IMPROVEMENT OF EARLY CASE DETECTION OF LEPROSY IN SICHUAN PROVINCE, P. R. CHINA

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China

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A thesis submitted in partial fulfillment of the requirement for the degree of

Master of Public Health

by

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China

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ABSTRACT

Leprosy has been endemic in China for more than 2000 years. Major changes have taken place in leprosy control situation in the last 40 years. The World Health Organization (WHO) elimination target of leprosy was achieved at national level in 1981 and at provincial level in 1992. Sichuan province has constantly been one of the provinces in China with a relatively high-endemic level of leprosy. In the post-elimination era, the major problem of leprosy control in Sichuan province is the delayed case detection situation with a high proportion of disability among the new cases.

The objective of this thesis is to generate the optimal and feasible strategies to improve early case detection in Sichuan province. Several major study questions are addressed in this thesis: "what factors contribute to delayed case detection?", "how can Geographic Information System (GIS) help early case detection?" and "how to improve early case detection?". In this descriptive exploratory study, several study methods are used, such as literature review, a problem tree analysis, the 3 Delay model of health seeking behaviour, and the techniques of GIS, scan statistic and probability mapping.

There are a number of reasons that contribute to delayed case detection in leprosy. Lack of awareness about leprosy among the public, cultural beliefs, stigma and discrimination, gender inequities and poverty cause delays of health seeking of leprosy patients; loss of interest of the government, misdiagnosis in general health services, an underdeveloped referral system and less active case detection contribute to the delay within the health system; Lastly, geographical barriers and underdeveloped transportation in remote mountainous areas also lead to delay.

Experiences from other provinces of China and other leprosy-endemic countries, literature review and analysis on leprosy case detection methods indicate that application of GIS would provide new opportunities for leprosy control, especially early case detection. Meanwhile, a leprosy GIS database of routine epidemiological data of Sichuan province (2002-2008) was established by use of ArcGIS 9.3 software. Three spatial-temporal clusters of new cases were identified through application of SatScan 8.0 software. A probability map at district level was made to analyze the disability situation in Sichuan province.

In the context of the overall low-endemic situation, with limited resource allocation, the following are likely to be cost-effective and feasible strategies to improve early case detection of leprosy in Sichuan province: political commitment on early case detection, initiation of GIS at provincial level, encouraging voluntary reporting, strengthening contact examination, proper application of "clue survey", short Suspect&Refer training of general health workers, professional training of dermatologists and leprosy health staff, health education of the public through mass media, reinforcing community participation, involvement of people affected by leprosy and promoting integration.

Key words: Leprosy, case detection, Geographic Information System and China.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
BCG	Bacille Calmette Guerin
CDC	The Center of Disease Control and Prevention
CBR	Community-Based Rehabilitation
CDR	Case Detection Rate
CLA	China Leprosy Association
FGD	Focus Group Discussion
GDP	Gross Domestic Product
GIS	Geographic Information System
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
LEC	Leprosy Elimination Campaign
MB	Multi-bacillary
MDT	Multiple Drug Treatment
MMR	Maternal Mortality Rate
MOH	Ministry of Health
NCMC	New Cooperative Medical Scheme
NGO	Non-Governmental Organization
NLR	Netherlands Leprosy Relief
PAL	People Affected by Leprosy
PPP	Purchasing Power Parity
PB	Pauci-bacillary
PHC	Primary Health Care
POD	Prevention of Disability
RVS	Rapid Village Survey
SARS	Severe Acute Respiratory Syndrome
TB	Tuberculosis
UNICEF	The United Nations Children's Fund
WHO	World Health Organization

INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, which mainly affects the peripheral nervous system and the skin, often leading to visible impairments and disabilities. In additional to the physical influence on patients, leprosy also causes social and psychological negative impacts, and it is nearly always accompanied with stigma and discrimination.

Sichuan province has constantly been one of the provinces in China with a relatively high-endemic level of leprosy. After reaching the WHO target[1] of "leprosy elimination" at provincial level in 1992, especially after health sector reforms in 1999, there was loss of interest of the government in leprosy control. In the post-elimination era, the major problem of leprosy control in Sichuan province is the delayed case detection situation with a high proportion of disability[2] among the new cases. A total of 1824 new cases were detected between 2001 and 2008 with an average case detection rate of 0.26/100,000. The average disability proportion was 21.8%, which was much higher than that of other countries. In the context of overall low-endemic situation, with limited resource allocation, the issue of how to improve early case detection has become important in Sichuan province.

GIS is a computer-based mapping system for integration and analysis of geographic data (Cromley & Mclafferty, 2002). Several countries have developed a GIS database for use in their leprosy control programmes, such as Brazil and India. In Brazil, De Souza Dias *et al* (2007) identified that GIS had shown to be effective through providing a clear visual understanding of distribution of leprosy, resulting in targeted interventions and cost reduction in leprosy control, especially in case-finding activities.

I would like to carry out this study to generate the optimal and feasible strategies to improve early case detection of leprosy in Sichuan province. In this thesis, Chapter one introduces the basic information on China and Sichuan province; Chapter two describes problem statement, objectives and methodology; Problem analysis and factors contributing to delayed case diction are explored in Chapter three; Chapter four focuses on a literature review about case detection methods and application of GIS in leprosy control, as well as the description of spatial and temporal distribution of leprosy between 2002 and 2008; How to improve early case detection is discussed in Chapter five; Lastly, conclusions and recommendations are given in Chapter six.

The author works in the Institute of Dermatology and Venereology of Sichuan Medical Science Academy· Sichuan Provincial People's Hospital in China. Since she graduated from the West China Medical Center of Sichuan University, she has participated in management and supervision of leprosy control programmes at provincial level and clinical practice of dermatology. This thesis is the result of learning process at KIT.

[1] The WHO elimination target is defined as reducing the prevalence of leprosy less than 1 case per 10,000 persons.
[2] In this thesis, the proportion of disability refers to the proportion of WHO grade 2 disabilities among new cases.

CHAPTER 1 BACKGROUND INFORMATION

1.1 SITUATION IN CHINA

1.1.1 Geographical, Demographic and Economic

With an area of 9.6 million square kilometer and a coastline of 18,000 kilometers, the People's Republic of China is located in the Southeast Asia. China is the third largest country in the world, just behind Russia and Canada. It ranges from mostly plateaus and mountains in the west to the lower land in the east. The divisions of administrative areas in China include 23 provinces, 5 autonomous regions, 4 municipalities and 2 special administrative regions (Hong Kong and Macau).

With a total population above 1.3 billion, China has the biggest population in the world, accounting for about 20% of the world's population. The national average population density is 137.0 persons per square kilometer. Partially due to the One-Child policy, China is characterized by a large population with a relatively small youth cohort. In 2007, people aged under 15 represented 20.3% of the total population, the annual population growth rate was 6.06‰, and the male/female ratio of total population was 1.06 (National Bureau of Statistic of China, 2008)

The economy of China is the second largest in the world after that of the United States, with a gross domestic product (GDP) of 7.8 trillion in 2008[3]. China has been among the fastest-growing economies. But due to the huge population, the country's per capita income is classified in the lower-middle category by world standards, at about US$5,963 (100th of 180 countries/economies) in 2008 (International Monetary Fund, 2009).

1.1.2 Health status

Since the People's Republic of China was established in 1949, Chinese people's health status has improved significantly (Table 1). Although the health indicators have decreased dramatically, marked difference still exists between the health indicators in urban areas and those in rural areas. In 2000, maternal mortality rate (MMR) in Shanghai was 9.6 per 100,000 live births, while it was 466 and 161 per 100,000 live births in Tibet and Xinjiang autonomous region respectively (UNICEF China, 2008). With regard to disease burden, major infectious diseases such as poliomyelitis, diphtheria, pertussis and measles have been controlled (Wei, 2002). But communicable diseases such as tuberculosis (TB) and leprosy are still an "unfinished business". The top three causes of death in China were cancer, cardiovascular disease and cerebrovascular disease in 2008 (MOH, 2009).

1.1.3 Health system

The health system in China comprises governmental health management sectors, curative sectors, public health/ preventive sectors and research sectors. There is a six-tier structure of

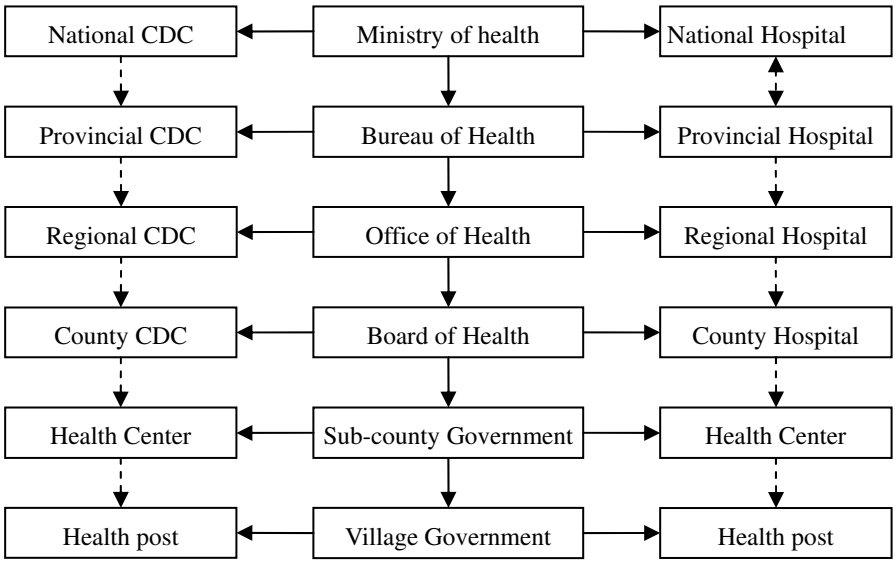
[3] This is measured on purchasing power parity (PPP) basis.

government, health administrative and health care (Figure 1). From county to village level, the health system is the so called “rural three-tier system”.

Table 1: Health indicators of China

Indicators	Rate/figure	Year	Sources
Child under 1 year old immunized (%) BCG	94	2007	UNICEF
Child under 1 year old immunized (%) DPT3	93	2007	UNICEF
Child under 1 year old immunized (%) polio3	94	2007	UNICEF
Child under 1 year old immunized (%) measles	94	2007	UNICEF
Child under 1 year old immunized (%) HepB3	92	2007	UNICEF
Infant mortality rate (per 1000 live births)	20	2006	WHO
Under 5 child mortality rate (per 1000 live births)	24	2006	WHO
Maternal mortality rate (per 100,000 live births)	45	2005	WHO
Life expectancy at birth (year) Male	72	2006	WHO
Life expectancy at birth (year) Female	75	2006	WHO

Figure 1: The structure of the health system of China (Source: The health system and its reforms of P.R. China, Meiwen Yu)



The structure of the health system in P. R. China

The total expenditure on health rose from 3% of GDP in 1978 to 4.5% of GDP, or US$ 342 per capita in 2006, and the general governmental expenditure on health represented 42% of total expenditure on health (WHO, 2006). In 2004, there were a total of 288,000 medical service institutions with 3,251,000 beds in China. Among those institutes, 46.5% were non-profit, owning 95.9 % of total beds. Therefore, non-profit medical service institutions were still the dominant providers in China. There were 2,997 women and children health care institutions and 3,586 Centers of Disease Control and Prevention (CDC). The numbers of registered doctors and nurses per 1,000 citizens were 1.5 and 1.03 respectively (Mao, 2005).

According to results of the third national public health survey in 2003, 20% of rural residents participated in the New Cooperative Medical Scheme (NCMC) or other medical insurance scheme, resulting in 80% without any medical security. In Urban areas, 55.2% of citizens had the basic or other medical insurance scheme, leaving 44.8% citizens without any medical security (Mao, 2005). Since the 1990s, average expenditure on health services has increased. For example, average inpatient expenditure rose from RMB 1,668 (about US$ 238) in 1995, accounting for 106% of the per capita farmer income to RMB 3,911 (about US$ 559) in 2003, or 149% of the per capita farmer income (Mao, 2005). The total health care utilization rate has been falling. The bed occupancy rate of county hospitals decreased from 82.7% in 1985 to 60.8% in 2000 (Liu, 2004).

A series of health reforms has been initiated to make the health system more efficient and accessible. These reforms include reforms on strengthening the rural health service system, improving the health security system and enforcing the public health and disease control. The Ministry of Health (MOH) also formulated the Regulation on Construction of the Disease Control System. After the outbreak of Severe Acute Respiratory Syndrome (SARS) in 2003, the MOH began to pay more attention on public health problems (Mao, 2005).

1.2 SITUATION IN SICHUAN PROVINCE

Sichuan province is located in the southwest of China with an area of 480,000 square kilometer (Annex 1). This province is divided into 18 districts and 3 autonomous prefectures, or 180 counties. The western areas are plateau and mountainous regions, while the basin and hilly land are located in the east. Ninety-three percent of this province is mountainous, with a relatively undeveloped highway system.

In 2007, Sichuan province had a population of 81.3 million, the annual population growth rate was 2.39 ‰, the birth rate and death rate were 9.2‰ and 6.3‰ respectively, and the population density was 172 persons per square kilometer (Sichuan Provincial Bureau of Statistic, 2008). The majority of the province's population is Han Chinese, accounting for 95% of the total population. Significant minorities of Tibetans, Yi, Qiang and Naxi reside in the western areas. Most citizens live in the eastern areas (Annex 2). The GDP per capita in Sichuan province was 15,378 RMB in 2008 (about US$ 2,197), ranked 24 among 31 provinces (National Bureau of Statistic of China, 2008). As one of the western provinces in China, Sichuan province has a relatively underdeveloped economy and complicated geographical circumstances.

CHAPTER 2 PROBLEMS, OBJECTIVES AND METHODOLOGY

2.1 PROBLEM STATEMENT

Leprosy has been endemic in China for over more than 2000 years. Major changes have taken place in leprosy control situation in the last 40 years. After reaching the WHO target of "leprosy elimination" at provincial level in 1992, especially after health sector reforms in 1999, there was loss of interest of the government in leprosy control, especially at the provincial and county levels, which made the leprosy control programme much weaker (Yu, 2003). The leprosy control infrastructure had begun to collapse, and the number of leprosy professional units decreased notably. Meanwhile, a lot of specialists in leprosy control changed their jobs to take charge of other disease control such as HIV/AIDS and TB.

Sichuan province has constantly been one of the provinces in China with a relatively high-endemic level of leprosy. In the post-elimination era, the major problem of leprosy control in Sichuan province is the delayed case detection situation with a high proportion of disability among the new cases. After several decades' efforts of leprosy control, the average disability proportion among new cases had decreased from 46.6% in 1950s to 21.8% in a period of 2001 to 2008. But it was still much higher than that of other countries. For example, in 2008, the disability proportions reported in Nepal and Myanmar were 2.1% and 13.1% respectively (WHO, 2008). Meanwhile, the delay period between onset of symptoms and confirmed diagnosis of leprosy cases was long. During a period of 2002 to 2006, the average delay between onset of first symptom and diagnosis was 3.2 years, 49.5% of new cases were detected after a delay of more than 2 years since the symptoms occurred (Jin, 2007). Due to lack of an effective vaccine, early case detection of leprosy is very important for leprosy control, which contributes to prevention of disabilities and further reduction of the leprosy burden. Therefore, it is urgent to identify the optimal strategies to improve early case detection of leprosy in Sichuan province, taking feasibility and cost-effectiveness into consideration.

Therefore, I would like to carry out this study to find the optimal and feasible strategies to improve early case detection. In particular, I will explore how GIS might facilitate leprosy control, especially early case detection in Sichuan province.

2.2 OBJECTIVES

2.2.1 General objective

- To generate the optimal and feasible strategies to improve early case detection of leprosy in Sichuan province, for the purpose of further reducing the leprosy burden.

