RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED AND NON-AFFECTED PERSONS IN NON SOMBOON DISTRICT KHON KAEN PROVINCE THAILAND

Mr. Nils Kaehler

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ปัจจัยเสี่ยงต่อการรับรู้การตีตราในผู้ป่วยโรคเรื้อน และผู้ไม่ป่วยในชุมชน โนนสมบรูณ์ จังหวัดขอนแก่น

นาย นิลส์ เคลเลอร์

วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาสาธารณสุขศาสตรมหาบัณฑิต
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นิลส์ เคลเลอร์: ปัจจัยเสี่ยงต่อการรับรู้การตีตราในผู้ป่วยโรคเรื้อน และผู้ไม่ป่วยในชุมชน โนนสมบูรณ์ จังหวัดขอนแก่น (RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED AND NON-AFFECTED PERSONS IN NON SOMBOON, KHON KHAEN PROVINCE, THAILAND) อ.ที่ปรึกษาวิทยานิพนธ์หลัก: Robert S. Chapman, M.D., M.P.H., 117 หน้า.

ความเป็นมา: โรคเรื้อนเป็นโรคที่ถูกตีตราและถูกหวาดระแวงในสังคมอังกฤษ อันเนื่องมาจากการความหวาดกลัวในผู้ป่วย โรคเรื้อน ซึ่งส่วนใหญ่เกิดจากการขาดความรู้ และความเคลือบแคลงใจในโรคเรื้อน การศึกษาครั้งนี้เป็นการศึกษาถึงปัจจัยเสี่ยงต่อการรับรู้การตีตราในผู้ป่วยโรคเรื้อน และผู้ไม่ป่วยที่อาศัยอยู่ในชุมชนโนนสมบูรณ์ จังหวัดขอนแก่น

วิธีวิจัย: เป็นการศึกษาแบบภาคตัดขวาง เพื่อประเมินปัจจัยเสี่ยงต่อการรับรู้การตีตราในผู้ป่วยโรคเรื้อน และผู้ไม่ป่วย เก็บข้อมูลโดยการสัมภาษณ์โดยใช้แบบสอบถาม ผู้ป่วยโรคเรื้อน จำนวน 265 คน และประชาชนที่ไม่ป่วยด้วยโรคเรื้อน จำนวน 257 คนในชุมชน โนนสมบูรณ์

ผลการศึกษา: ผลการศึกษาบางส่วนมีความสอดคล้องกับการศึกษาอื่นๆที่ผ่านมา พบว่าในกลุ่มผู้ป่วยโรคเรื้อน การรับรู้การตีตราของโรคมีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติต่อปัจจัยดังต่อไปนี้ อาชีพ (p=0.013) การมีความรู้น้อยในเรื่องโรคเรื้อน และ การพิกลพิการของอวัยวะ(p=0.008). ปัจจัยเสี่ยงใหม่ที่พบว่ามีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติในการศึกษาครั้งนี้ได้แก่ สถานบริการที่ไปรับการรักษาครั้งแรก (p=0.004) การมีแผล(p=0.009) สำหรับในกลุ่มผู้ที่ไม่ป่วยด้วยโรคเรื้อน พบว่าปัจจัยเสี่ยงที่มีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติต่อการรับรู้การตีตราของโรค ได้แก่ อายุ (p=0.021) ระยะเวลาของการศึกษา (p=0.024) อาชีพ (p=0.002) และ การมีความรู้น้อยในเรื่องโรคเรื้อน

บทสรุป: ปัจจัยเสี่ยงสำคัญที่มีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติต่อการรับรู้การตีตราของโรค ได้แก่ การมีความรู้น้อยในเรื่องโรคเรื้อน การปรากฏความพิกลพิการของอวัยวะ การที่จะลดการตีตราต่อโรคเรื้อน ควรมุ่งการพัฒนาการให้ความรู้เรื่องโรคเรื้อน

สาขาวิชา : สาธารณสุขศาสตร์ ลายมือชื่อนิสิต:……………………………………..

ปีการศึกษา : 2555 ลายมือชื่อ อ ที่ปรึกษาวิทยานิพนธ์หลัก: ……………

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NILS KAEHLER: RISK FACTORS OF PERCEIVED STIGMA IN LEPROSY AFFECTED AND NON-AFFECTED PERSONS IN NON SOMBOON, KHON KHAEN PROVINCE, THAILAND.
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Background: Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English. The most common notion of stigma, however, still refers to people's fear of dealing with leprosy-affected people. This is often due to a lack of scientific knowledge and suspicious ideas about the disease. This study investigated risk factors of perceived stigma in leprosy affected persons living in Non Somboon *l*eprosy colony in Khon Kaen province, Thailand, and in non-leprosy affected persons living in the community nearby.

Methods: This is a cross-sectional study design to assess risk factors for stigma in leprosy affected and non-leprosy affected persons in Non Somboon, Thailand. 265 leprosy–affected subjects and 257 non-leprosy affected subjects were studied via questionnaire and interview.

Results: Some of the results of this study agreed with findings in earlier studies. As for leprosy-affected persons, there was a significant association between perceived stigma and occupation (p=0.013), low knowledge on leprosy (several sub-categories) and visible disfigurements (p=0.008). New risk factors were found to be the initial location of treatment (p=0.004) and the presence of ulcers (p=0.009). For non-leprosy affected subjects it was age (p=0.021), years of education (p=0.024), occupation (p=0.002) and poor knowledge on leprosy that had a significant impact on the level of perceived stigma.

Conclusions: Major factors that were associated with perceived stigma in leprosy were poor knowledge on the disease and visible or noticeable disfigurements. Strategies to reduce perceived stigma should therefore focus on the improvement of health educational programs on leprosy.

