 毫不利己) and 'service to the people' (*wei renmin fuwu* 为人民服务) in 1939 and 1944 (Mao 1961; 1969). Such an emphasis on service characterised the politico-moral stance of the Party-State to expect its workers to carry out its policies of care of the people.

In brief, China's welfare design during the collective era was based on a mix of Marxist utopia of equity, Leninist classification of people and Maoist mobilisation of workers. Leprosy control during this period was also planned according to these general principles, although it was greatly affected by stigma in ways that are critical to understanding the design and provision of its welfare programmes.

THE CHANGING APPROACHES TO AIDING LEPROSY SUFFERERS

The aid provided to leprosy sufferers in China since the early 20th century can roughly be divided into three distinct periods based on who was providing primary care: missionary efforts in the Republican era (1912–1949); socialist welfare programmes (1950–1980s); and the return of Christian charities in the market reform era and beyond (post-1980s). Different care providers might have worked together in certain transitional contexts, while at other times they appeared antagonistic to one another. I situate the PRC's leprosy welfare programme in the collective era within China's recent history in order to highlight its scale and influence in the present.

Leprosy in the Republican Era: Restrained State and Western Missionaries

Historians have pointed out that pre-modern Chinese society enjoyed high levels of local autonomy and was heavily involved in local philanthropy (see e.g. Leung 1997 and DuBois's chapter in this Handbook). However, in the case of leprosy relief in the late Imperial period, leper houses were nearly all State funded, due to the fact that traditional philanthropists were not interested in aiding lepers because of stigma (Leung 2009). The situation of only State-led relief to lepers gradually changed as Western missionaries landed on Chinese soil and introduced biomedicine in the 1840s (Leung 2009; Roemer 1993).

The image in the Bible of leprosy as an archetype of human sin and suffering drove Western missionaries to look for lepers when they were evangelising the world's 'backward' regions in the late 19th and early 20th centuries. China was a major destination for such salvation. As stated in a report about the work of the Mission to Lepers in China between 1874 and 1910, 'No class of the population have shown themselves so ready to receive the Gospel' (Gussow 1989: 210). Missionary dedication to leprosy was prominent throughout the Republican era, although Republican elites were unhappy with the lenient missionary approach to coping with leprosy (i.e. not enforcing strict isolation of lepers). The Republican government's ability to provide a viable leprosy policy was constrained by widespread political turmoil, while the limited relief to lepers was chiefly remedied by Christian charities (Leung 2009). The severe social stigma and exclusion sufferers faced compelled missionaries to care for them mostly in asylums or special hospitals in the name of Christianity.

Leprosy in the Collective Era: A Coercive Humanitarianism

After the PRC was founded in 1949, the Party-State, which considered Christianity an outgrowth of Western imperialism, expelled nearly all foreign missionaries. The State took over all foreign institutions, including charitable establishments that had been founded or aided by religious or other international organizations. For instance, the State issued a policy statement in 1950 that assumed control of some 20 leprosaria (leper asylums) that had been established by American missionaries (Liu 2013).

The leprosy control programme was not widely publicised, and its social invisibility is reflected in the comment of a senior leprologist who stated: 'Leprosy would never appear in the major newspapers before 1980.' The extreme stigma of leprosy made its control a significant controversy; it was the only major endemic in China that required grand segregation of the patients.

1. A unique form of universal welfare for leprosy patients

The administration of leprosy patients presented a different kind of challenge to the socialist government in the early 1950s. They could not be incorporated into the universal welfare framework for fear of contagion; however, they were also not classified as an undeserving political class that should be deprived of social security, such as the aforementioned class enemies. Ordinary people were unwilling to lend support to them. General medical establishments would not provide them with proper healthcare. Their health often deteriorated and resulted in deformity, which further reinforced the negative social stereotype of lepers. The extreme social exclusion they faced can be illustrated through a tragic episode that took place in Yunnan Province in 1951. In a single incident, a total of 115 patients in a leprosarium were murdered by local cadres and community members out of dread of the disease.³

Socialism, by definition, is intended to favour the underclass, based on its ideological commitment to social justice and equity, and in China the Party-State supported universal welfare policies to achieve those goals. Leprosy often affects people living in poor and rural environments. Lepers, by definition, were mostly part of the underclass and on the priority list of the socialist pro-peasant agenda. As one leprologist stated: 'As far as politics is concerned, leprosy was a peasants' problem, an iconic disease.' The State must therefore find a way to provide care to this special population, based on its ideal of 'service to the people.'