2.2.2 Specific objective

- To identify the problems and factors contributing to delayed case detection.
- To explore the application of GIS in leprosy control.
- To develop suitable strategies for improving early case detection of leprosy in Sichuan

province.
- To use findings for recommendations

2.3 STUDY QUESTIONS

- What is the current situation regarding leprosy case detection in Sichuan province?
- What are the factors contributing to delayed case detection?
- How can GIS help in improving leprosy case detection?
- What strategies would be the most effective to improve early case detection of leprosy in Sichuan province?

2.4 METHODOLOGY

2.4.1 Study design

Descriptive exploratory study

2.4.2 Study methods

- Annual leprosy reports and available epidemiological data are used to describe the leprosy endemic situation in Sichuan province.
- The 3 Delay model of health seeking behaviour, a problem tree analysis and literature review are used to identify factors contributing to delayed case detection of leprosy.
- Reviewing the literature published in the international and national journals and publications of WHO, I explore the application of GIS in leprosy control in relation to early case detection and leprosy case detection methods in other provinces of China and other countries. Internet search for literature include Pub-med, Google, WHO, Leprosy Review website. Key words include leprosy, case detection, delay, GIS, health seeking behaviour, stigma, elimination, training, heath education, integration, community participation.
- The leprosy GIS database of routine epidemiological data of Sichuan province (2002-2008) is established by use of GIS technology (ArcGIS 9.3). Meanwhile, the SaTScan programme (version 8.0) is performed to analyze the spatial-temporal clusters of new cases detected between 2002 and 2008. A technique of probability mapping is used to analyze the disability situation at district level.
- According to my personal experiences in leprosy control programmes and research, linked with literature review and the knowledge and skills I learned during the course, I formulate the strategies and recommendations for improving early case detection of leprosy in Sichuan province.

2.5 LIMITATION OF THE STUDY

This study is conducted in Amsterdam. Some research tools such as Focus Group Discussion (FGD), interview and observation could not be used, as it is impossible to go back to China to collect data or do some field research. Regarding the GIS database, the routine epidemiological data which I have is aggregated data at county level, not at individual level.

CHAPTER 3 PROBLEM ANALYSIS AND ITS CONTRIBUTING FACTORS

3.1 LEPROSY AND ITS SITUATION

3.1.1 Leprosy

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. The incubation period for the disease is about 2 to 20 years. Leprosy mainly affects the peripheral nervous system and the skin, resulting in deformity and disability. It is transmitted via droplets from the nose and mouth of infectious untreated patients, but it is not highly infectious. Most people have natural immunity to leprosy and only a few people develop the disease (Britton & Lockhood, 2004).

The diagnosis of leprosy is commonly based on the clinical signs and symptoms. Current chemotherapy of leprosy, namely MDT, comprises Rifampicin, Clofazimine and Dapsone. It has been recommended since 1982, and it is the cornerstone of the leprosy elimination strategy. Disability in leprosy can be distinguished into primary and secondary impairment. The simplest grading of impairments is the three-grade system suggested by the Sixth WHO Expert Committee on Leprosy in 1998 (Table 2)

Table 2: WHO grading of impairments

Grade	Manifestation
Grade 0	normal sensation, no visible impairment
Grade 1	impaired sensation, no visible impairment (like anesthesia)
Grade 2	visible impairment/ deformity (like bone absorption or ulcers)

3.1.2 Global situation

Leprosy is considered one of the special public health problems in the world, due to the permanent disability and deformity it causes, leading to stigma and discrimination. Nowadays, leprosy is no longer an incurable disease thanks to the development of treatment. The elimination target, defined as reducing the global prevalence of leprosy less than 1 case per 10,000 persons by the Forty-fourth World Health Assembly in 1991, was achieved in 2000 globally (Richardus & Habbema, 2007). A study on the trend of new case detection between 1985 and 2000 showed that there was no general decline in case detection at global level up to 2000, even though the prevalence of leprosy decreased significantly (Habbema, 2004).

According to the epidemiological records of global leprosy situation (WHO, 2008), the number of annual new cases (excluding the small number of cases in Europe) declined gradually from 763,262 in 2001 to 254,525 in 2007. At the beginning of 2008, the global registered prevalence of leprosy stood at 212,802 cases. Only three countries, namely Brazil, Nepal and Timor-Leste had not yet achieved the elimination goal. Wide diversities were found among the countries in terms of the proportion of new cases who were MB, children, females and who had grade 2 disabilities. Despite the enormous success achieved, future projections of the global leprosy burden estimated that at least 5 million new cases would arise between 2000 and 2020. There would be about 1 million people with grade 2 disabilities by the 2020 (Richardus & Habbema, 2007).

3.1.3 Situation in China

- **Leprosy control in China**

The leprosy control programme was initiated by the MOH when the People's Republic of China was established in 1949. China achieved the WHO elimination target of leprosy at country level in 1981 and at provincial level in 1992. Since then China has been endeavouring to achieve this target at county level (Shen *et al*, 2005). By the end of 2008, there were 48 counties with a prevalence rate more than 1/10,000. The structure of leprosy control system in China is showed in Annex 3. Reviewing the historical process of leprosy control, the procedure of leprosy control can be roughly divided into three phases:

(1) Basic control phase (1949-1981):
With the lead of the MOH, a series of policies regarding leprosy control were formulated, and a vertical leprosy control system was established. Large numbers of leprosy patients were detected and treated by Dapsone within the isolated leprosy villages in remote mountainous areas.

(2) Elimination phase (1982-2000):
The national target of eliminating leprosy at the end of the 20th century was declared by the MOH in 1982, defined as reducing the prevalence rate to less than 1/10,000 at county level. 95% of counties had reached this target by the end of 2000. MDT was first introduced in China in 1983 and then expanded all over China in 1986. 98% of patients were treated with MDT by the end of 2000.

(3) Current phase (from 2000 to now)
In the post-elimination era, there are still several major challenges lying ahead. Firstly, early case detection is problematic in China, especially in Southwest China. In the last 10 years, about 1600 new cases were detected annually, with more than 50% being reported from China's south-western provinces like Yunnan, Guizhou and Sichuan. In those areas, early case detection was relatively difficult due to inaccessible health services, geographical barriers and language barriers with minorities living there (Shen *et al*, 2005). Secondly, China still has an estimated 210,000 cured living persons affected by leprosy, among whom 100,000 have various disabilities. They need sustainable prevention of disability (POD) and rehabilitation services (Shen *et al*, 2007). Last but not least, the government's interest has transferred to other priority diseases, due to the achievement of the "elimination target" of leprosy. With the relatively scarce government commitment, it is a big challenge to make leprosy services sustainable without sacrificing the quality.

- **Leprosy case detection in China**

With the massive implementation of MDT in China in the 1980s, an evolution in the modes of leprosy case detection has happened gradually. A national study on the modes of case detection between 1981 and 1998 found an increasing trend in percentage of cases detected through dermatological clinics[4] and contact examination[5], while the percentage detected

[4] This refers to people with skins lesions seek health care in dermatological clinics, having not considered themselves as leprosy patients.
[5] Contact examination refers to routine examination of leprosy contacts, mainly household contacts.

through "clue survey"[6] and mass survey[7] decreased (Chen *et al*, 2001). It has already been shown that systematic population surveys are unsuitable for the present situation owing to the poor cost-effectiveness and large time investment. Passive case detection through voluntary reporting[8] and dermatological clinics has played an increasingly important role in leprosy case detection.

3.1.4 Situation in Sichuan province

- **Leprosy control in Sichuan province**

Sichuan province has constantly been one of the provinces with a relatively high-endemic level of leprosy. The leprosy cases were mainly detected in mountainous areas along the edge of the province and in minority regions, like Liangshan and Garze prefecture. By the end of 2008, there were a total of 14,780 cured people affected by leprosy, and among them, 6950 had grade 2 disabilities. There were 1138 registered cases[9] by the end of 2008. The trends of case detection rate (per 100,000 persons), prevalence rate (per 10,000 persons) and disability proportion among new cases during the last six decades are showed in Figure 2, 3 and 4.

Figure 2: Average case detection rate of leprosy, Sichuan province (1951-2008)

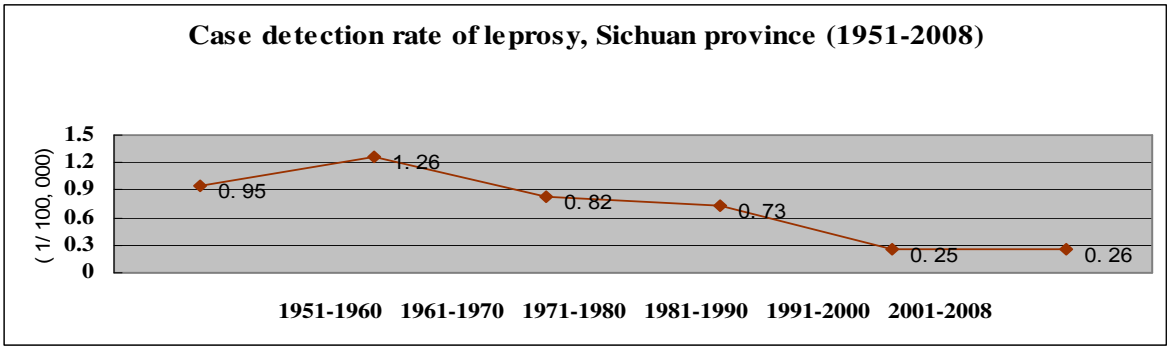
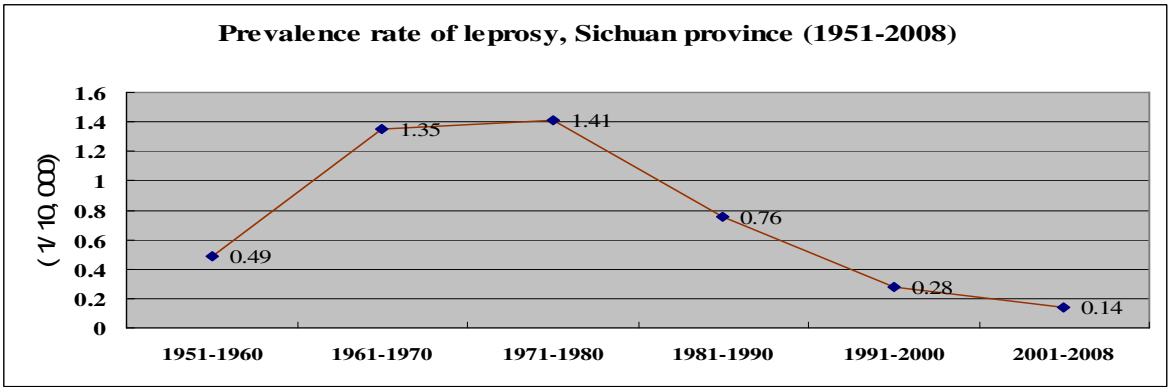
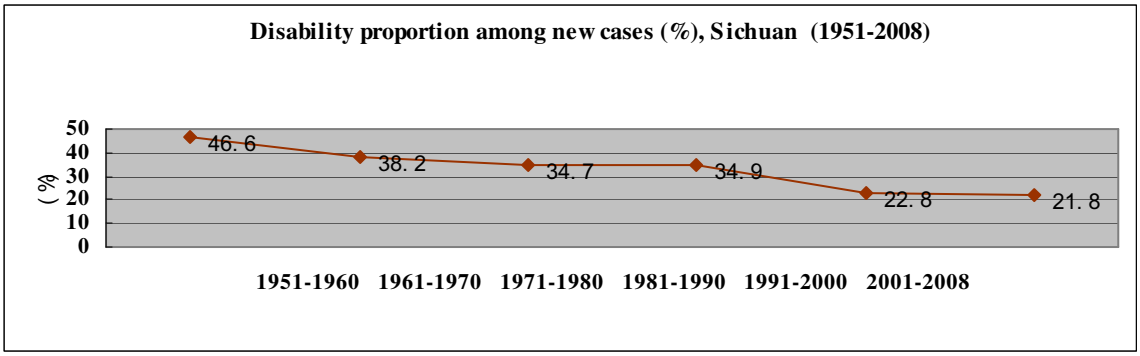


Figure 3: Average prevalence rate of leprosy, Sichuan province (1951-2008)



[6] "Clue survey" is defined as group examination based on specific clues of leprosy and organized by professional institutions of leprosy control.
[7] Mass survey refers to systematic population survey or specific population survey, e.g. school survey.
[8] Voluntary reporting refers to that patients report himself/herself to medical facilities due to suspected leprosy symptoms.
[9] In China, registered cases include both leprosy patients who are under MDT treatment and those who have finished MDT but still have a positive skin smear.

Figure 4: Average disability proportion among new cases, Sichuan province (1951-2008)



- **Leprosy case detection in Sichuan province**

Reviewing case detection methods and strategies in Sichuan province since 1949, four specific periods are distinguished in the historical procedure of leprosy control.

(1) 1949-1982

All patients were diagnosed and treated by an isolation strategy of leprosy control. During that period, most cases were detected through mass survey and "clue survey", and most of new cases had a long delay before detection and severe disabilities.

(2) 1982-1984

The leprosy control strategy was changed from the isolation treatment to the out-patient treatment. The mass epidemiological survey was implemented all over Sichuan province. Many hidden backlog cases were detected during these 3 years.

(3) 1985-1999

Many case detection activities were performed during this period. Meanwhile, MDT was implemented extensively. More and more leprosy cases were detected through voluntary reporting and dermatological clinics. Mass survey and "clue survey" were also applied widely. In 1999, several Leprosy Elimination Campaigns (LECs) were implemented in relatively high-endemic counties in Liangshan prefecture.

(4) 2000 to now

The active case detection methods did not play a main role in leprosy case detection any more. Methods of passive case detection were increasingly used. The intensity of leprosy case detection decreased to some extent and fewer leprosy cases were found.

3. 2 THE MAJOR PROBLEM AND THE 3 DELAY MODEL

3.2.1 The major problem

Through analyzing all newly detected cases from 1951 to 2008, it is found that the situation of delayed case detection of leprosy is serious in Sichuan province. Furthermore, in the post-elimination era, the major problem of leprosy control in Sichuan province is the delayed case detection situation with a high proportion of disability among new cases.

- **High disability proportion among new cases**

After six decades' efforts of leprosy control in Sichuan province, the leprosy disability proportion among new cases had decreased gradually. The average disability proportion among new cases was 46.6% in the 1950s. During a period of 2001 to 2008, a total of 1824 new cases were detected with an average case detection rate of 0.26/100,000, 21.8% of them had grade 2 disabilities. This disability proportion was still much higher than that of other countries. For example, in 2008, the disability proportions reported in Nepal and Myanmar were 2.1% and 13.1% respectively (WHO, 2008). The disability proportion among new cases has been considered as a rough indicator of the quality of case detection activities. The high disability proportion may indicate that the leprosy cases are not detected as early as would be desirable. Alternatively, people in some countries appear to have a much higher risk of developing disabilities, which may also contribute to this high proportion.

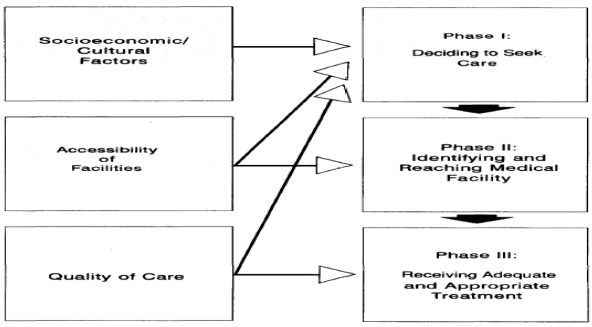
- **Long delay in case detection**

Through the analysis of the delay period of new cases detected from 1951 to 2000, it was found that the delay period between onset of symptoms and confirmed diagnosis was shortening gradually. The longest average delay of case detection was 5.1 years in the 1950s, compared to 3.1 years in the 1990s (Wu *et al*, 2000). But during a period of 2002 to 2006, the average delay between onset of first symptom and diagnosis was 3.2 years. 49.5% of new cases were detected after a delay of more than 2 years since the symptoms occurred. The average delay in detection of disabled cases (WHO grade 2) was 4.5 years, compared to 2.7 years of those who had grade 1 or no disabilities. There was a significant difference between the two groups, which showed that, if cases were detected much later, they were more likely to have disabilities (Jin, 2007).