Field of Study: Public Health Student's Signature

Academic Year: 2012 Advisor's Signature

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LIST OF ABBREVIATIONS

CBR	Community Based Rehabilitation
EMIC	Explanatory Model Interview Catalogue
ILEP	The International Federation of Anti-Leprosy Associations
MB	Multi Bacillary
MDT	Multi Drug Treatment
MKS	Modified Kuppuswamy Scale
PB	Pauci Bacillary
PR	Prevalence Rate
PSQ	Perceived Stigma Questionnaire
SEA	South East Asia
SEARO	South East Asia Regional Office
SALSA	Screening of Activity Limitation and Safety Awareness
SF-36	Short Form of Medical Outcome 36 Items
WHO	World Health Organization

CHAPTER I

INTRODUCTION

1.1 Background and Rationale

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English (1). Stigma has been defined variously since the beginning of its use and derived its meaning in different aspects of sociology and clinical science. The most common notion of stigma, however, still refers to people's fear of dealing with leprosy-affected people. This is in most cases due to a lack of scientific knowledge and suspicious ideas about the disease (2).

The fact that most untreated leprosy cases, and even some of those who underwent full treatment, may end up with severe disfigurement, has contributed to the process of stigmatization (3).

The impact that stigma has on the leprosy-affected person's life, shows a wide variety of complications ranging from effects on mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious events (4).

Considering the severity in terms of human suffering, the consequences of stigma in leprosy often outweigh the burden of physical afflictions. Many people may live a normal and dignified life even with severe physical impairments, as long as they are accepted and respected by those around them and are able to participate meaningfully in the society in which they live(4).

The development of stigma in leprosy can have different causes like fear, unattractiveness; unease of how to deal with leprosy affected persons, superstition and false believes and has been topic to earlier studies (5-8).

It is important to clarify that stigma is a complex expression, which is used for both the stigmatized, the affected person, as well as for 'the stigmatizer', the non-affected person, who stigmatizes others, intentionally or unintentionally. Identifying risk factors that contribute to the process of stigmatization is therefore of highest important when combating this burden of the leprosy sufferer.

For example, if a leprosy affected or non-affected person has better knowledge on the disease, he might be more resistant to stigmatization and consequently stigma may not occur or in a less intense matter.

With a better knowledge of risk factors of stigma in leprosy, appropriate treatment to fight stigmatization can be initiated at an earlier stage and may reduce the cruel consequences of stigma and it's possible defacing secondary physical outcome(5).

This study looked for risk factors of stigma in leprosy affected persons living in Non Somboon leprosy colony in Khon Kaen province, Thailand, as well as in non-leprosy affected persons living in the community nearby.

1.2 Statement of the problem

Stigma has a strong negative effect on the quality of life of persons affected by leprosy. It can cause severe psychological- but also secondary physical damage due to hiding the disease, in order to prevent possible discrimination, instead of seeking for medical help when discovering first signs and symptoms of leprosy(6). Preventing stigma is therefore of highest importance when dealing with leprosy-affected persons. Certain risk factors support the process of stigmatization and its early detection may help to improve its treatment and the outcome of the disease.

This study looked for these factors within leprosy-affected persons living in a leprosy camp, as well as in unaffected persons living in the nearby community. All assessment were in regard to their current health situation and location of living.

1.3 Purpose and objectives

This study was looking for risk factors that contribute to the development of stigma in leprosy affected and non-affected persons. The leprosy-affected subjects were living in Non Somboon leprosy colon in the Khon Khaen province, Thailand. The non-leprosy affected persons were living in the community nearby.

The following factors were assessed for their contribution to stigmatization in leprosy:

For the leprosy affected person:

- Socio-demographic characteristics:
    - Age, sex, religion, ethnicity.
    - Family history and family medical history.
    - Education and occupation.
    - Financial status

- Knowledge on leprosy (cause, transmission, signs and symptoms)
- Physical affection by leprosy?
    - Symptoms
    - Signs
    - Treatment history (initiation time related to first symptoms, initiator?)
    - Level of health institution
    - Disability grading (WHO)
    - Leprosy reaction in medical history

For the non-leprosy affected person:

- Socio-demographic characteristics:
    - Age, sex, religion, ethnicity.
    - Family history and family medical history.
    - Education and occupation.
    - Financial status
- Knowledge on leprosy (cause, transmission, signs and symptoms)

1.4 Research Questions

Main Research questions:

1. What are risk factors of stigma in leprosy-affected persons that contribute to the development of stigma?
2. What are risk factors of stigma in non-leprosy affected persons, the potential stigmatizers who live in the nearby community, which contribute to the development of stigma?

Secondary Research Questions:

- What are the affected and non-affected person’s socio-demographic characteristics?
- What is the affected and non-affected person’s knowledge on leprosy?
- What is the affected persons medical history on leprosy?
- What is the affected person’s physical affection by leprosy?
- What is the affected person’s disability according to the WHO classification

1.5 Research hypotheses

1. There is an association between defined socio-demographic characteristics (age, sex, religion, ethnicity, family history, family medical history, education, occupation and financial status, duration of stay, age at diagnosis) and stigma in leprosy.
2. There is an association between the affected- and non-affected person’s knowledge on leprosy and stigma in leprosy
3. There is an association between the affected person’s physical affection of leprosy and stigma in leprosy.