A distinct socio-medical space for leprosy treatment and welfare in China thus took shape in the 1950s, when the segregation of lepers into colonies became official national policy and practice after the first National Leprosy Prevention and Treatment Meeting in Jinan, Shandong Province in 1957 (Liu 2013). The State's treatment of leprosy patients, and their continued social exclusion, can be examined in the practice of the two policies outlined below: the institutionalisation of leper colonies and the recruitment of leprosy doctors.

2. The institutionalisation of leper colonies

Beginning in the 1950s, especially from 1957 onward, lepers were sought across China's urban and rural areas and, once found, were sent to leper colonies. Concentrating sufferers in a confined space made preventing transmission of the disease to the general public

and the patients' long-term medical treatment feasible while also sheltering them from societal hostility (Department of Health of Guangdong Province 1957).

By the end of 1956, 52 leprosaria, 114 leprosy villages and 157 institutes for leprosy control had been either newly established or expanded from old facilities to accommodate 19,148 patients across China (Ministry of Health 1957). The number of leper colonies continued to increase in subsequent years. By 1973, there were 60 leprosaria and over 700 leprosy villages across the country (Jiang 2006).

Leper colonies typically were leprosaria – institutionalised hospitals or living compounds with medical staff and resources based in the cities or towns – or similar to ordinary rural villages, but with doctors coming in for check-ups and to provide medication. I visited both types of colony in Yunnan, Sichuan, Guangdong, Zhejiang, Shaanxi and Shanghai City numerous times and found the conditions there to be significantly influenced by the subsidies local government provided.

The welfare benefits that leprosy patients received generally followed the Party-State's division of its citizens, based on residential (rural vs. urban) and class (politically favoured vs. non-favoured) categories. In cities and towns, once identified, patients were assigned to urban or suburban leprosaria and received State subsidies. Some of these patients hailed from favoured categories that included Party cadres, military personnel, State agents and even overseas Chinese. In general, these patients lived in better-equipped leprosaria and enjoyed better services than other patients. In rural areas, patients were clustered in simple leprosaria or leprosy villages nearest to their hometowns, where they also received free medication.

Whether in urban or rural areas, the leper colonies were mostly located on the city periphery or separated by mountains and rivers in order to isolate patients from mainstream society. As one leprologist commented, the colonies were 'mostly out in the out-of-the-way periphery, separated from the outside world, for the sake of preventing transmission'. For instance, I visited Taikom (大襟) leprosarium on a small island off southern Guangdong Province, which in 2009 was accessible only by motorboat.⁴ Another leprosy village I visited in Yunnan Province in 2011, is located in a valley surrounded by high mountains and requires half a day's travel from the nearest county seat along winding, rugged roads.

The naming of the leper colonies also points to the State's awareness of the issue of stigma. In the early 1950s, the Chinese word for leprosy, *mafeng* (麻风), was sometimes included as part of the colony's name, whether urban or rural. In 1955, the State issued a policy statement recommending the removal of *mafeng* from the names of the institutes and villages, so as to avoid disclosure. The word *mafeng* was gradually replaced with the word 'rehabilitation' (*kangfu* 康复) and leper colonies, thus, in name, became 'rehabilitation villages' (*kangfu cun* 康复村) or 'rehabilitation institutes' (*kangfu yuan* 康复院). China has not followed the international trend in replacing 'leprosy' (*mafeng*) with 'Hansen's disease' (*hansenbing* 汉森病, as is officially used in Taiwan). In China, the disease officially remains *mafeng*.

People's livelihoods in the leper colonies varied from place to place. In leprosaria, patients generally received sufficient living subsidies from the State. But State policy in rural leprosy villages generally followed the Soviet Union's slogan: 'From each according to his ability, to each according to his work' (Jukes 1973: 225). Just as in ordinary communes where peasants received livelihood support in exchange for their labour, unless they

were badly disabled, patients in leprosy villages were also required to contribute labour to supplement the State's meagre subsidy. This policy of self-reliance created huge challenges for patients who were disabled or afflicted with serious ulcerations. The only way to heal an ulcer is to rest and keep it untouched and clean. Earning a living through farming or some other form of hard labour made the goal of staying physically healthy quite difficult for most patients.