3.2.2 The 3 Delay model

There are various studies on the delay of presentation, diagnosis and treatment of leprosy patients, exploring diverse factors contributing to the delay. Models of health seeking behaviour are applied to investigate the individual's or population's interaction with the health system: studying factors that enable people or prevent them from making "healthy choices" in either their lifestyle behaviour or their use of health care. **The 3 Delay model** proposed by Thaddeus Maine is an operational model used to identify the reasons for the delay in the context of emergency maternal issues (Figure 5).

Figure 5: The 3 Delay model (Source: Too far to walk: Maternal mortality in context: Soc. Sci. Med. Vol. 38. No. 8, 1091-1110, 1994)



To some extent, the delayed case detection of leprosy has similarities to the delay of emergency maternal issues. The delayed case detection of leprosy is linked to severe impairments and disabilities of patients, resulting in numerous negative impacts on individuals, communities and societies. The reasons for the delay also can be roughly classified into three categories, namely reasons from the leprosy patients' side related to health seeking behaviour, reasons from the health providers' side related to quality of case detection and accessibility of health facilities. Due to the chronic characteristic of leprosy, the delay due to accessibility of health facilities is not as important as that in emergency maternal issues, but it is still a main reason which can cause a delay.

According to the 3 Delay model, an adjusted framework concerning leprosy case detection is made (Annex 4). I simply explain the factors contributing to the delayed case detection through a problem tree (Annex 5), and I further elaborate on these factors in detail subsequently.

3.3 CONTRIBUTING FACTORS

3.3.1 Health seeking behaviour of leprosy patients

- **Patients' awareness and beliefs about leprosy**

Owing to the fact that early signs and symptoms of leprosy are not easy to perceive, leprosy patients can not become aware of the disease at the early stage. One qualitative study in Bangladesh and India found that the most important contributor to the delay in action to seek health care was ignorance of the early symptoms of leprosy (Nicholls, 2005). In Nepal, Heijnders (2004) found that most of leprosy patients did not regard their symptoms as severe and thought that symptoms would disappear naturally or thought it was another common disease like rheumatism.

Cultural beliefs about leprosy vary in different countries and in different religions. These beliefs attributed leprosy to punishment for sins, immoral sex with prostitutes, evil spirits, God's will, food and water, being hereditary and natural environment (Wong *et al*, 2002). These cultural beliefs and misconceptions about causes and transmission of leprosy have an influence on individuals, communities and societies. Furthermore, decisions to seeking health care are not only made by leprosy patients, but are also influenced by families, friends and community leaders, which might cause a delay in seeking health care or lead to choose traditional healers that might worsen the delay in diagnosis. In northern Nigeria, Van de Weg *et al* (1998) found that consultation with folk healers was a major reason for the delay. Most leprosy patients visited folk healers, who never referred them to the leprosy services.

In Sichuan province, many leprosy cases are detected in remote mountainous areas, where education and communication are underdeveloped, and knowledge concerning leprosy among the public is quite deficient. Meanwhile, being members of ethnic groups, people have various cultural beliefs about leprosy, leading to a delay in seeking health care or seeking care from traditional healers. Some people prefer to consult doctors of Traditional Chinese Medicine rather than to choose western medical services, especially old people and women, which also contributes to a delay to some extent.

- **Stigma and discrimination**

Leprosy has been associated with stigma and social exclusion throughout history and around the world (Arole *et al*, 2002). Leprosy not only affects patients physically, but also results in social and psychological negative consequences, caused by stigma and discrimination (Rafferty, 2005). Patients worry more about the disabling consequences of leprosy, such as unemployment, divorce, economical independence and social isolation, than about the infection itself. The stigma and discrimination against leprosy is linked to disabilities of leprosy patients that are visible in the community, but is also partly due to cultural beliefs and misconceptions about causes and transmission of leprosy.

Stigma and discrimination against leprosy has been found to be a major factor contributing to the delay in patients' health seeking behavior in many countries. In Ethiopia, the high level of stigma was identified to be associated with a high disability proportion and greater delay in health seeking behavior and starting treatment (Bekri *et al*, 1998). With the serious and constant stigma from communities, sometimes even also from families and relatives, patients might be driven into self-stigma and be more isolated from the society. These could be serious barriers to health seeking. Even active case detection activities may be affected, for example, the leprosy-affected persons who do not want to be exposed might never seek health services actively and even escape a leprosy survey to keep their condition a secret.

In Sichuan province, stigma and discrimination always accompanies leprosy patients and their families, even whole communities. Due to the isolation policy for leprosy in the 1950s, many leprosy colonies were built in remote mountainous areas. Despite the implementation of the out-patient treatment of MDT in the 1980s, most cured disabled former patients still like to live in these colonies due to the stigma and exclusion of societies. In the relatively high-endemic, mostly mountainous areas that are less developed, stigma and discrimination are more serious than in urban areas. Severe negative consequences of stigma still occur occasionally in those areas, for example, leprosy patients are abandoned or even killed by family members.

- **Socio-economic factors**

The perceived and actual social and economic cost of being diagnosed and involved in treatment is another important factor that affects decisions to seeking care, especially for the low-income population (Butlin, 2000). This is included in the group of barriers for early case detection of leprosy mentioned by WHO in the Operational Guidelines of the Global Strategy for Leprosy from 2006 to 2010, which includes gender, ethnic group and poverty. These require specific approaches, for instance, advocacy for supportive legislation and services, and general poverty alleviation (WHO, 2005).

In China, Zhen (2000) found that the biggest barrier of utilization of health services by leprosy patients was poverty, followed by stigma and discrimination. In Sichuan province, the majority of patients are farmers living with low incomes that are not enough to supply their livelihood. In addition, owing to the underdeveloped health insurance system in China, most leprosy patients have to pay for health care out of pocket. Therefore, they always decide to seek health care only when they have severe symptoms, such as impairments and disabilities.

- **Gender**

Gender inequity in health has a cardinal impact on women's health. As leprosy is a highly stigmatized disease, gender inequities concerning leprosy may be even more serious than in other diseases (Le Grand, 1997). One study conducted in India found that the social impact was more severe for women affected by leprosy than men in terms of isolation from daily life activities (Rao *et al*, 1996). In Nepal, Rajendra Kumar *et al* (2004) found a significant association between the leprosy treatment completion status and gender, showing that more women did not finish MDT than men.

In Sichuan province, gender inequities of leprosy are more serious in the rural, mountainous areas, especially among the ethnic groups. Due to the poverty, the relatively low education level and cultural beliefs in those areas, female leprosy patients are more likely to delay seeking health care, resulting in severe disabilities. Within the ethnic families, the social status of children and men is much higher than that of women. Women always have to ask permissions and money from husbands before seeking health care. On the other hand, female leprosy patients always receive more serious stigma and discrimination than male, resulting in severe consequences, such as being abandoned or committing suicide.

3.3.2 Health services related factors from the providers' side

- **Policy related factors**

After the WHO elimination target was achieved in China, the government's interest shifted to HIV/AIDS and TB issues gradually, leading to a sharp decrease in interest of the government regarding leprosy control. Meanwhile, maintaining the vertical system of leprosy control became lack of cost-effectiveness owing to the considerable reduction in overall workload (Wei, 2002). The leprosy control programme has not been a priority of the MOH any more. Since 2001, a health system reform has been implemented throughout China, which required all the units responsible for public health problems at or above county level to be merged into the CDC. This caused a notable decrease of leprosy professional health services. Meanwhile, a lot of specialists in leprosy control changed to take charge of other disease control programmes, resulting in considerable deficiency in human resources (Shen *et al*, 2007). With loss of interest of the government and limited resource allocation, the leprosy control programmes decreased significantly, including case detection activities.

- **Case detection activities**

In a national survey in China, 27,928 cases of leprosy detected between 1984 and 1998 were explored (Chen *et al*, 2000a). The results showed that leprosy cases had a 22-month median delay period between onset of symptoms and confirmed diagnosis. The delay was greatest in areas where leprosy was endemic and/or where the health services were inaccessible, such as Yunnan, Guizhou and Sichuan province. With regard to the delay in different modes of detection, it was interesting to find that cases detected through dermatological clinics and "clue survey" had a significantly shorter delay period than cases detected in other ways.

In a survey of new cases detected between 2002 and 2006 in Sichuan province (Jin, 2007), about 22.7% of new cases were reported voluntarily, 16.4% were reported by others (families, friends or community members), and 26.8% were detected by dermatologists, which made up the total of 65.9% for passive case detection. 5.9% of new cases were detected through contact examination and 23.6% through "clue survey". Other active methods included mass survey and census. The active case detection had not played a main role in case detection, which just accounted for 30.9% of case detection. The information of modes of detection of the odd 3.2% of new cases was not given. Fewer priorities to active case finding might cause a delay of case detection to some extent, when the awareness concerning leprosy among general population is not sufficient in Sichuan province.

- **Diagnosis of leprosy and referral system**

One study in the United Kingdom showed that, due to the low-endemic situation of leprosy, the awareness of health staff in the primary health services and general hospitals regarding leprosy was deficient. Misdiagnosis was proved a main reason for the delay and the delay in referral from general practitioners to dermatologists was also identified (Lockhood & Reid, 2001). Sun *et al* (1991) reported that among a group of 335 new cases in China, 70% were misdiagnosed on their first visit to general health services. Another analysis of 50 new cases with disabilities found that the main reason for the delay was insufficient leprosy knowledge and experiences of general health workers (Ma, 1990). In Shandong province, Chen *et al* (2004a) found that only 43.7% of doctors who worked in general hospitals knew where and how to refer the suspected leprosy patients. In Sichuan province, many leprosy patients with a long period of delay can be found in dermatological clinics, most of them have visited several health facilities at different levels. This situation demonstrates that the knowledge of general health workers is deficient to detect and diagnose leprosy patients. The effective referral system has not been established.

3.3.3 Inaccessibility of health facilities

The delay can also happen due to a long distance between the location of health facilities and the place of patients' residence, high cost of transportation, inconvenient transportation and clinic schedules. Butlin (2000) found that living in a rural area was a significant indicator for the delay, and travel time had a very significant relationship with delayed presentation in Nepal. In Bangladesh and India, Nicholls *et al* (2005) found that the attendance in the nearest clinic was associated with reduced delay, suggesting that the integrated services were effective in reducing the delay. In China, Chen *et al* (2000a) found that cases in low-endemic areas were detected earlier than in high-endemic areas. It was explained that most of high-endemic areas were less developed, poorer and with less accessibility of health care than low-endemic areas. In Sichuan province, most leprosy patients live in the mountainous areas with poor accessibility of health services and complicated geographic circumstances. For them, the cost of seeking health care not only includes the cost of health care itself, but also that of transportation. Due to these reasons, it is very difficult for them to seek health care promptly. Meanwhile, the active case detection activities are also hindered due to geographical barriers.

CHAPTER 4 CASE DETECTION MODES AND APPLICATION OF GIS IN LEPROSY CONTROL

4.1 CASE DETECTION MODES

There are two modes of case detection: passive and active. According to the Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (WHO, 2005), active case detection is no longer recommended, except in certain areas where the health services are inaccessible. The passive modes of case detection, such as voluntary reporting, are recommended in all other areas. In fact, most endemic countries adopt a case detection strategy of combining both modes.

4.1.1 Modes of active case detection

Active case detection refers to cases of leprosy being found or detected by the health staff actively. It includes population surveys, such as mass survey, Rapid Village Survey (RVS) and Leprosy Elimination Campaign (LEC); surveys of special groups, such as school survey and contact survey. The advantage of active case detection is that cases are detected earlier than with passive case detection, resulting in fewer disabilities. The sacrifice is reduced cost-effectiveness, which manifests in being time-consuming and requiring massive human resources. Another issue about active case detection is over-diagnosis of self-healing cases, but it is better to diagnose and treat some self-healing cases than have some patients become disabled (Tiendrebeogo *et al*, 1999).

- **Rapid Village Survey**

RVS can be used to estimate the magnitude of the leprosy problem in relatively low-endemic areas. This is a valid, simple and more cost-effective method compared to the mass survey. RVS is based on health education campaigns in certain areas, after that, the population who report voluntarily or those who are referred by the communities with skin problems or disabilities will be examined. In Thailand, Pinitsoontorn *et al* (1996) argued that the RVS was a valid replacement of the total population survey. It can be applied under low-endemic condition and can be carried out by general health workers.

RVS is also called a “clue survey” in China, and has played an important role in leprosy case detection. During the survey, people with any signs of leprosy, such as claw hands, foot ulcers and anaesthetic skin lesions, are asked to report to the survey teams voluntarily or are reported by key informants, such as village doctors, religion leaders and teachers. The survey teams offer free consultation and diagnosis for the people suspected of having leprosy. Meanwhile, leprosy families will be visited for contact examination and checking cured leprosy cases for relapse. In Shandong province, around 80% of cases were detected by RVS between 1955 and 1994 (Wang *et al*, 2007).

- **Leprosy Elimination Campaign**

LECs, as advocated by the WHO, have become an important strategy in implementing intensive case-finding and improving MDT coverage (Shen *et al*, 2004). The objective of

LEC is to detect new cases and 'mop up' hidden backlog cases in communities, to increase the awareness among the general population, and to mobilize and train rural paramedical workers. School surveys can be included in LECs in relatively high-endemic areas (Schreuder *et al*, 2002). A retrospective cohort study was conducted to compare the cases detected through LECs with those reported voluntarily in Mozambique. The result revealed that the LEC was a useful addition to the passive case detection through reporting voluntarily and has a lasting impact on case detection (Phaff *et al*, 2003). The Modified LEC was proved to be one of the most successful health interventions undertaken in India, characterized by extensive house-to-house screening for a short period of 6 days to detect suspect leprosy cases by general health workers and volunteers (Dharmshaktu *et al*, 1999).

In China, a LEC includes a mass health education campaign, the collection of clues from key informants and examination of leprosy suspects by mobile medical teams. Shen *et al* (2004) argued that although the number of new cases detected during the year in which LECs were conducted was significantly higher than previously, carrying out LECs was unlikely to have a significant impact on the trend of case finding within a short time in local areas, but it may improve leprosy control in local areas due to improved awareness of the public, active community participation and mobilized health staff.

- **Mass survey**

Systematic population surveys can be performed by professional leprosy workers and dermatologists through screening the skin, checking the nerves and examining physical condition of suspect leprosy patients. The targeted population are all residents in the particular regions. It is usually time-consuming, expensive and labor intensive. In Nepal, Theuvenet *et al* (1994) found the cost of detecting one new case through mass surveys was US$ 298. Mass survey was used in the early stage of leprosy control in China. It contributed to the detection of most leprosy cases at that time, especial the backlog of patients. However, with the present low-endemic situation in China, mass survey is not cost-effective any more, but it still has its place in prevalence surveys (Chen *et al*, 2001).