1.6 Conceptual Framework

Independent variables ***Dependent variables***

Leprosy affected:

1. ***Socio-demographic characteristics***
   - Age, sex, religion, ethnicity
   - Location
   - Duration of stay
   - Marital status
   - Family medical history
   - Education
   - Type of occupation/work
   - Financial status
2. **Knowledge on leprosy**

   Information, cause, infectiousness, transmission, treatment, signs and symptoms
3. **Physical effect**
   - Level of health institution
   - Clinical history
   - Deformities
   - Chronic ulcers and odor
   - Disability grades (WHO*)*
   - Leprosy reaction

→ **Perceived stigma in leprosy affected persons, nature and severity**

Non-Leprosy affected:

1. **Socio-demographic characteristics**
   - Age, sex, religion, ethnicity
   - Duration of stay
   - Marital status
   - Family medical history,
   - Education
   - Type of occupation/work
   - Financial status
2. **Knowledge on leprosy**

Information, cause, infectiousness, transmission, treatment, signs and symptoms

→ **Perceived stigma in non-leprosy affected persons, nature and severity**

1.7 Operational definitions

- **Leprosy affected person**: A person with a medical history of leprosy based on his medical record or medical approval.
- **Leprosy unaffected person**: A person with no medical history of leprosy and no current evidence to have leprosy, which will be confirmed by a study investigator as medical officer. The person is living in a near-by community from the Non Somboon leprosy colony, Khon Khaen, Thailand.
- **Perceived Stigma:** Perceived stigma in this study refers to the outcome measured by EMIC scale in leprosy affected and non-leprosy affected persons. The higher the outcomes score of EMIC, the higher the perceived stigma.
- **Disfigurement/deformity**: A visible part of the body that spoils the appearance or completeness of the whole body, which occurred after a known infection with leprosy.
- **Disability**: Disability is defined according to the WHO classification of disability in leprosy-affected persons. It only describes disabilities in hands, feet and eyes. This classification grades disability into 3 grades.
    - ‘Grade 0’ - no disability was found.
    - ‘Grade 1’ - loss of sensation in the hand or feet.
    - ‘Grade 3’ - visible damage to the hands or feet, or pathological affection of the eyes.
- **Perception**: The way in which something is regarded, understood, or interpreted.
- **Attitude**: A settled way of thinking or feeling about something (leprosy or a leprosy-affected person).
- **Risk factor of stigma in leprosy**: A factor contributing to the development of stigma associated with leprosy. Risk factors can be within the patient affected by leprosy or in the non-affected person within the community. Risk factors in this study mean any of the factors out of socio-demographic characters, history of the disease development, clinical presentation and disability grades, which have potential to change the outcome as stigma of leprosy.

- **Leprosy reaction:** A medically verified reaction that may occur under infection with leprosy and which can lead to obvious visible changes.
- **Knowledge on leprosy:** The knowledge of leprosy will be in regard to the participant’s knowledge on leprosy dependent on the answers within the questionnaire of this study.
- **Occupation/work:** Any kind of paid or unpaid activity that a person does to contribute to his own economical situation or to the well being of others.
- **Chronic ulcer:** A persisting wound or skin-defect that has not been healed over a period of 3 months.
- **Family medical history:** The families’ medical history concerning leprosy affection.
- **Primary health center**: A health center which is run by a group of health workers and lead by a medical officer. It usually carries basic laboratory facilities and primary management facilities.
- **Local hospital**: A local hospital refers to any hospital near the vicinity where a patient seeks health problems. Local hospitals usually have moderate size laboratory facilities, few beds with or without a medical officer but essentially health workers.
- **Tertiary hospital**: Tertiary hospital refers to the hospital with all kinds of specialist facilities, laboratory facilities; surgical care facilities, inpatient wards and outpatient department.

CHAPTER II

LITERATURE REVIEW

2.1 Natural history of Leprosy

Leprosy has tormented humans throughout recorded history. The earliest possible account of a disease that many scholars believe is leprosy appears in an Egyptian Papyrus document written around 1550 B.C. Around 600 B.C. Indian writings describe a disease that resembles leprosy. In Europe, leprosy first appeared in the records of ancient Greece after the army of Alexander the Great came back from India and then in Rome in 62 B.C. coinciding with the return of Pompeii's troops from Asia Minor.

Throughout its history, leprosy has been feared and misunderstood. For a long time leprosy was thought to be a hereditary disease, a curse, or a punishment by God. Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. As an example, in Europe during the middle Ages, leprosy sufferers had to wear special clothing and ring bells to warn others that they were close and had to walk on a particular side of the road, depending on the direction of the wind.

Until today, the stigma of leprosy has caused that leprosy treatment has often occurred in separate hospitals or institutions and people livedin special colonies, called leprosaria. Since it has been prevalent in multi-cultural communities throughout the history and has swept along the different cultural aspects and beliefs making itself a complex socio-clinical entity.

Modern history of Leprosy began after the discovery of ‘*Mycobacterium leprae’* by the Norwegian scientist Dr. Gerhard Henrik Armauer Hansen in 1873.Since the identification of the bacilli, several types of treatment have been developed, among them Chaulmoogra nut oil, which has long been an injectable drug until the 1940s. This drug seemed to be popular in those days despite that it was beneficial to only some patients and often caused severe pain under application. A

Leprosy research center in Louisiana, United States, introduced in 1942 a following drug called ‘Promin’, a sulfonic-derivate, which unfortunately experienced early resistance. ‘Promin’ was soon followed by the discovery of ‘Dapsone’ in the 1950s, which was highly efficient but again, developed early problems with resistance. Not until the 1970s, the concept of ‘multi-drug treatment’ (MDT) was developed, which significantly reduced the risk of resistance. Nevertheless, it was only in 1981, when the World Health Organization finally recommended the use of ‘MDT’ as Gold Standard Method (9).

2.2 Epidemiology of Leprosy

2.2.1 Global Leprosy Situation

According to the official WHO report from 2012 (received from 105 countries and territories), the global registered prevalence of leprosy at the beginning of 2012 stood at 181 941 cases. The number of new cases detected during the year 2011 was 219 075 compared with 228 474 in the year 2010.

There are still pockets of high endemicity in some areas of Brazil, Indonesia, Philippines, India, Democratic Republic of Congo, Madagascar, Nepal, Mozambique and the United Republic of Tanzania. All endemic countries show a high commitment to eliminating the disease and continue to intensify their leprosy control activities(10). The global prevalence rate of leprosy is illustrated in Figure 1 below.