Other forms of welfare, such as education and recreation, also varied in different leper colonies. In the Shanghai Rehabilitation Hospital, for instance, doctors and educated patients served as teachers for young patients who ranged from children to young adults. Some leprosaria and organised villages also provided patients with recreational programmes such as film screenings or theatre performances presented by patients themselves. But patients in remote rural villages generally received few such benefits, and their children received little schooling. Few qualified teachers would work in the leprosy villages and ordinary schools would not accept children from the colonies. From the 1960s to 1978, the ration coupons used for all life supplies in China were also distributed in some leper colonies, including for watching films and acquiring sugar, oil, rice and sundries. These coupons bore stamps that clearly marked them for circulation in leper colonies only.

3. The recruitment of leprosy doctors

The doctors on the frontlines of planning and delivering medical treatment to patients were yet another crucial component of China's leprosy policy during the collective era. As mentioned above, in the Republican era the treatment of leprosy was largely sponsored by Western missionaries. After 1949, when the missionaries were driven out of China, only a handful of local doctors and health workers had sufficient experience of caring for lepers. It is no exaggeration to say that socialist China began its policy of controlling leprosy with only limited economic resources and technical knowledge, and this situation was only exacerbated when the country withdrew behind a closed-door policy in the 1960s and 1970s.

The State needed workers at various administrative levels to implement its large-scale leprosy control programme. Training more doctors in leprosy diagnosis and treatment became a critical policy mandate at the first national meeting on leprosy, held in Jinan, Shandong Province in 1957. To staff the programme, the Central government initially selected a few physicians who originally specialised in dermatology or sexually transmitted diseases (STDs) and directed them to refocus on leprosy. The number of leprosy doctors grew quickly nationwide throughout the 1960s and 1970s. By 1973, health personnel specifically engaged in leprosy control totalled 7,290 (Jiang 2006).

How did the State manage to mobilise so many doctors to work on leprosy control, given the stigma attached to the disease? My interviews with leprosy doctors reveal that, of all the means used, the most salient method was assigning people categorised as 'class enemies' to this area of medicine and healthcare. Between the 1950s and 1970s, many doctors and new medical graduates with 'bad' class backgrounds were selected to work on leprosy control. State agencies at various levels also recruited and trained young ordinary people with 'bad' family backgrounds as local health workers to treat leprosy.

The government also provided tangible incentives (such as wage subsidies) and symbolic incentives (such as the socio-political symbolic recognition bestowed under 'service to the people') to encourage and mobilise doctors. However, out of the 42 doctors inter-

viewed, only one voluntarily chose to specialise in leprosy treatment, although even he was persuaded by his professor to 'serve the country'. As he told me in 2009, 'he [his professor] mobilised me with thought education.' Many of the other interviewed doctors said they felt reluctant at first, but had to accept the assignment under pressure from the Party-State. Some said that they did not even consider whether they were willing or not to participate, because personal choice was not an option at that time. During the collective era, few people could choose their own careers.

Under the overwhelming heat of patriotic sentiment and implicit (or explicit) coercive measures, these doctors worked hard to materialise leprosy control. The experienced doctors with administrative credentials organised various kinds of workshops or short-term healthcare programmes to provide on-the-job training to doctors from various administrative scales and with other levels of medical knowledge. This sort of activity also allowed leprosy doctors to exchange information and ideas about their work. We can imagine that the high-level, experienced leprosy doctors were mobile and itinerant, tackling assignments of various lengths in different places across China at that time.

Through all of these activities and interpersonal exchanges, a close-knit network of leprosy control workers began to take shape. However, this particular medical community remained largely invisible to the public because of the enduring stigma of the disease. Leprosy doctors were mostly looked down upon by other physicians and health workers, and they generally would not tell others about their work (Liu 2013).

4. Changing perceptions of leprosy doctors and their careers

Over the duration of my research with leprosy doctors, I was intrigued by the changes in their attitude toward their work. Most of them changed gradually from initial reluctance to embracing leprosy control as a career, to finally settling on acceptance of the profession tinged with self-fulfilment. Over time, the reluctant doctors developed a genuine sense of empathy for the patients and internalised their humanitarian mission out of the State's coercive tactics. The dramatic changes in their perspectives, apparently driven by their close and frequent encounters with human misery, however, remained invisible to the ordinary social world.