- **Contact examination**

Because the distribution of leprosy tends to follow a cluster pattern, contact examination has been accepted as one of important methods in leprosy case detection. In Brazil, the strategy for leprosy control is based on early case detection and treatment with MDT. Tracing of household contacts is the third measure recommended by the MOH (Cunha *et al*, 2004). Contact with leprosy patients is a major determinant of incidence of leprosy. This includes household, neighbour and social contacts. Social contacts include relatives, close friends, colleagues and business partners. One study indicated that not only household contacts, but also neighbours and social contacts had an increased risk of developing leprosy. The challenge for the contact examination is to determine which contact level needs to be surveyed in order to interrupt the transmission of leprosy in the population (Bakker, 2005). In Indonesia, Van Beers *et al* (1999) suggested enlarging the scale of contact screening not only for household contacts, but also for the neighbours of the leprosy cases.

Leprosy case detection through surveying household contacts is a routine method in China.

The latest national study on the value of household contact survey argued that household survey was still a useful method for case detection in an overall low-endemic situation. Furthermore, in the relatively high-endemic areas in Southwest China, the active household contact survey was a main case finding method, 36.1% of all cases were detected through this method (Shen *et al*, 2009). Chen *et al* (2000b) explored 1208 child cases detected from 1986 to 1997 in China. A total of 70% of those child cases had a history of household contact, 35.6% of them were detected through contact examination. The author emphasized the importance of household tracing, especially for screening children in leprosy-affected households.

- **School survey**

The school survey is an effective and efficient method of case detection of leprosy in high-endemic areas (Norman *et al*, 2004). The school survey requires leprosy survey teams to visit targeted schools. All children are to be checked by trained leprosy workers and cases detected or suspected are referred to professional leprosy facilities for confirmation. India used to conduct annual school surveys, because one-third of the population are school children. As a result, almost 20% of new cases were detected among schoolchildren (Norman *et al*, 2004). The advantages of school surveys are not only screening the children, who are susceptible to leprosy, but also enhancing the community awareness about leprosy through diverse categories of society, such as teachers, schoolchildren and their families, village leaders and community members. On the other hand, the disadvantages are that such surveys are time-consuming and labour intensive. Nowadays, because leprosy has become low-endemic in most countries, school surveys are no longer considered to be cost-effective unless they are part of a general school health programme.

4.1.2 Modes of passive case detection

Passive case detection refers to cases reported voluntarily or referred by others. It is based on the adequate public awareness of leprosy (Chen *et al*, 2001). The main passive case detection methods are voluntary reporting and notification through dermatology clinics and general health services. They are applied as the routine case detection methods in most leprosy-endemic countries. Integration of leprosy control into comprehensive health services is a strategy to improve passive case detection, which requires fundamental training of general health staff, intensive health education campaigns among the public, an efficient referral system and supervision (Tiendrebeogo *et al*, 1999).

- **Voluntary reporting**

Largely, efforts to improve early case detection through passive methods are focused on facilitating self-referral by people affected by leprosy, namely reporting voluntarily. It is crucial to increase the awareness of early signs and symptoms among the public, together with efforts to remove the barriers, which prevent people reporting for examination, such as fear and stigma. The case detection in the integrated system of leprosy control is mainly based on voluntary reporting of cases. In Sri Lanka, leprosy services have been integrated

into the general health services since 2000, and leprosy case detection mainly consists of voluntary reporting and notification through the general hospitals and dermatological clinics (Wijesinghe & Setinayake, 2005). Health education of the public is very crucial for voluntary reporting. Four key messages recommended by WHO should be provided to the public, including leprosy being a curable disease, early signs of leprosy, no need to be feared and need of support from families and communities (WHO, 2005).

- **Notification through dermatological clinics and general health services**

WHO Operational Guidelines for Leprosy Control from 2006 to 2010 mentions that effective leprosy control requires an integrated approach. This implies that leprosy control activities should be implemented by general health services, including integrated referral facilities (WHO, 2005). In Thailand, the major decline in cases was attributed to the integration of leprosy control into general health care system since 1971, despite little priority being given to active case-finding activities (WHO, 2007). In Brazil, although general health workers have taken over leprosy control, dermatologists are still involved in diagnosis and treatment of leprosy patients, and training of specialists and internal medicine physicians (Penna & Telhari, 2007). In China, detection of cases through dermatological clinics and voluntary reporting has become the main modes of case-finding gradually (Chen *et al*, 2001). Notification by dermatologists might be the most cost-effective way of case detection in China (Chen *et al*, 2000a).

4.2 APPLICATION AND BARRIERS OF GIS IN LEPROSY CONTROL

GIS is a computer-based mapping system for integration and analysis of geographic data (Cromley & Mclafferty, 2002). GIS provides an excellent means of data input and management, including storage and retrieval, data manipulation, analysis and display of geo-referenced data. It has been applied in research in various sectors, such as ecology, forestry, archaeology and epidemiology (Tanser & Le Sueur, 2002). In Public Health, GIS can be used to analyze the epidemiological data, reveal trends, clustering of cases and interrelationships between factors that would remain hidden in data shown only in a tabular format. GIS has been applied in prevention and control of several public health problems, such as malaria, tuberculosis, HIV/AIDS, dengue and leprosy.

4.2.1 Application of GIS in leprosy control

The GIS has been seen as a valuable management tool in the leprosy elimination programme. It can be applied to provide graphical analysis of epidemiological indicators over time and spatial distribution of leprosy, identify high-endemic areas, and indicate priorities for resource allocation (Br, 2009). Several countries have developed a GIS database for use in their leprosy and tuberculosis control programs, such as Brazil and India. An increasing number of articles have been published related to the application of GIS in leprosy control, mainly with regard to three aspects, shown below:

- **Epidemiological surveillance**

Epidemiological data can be visualized through the mapping technology of the GIS software, which allows us to get an integrated view involving time, space and indicators of the occurrence of infectious disease. GIS maps convey information at a glance. For a GIS surveillance system regarding leprosy, data of the common indicators such as prevalence rate, CDR, proportions of grade 2 disabilities, MB cases and child cases among new cases are collected and compiled for various time periods and geographic units. Through GIS, the spatial and temporal distribution of leprosy can be visualized, and clusters in the distribution of leprosy can be identified (Fischer *et al*, 2008). Brazil has an advanced health information system, in which GIS is used to store and manage routine data on leprosy and tuberculosis control. In Ribeiro Preto, Brazil, one cross-sectional study described the spatial distribution of leprosy through a GIS. The result showed a concentration of cases in the northern region of this city, characterized by poor neighbourhood (Gauy *et al*, 2007).

WHO acknowledges GIS as a valuable management tool in the leprosy elimination programme, with potential for strengthening national, regional and sub-regional capacities for surveillance (Gauy *et al*, 2007). In the post-elimination era, there are still some endemic pockets at sub-national level (province and district) in several the large countries that have already reached elimination at national level. These could be visualized more clearly using GIS. WHO is willing to provide the technical and operational support to develop a post-elimination leprosy surveillance system, in conjunction with a GIS for the purpose of improving case detection of leprosy in those countries (WHO, 2001). It has been piloted by the West Pacific Regional Office in selected countries. For example, they supported a training programme of surveillance and GIS in Cambodia and Vietnam.

- **Programme planning, management and evaluation**

As a powerful tool, GIS is also used to provide support for decision making. Through GIS, the information about the endemic situation of leprosy, the distribution of health infrastructure and health staff, together with the information from more advanced GIS analysis, can be provided to decision makers to plan optimal resource allocation and interventions. For example, the geographical planning of health infrastructure, redistribution and training of health staff, and planning of particular programmes and campaigns can be performed for the purpose of delivering effective interventions where the need is greatest.

India has made good use of GIS technology in the planning, monitoring and evaluation of the National Programme for Eradication of Leprosy. Apart from the information system, special surveys such as LECs have been conducted in particular areas with inaccessible health services and high-endemic situation guided by spatial analysis through GIS (Br, 2009). In 2006, the British Leprosy Relief Association initiated a project using GIS to identify hidden leprosy cases in Brazil. One study about the use of GIS to improve the active leprosy case finding campaigns was conducted in one state of Brazil. De Souza Dias *et al* (2007) argued that GIS had shown to be effective through providing a clear visual understanding of distribution of leprosy, resulting in targeted interventions and cost reduction in leprosy

control, especially case-finding activities.

- **Research**

A cluster in disease control is defined as a geographically and/or temporally defined population with a high incidence rate (Fischer *et al*, 2008). It can manifest as temporal, spatial or mixed type of clustering. The cluster distribution of leprosy has been observed more clearly through the GIS technology. For example, Fischer *et al* found several spatio-temporal clusters for voluntarily reported cases through the analysis of routine data from 1989 to 2003 in Bangladesh.

GIS also provides an opportunity for complex analysis and research on the relationship between leprosy and various factors such as physical, socio-economic, socio-cultural, the health system, genetic factors and other diseases (Tanser & Sueur, 2002). One study in the Brazilian state of Ceara found that the distribution of leprosy reflected the socioeconomic differences within the state (Montenegro, 2004). In Karonga, Malawi, Sterne *et al* (1995) found a positive relationship between the proximity of water and leprosy incidence. One study was conducted in five isolated islands in the Flores Sea, Indonesia with an overall case detection rate of 205 per 10,000. Several risk factors were identified related to the leprosy distribution, including male sex, harbouring anti-*M.leprae* antibodies, being a household contact and genetic predisposition (Bakker, 2005). To trace contacts of leprosy through GIS, van Beers *et al* (1999) found the estimated risk for leprosy was about nine times higher in households of patients and four times higher in direct neighbouring houses of patients compared to the households that had no contact with patients.

4.2.2 Barriers to GIS in leprosy control

The GIS technology has been proved to be a tool of great potential for health research and management. But there are some barriers to its initiation and implementation.

- Financial input for computer hardware and software

The current computers are powerful enough to run GIS software, but the cost of GIS software and the running of a GIS server on the internet are still expensive.

- Capacity building of human resource

Staff need to be trained to operate and maintain the GIS database. Due to the technical complexity of GIS, a high level of technical competence of users is required.

- Data

Available, reliable and updated data is important for running a GIS, such as epidemiological data, computerised databases of individual cases, socio-economic and geographic data. But in most developing countries, reliable and timely data is not available.

- Maps

Although Internet Mapping Servers like ARCIMS provide the possibility to access maps and relevant GIS data, some GIS data of developing countries is still not available and accessible. Even if some maps are available, the cost is high.

4.3 THE SPATIAL AND TEMPORAL DISTRIBUTION OF LEPROSY IN SICHUAN PROVINCE

For the purpose of describing the spatial and temporal distribution of newly detected leprosy cases between 2002 to 2008, a GIS was used to visualize the routine epidemiological data, which included the number of new cases, MB cases, child cases[10] and cases with grade 2 disabilities, CDR (per 100,000 population) and prevalence rate (per 10,000 population) at county and district level. The data came from the provincial leprosy epidemiological surveillance system. The leprosy professional institutions at county level are responsible for collecting and reporting primary data of leprosy cases. The geographic information of Sichuan province was downloaded from the Healthmapper database developed by WHO.

A total of 1824 leprosy new cases were detected from 2001 to 2008. Among them, 398 cases had already developed grade 2 disabilities, accounting for 21.8% of new cases. 73.8% of new cases were MB cases. A total of 48 child cases were detected with a proportion of 2.6% of all new cases. The average CDR was 0.26 per 100,000 persons. The trends of prevalence rate, CDR, and the proportion of MB cases, child cases and cases with grade 2 disabilities among new cases of each year are shown below (Figure 6 and 7).

Figure 6: Prevalence rate and CDR of leprosy, Sichuan province (2001-2008)

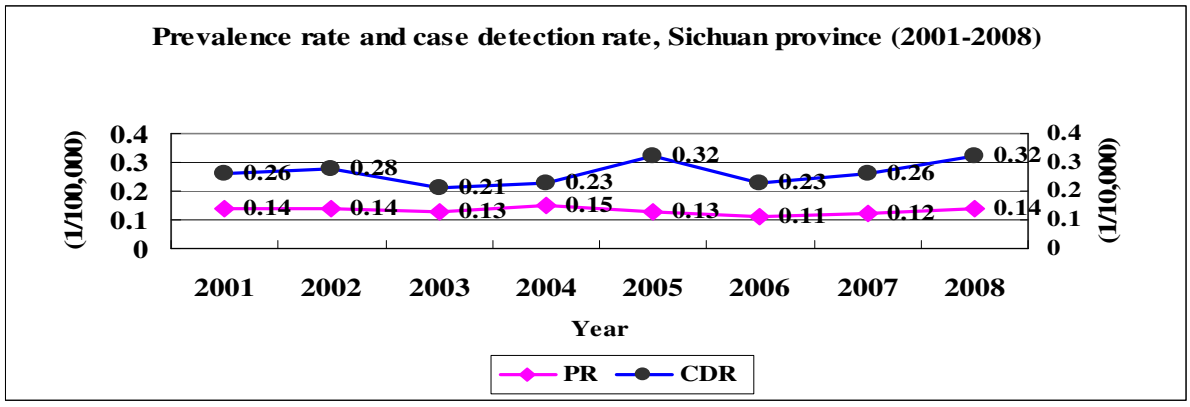
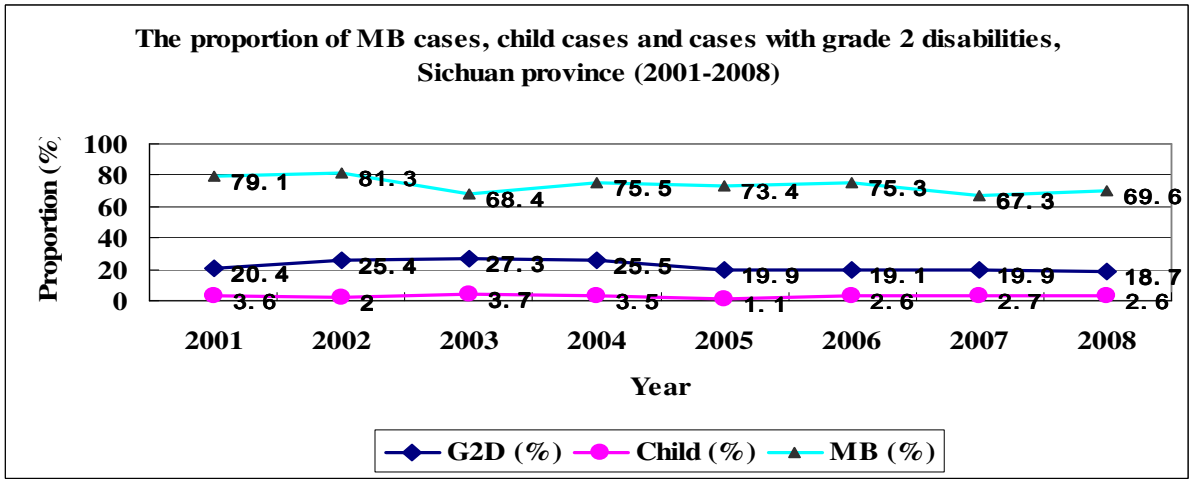


Figure 7: Proportion of MB, child cases and grade 2 disabilities, Sichuan (2001-2008)



[10] Child case is defined as a leprosy patient under 15 years of age.