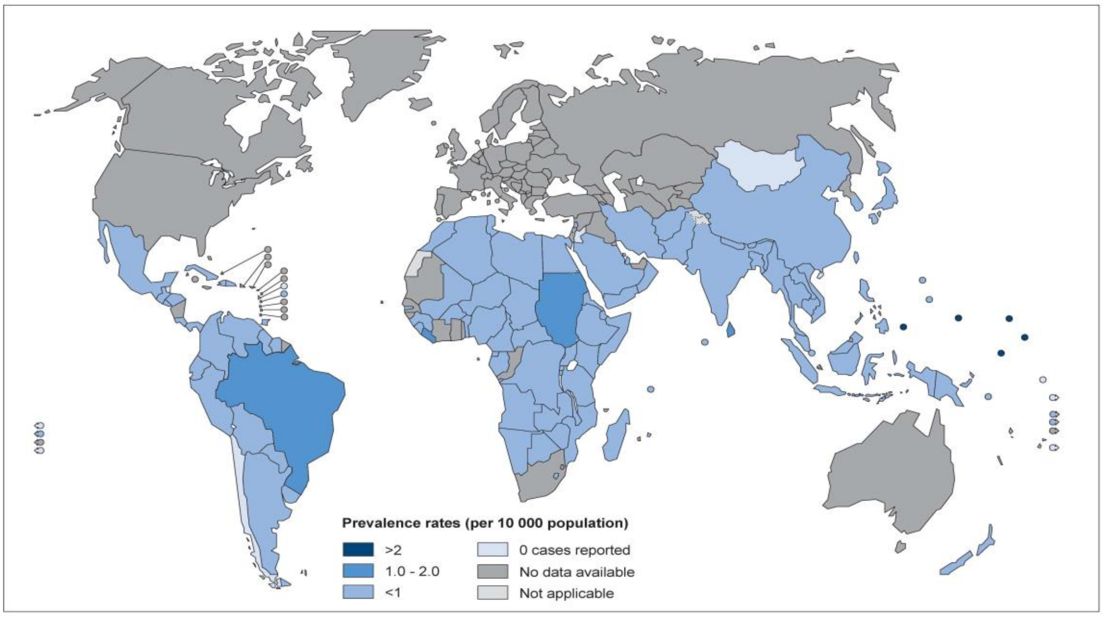

Figure 1: Global leprosy prevalence rates reported to WHO as of beginning of January 2011(10)

When considering the impact of leprosy it is not only the numbers of new cases being detected and treated that has to be taken into account. Many of those patients cured of the disease will have to live with the consequences of leprosy for the rest of their life. It is estimated that at least 3 million people are living worldwide with some form of permanent disability due to leprosy, although the exact figure remains unknown(8).

2.2.2 Leprosy in South East Asia

Countries in the South East Asia region contributed to about 69% of the total 2005 global new case detection. The Regional prevalence rate steadily declined from 4.6/10,000 populations in 1996 to 0.82/10,000 population as of July 2006.The Regional new case detection also declined from a peak of 47.8/100,000 in 1998 to 11.9/100,000 as of March 2006.Between 1985 and 2005, more than 15 million leprosy cases were cured globally. Of these, about 12.8 million were from the SEA Region, of which India accounted for about 11.8 million. The SEA Region has achieved the goal of elimination of leprosy as a public health problem i.e. prevalence <1 case per 10,000 population, in December 2005. This has made a substantial contribution to the achievement of leprosy elimination globally(11).

The figure below shows the prevalence rates of Leprosy as on November 2005 in South East Asian countries with the highest level of prevalence in Northern India and Nepal. However the prevalence rate has been steadily falling as both Nepal and India both achieved the Elimination in 2009 and 2005 respectively.

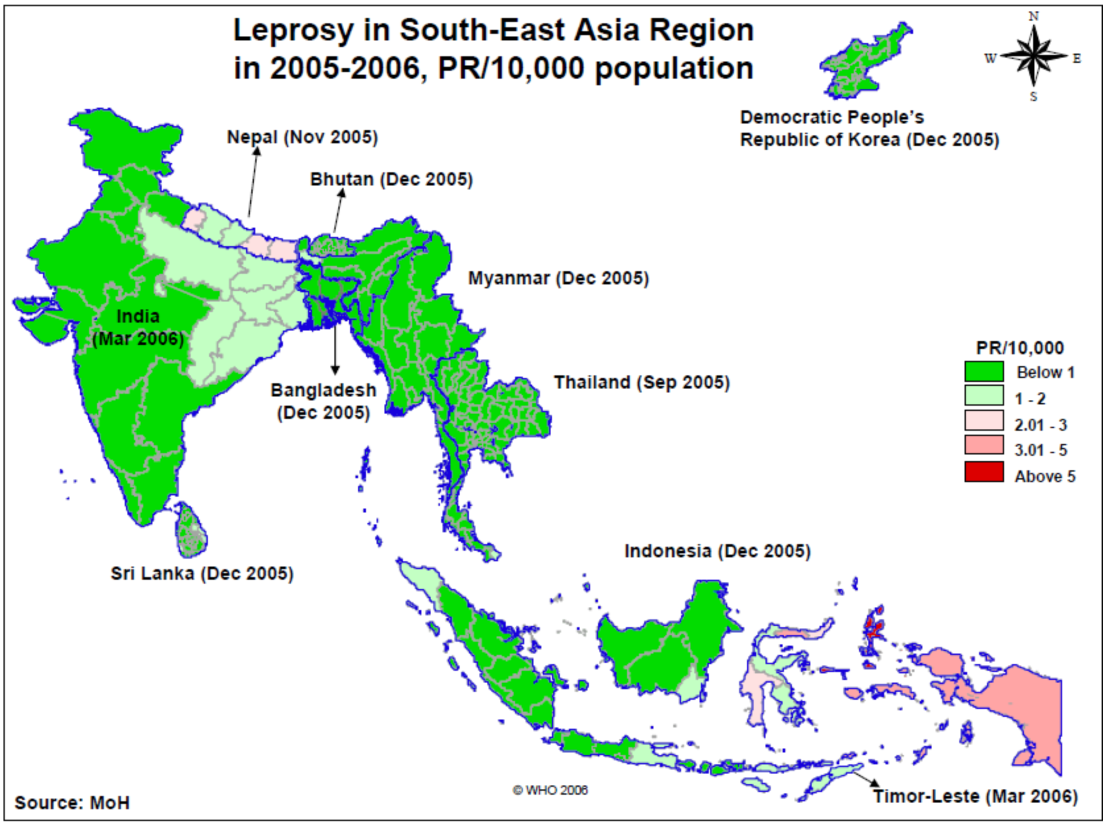

Figure 2: Prevalence rates of leprosy in South East Asian countries 2005-2006 (11).