All doctors I interviewed began their careers in leprosy control and treatment in their 20s–30s. During the interviews, they usually commented not just on their own lives, but would all similarly recall: 'It would be a lie to say [there was] no fear of leprosy in the beginning.' For instance, a doctor, in his late 80s at the time of our interview, who began his leprosy profession in Zhejiang Province in 1952, told me:

[It was said that] good people (*haoren* 好人) wouldn't do this type of work. Then coming to the [leprosy] hospital, the work meant [you were] no good . . . Everyone said workers at this [leprosy] *danwei* were not good people.

Another well-known doctor in Beijing, who began working on leprosy in the early 1950s described the difficulties he faced this way:

Leprosy doctors were not like other doctors who waited for patients in hospitals or clinics . . . [Our] work was harsh, no cars, no motorbikes . . . People were afraid of leprosy . . . To talk about the psychological struggle [of doing the work], I was not alone . . . If you were not yet married, working on leprosy would make it hard to find a spouse.

Another doctor in his early 60s, who worked in a big leprosy village with hundreds of residents in the mountains of Sichuan Province, complained about how hard it was to locate rural patients and send them to the leprosy village:

Patients would send their dogs to attack us, telling us not to call on them. [They thought when] we leprosy doctors approached them, [it meant that] they were lepers. No one wanted others to suspect them of being infected . . . Patients would spit on us as we examined their skin. Some leprosy patients even rubbed their pustule and smeared it on us, so loathsome! It's very tough to educate [leprosy] patients. They didn't want us to approach them; they'd rather hide their illness until some irreversible deformity appeared. Alas!

A female doctor around 60 years of age told me about the misunderstanding of leprosy among health workers while addressing her painful memories of working in rural areas in the early years of her work assignment:

Until the 1970s, we were still somewhat ignorant of the leprosy bacillus and always put on safety blouses, gloves and caps to prevent infection. We could only have bowel movements after going back to our makeshift residence in the field. Sometimes my menstrual blood just streamed down my legs to the ground. I couldn't change the pads! . . . Our teachers didn't allow us to touch the grass and flowers by the roadsides lest we transmit germs to them and in turn infect the others. Alas! My daughters hated me when they were small. Our relationship was not so good. They always stared at me when I went home, because I didn't dare give them a hug owing to my fear of infecting them.

In my interviews, all doctors expressed disapproval of leprosy stigma, based on their belief in science; but the fear and stigma they faced in their work and personal lives still haunts them and shapes some of their most painful memories.

To continue mobilising leprosy doctors to work in the shadow of enduring stigma, the Party-State implemented other strategies during the collective era, in addition to coercive measures described above. Sometimes the State clearly acknowledged the stigma problem and honoured doctors publicly in ritualised events or in propaganda-like speeches addressed to them at conferences and other occasions. This rhetoric and these public rituals were critical in making their suffering morally tolerable, as they faced discrimination while serving the State's health agenda. For instance, in one 1957 meeting, the Vice Minister of Health, He Biao, mentioned the fact that leprosy doctors were socially stigmatised as the 'head of the lepers' (*mafeng tou* 麻风头) or 'leprosy suspects' (*mafeng xianyifan* 麻风嫌疑犯), and praised their sacrifice and devotion to controlling the disease under the circumstances (Liu 2013). Prime Minister Zhou Enlai also commended a group of leprosy doctors in 1971 because they '*dare* treat leprosy patients, which highlights the spirit of serving the people' (Jiang 2006: 14, emphasis added).

The State's praise of leprosy doctors reveals its tacit deployment of 'coercive humanitarianism'. On the one hand, the strategy was intended to raise the morale of leprosy doctors and to have them internalise the altruistic value of service. Their suffering was to be seen as altruistic self-sacrifice to serve the leprosy patients and the State's agenda. Although some doctors still expressed strong aversion to their leprosy work, the views of most of the interviewees ultimately transformed over time, as they really cared about the patients. They did not change their job after market reforms in the 1980s presented other options, such as transferring to the fields of venereal and skin diseases. They maintained

their work ethic both as patriots in socialist nation-building and as concerned healers helping suffering patients.

On the other hand, however, the State's praise and aforementioned policies may have also underscored and reinforced their stigmatised condition. During the collective era when China espoused Marxist materialism and suppressed spirituality, the government nevertheless mobilised politically vulnerable workers to dive into a stigmatised field by calling for their class-based repentance through work. Their concern about the condition of the patients and the State's goal was real, yet so were their painful memories of the forced work assignment.