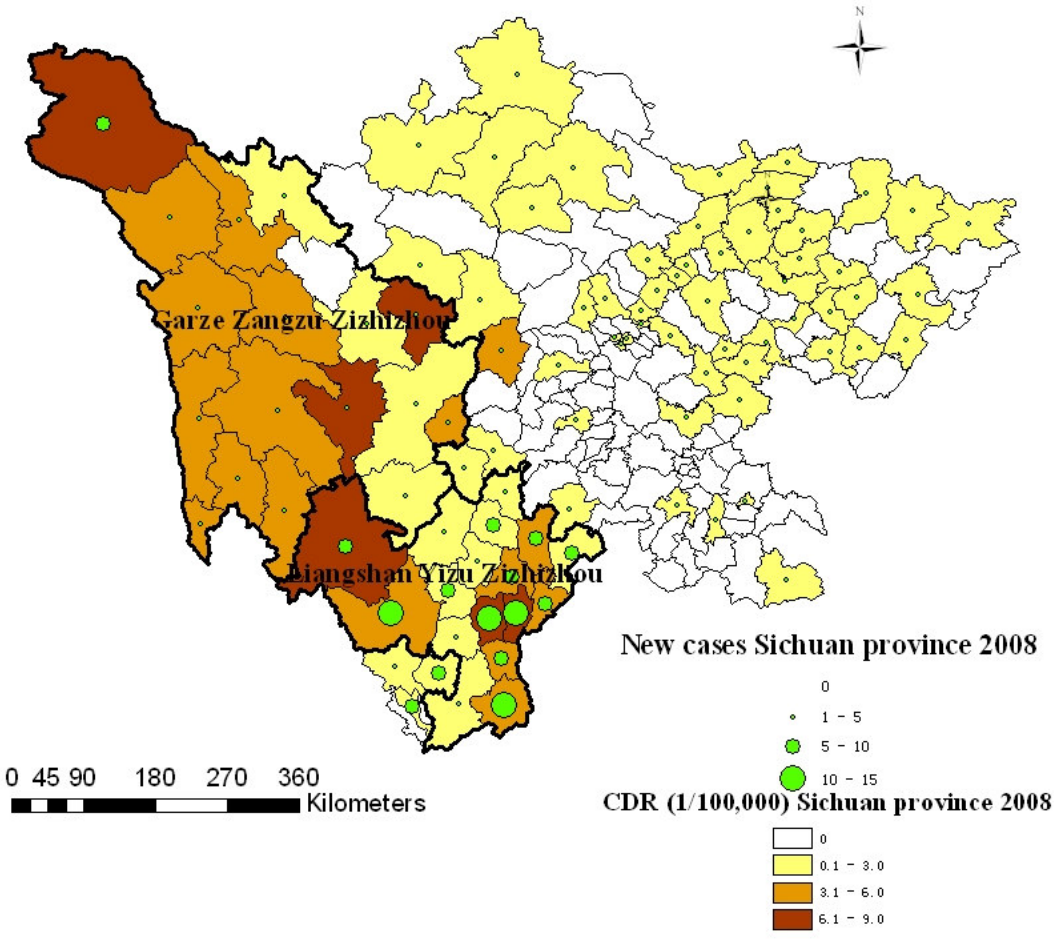
4.3.1 The description of spatial and temporal distribution of leprosy at county level

- Figure 8

The map visualizes the distribution of new cases and the CDR of each county in 2008. The green dots with a gradual size represent the number of total new cases of each county. Sizes of dots increase with the rise of number of new cases. Most new cases are found in the southwest, namely Liangshan prefecture. The colour of shades of counties becomes deeper with the rise of the CDR. Counties with a relatively high CDR are found in Liangshan and Garze prefecture, mostly located in the west, which are underdeveloped and with poor accessibility of health care. Compared to ordinary statistic tables, the relative high-endemic areas and distribution of new cases can be easily identified at a glance through this map.

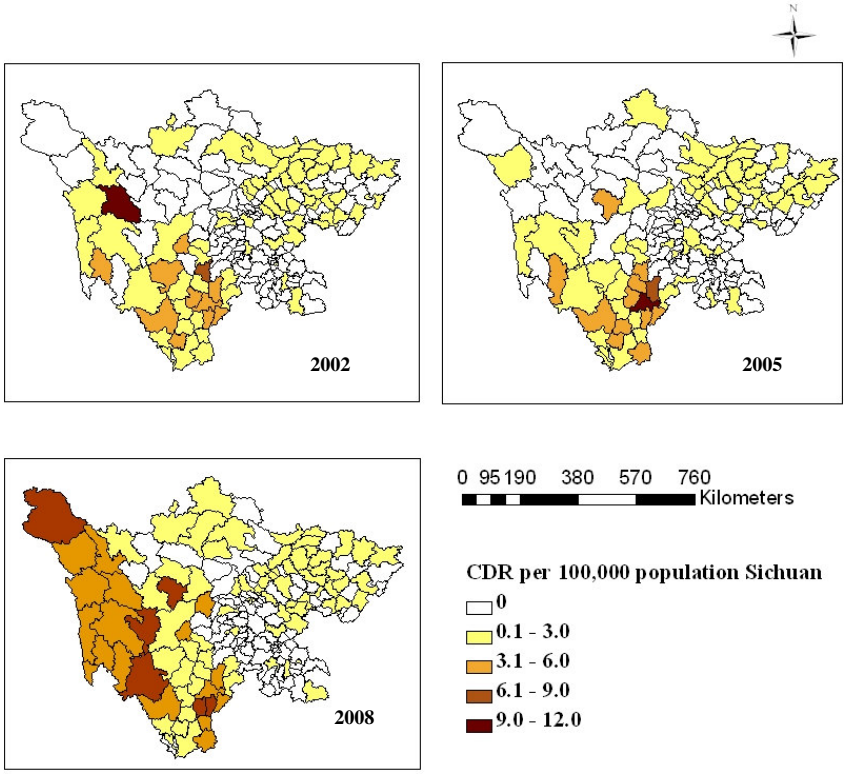
On the other hand, owing to the influence of population size, the fact that many new cases are detected in a certain area dose not necessarily mean a high CDR there. Therefore, both the absolute number of new cases and the relative rate of case detection should be considered when we evaluate the magnitude of leprosy in a certain area. The absolute number of new cases represents the disease burden or workload of leprosy control, while the CDR roughly demonstrates the overall endemic situation in a certain area.

Figure 8: CDR and newly detected cases (county level), Sichuan province (2008).



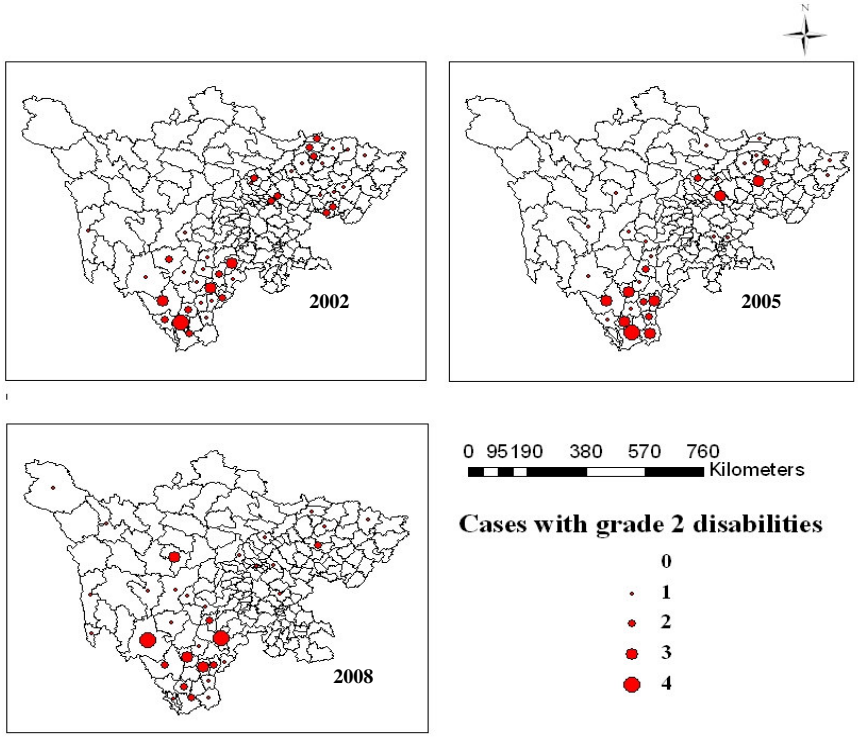
- **Figure 9: CDR (county level), Sichuan province (2002, 2005 and 2008).**

This figure shows the CDR of each county in 2002, 2005 and 2008 respectively. An overall higher CDR is found in the west than that in the east. In the map of 2008, the CDR in the western areas increases, compared to that in 2002 and 2005. This may due to the increase of financial support from the government in 2008, leading to more leprosy case finding activities. Through those maps, the temporal trend of the CDR of each county can be identified easily. Meanwhile, the change of endemic situation can be understood at a glance.



- **Figure 10: Cases with grade 2 disabilities, Sichuan province (2002, 2005 and 2008).**

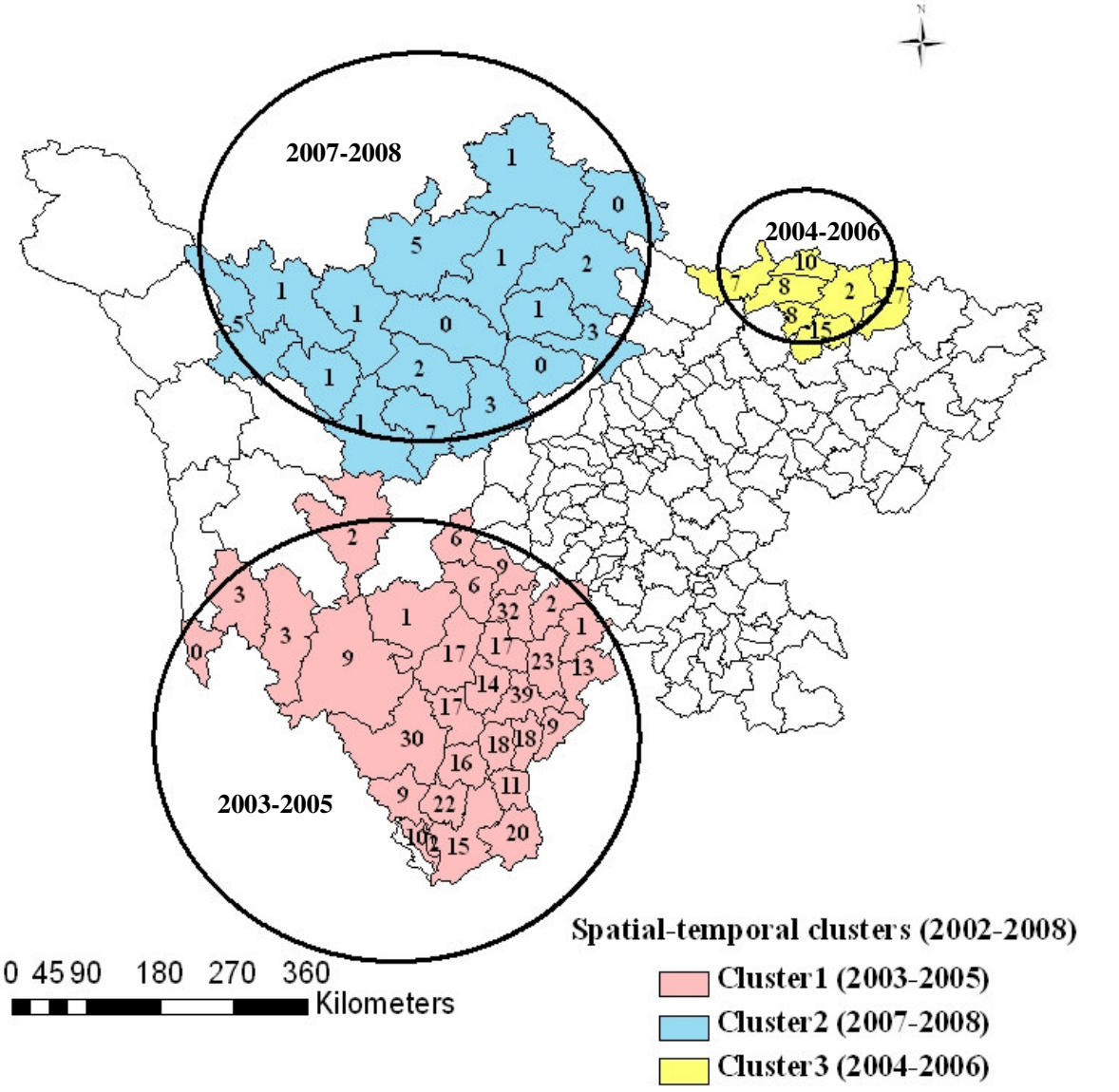
This figure shows the distribution of new cases with grade 2 disabilities in 2002, 2005 and 2008. The red dots with diverse sizes represent the number of new cases with grade 2 disabilities. In the map of 2002, two concentrations of dots are found in the southwest and northeast respectively. In the map of 2005, the number of big dots decreases in the northeast. Disabled new cases are mainly found in the southwest in 2008. This might due to most of new cases are detected in the southwest. For further identifying the disability situation among new cases in different areas, I compare the disability proportion at district level in Figure 14.



- Figure 11

The map shows three spatial-temporal clusters of new cases detected between 2002 and 2008. Three clusters are distinguished by use of the scan-statistic technology (SaTScan 8.0 software). The discrete Poisson model is chosen to perform the space-time scan-statistic analysis. All clusters have a time period of 2 to 3 years. The most likely cluster is found in the southwest during the period between 2003 and 2005. The figures in the map represent the number of newly detected cases of each county during a corresponding time period. Research on the characteristics of new cases within clusters and risk factors of incidence could be carried out in the future.

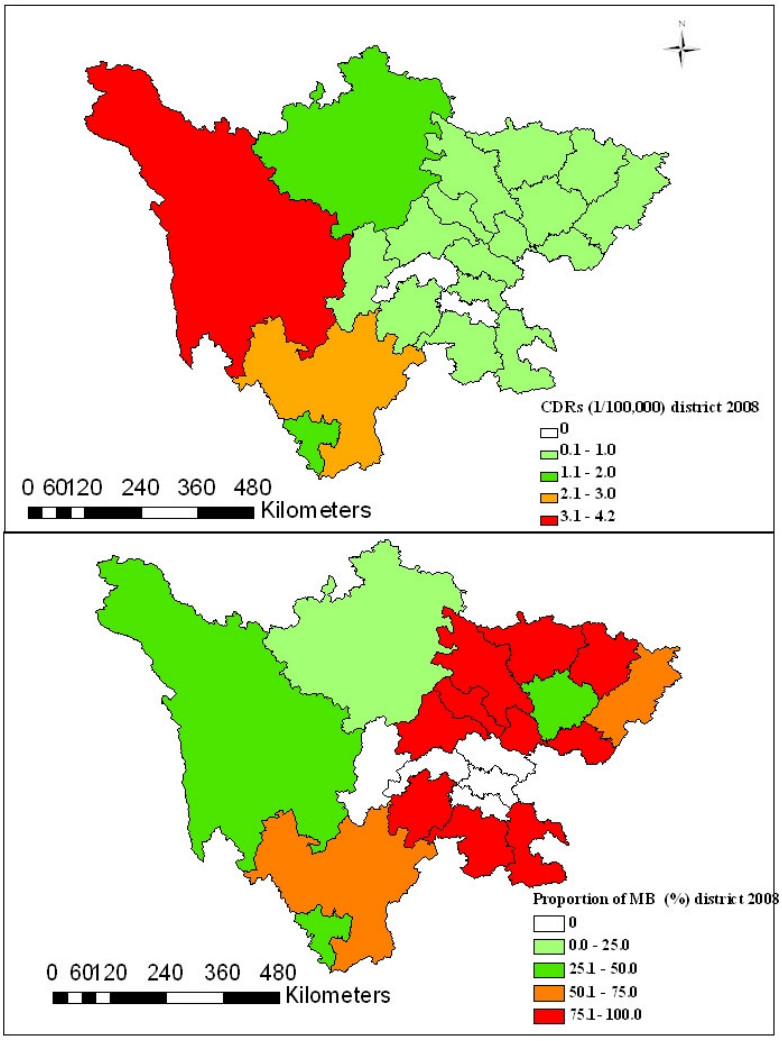
Figure 11: The spatial-temporal clusters of new cases, Sichuan province (2002-2008).