2.2.3 Leprosy in Thailand

The incidence of leprosy in the year 2010 in Thailand was 405 new detected cases. A sub-specification of the incidence counts between 2004-2010 is illustrated in *Table 1 and Figure 3* below.

Table 1:Incidence rates of leprosy in Thailand

Year	Newly detected cases	No. of new cases MB (a)	No. of new cases female cases	No. of new cases among children (b)	No. of new cases with G2D (c)	Relapses
2004	652	416		40	72	
2005	638	414	234	32	77	
2006	665	454	253	30	95	
2007	506	322	200	17	58	6
2008	401	275	167	12	49	6
2009	300	215	108	11	41	16
2010	405	267	159	26	60	9

a: MB = Multibacillary leprosy

b: Children are cases 0-14 years

c: New G2D = WHO grade 2 disabilities among new cases

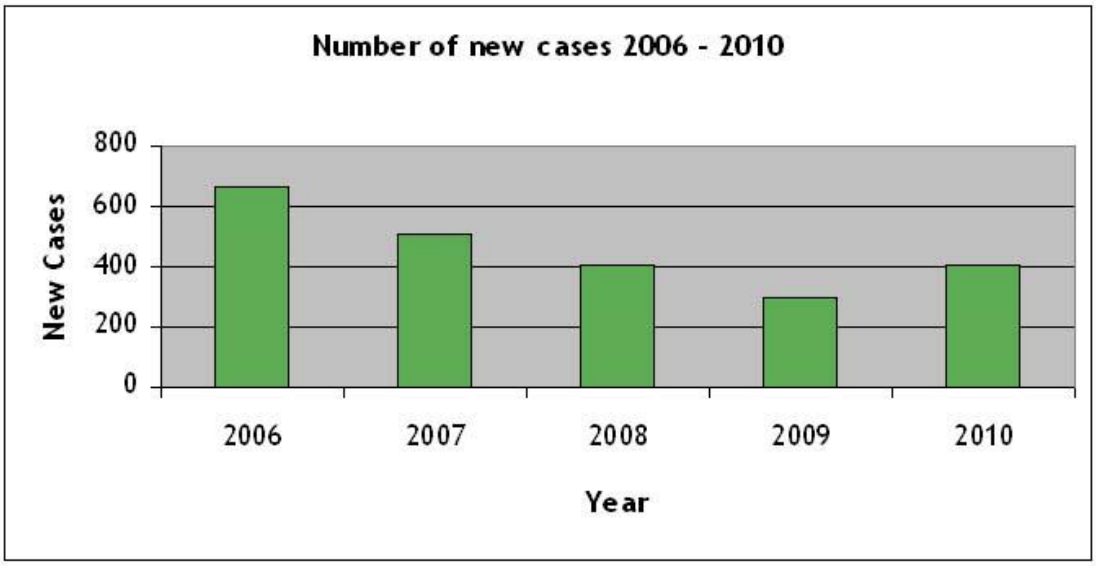

Figure 3: Incidence of leprosy in Thailand (10)

The prevalence of leprosy in Thailand in September 2005 was 0.21 per 10.000population. By that time the elimination was achieved in 75 of the 76 provinces(12). The regional prevalence rates of Thailand are illustrated in *Figure 4*below.