As a result of such coercive humanitarianism, leprosy stigma remained and was even exacerbated by welfare design. As described above, enduring social stigma based on a disease (leprosy) was conflated with political stigma in the collective era, and thus the medical treatment and care of leprosy became tainted by these other kinds of stigma. Such a paradox can be summarised in the subtle remarks of a female doctor, in her late 50s in 2007, who could only find a job in leprosy healthcare because of her disfavoured family background. She said:

The most I reap from it [leprosy] is it has given me a vocation . . . I have lived a life of hardship. So [having] a job was good for me – even though a stigmatised one. I can understand the suffering of being marginalised. Those despised [lepers] were to be cared for by the despised [doctors].

Stigma not only damaged the patients' self-image, but also shaped the self-image of the doctors and their social interactions with both the general medical community and mainstream society. Even in 2016, one can occasionally find the biographical sketches of some well-known leprologists, living or in the past, through internet search engines such as Baidu or Chinese Wikipedia, but one can rarely find the stories behind their careers in public sources as this study has uncovered.

Leprosy in the Reform Era: Declining State Welfare and Returning Christian Organisations

A brief review of changes in leprosy control in the reform era can help us understand the consequences of State aid to patients provided in earlier decades. In 1978, China launched the open-door reform policy that gradually nudged the country towards market-driven development. Since this time, its social security programmes have also gradually, and in some ways radically, moved away from universal coverage (see, also Fisher, Shang and Blaxland, and Frazier and Li's chapters in this Handbook). The nationwide changes in the health sector, for example, were characterised by tasking local governments with providing medical care with drastically reduced resources from the Central government. These changes have created glaring inequalities between regions and people in terms of health, wealth and diseases, a salient feature of China's reform era (Liu 2011). In the field of leprosy control, a similar change can also be observed. Gradually, in the late 1980s and 1990s, leprosy control was nearly abandoned as health offices faced pressure to partially self-fund healthcare, and leprosy doctors nationwide gained the freedom to change jobs. Under these circumstances, the welfare of leprosy patients fell out of official concern. Changes to China's leprosy policy in the 1980s and their impacts on patients and their doctors are discussed below.

1. Post-1980s developments

Early in the reform era, China's market-oriented policies, its internationally recognised achievement of leprosy control and the global developments in the disease's medication regimen jointly engendered a major shift in China's policy on leprosy. In 1987, China adopted the WHO-recommended MDT approach nationally. The combination of drugs was considered successful at preventing drug-resistant mutations, and gradually replaced the earlier single-drug treatment (Noordeen 1991).

The increase in international support and scientific collaborations during this period had several unexpected consequences for China's leprosy control policy. One of the major changes was shifting the focus of leprosy control as a public health campaign, toward an emphasis on medical advancement and laboratory research. As part of its development strategy, China has been eager to reinvigorate its scientific and technological modernization, which was interrupted by the Cultural Revolution (1966–1976); and authorities have enthusiastically sought or welcomed international collaborators to assist them with financing, knowledge and technology in their efforts to combat leprosy in compliance with global trends (Institute of Dermatology 1993: 6).

Chinese scientists and research programmes have been welcomed into the network of global health partnerships, and have also engaged in pharmaceutical experimentations and treatment research. Some leprosy doctors, especially those affiliated to high-ranking institutions with research capacity, participate in collaborative research with international agencies and donors. In so doing, they often receive social recognition, in addition to intellectual rewards and research funding support.

But not all doctors have the same capacity to change their professional status and social image as practitioners of leprosy medicine. This implies that an internal differentiation of leprosy doctors in terms of stigma and self-respect has emerged, whereby many may not be able to shake off the stigma they have internalised since the collective era. The aforementioned words of a doctor – 'Those despised [lepers] were to be cared for by the despised [doctors]' – is one such example. Another leprosy doctor told me in 2009 about how his stigmatised work strongly affected the way his uncle viewed him:

Even today, my uncle still will not allow me to enter his house. My kith and kin in Anhui [Province] also look down on me. Regardless of how hardworking I have been or the promotions I have gained, as I am the superintendent of a leprosarium [in Guangdong Province], they still look down on me!