4.3.2 The description of spatial and temporal distributions of leprosy at district level

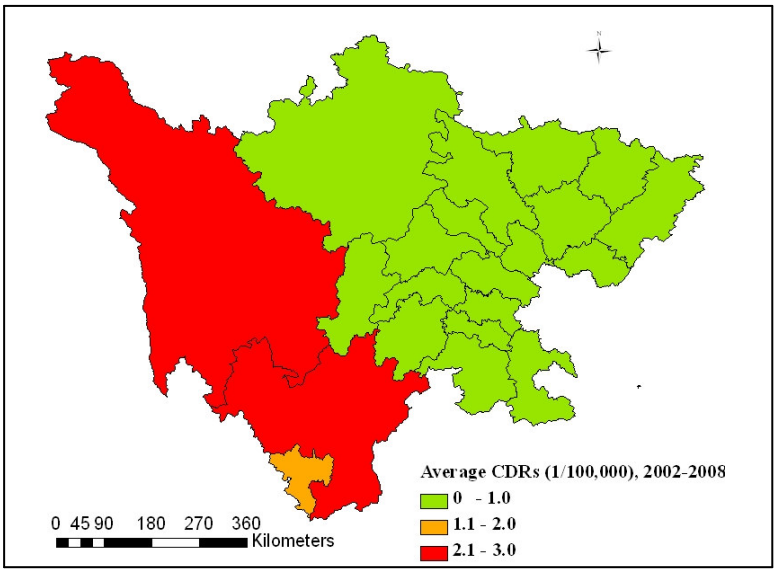
- **Figure 12: CDR and proportion of MB cases (district level), Sichuan (2008)**

The CDR and the proportion of MB cases among new cases of each district in 2008 are visualized in these two maps. In the upper map, light green areas with a CDR less than 1 case per 100,000 population concentrate in the east. The orange and red areas have a high CDR (>2/100,000), mostly located in the west. In the lower map, a high proportion (>50%) of MB cases among new cases is found mostly in the eastern areas with a low CDR, showing in red and orange. Meanwhile, more PB cases were detected than MB cases in western areas with a high CDR, showing in green. These maps demonstrate that most new cases in low-endemic areas are MB cases.



- **Figure 13: Average CDR (district level), Sichuan province (2002-2008)**

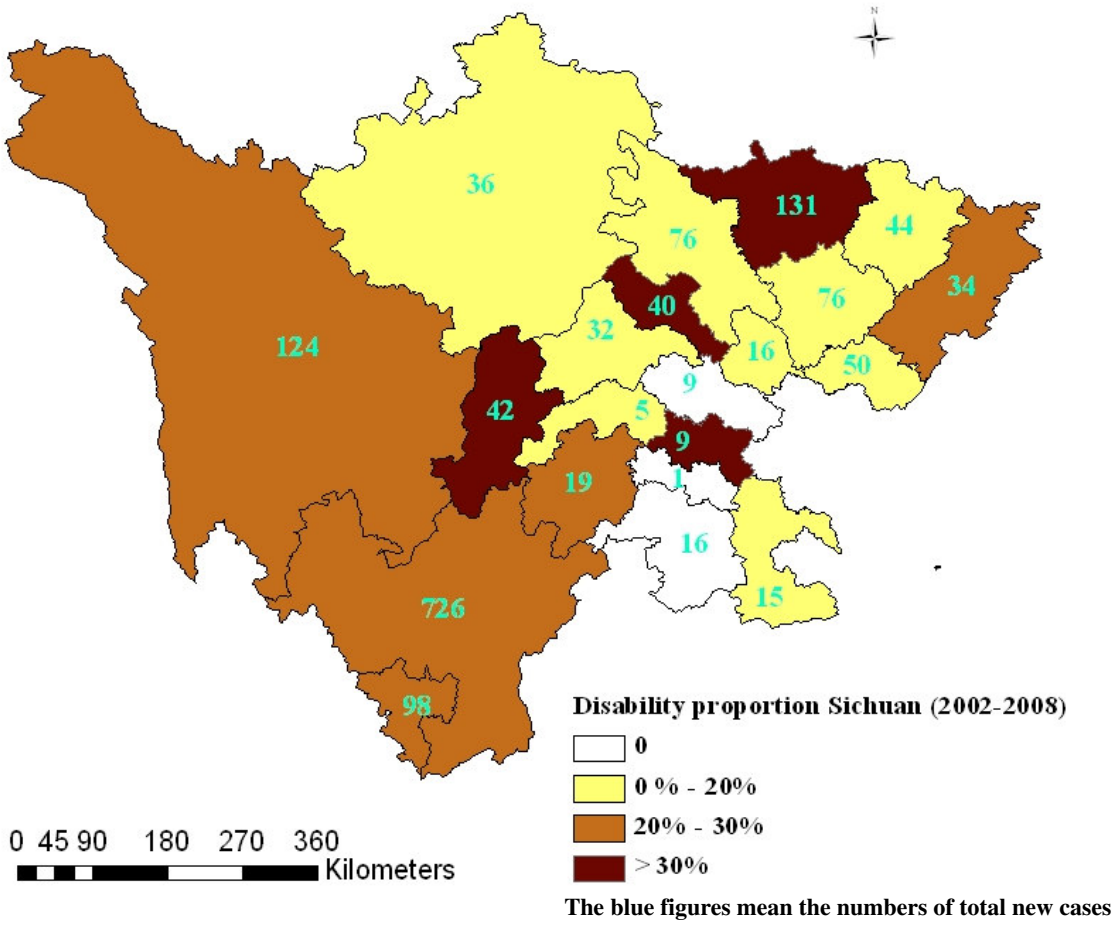
The map shows the average CDR of each district during a time period from 2002 to 2008. Green areas represent districts with a CDR less than 1 case per 100,000 persons. Districts in red have a high CDR (>2 /100,000). One district in orange has a CDR between 1 and 2 cases per 100,000 persons. Relatively high-endemic areas are identified in the west.



- **Figure 14**

The average disability proportion among new cases detected between 2002 and 2008 of each district is showed in this map. The colour of shades of districts becomes deeper with the rise of the disability proportion. The blue figures in the map represent the number of total new cases of each district. A high disability proportion more than 20% is found in both relatively high and low endemic areas. It is interesting to find that four districts with a high disability proportion (>30%) are located in the center and east, in low-endemic areas, showing in deep brown. But this may be partly due to the small number of total new cases detected in one of these four districts, namely the district in the east with a total of 9 new cases.

Figure 14: The average disability proportion (grade 2), Sichuan province (2002-2008)



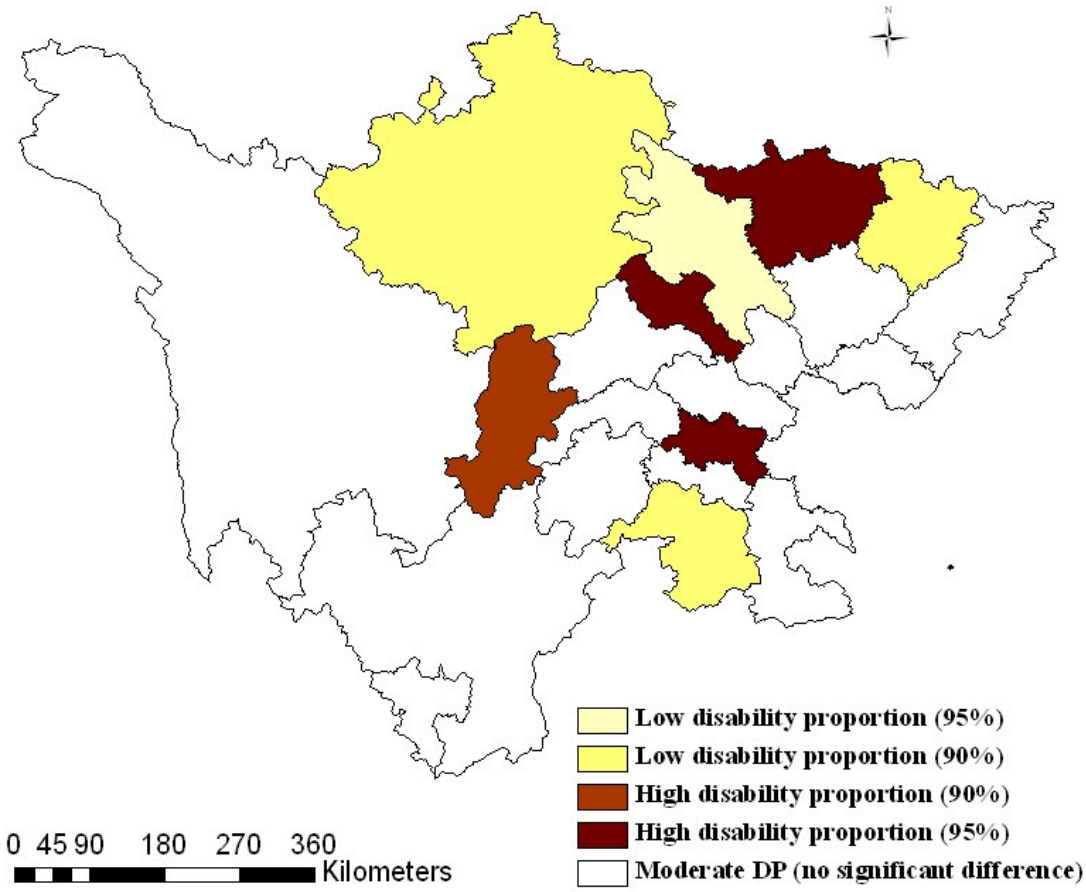
The blue figures mean the numbers of total new cases

- **Figure 15**

For the purpose of addressing the small number problem, the technique of probability mapping is used to visualize the districts with a significantly higher or lower disability proportion, compared to the overall average disability proportion in Sichuan province. The chi square test is used to compare the expected and observed number of disabled cases (WHO grade 2) among new cases in each district. Four districts (in brown) have a significantly higher disability proportion than the overall average in Sichuan province (three districts in deep brown with 95% certainty, the other one in light brown with 90% certainty). All these

districts are located in low-endemic areas. Therefore, early case detection in both relatively high and low endemic areas needs to be improved. On the other hand, four districts (in yellow) have a significant lower disability proportion than the overall average (three districts in deep yellow with 90% certainty, the other one in light yellow with 95% certainty).

Figure 15: The probability map of disability situation, Sichuan province (2002-2008)



CHAPTER 5 HOW TO IMPROVE EARLY CASE DETECTION OF LEPROSY IN SICHUAN PROVINCE

According to the WHO criterion of leprosy elimination with a prevalence rate below 1/10,000, leprosy has been eliminated as a public health problem at provincial level in Sichuan province. But there are still some endemic districts, namely Liangshan and Garze prefecture, mostly located in the western areas. Based on the analysis given in Chapter 2 and 3, early case detection of leprosy appears to become more difficult due to various reasons in the post-elimination era. New strategies need to be generated to improve early case detection, taking into account feasibility and cost-effectiveness. In this Chapter, based on the analysis given in Chapter 3 and 4, I will discuss appropriate strategies and interventions for improving early case detection of leprosy in Sichuan province.

5.1 POLITICAL COMMITMENT

The government has played a unique role in providing political and financial support for leprosy control programmes in the past several decades. Support from government for leprosy control has diminished significantly in the post-elimination era. Actually, leprosy is an "unfinished issue" in China, which still needs continuous attention of the government. Therefore, continuous advocacy for political commitment at each level of government is crucial for the whole of leprosy control, especially at the local level. Good policy cohesion from national level to village level would facilitate planning and implementation of leprosy control programmes (Yu, 2003). In relatively high-endemic areas, putting leprosy control on the agenda should be advocated to the government.

Advocacy should be conducted to policy makers to make political commitments for early case detection of leprosy. Leprosy policy should make early case detection a priority for the entire leprosy control programme. It is critical to get adequate political and financial support from government through proper explanation and communication. Related policies can facilitate early case detection, such as policies about health education of the public concerning leprosy, welfare for leprosy health staff, training of health workers, leprosy courses in medical university and cooperation with international and national partners.

A good example of political commitment is seen in Liangshan prefecture. The local government has consistently regarded leprosy as a key public health problem, putting leprosy control on the political agenda. Contracts are signed by local governments at county, town, and village level respectively, to ensure the accomplishment of annual tasks of leprosy control programs. Incentives and punishments are given to local governments according to the performance of leprosy control activities. Related policies include leprosy health education through mass media, leprosy health education in schools, favorable welfare of leprosy health workers, and leprosy pre-occupational training of general health workers. Those political commitments have created an enabling environment for leprosy control programs in Liangshan prefecture.

5.2 APPLICATION OF GIS

Based on the reviews and analysis about the application of GIS in Chapter 4, I think the application of GIS would provide new opportunities for leprosy control through improving epidemiological surveillance, guiding resource allocation and planning optimal programs, especially contributing to early case detection. In the beginning, a trial application of GIS will be initiated at provincial level in Sichuan province.

In China, the health information system concerning leprosy has not been developed well. The national computer-based recording and reporting system was established in 1990, including data collection at county level, data entry by optical scanner or manual mode, and data analysis (Chen *et al*, 2000c). The routine epidemiological data, mostly stored in Excel and Words files, is reported from the county level up to the national level gradually. It is difficult to figure out the trends, cluster distribution and relationships between factors through a tabular format. In Chapter 4.3, the spatio-temporal distribution of leprosy and the trend of leprosy endemic situation were identified by use of the GIS technology. The GIS would contribute to establish the efficient surveillance system of leprosy in Sichuan province.

A GIS could provide powerful evidences for decision making in terms of resource allocation. In Sichuan province, the annual resource allocation of leprosy control programmes is made by the senior specialists at provincial level, based on previous resource allocation and personal experiences. There are potential risks to make unreasonable resource allocation due to the personal bias. The application of GIS can facilitate evidence-based resource allocation, through showing the place where the need of resource is greatest to decision makers. GIS can be used to identify relatively high-endemic areas, indicating priorities for programme planning concerning early case detection. For example, in Sichuan province, the relatively high-endemic areas identified through the GIS are mostly located in the west, which has geographic barriers and inaccessible health services, active case detection programmes like “clue surveys” could be planned in an appropriate way in those areas.

The GIS technology can also facilitate research on leprosy control in Sichuan province in the future. For example, using GIS and molecular epidemiology, clusters of incidence and transmission routes may be identified through DNA typing of *Mycobacterium leprae* collected from leprosy patients in certain areas. Operational research on the value of application of GIS in leprosy control can be carried out through measuring the cost-effectiveness of use of GIS, especially in terms of case detection management.

5.3 CASE DETECTION MODES

In Sichuan province, voluntary reporting, notification by dermatologists and general health workers, and contact examination should be encouraged as routine case detection methods. Active case detection methods, such as “clue survey”, should be applied only in relatively high-endemic areas.

- **Voluntary reporting**

In the post-elimination era, by the increasing awareness among the public and alleviation of

stigma and discrimination, voluntary reporting will become the main case detection method of leprosy. In Sichuan province, awareness among the public concerning leprosy is deficient in most areas, especially in relatively low-endemic areas. Stigma and discrimination still exist, especially in remote mountainous areas. Therefore, for the purpose of improving voluntary reporting, health education of the public about positive images and early signs of leprosy needs to be strengthened. Systematic stigma-reduction strategies should be designed well from the individual level to the government level. It is also critical to encourage community participation and patients' involvement in reduction of stigma (Heijnders & Van Der Meij, 2006). On the other hand, due to geographical barriers in some areas, especially those areas with inaccessible health services, flexible arrangements of diagnostic and referral services are necessary. For example, village doctors and mobile health teams should visit those areas regularly, so that people can report themselves or health workers can refer suspected leprosy cases to referral units in a timely manner.