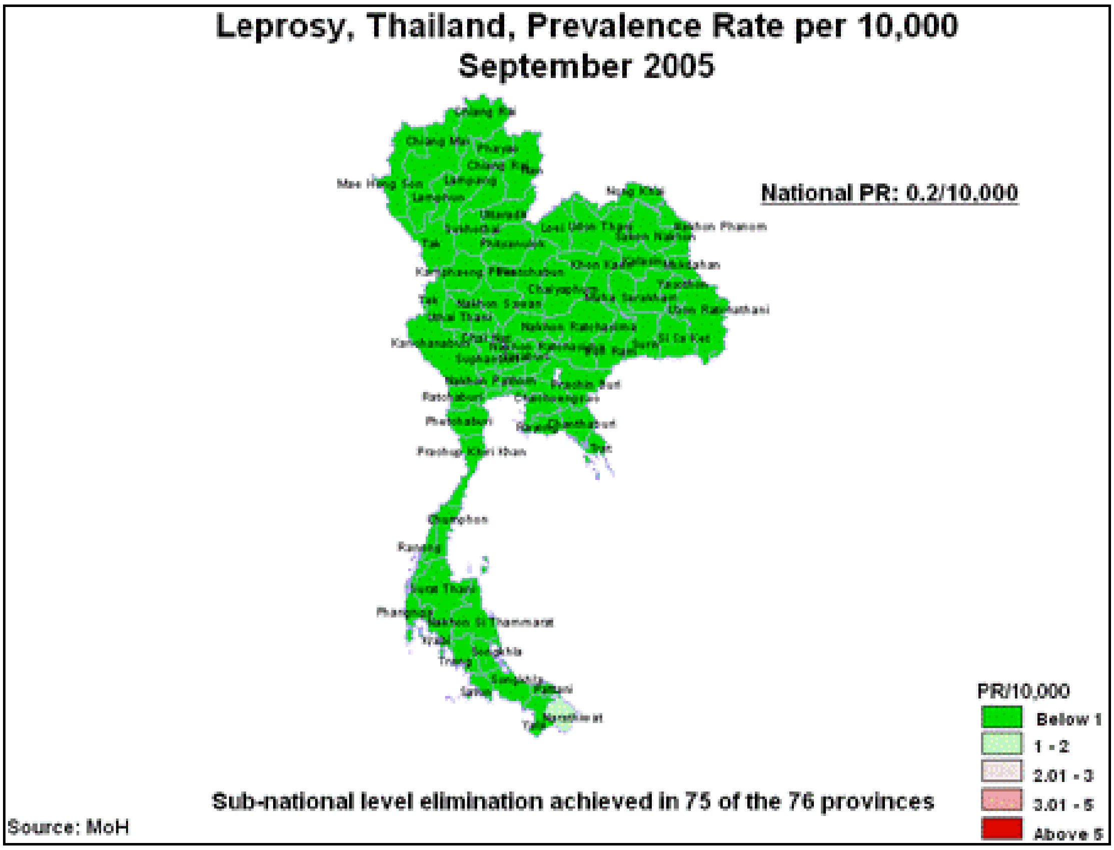

Figure 4:Prevalence of leprosy in Thailand (12)

In this context, the WHO defines “elimination” as the reduction of the proportion of leprosy patients in the community to very low levels, specifically to below one case per 10 000 population (13).

2.3 Transmission of leprosy

Leprosy is caused by a slow-growing bacillus called ‘*mycobacterium leprae’* and is most likely transmitted through droplets from the nose and mouth of untreated patients who suffer of severe disease. However, leprosy is not highly infectious, as still believed by many people. If left untreated though, the disease can progress and cause nerve-damage leading to muscle weakness and atrophy as well as to the classical deformities and disabilities(11).The incubation period is very long, usually between 2 and 8 years but may last up to 20 years in some cases. Casual contact with a person affected by leprosy does not seem to lead to infection. The evidence suggests that residence for several years in an endemic area is needed before the risk of infection becomes appreciable(8).

2.4 Signs and symptoms of leprosy

The following are typical signs or symptoms of leprosy that may occur during the disease:

- Pale or reddish patches on the skin (the most common sign of leprosy).
- Loss or decrease of sensitivity in the skin patches.
- Numbness or tingling of the hands or feet.
- Weakness of the hands, feet or eyelids.
- Painful or tender nerves which are often thickened and palpable.
- Swelling or lumps in the face or earlobes.
- Painless wounds or burns on hands or feet.

Although the majority of leprosy patients have typical skin lesions, which are often easy to see, experienced workers might have difficulties to differ them from other skin diseases or even normal skin varieties. This is caused by the enormous variety of skin lesions that leprosy may present. If a clear differentiation is not possible, typical symptoms and signs, like a locally reduced sensitivity of the skin, become more important for proper recognition. However, the diagnosis of leprosy should be made with a reasonable degree of certainty as it may have adverse social consequences.

Leprosy may present with at least one of the following cardinal signs(14):

1. Loss of sensation in a pale (hypo-pigmented) or reddish skin patch.

2. A thickened- or enlarged peripheral nerve with loss of sensation and/or weakness of the muscle supplied by that nerve.

3. The presence of acid-fast bacilli in a slit skin smear.

2.5 Disabilities in leprosy

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person. Disability is more than a mere physical dysfunction and includes activity limitations, stigma, discrimination and social participation restrictions (5). Disability has long been taken as an indicator of the stigmatization in leprosy as it can cause the progressive and permanent physical disabilities (15). Every new case of leprosy must be assigned a disability grade, which shows the condition of the patient at diagnosis. The World Health Organization (WHO) classifies leprosy related disabilities into three grades (5):

1. **Grade 0,** means no disability found.

2. **Grade 1,** means loss of sensation noted in the hand or foot (eyes are excluded from grade 1). Loss of sensation in hand or foot means that one of the main peripheral nerve trunks has been affected by leprosy. This is more common in later stages of the disease than at time of diagnosis. It should not be confused with the loss of sensation in a skin patch, which is caused by local damage to the small nerves in the skin, and not to the main peripheral nerve trunks. People with loss of sensation on the soles of their feet, but no other abnormality, are at high risk for developing plantar ulcers.

3. **Grade 2,** means visual damage or disability is noted. The eyes can be affected by the inability to close them fully, or an obvious redness is visible, often caused by either a corneal ulcer or by uveitis. Visual impairment or blindness also qualifies for a disability ‘grade 2’.Regarding the hands and feet, visible damage includes wounds and ulcers, as well as deformity due to muscle weakness, such as a drop-foot or a claw-hand. Loss of tissue, such as the loss or partial or complete fingers or toes is a late sign in leprosy, but also qualifies for a disability grade of 2.

2.6 Reactions in leprosy

Leprosy reactions may occur in 25% of all patients at any time after infection. They are immune phenomena with signs of severe inflammation. As they promote nerve damage, they contribute significantly to the accompanying deformity and disability associated to leprosy (16, 17). A leprosy reaction is suspected when appearing of new lesions, worsening or exacerbation of old lesions and appearance of tender nodules in the skin (17). The following are typical symptoms of a leprosy reaction:

- *Skin*: inflammation of skin patches
- *Nerves*: new loss of sensation, new muscle weakness, pain or tenderness in a nerve.
- *Eye*: New loss of vision, weakness in eye muscles, redness and pain of the eye

There are two types of leprosy reaction:

Type 1 reaction: This type is also called a reversal reaction, which is caused by the increased activity of the body's immune system when fighting the leprosy bacteria. This reaction leads to strong inflammation wherever there are leprosy bacteria in the body, which is mainly in the skin and the nerves. About 25% of all people are affected by this reaction and it occurs mostly within the first 6 months of treatment. It is more a local reaction and generalized symptoms are seldom(18).

***Type 2 reaction*:** This reaction is also called erythema nodosum leprosum (ENL), and occurs when large numbers of leprosy bacteria get killed and eliminated. This leads to an allergic reaction, which is provoked by some of the bacteria's proteins. This reaction usually comes with generalized symptoms, as the proteins are present in the peripheral bloodstream. In Asia reported figures vary between 19-26% of Type 2 reactions (19), which often occur during the first 3 years after start of leprosy treatment(18).