At the beginning of the interviews, I found that most of the leprosy doctors, especially those stationed below provincial level, were reticent to discuss their past. At least at the outset, they usually responded to my questions by talking about leprosy control success and the suffering of patients, while revealing little substance about their own lives. Some also requested their names remain anonymous in my future writing. By and large, they are low-profile and low-key, an image quite different from the persona of ordinary doctors in China.

As the reform era took off, many leprosy doctors grew frustrated by the market-driven changes and their local work not being incorporated into projects sponsored by international collaboration. Some quit or sought new positions in order to shake off the leprosy stigma of their State-assigned profession or when local governments did not support their

work. As one doctor who was working at a local leprosy village in Sichuan Province told me in 2007:

Everyone in the county knows what we are working on. There is no way to disguise it. Our work is difficult, so many of us quit the job. I am in my 50s, the youngest in the [leprosy] office. There is no successor to continue the work.

The changes to the healthcare system further challenged the morale and work ethic of the remaining leprosy workers, especially those at county level and below. Some revised their work to engage in profitable treatments of STDs and skin diseases other than leprosy – of their own accord or as demanded by their institutes. As various disease-control offices have been incorporated into an umbrella administrative organization – i.e. the Chinese Center for Disease Control and Prevention (China CDC) – leprosy is competing with many other diseases and public health issues for its share of dwindling budgets and official attention.

China's market reforms have also widened the gaps in economic development and health inequality between China's coastal and inland regions. Although the WHO-recommended MDT regimen and international aid helped China's treatment of leprosy, some poor regions in Sichuan, Yunnan, Guizhou, Hunan and Tibet still harbour stubborn pockets of disease resistance (General Office of Ministry of Health of PRC 2011). In the collective era, these regions already had difficulties financing and staffing health personnel to treat the disease. In the reform era, they have experienced decreases in the number of leprosy doctors and have seen limited numbers of new practitioners entering the field. The continued stigma and deepening market reforms have made sustaining leprosy policy in peripheral regions a daunting challenge.

All these changes are part and parcel of the gradual deinstitutionalisation of leprosy control that has taken place since the 1980s; the highlight of which was the termination of committing new patients to the leper colonies. In the wake of adopting the MDT regimen, China's policy became 'treatment in society', which has translated into providing outpatient treatment to new cases. Doctors ask newly identified patients to report to the leprosy control office to receive medication on a regular basis for one to two years, depending on the state of their illness. But patients may not come as regularly as expected, according to informants, mainly because of fear of illness disclosure, living far away from the control office or moving beyond their residential region for work. All in all, this regimen change has turned the government's attention away from leper colonies and changed the control policy.

Still, many leper colonies remain because many cured patients are either badly deformed, disabled or have nowhere else to go. Sometimes new cases among families of patients, or relapses among old patients, occur in these colonies and follow-up treatment has been put at risk because of the lack of doctors and funding. In these isolated, poor colonies, the lives of remaining residents are increasingly difficult because they cannot seek work outside. Their continual marginality stands in sharp contrast to the rest of China, where increased individual economic liberty and mobility has been experienced. Given the deteriorating conditions for the remaining residents, concerned doctors have been calling on the government to provide assistance to the nearly abandoned colonies (Hu 1994).

Another side-effect of China's health reform on leprosy care in the reform era is comparable to the deinstitutionalisation of the mentally ill in the United States in the 1960s; a reform that is widely considered a failed policy. The American deinstitutionalisation highlights a key problem created when the State transferred healthcare of the mentally ill to local and private agencies: the result was increased homelessness that only exacerbated the social stigma of mental illness (Mechanic 1990). In 2010, as I was observing the work in a leprosarium in Shanghai, a senior leprologist there criticised the existing leprosy policy for creating similar problems to the issues raised in the United States:

The [announcement of the] elimination of leprosy was too optimistic. There are still many people infected [with leprosy] in the country and [the 'treatment in society' programme] poses a public health risk . . . It requires attending at least one week for [clinical] examination and diagnostic confirmation. Patients usually go elsewhere [away from home] for diagnosis [to prevent disclosure of their illness] . . . But now [after deinstitutionalisation] who can offer such treatment?

Nearly all the doctors I interviewed pointed to the decline of available care for leprosy patients and the negative impact on disease control efforts. They also all lamented the enduring leprosy stigma that continues to cause challenges for early diagnosis; for treatment and transmission prevention; and for the drastic decline in number and the ageing of remaining leprosy specialists. As the above-mentioned Shanghai leprologist said to me: 'You think of it, I am turning 80 years old and am still working here. If there are others at work, why am I still here?'