- **Notification by dermatologists and general health workers**

Dermatologists are the optimal health staff who could contribute to early case detection of leprosy. In Sichuan province, knowledge and skills of dermatologists concerning leprosy vary widely at different levels. Therefore, there is a continuing need of training programmes for dermatologists, especially for those who work at the lower level and in private skin clinics. Also dermatologists can establish a bridge between the leprosy control managers and general health workers, for the purpose of ensuring early case detection of leprosy (Chen *et al*, 2004).

As the first line health system, where a great number of people are seen and managed, a well-functioning primary health care can facilitate timely leprosy case detection and decrease the delay within the health system. Once the knowledge and skills concerning leprosy of general health workers are improved, early leprosy case detection will be improved significantly. But under the overall low-endemic situation in Sichuan province, it is very difficult to conduct large-scale leprosy training. Therefore, an appropriate approach to improve early case detection in low endemic areas could be providing short Suspect & Refer training of general health workers and encouraging their involvements.

- **Contact examination**

As mentioned before in Chapter 4, many studies emphasized the value of contact examination in early case detection of leprosy. Furthermore, it was said that contact examination should not be confined to household contacts. Van Beers *et al* (1999) estimated that the risk of leprosy for households of PB patients roughly equated to that for people who lived in direct neighboring houses of MB patients. Therefore, in additional to further strengthening household contact tracing of both MB and PB patients, contact examination of people who live in a house direct neighboring MB patients could be applied, especially in relatively high-endemic areas. But this should be considered carefully with regard to cost-effectiveness and feasibility. In the past 10 years, above 70% of newly detected cases were MB cases. So it may be possible to detect new cases earlier through enlarging the scale of contact examination. Due to the long incubation time of leprosy, contact examination should be conducted annually at least 5 years.

- **Clue survey**

"Clue survey" has played an important role in leprosy case detection in Sichuan province. Presently, it still can be conducted in some relatively high-endemic areas with inaccessible health services. In Sichuan province, most leprosy cases were detected in the remote mountainous areas. Due to geographic barriers, it is impossible to carry out active surveys all over endemic mountainous areas. Therefore, "clue survey" is the optimal approach to detect cases intentionally, guided by certain clues. "Clue survey" largely depends on reliable clues of suspect patients and the competence of leprosy health workers, so it is closely linked with health education and training programmes. Meanwhile, community participation could also contribute to "clue survey" through active reporting of clues of suspect leprosy patients.

5.4 TRAINING OF HEALTH WORKERS

In Sichuan province, due to the decreasing workload and other operational factors, human resources in leprosy control are relatively deficient. With regard to leprosy case detection, it would be essential to motivate and utilize diverse levels of human resources of the health system, especially staff at the primary health care level. Meanwhile, with the urban population growing rapidly, increasing numbers of patients with leprosy will consult dermatologists. Training and retraining of those diverse groups of health workers could contribute to early case detection of leprosy. Furthermore, the training curriculum should be adapted to the tasks expected of each type of health worker. The modes of training should be diverse, such as training courses, workshops and on-the-job training.

- **Training of general health workers, especially primary health workers**

As discussed in chapter 3, misdiagnosis is a main factor contributing to delayed case detection from health services' side, especially misdiagnosis in the general health services. Therefore, training of general health workers is essential for early case detection, especially at the primary health care level. The ability to suspect and refer leprosy patients is the most important skill requirement for primary health care workers (WHO, 2005). In Mali, Faye *et al* (2007) found that it was a cost-effective approach to improve leprosy case detection by providing a very short-term training in basic dermatology to primary health care workers.

The core curriculum of training for general health workers should focus on the knowledge of when and how to suspect and refer leprosy patients. In certain higher endemic areas of Sichuan province, village doctors, community doctors, and health staff at township level are required to receive pre-occupational training about leprosy. However, in most low-endemic areas, training of general health workers does not perform well. One feasible alternative approach in those areas might be to integrate leprosy training into other disease training programmes such as TB or HIV/AIDS. In Sichuan province, a number of people seek health care from health services of Traditional Chinese Medicine, especially elderly people and women. Therefore, training of doctors of Traditional Chinese Medicine may be another feasible and effective approach to improve early case detection.

- **Training of dermatologists**

Training of dermatologists should focus on comprehensive leprosy clinical knowledge, such as diagnosis, differentiated diagnosis, treatment, management of leprosy reaction and drug side effects, also including how to suspect and refer leprosy patients to referral units. In Sichuan province, most training programmes for dermatologists are conducted through a short-term training course. Therefore, other formats of training such as on-the-job-training, with demonstration of leprosy cases, could be applied. In addition, updated information about leprosy could be conveyed to dermatologists through presentations in dermatology academic conferences, such as the annual meeting of dermatologists. On the other hand, experienced dermatologists could also participate in training of general health workers regarding the clinical knowledge of leprosy.

- **Training of leprosy health workers**

Leprosy health workers have been dedicated to leprosy control for several decades in China. Their competence is closely associated with implementation of leprosy control programs. Maintaining the expertise level of leprosy health workers is critical for the quality of leprosy control activities. The curriculum of training should be adapted to the job descriptions of leprosy health workers at different level. Regarding early case detection, training should aim to improve leprosy health workers' competence to confirm suspected patients, plan and manage case detection activities, and provide supervision at lower level. Furthermore, training on communication skills and training for trainers are also necessary (Yu, 2003).

5.5 HEALTH EDUCATION

With regard to interventions addressing patient-related delay, health education of diverse target groups is critical for promoting early case detection of leprosy. Properly designed health education programmes could not only promote voluntary reporting of leprosy patients but also influence active case detection activities positively. According to the annual report of provincial supervision of leprosy control in 2008, implementation of health education was unsatisfactory. Health education was not performed in most low-endemic counties. In some relatively high-endemic counties, Information, Education and Communication (IEC) materials were found in rural health centers, some health education activities were performed in schools. But formats for health education activities were monotonous, the frequency was low and IEC materials were not updated. Therefore, health education concerning leprosy needs to be reinforced in Sichuan province. The optimal strategy for health education is to design suitable contents and formats of health education activities for diverse target groups.

- . **Health education activities focusing on key individuals/informants**

Key individuals/informants in communities have played an important role in leprosy case detection in Sichuan province. Key individuals mainly include school teachers, village leaders, traditional healers, individuals leading women's groups and religious groups. Usually they are respected by community members, what they perceive and believe may also be accepted by community members. Health education programmes could be designed to address the knowledge and attitude concerning leprosy of those key individuals, encouraging them to influence other community members. They also have the potential to influence health

seeking behavior of other community members, contributing to health promotion. Furthermore, key individuals are the main informants in a "clue survey". In Bangladesh, Krishnatray and Melkote (1998) involved of people who are key individuals in alternative health education programmes and identified this to be an effective way to influence the entire community.

In Liangshan, which is a minority-inhabited region, health education for key individuals in communities functions well. Mobile health education teams are sent to provide a simply training course to key individuals concerning basic knowledge and related policies of leprosy, and also to distribute IEC materials to the public. Furthermore, village or community doctors who received leprosy training before are also assigned to train key individuals of their own villages or communities. But in other relatively high-endemic areas, this useful human resource for early case detection and health promotion is not sensitized. Therefore, more efforts should be made to motivate community participation of early case detection of leprosy.

- **Health education activities for the public**

Health education of the public can facilitate early case detection of leprosy through reducing stigma and discrimination and guiding timely health seeking. In Sichuan province, health education concerning leprosy of the public lags behind compared to health education on HIV/AIDS. People even do not know that leprosy still exists in certain areas presently. Most of young generations never hear about this disease. Health education through mass media should be reinforced, especially in relatively low-endemic areas. The formats should be various, such as poster, newspaper, leaflet, slogan, broadcast and TV. Information should be transferred to the public in an understandable and acceptable way to promote a positive influence on the public. For instance, academic terms should not be used in IEC materials. Meanwhile, health education activities among the public on International Leprosy Day should be maintained. The information such as "leprosy can be prevented and cured" and "no need to be feared" should be conveyed to the public regularly, especially to the ethnic groups in their own languages.

- **Educational activities among students, including medical students**

In some relatively high-endemic areas of Sichuan province, health education activities are carried out in schools, for the purpose of teaching young generations about positive images of leprosy and encouraging them to disseminate knowledge to family members. Nicholls *et al* (2006) questioned children's ability to spread health education messages to family members. He argued that incomplete and inadequate communication might have the opposite effect to that expected. Therefore, health education in schools should be designed carefully, such as health education for high school students, or for a group of schoolchildren, their parents and teachers.

As health workers of the future, medical students should be considered a strategic focus for health education activities. Meanwhile, with a certain medical background, medical students can accept more academic information in terms of case detection, diagnosis and treatment of leprosy. Therefore, information on leprosy in the educational textbooks of medical school and

university should be updated. Diverse formats of health education for medical students could be applied, such as posters, leaflets, radios and workshops.

5.6 COMMUNITY PARTICIPATION

In Public Health, community participation is defined as members of a community being actively involved in decision-making about how to tackle individuals' and communities' health problems. Community participation has been seen as an effective approach in leprosy stigma-reduction and rehabilitation programmes (Heijnders & Van Der Meij, 2006). Furthermore, community participation can also contribute to early case detection of leprosy through sensitizing and motivating people affected by leprosy and their families, key individuals and community volunteers to report clues of leprosy and participate in health promotion. The challenge is how to sensitize and motivate the community as a whole to tackle the leprosy problem in relatively high-endemic areas. A community health committee could be set up, involving leaders of government, individuals leading religious and women's groups, and teachers. Meanwhile, the involvement of the community Women's Committee in providing special care and support to affected women is an approach to tackle gender inequities of leprosy. Community-based rehabilitation programmes could also be conducted to enhance the quality of lives of leprosy patients with disabilities and their families. This may enhance the credibility of the programmes within the communities, and thus promote early case detection indirectly.

5.7 INVOLVEMENT OF PEOPLE AFFECTED BY LEPROSY

As a severely stigmatized disease, leprosy not only affects the patients physically but also influences their daily lives and social participation. In Shangdong province, China, Chen *et al* (2004b) found that 46% of 4240 people affected by leprosy had participation restrictions. Many people affected by leprosy worry more about activity limitation and restriction in social participation than about their health condition (Van Brakel *et al*, 2006). Therefore, there are interventions to encourage the involvement of people affected by leprosy in social participation, such as rehabilitation and stigma-reduction programmes. Involvement of people affected by leprosy could also contribute to early case detection. If affected people share their personal experiences with others, this may contribute to reduction of stigma and thus to early case detection. In Nepal, Floyd-Richard and Gurung (2000) suggested that individuals directly affected by leprosy could be encouraged to share their experiences with others and promote early case detection and reduce stigma in turn. On the other hand, affected people are also encouraged to report clues of suspect leprosy patients among their relatives and fellow community members or to suggest to them to seek health care timely. This contributes to both early case detection and health promotion, also resulting in more social participation. In Brazil, Pennini *et al* (1998) pointed out that a simple education programme for new patients was as effective as contact surveys in locating new cases.

5.8 INTEGRATION OF LEPROSY CONTROL INTO GENERAL HEALTH SERVICES

As currently recommended by WHO, effective leprosy control needs an integrated approach to improve equity and accessibility (WHO, 2005). Nowadays, the integration strategy is partly implemented in some areas in China. From 2003 to 2007, an international project sponsored by the Netherlands Leprosy Relief (NLR) was implemented in 5 pilot provinces in China, including Sichuan province. This programme focused on improving leprosy control services through integrating leprosy control into the general health services. In Liangshan prefecture, Mianning county was chosen as a pilot county. During the period of this programme, many general health workers and dermatologists were trained to suspect and refer leprosy patients. Health education was conducted extensively and intensively. The leprosy health facility at county level worked as a referral unit, conducting case and programme management. At the next stage, the integrated strategy will be extended to other areas of Sichuan province.

The integration of the leprosy control programme into the general health services is a gradual process, which needs careful planning and sufficient preparations (Yu, 2003). Presently, the integration strategy can not be implemented fully all over Sichuan province in a short term. Professional leprosy health workers will continue to play an essential role in case management, programme management and supervision. It is also a challenge to determine at which level leprosy specialists need to be maintained in the overall low-endemic situation. On the other hand, an effective referral system should be organized from village level to national level. The information about how and where to refer suspect patients should be conveyed to diverse health workers, especially general health workers. The involvement of general health workers and dermatologists in early leprosy case detection will increase gradually. An integration strategy fitting into the leprosy control situation of Sichuan province will be explored through continuous efforts in the near future.

CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

Sichuan province has constantly been one of the provinces with a relatively high-endemic level of leprosy in China. In the post-elimination era, there is loss of interest of the government in leprosy control, especially at the provincial and county levels, which makes the leprosy control programme much weaker. Currently, one of the key challenges in leprosy control in Sichuan Province is delayed case detection with a high proportion of disability among new cases. 1824 new cases were detected between 2001 and 2008, 21.8% of them had developed grade 2 disabilities. About half of new cases were detected after a delay of more than 2 years since the symptoms occurred. Nowadays, voluntary reporting, notification by dermatologists and household examination are main case detection methods of leprosy, and "clue survey" are applied in some relatively high-endemic areas in Sichuan province

The factors contributing to delayed case detection include lack of awareness about leprosy among the public, wrong cultural beliefs, stigma and discrimination, gender inequities and poverty, causing delays in health seeking of leprosy patients. Loss of interest of the government in leprosy control, misdiagnosis in general health services, an underdeveloped referral system and less active case detection contribute to the delay within the health system. In the remote mountainous areas, where most leprosy cases were detected, geographical barriers and inconvenient transportation also lead to delay.

Experiences from other provinces of China and other leprosy-endemic countries, literature review and analysis on leprosy case detection methods indicate that application of GIS would provide new opportunities for leprosy control, especially early case detection. GIS can be used to identify the relatively high-endemic areas, indicating priorities for programme planning and resource allocation regarding early case detection. Meanwhile, it would also facilitate epidemiological surveillance and research in leprosy control.

In the context of the overall low-endemic situation, with deficient resource allocation, the following are likely to be cost-effective and feasible strategies to improve early case detection of leprosy in Sichuan province: political advocacy, application of GIS, application of proper case detection methods (voluntary reporting, contact examination and "clue survey"), training of diverse groups of health workers, health education focusing on diverse target populations, community participation, involvement of people affected by leprosy and integration.

6.2 RECOMMENDATIONS

For the purpose of improving early case detection of leprosy in Sichuan province, comprehensive strategies should be implemented to tackle the factors contributing to delayed case detection. A GIS could be used to distinguish the relatively high-endemic and low-endemic areas. Different strategies should be emphasized in different endemic situation of certain areas, taking accessibility of health services into consideration. Based on the issues highlighted above, the recommendations are as follows:

- **Political commitment**

In the post-elimination era, continuous advocacy of political commitment concerning early case detection should be carried out at each level, especially at the local level. In relatively high-endemic areas, leprosy control should be put on the agenda. Leprosy policy should constantly make early case detection a priority for the entire leprosy control programme. Related policies on health education of the public concerning leprosy, training of health staff, leprosy courses in medical university and international cooperation should be established well.

- **Application of GIS**

The GIS should be applied in leprosy control, especially to guide evidence-based resource allocation and plan optimal programmes regarding early case detection in Sichuan province. Meanwhile, GIS technology should also be used to improve the surveillance information system and facilitate research. In the beginning, a trial application of GIS should be initiated at provincial level.

- **Case detection methods**

Voluntary reporting, notification by dermatologists and general health workers, and contact examination should be applied as routine case detection methods in Sichuan province. It is critical to encourage general health workers and dermatologist to participate in early case detection, especially in low-endemic areas. In addition to further strengthening household contact examination of both MB and PB leprosy patients, examination of people who live in a house direct neighboring MB patients should be applied, especially in relatively high-endemic areas. “Clue surveys” could be applied in relatively high-endemic areas with poor accessibility of health services.