As leprosy reactions do contribute to the development of disfigurement and disability, it consequently might play a supporting role in the process of stigmatization, as well.

2.7 Ulcers in leprosy

About 10% of leprosy affected persons will develop ulcer at any one time. Despite of that low percentage, most people cannot imagine a leprosy patient without it. This shows how intensely leprosy is identified with this symptom (20). Ulcers in the feet are considered of greatest importance because impaired mobility due to ulcers is a serious restriction for leading a normal life in society. In addition to that, the frequent bacterial infections of the ulcers can lead to strongly displeasing smell and cause rejection and ostracisation by society, Ulceration of the feet is considered as the most common cause of morbidity and rehabilitation in leprosy affected persons.

Based on the existence of pre-existing nerve damage, ulcers can be categorized as ‘neuropathic’ or ‘non-neuropathic’:

- *Neuropathic ulcers* only occur at locations where there is a partial- or total sensory nerve deficit and this area gets physically damaged by the external world. Neuropathic ulcers are therefore mostly found under the feet and described as ‘plantar’ or ‘extra plantar’ ulcers. Neuropathic plantar ulcers are clinically the most important ones and account the major cause for WHO grade-2 disability in leprosy patients (21).

- *Non-neuropathic ulcers* are not caused due to a nerve dysfunction and can be divided into specific- and non-specific ulcers. Specific ulcers are considered as part of the process and clinical picture of leprosy. Non-specific ulcers are not part of the leprosy pathology and are usually ulcers caused by stasis. Specific ulcers can be sub-specified into leprous ulcers, as seen in advanced cases of lepromatous leprosy, and reactional ulcers, as found in association with severe leprosy reaction Type 2 (ENL)(20).

2.8 Stigma

2.8.1 Definition of stigma

The most conventionally used definition of ‘Stigma’ was introduced by Goffman in 1963as “the attribute that is deeply discrediting” and “that reduces the bearer from a whole and usual person to a tainted, discounted one.” Thus, Goffman’s definition rendered the stigma as a relationship between attribute and stereotype(22). Conceptualization of stigma exists, when all its components have been put in order to make them comprehensible. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics – to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of them to us. In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion, and discrimination(23). Along with the series of concepts in stigma, an operational definition of stigma has been compiled with the inclusion of all the components and dimensions by Van Brakel as following(24) ;

1. A social process that exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows for them to exist(23).

2. A social process or a related personal experience characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition (25).

2.8.2 Circle of stigmatization

Stigmatization usually starts with the process of 'labeling' of a person who is perceived to be different, e.g. a person affected by leprosy. This is to mark the difference and to distinguish him from others. In the second step, this labeled person gets linked to a certain negative stereotype, which often is rooted in society and which pretends to describe how that person really is. People now no longer see the actual person but only his stereotype and tend to separate themselves from him. Consequently, the stigmatized person looses his status in society, which leads to actual discrimination and which again supports the process of labeling (26). The circle of stigmatization and its different components are illustrated in *Figure 5*below.

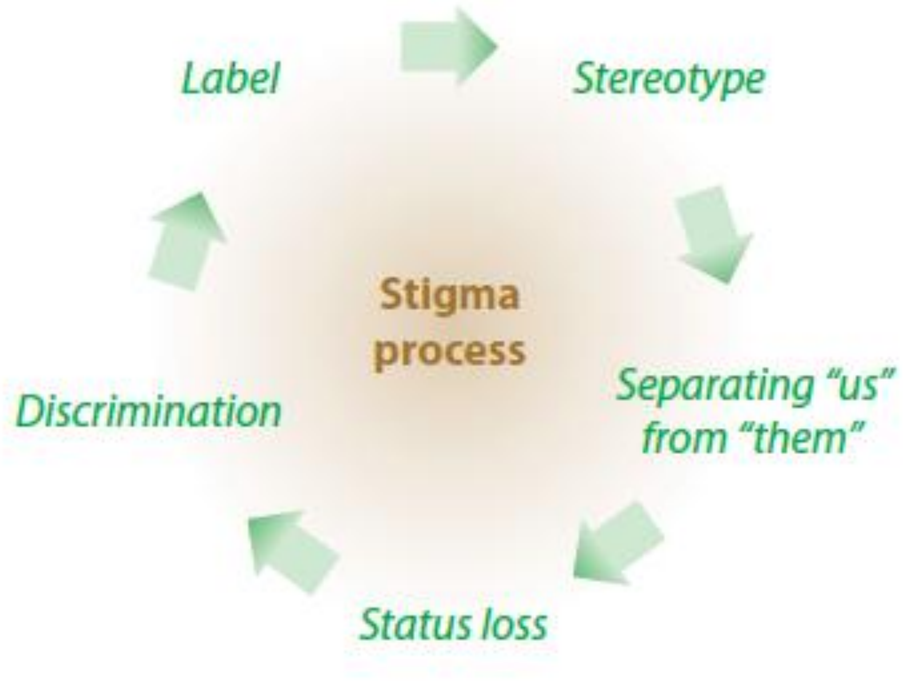

Figure 5:Circle of stigmatization (26)

2.8.3 Process of stigmatization

A proper understanding of the process or development of stigma is crucial for planning strategies to reduce it. Stigma associated with leprosy does not start immediately after the disease has started, but develops over time in two stages (27, 28):

I. *Stage 1* - the cognitive dimensions. This first stage describes how certain cognitive dimensions lead to different affective responses towards the disease.

II. *Stage 2* - the affective stage. This stage shows how those affective responses contribute to the social devaluation of the leprosy-affected person and may lead to the adoption of negative behavior towards them.