2. The return of Christian welfare organisations

In the reform era, the simultaneous forces of socialism and neoliberalism within State welfare policy have caused cracks in the social safety net through which many people have fallen because of changes to the identification of welfare recipients. The remaining leprosy stigma has also prevented mainstream society from being concerned with people affected by the disease, including both treated and untreated patients and their families. In an historical moment, since the 1980s, international non-governmental organisations (INGOs), firstly in the form of religious charity groups, returned to China to help remedy the security chasms of the leper colonies. As far as leprosy is concerned, Casa Ricci Social Services (CRSS) from Macao was one of the first that spearhead aid to disabled patients and leprosy sufferers. Considerable inflow of international aid from similar Christian organizations – and later secular INGOs from Macao, Hong Kong, Taiwan, Japan, the United States and other countries – poured into China in response to the inadequacies identified in leprosy care.

Chinese leprologists have also formed foundations or associations in the name of leprosy prevention and rehabilitation, and received foreign aid to provide treatments such as eye surgery, prosthetics or tailored shoes to disabled leprosy patients. For instance, in 1985, the China Leprosy Welfare Foundation was founded to focus on the rehabilitation of former patients. The term 'welfare' (*fuli* 福利), in relation to leprosy, first emerged when this government affiliated non-government organisation (or GONGO) was established (Nan 1985). Although this foundation was phased out soon after its conception, according to the leprologists I interviewed, it illustrated how the term 'service', as used in

the collective era, was replaced with a common term used internationally in the welfare arena.

The Chinese government has been rather ambivalent about the return of Christian – particularly Catholic – charities for leprosy patients. Given China's hostility toward the Vatican since 1949, local governments faced a predicament when they let Catholic charities take on such care. On the one hand, the local governments welcomed the tangible foreign assistance in dealing with marginal people they could no longer help. The charity groups provided patients with services in the form of monetary subsidies, food, clothes or healthcare. Catholic groups, such as CRSS, also sent local Chinese nuns to care for leprosy patients in the colonies. Local governments monitored the charity groups to prevent religious conversion, although evangelising did indeed take place alongside service provision. Leprosy patients were happy to receive assistance, regardless of who the donors or caretakers were. For instance, in four of the leper colonies I visited in Sichuan and Guangdong Provinces, many discharged patients had left and then returned to live there because they also wanted to receive Catholic aid.

The Catholic aid to leprosy patients is influenced by their religious beliefs and the fear of the State's antagonistic stance on religion. Take a Catholic group working in the most leprous Liangshan region of Sichuan as an example. Under the government's watchful supervision, and motivated by their belief in serving the lepers as idealised sufferers in the Bible, the Catholic service to patients was low profile and sometimes carefully tinged with clandestine proselytising, and hence their work remains mostly invisible to broader society. The effect of this style of aid, both because of its political sensitivity and its religious devotion, keeps patients in the small confines of Christian charity.

All in all, the changes to leprosy control in the reform era have been seen mainly in three related areas: in the transition to a market economy and the related technological advancement; in the government's retrenchment from the universal security of the needy; and in the arrival of international aid and religious organisations caring for people affected by leprosy. In spite of the movement away from China's closed-door policy decades before, leprosy remains stigmatised, and the difficulties of patients and their descendants and caretakers remain largely invisible to the outside world. Stigma, as the legacy of the control programme of the collective era, remains – and continues to influence how the State and subsequent charities and doctors provide support to leper colonies in the reform era.

CONCLUSION

The case of leprosy control in China highlights the importance of preventing and reducing stigma as integrated goals in welfare programme design. How support to people living with leprosy is conceptualised and planned leads to my main argument: sufferers of a highly stigmatised disease indeed need support; but unless their participation in all aspects of welfare is normalised, a future without the stigma of leprosy will remain an elusive goal. This normalisation will entail the elimination of the labelling and exclusion of patients and their caretakers from mainstream society, as well as the decoupling of the leprosy stigma from welfare design.