- **Training of health workers**

Training programmes of leprosy should be designed and organized in a proper way for different health workers. The curriculum should be adapted to the job descriptions of diverse health workers. Training and retraining of general health workers, such as short Suspect & Refer training, should be reinforced in the whole areas, especially in low-endemic areas. Professional training of dermatologists should be strengthened, especially for those who work at lower levels and in private dermatological clinics. Leprosy health workers should receive systematic training about case confirmation, program management and supervision. Furthermore, training of trainers is also necessary.

- **Health education**

Health education of the public through mass media should be strengthened, especially in low-endemic areas. Health education activities on International Leprosy Day should be maintained, especially for the ethnic groups who live in the remote mountainous areas. Health education of medical students should be strengthened. In relatively high-endemic areas, health education of key individuals and students should be reinforced.

- **Community participation**

Community participation should be reinforced, especially in relatively high-endemic areas. A community health committee could be established, involving leaders of government, individuals leading religious and women's groups, and teachers. Meanwhile, the involvement of the community Women's Committee in providing special care and support to female affected people should be encouraged. Community members should be encouraged to report the clues of leprosy and participate in health promotion.

- **Involvement of people affected by leprosy**

The people affected by leprosy should encouraged to share their personal experiences with others, this may contribute to reduction of stigma and thus to early case detection. Meanwhile, they should also be encouraged to report the clues of leprosy and participate in health promotion, contributing to both early case detection and health promotion, also resulting in more social participation.

- **Integration of leprosy into general health services**

For providing sustainable leprosy services in a cost-effective way, integration of leprosy into general health services should be extended all over Sichuan province. But the implementation of integration should be planned and prepared carefully. An effective referral system should be organized from village level to national level. The information about how and where to refer suspect patients should be conveyed to diverse health workers, especially general health workers.

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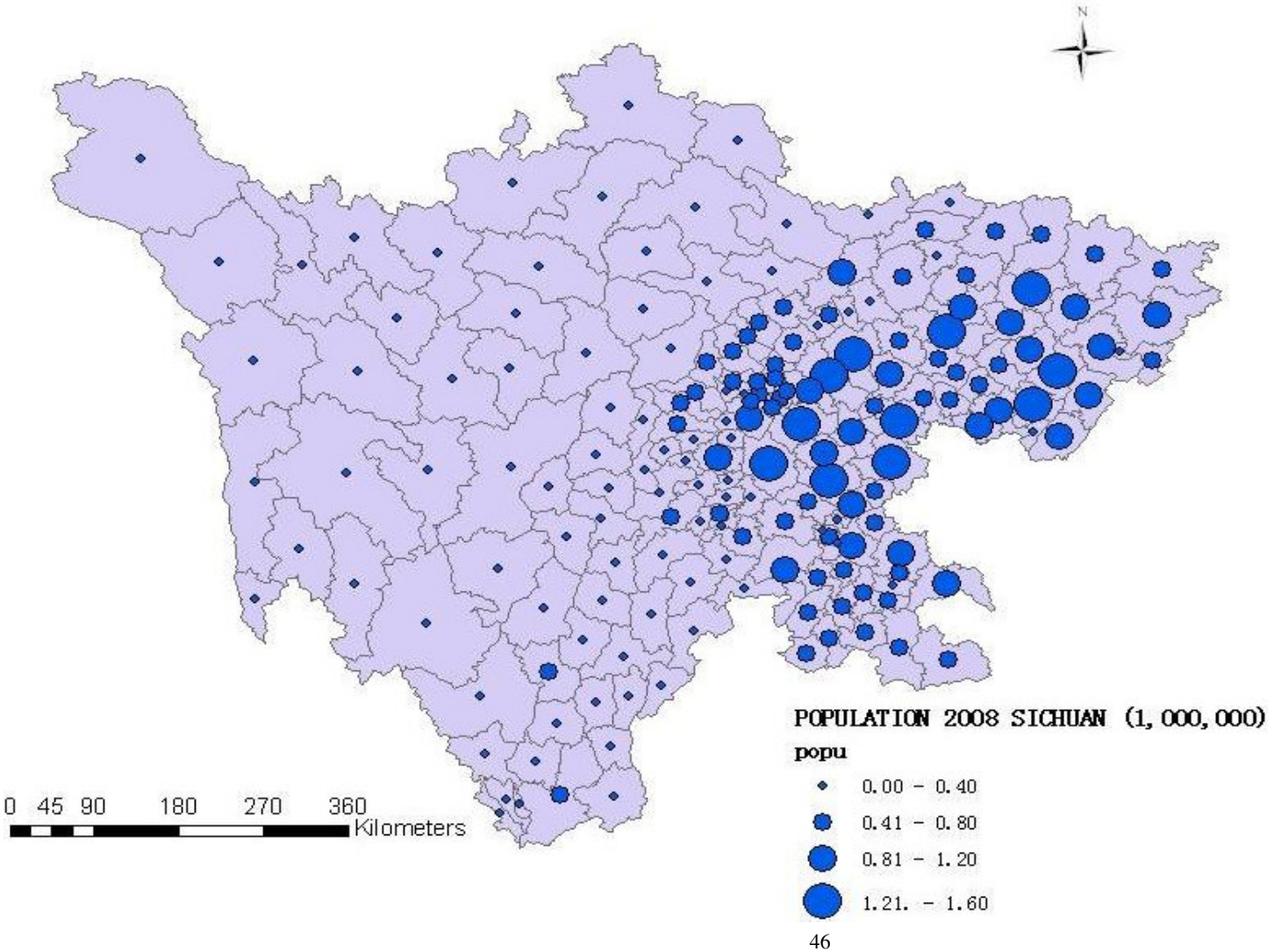
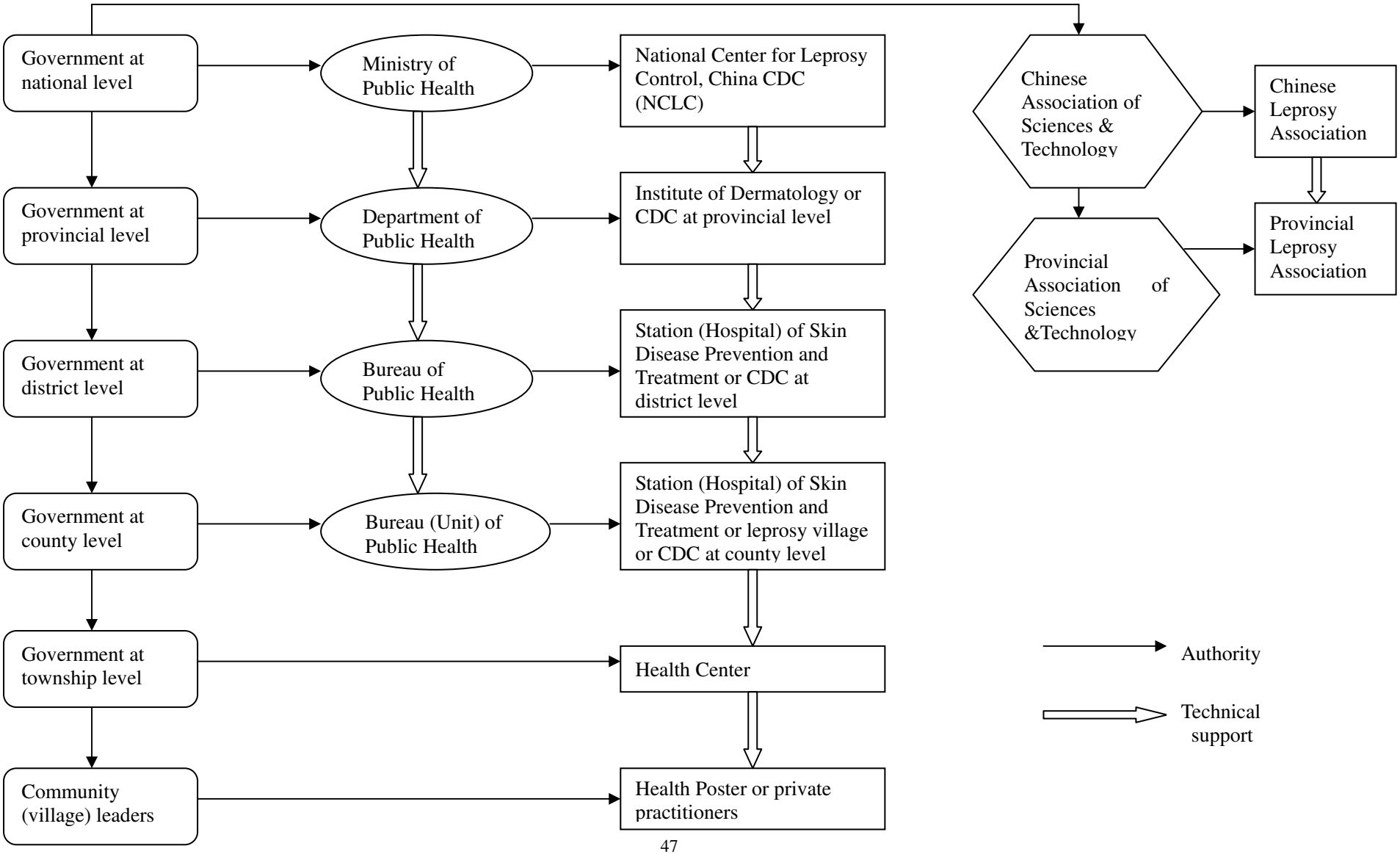
ANNEX

ANNEX 1 MAP OF CHINA AND SICHUAN PROVINCE

ANNEX 2 POPULATION DISTRIBUTION OF SICHUAN PROVINCE (COUNTY LEVEL) 2008



ANNEX 3 THE STRUCTURE OF LEPROSY CONTROL SYSTEM IN CHINA



ANNEX 4 DEFINITIONS

Leprosy case

In a leprosy-endemic country or area, an individual should be regarded as having leprosy if he or she shows ONE or more of the three following cardinal signs: skin lesions consistent with leprosy and with definite sensory loss, thickened peripheral nerves, and acid-fast bacilli on skin smears or biopsy materials. Leprosy case is defined as an individual who is confirmed leprosy and has not completed a full course of MDT treatment. Leprosy cases can be simply classified into two types: Pauci-bacillary (PB) leprosy patients, who have 1-5 skin lesions, are given a regimen of two drugs – Rifampicin and Dapsone for 6 months; Multi-bacillary (MB) patients have more than 5 skin lesions and are given a regimen of three drugs – Rifampicin, Clofazimine and Dapsone for 12 months. In China, PB case is defined as a leprosy patient who has 1 to 5 skin lesions with a negative skin smear and without damaged nerve trunk; MB case is defined as a leprosy patients with more than 5 skin lesions or/and more than one nerve truck damaged, and a positive skin smear.

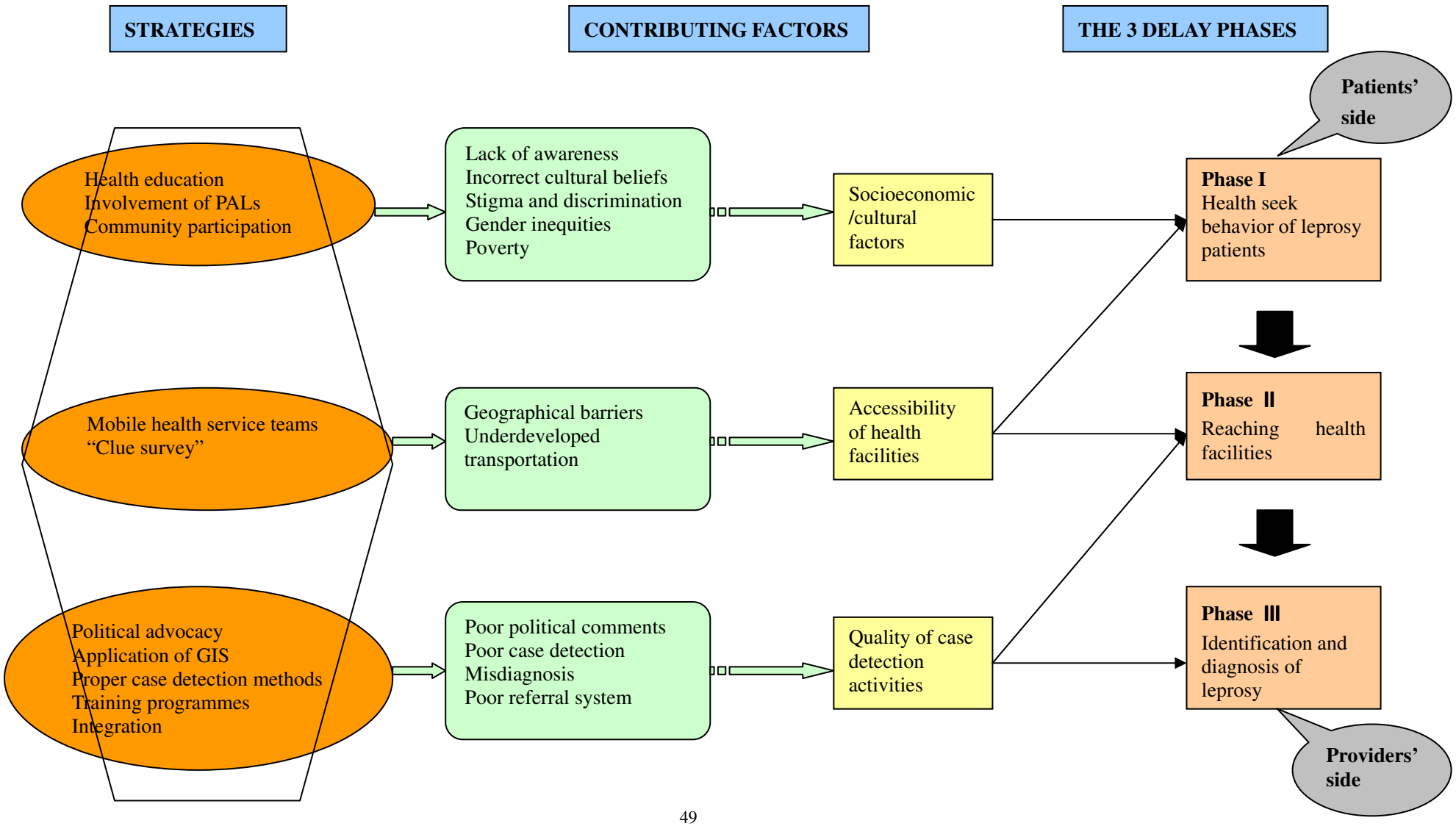
Prevalence rate

The prevalence of a disease tells us what proportion of a population actually has the disease. It presents in two ways: point prevalence and period prevalence. Point prevalence rate is defined as the number of people with disease at a given point in time divided by total number of people in the population. Period prevalence rate refers to the proportion of people with the disease during a specific period. WHO defines a prevalence rate of leprosy as the total number of leprosy cases registered for chemotherapy at the end of the reporting year divided by the total population. In China, the registered cases include both leprosy patients who are under MDT treatment and those who have finished MDT but still have a positive skin smear.

Case detection rate and incidence rate

The incidence of a disease measures how quickly people are developing a disease. The incidence rate refers to the number of people who develop disease in one year divided by average number of people in the population in the same year. In leprosy control, the case detection rate is used to estimate the incidence rate, using the number of newly detected cases per year divided by the total population. The proportions of grade 2 disabilities, child cases, and MB cases among newly detected cases are another three important epidemiological indicators of leprosy.

ANNEX 5 THE 3 DELAY MODEL OF LEPROSY CASE DETECTION



ANNEX 6 PROBLEM TREE