By many measures, China's leprosy control during the collective era can be defined as a

success. According to my informants and comments compiled from medical publications (e.g.; Institute of Dermatology 1993; Jiang 2006), the Chinese government and senior leprologists involved in leprosy control have attributed this public health success to the unwavering determination of the Party-State and the dedication of its health workers to treating and eradicating leprosy. However, my research also identifies that the stigma endured by patients and doctors beyond the course of the disease pathogen is a crucial yet overlooked factor for evaluating the control programme and practices continuing into the reform era. China's unprecedented leprosy control policy and achievements during its collective era are a telling lesson in this regard. Chinese leprologists in their interviews or writings also remarked on leprosy stigma as a side-effect of China's early segregation policy (Jiang 2006). But they usually brushed aside the same stigma that had shadowed and continues to haunt many doctors and health workers who were involved in leprosy treatment in the collective era. The enduring stigma, alongside dwindling State aid in the reform era, has jointly impacted on the much-needed support to both cured and new patients.

The design and practice of welfare are the outcome of intersecting politico-economic ideologies and State-society relationships. The aforementioned periods of leprosy care in China since the 20th century illustrate that despite various State or religious support to leprosy victims at different political periods, the lives of sufferers have remained mostly invisible to the general public because of China's distinctive welfare style. What made leprosy welfare in the collective era particularly noteworthy was its scale and the stigmatisation that expanded to leprosy doctors. The negative consequences of coercive humanitarianism in leprosy control were thus inevitable; owing to the 'stigmatised selectivity' that played out not only on patients, but also on doctors. It enlightens us as to how welfare and stigma shaped each other interactively: leprosy stigma informs the control policy and its welfare programme reinforces stigma. The leprosy case reveals a complicated trajectory involving welfare stigma.

Although in the collective era China adopted a universal social security programme, preventing the loss of patients' dignity and improving their social integration continued to fall outside the State's concerns, which instead focused mainly on improving the political purity and status of its people. The unspoken effects of this kind of universal welfare on leprosy patients produced a result similar to the common correlation of welfare with stigma in societies that practise residual welfare.

Furthermore, the State's top-down governance and political classification of people according to class limited the role of society in devising alternative routes to supporting leprosy sufferers and to de-stigmatising the disease. As a consequence, even after a century since foreign missionary and charity groups engaged in leprosy relief, and despite the policy changes of the collective era, leprosy care remains outside contemporary China's general healthcare framework. The disease continues to be stigmatised, and thereby continues to prevent society from having an open discussions about and engagement with it.

Although China has achieved the elimination of leprosy according to WHO criteria, the disease is hardly a bygone health problem. Its ongoing prevalence in the southwest remains a major challenge. For instance, new cases found in Yunnan, Sichuan and Guizhou Provinces in 2010 constituted 55 per cent of the total 1,324 new cases around the country (Sun et al. 2012). Easing the mobility restrictions on Chinese citizens under the

reform policy since the 1990s has contributed to an increase in new leprosy cases in big cities. I encountered a few newly diagnosed patients who were migrant workers from the provinces of Hunan, Guizhou and Sichuan, and who were hospitalised in Shanghai and Guangdong Province. They would not return home for treatment for fear of disclosure and senior leprosy doctors in the cities were worried about the costly hospitalisations being billed to their poor patients.

In conclusion, the case of China's leprosy care illustrates the controversy and dilemma of a welfare programme aimed at helping disease sufferers, while overlooking the impact of the disease's stigmatisation on both sufferers and their carers. Marginalisation and uncertainty continue to characterise the future trajectory of leprosy treatment in China. As long as leprosy remains highly stigmatised, patients will worry about the side-effects of disclosure and may delay treatment. If the State or the social support for leprosy cannot be normalised and universalised as part of its welfare and primary healthcare policies, then people affected by the disease may have to remain excluded from the ordinary social world because of the root problems concerning social, biological, political and economic stigma, despite the variety of efforts attempting to help people in dire need.

NOTES

1. At this time, the use of the term (medical) doctor (*yisheng* 医生) refers to all health practitioners with and without full medical degrees, such as the barefoot doctors.
2. Norman Bethune, whose Chinese name was Bai Qiu'en, was a Canadian surgeon who joined the Chinese communists during the Sino-Japanese war in 1937. Zhang Side, a peasant, joined the Chinese Red Army in 1933 and died in a production campaign accident in 1944.
3. Yunnan Yongrenxian ceng shaosha mafengbingren yibaiyishi ming [The killing of 110 leprosy patients with fire in Yongren County, Yunnan Province], *Neibu Cankao*, 13 May 1953, pp. 168–170.
4. This leprosarium has since closed, and all patients were relocated to Sian leprosarium in Guangdong Province in 2011.

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