Heijnders describes a similar process of stigmatization in her studies in Nepal, where people with leprosy go through two stages in coping with their condition: the first phase as the concealment phase and the second one as the exposure phase. In moving from one phase to the other, there are triggers to discrimination and exposure such as the visible signs of the disease. However, she found that in the process, stigma enforces the inequalities that are found in the community with regards to age, gender and social class(29).

Summarized, the mechanism of stigmatization is a complex phenomenon combining cognitive and affective components. Thus, the causes of stigma can range from fear, anger and pity influenced by the attributes of the affected individual or the attributes of the society where he/she lives in.

2.8.4 Types of stigma

There are three types of Stigma (26, 30):

1. *Perceived/anticipated or felt-stigma:*

   This type of stigma arises out of fear within the affected person, the fear of being discriminated against and awareness of negative attitudes or practices in society. This type of stigma arises out of the individual's perception and not necessarily by any real discrimination or practice. This study focuses on the assessment of perceived stigma within the leprosy-affected persons and to which extent non-affected persons in the community bear a negative attitude towards the affected ones.

2. *Experienced or enacted-stigma, discrimination:*

This is the most common type of stigma in which there are actual experiences of discrimination. This occurs when any member of society, healthcare provider or person in the surrounding behaves negative or discriminates by some means to the affected person.

3. *Internalized or self-stigma:*

Continuous stigmatization to a person over a long time may make the affected person believe what others think and say about him. This experience may lead to loss of self-esteem and dignity, fear and shame as well as hopelessness and guilt. People may start excepting diminished expectations about themselves and start behaving accordingly. As a result, this may finally lead to social exclusion and rejection by society in the same way as discrimination.

2.8.5 Assessment of stigma

Stigma assessment is broadly classified into two categories:

1. The first one assesses stigma ‘within the affected person’.
2. The second one assesses stigma ‘within the communities’.

Studies on stigma assessment have therefore been either one of the following two types (4):

- Studies that assess the effects of stigma ‘on the person affected’.
- Studies that assess attitudes and/or practices ‘towards people affected by leprosy’.

Dependent on the type of stigma and the analyzed group (affected person or community), there are several types of tools designed to assess stigma. Different tools for the assessment of different stigma dependent on the stigmatizing or stigmatized object are classified in the following *table 2(26).*

Table 2:Different tools to assess stigma in leprosy, ILEP guidelines (26)

	Type of Stigma	Tools
Leprosy affected persons	**Perceived stigma**; anticipated- or felt stigma	**EMIC-a (31)** *'Explanatory Model Interview Catalogue - affected',* Jacoby Scale
	Experienced or enacted stigma; discrimination	Questionnaire
	Self stigma; internalized stigma	ISMI *'Internalized Stigma of Mental Illness'*
	Participation restriction	P-scale *'Participation scale'* GPAS scale *'Green Pastures Activity Scale'*
Community members	**Perceived stigma**	**EMIC-c (31)** *'Explanatory Model Interview Catalogue - community',*
	Attitude stereotypes	None
	Attitude emotional reaction	None
	Attitude social distance	SDS *'Social Distance Scale'*

2.8.6. The Explanatory Model Interview Catalogue (EMIC)

As this study is focusing primarily on the assessment of perceived stigma, the EMIC (*Explanatory Model Interview Catalogue)*, adapted for leprosy–affected persons (EMIC-a) and non-leprosy-affected persons (EMIC-c) was selected as instruments of choice.

This catalogue has been developed to study cultural meanings of leprosy, its emotional impact and compliance with treatment, and to elicit illness-related perceptions, practices and beliefs (31). The explanatory models are rooted in local cultural concepts and reflect the way people think about themselves, their world, health and health problems.

The EMIC was first introduced in 1986 in Bombay, India, to elicit illness-related perceptions, beliefs and practices in a cultural study of leprosy and mental health(31). Leprosy was chosen to be an appropriate disease to investigate the inter-relationship of culture, medical illness and mental health, because of leprosy's deeply rooted cultural meanings, its emotional burden on the affected persons and the underuse of effective treatment. The results indicated that more than 20% of the participants believed magico-religious or germs/dirt as the reason for their leprosy infection and half of the patients were affected by depression or anxiety. Those patients believing in a humoral cause (heat, cold, wind, bile) of the disease actually had a higher attendance at the leprosy clinic for treatment and follow up. This shows how important the consideration of cultural meanings and beliefs can be for the outcome of a disease (31).

For a better understanding of the '*Explanatory Model Interview Catalogue',* two terms distinguishing frameworks for social analysis need to be clarified:

1. *Emic*, the insiders' perspective. A study that describes local concepts of health and illness among patients for whom these concepts are meaningful. An 'emic' model is rooted in local cultural concepts, reflecting the way people think about their world, themselves, health and health problems. The focus is on the description of ideologies of local communities.

2. *Etic*, the outsiders' perspective. Describes exogenous professional ideologies, like epidemiological surveys of professionally defined categories, for example, on influenza, malaria or social class.

This distinction of emic and etic perspectives was first described by Kenneth Pike in 1954 and was based on principles derived from comparative linguistics (32). Subsequent comparable formulations, applied to medical anthropology and social medicine, of the underlying dichotomy distinguishing local insider and professional outsider perspectives include the relationship between explanatory models and clinical diagnoses and the relationship between illness and disease. Emic and etic perspectives provide a framework for a better understanding of the relationship between biomedical models and the patients' experiences. Nevertheless, the relationship between local and professional ideas about a disease is not necessarily always dichotomous or clear, as professional medical ideologies may influence popular ideas about the disease. This may be caused by the patients' interactions with medical professionals, acquired knowledge and opinion through health education, the media or medical writings. Summarized, explanatory models do refer to both independent and locally rooted concepts as well as to local interpretations of professional ideas. This explains, that ideas about illness are not always easily classifiable into 'emic' and 'etic'(33).

The instruments used to assess perceived stigma in this study will be two versions of the '*Explanatory Model Interview Catalogue' (EMIC-a& EMIC-c*), adapted for *leprosy-affected* and *non leprosy-affected* persons.
The questionnaires contain questions related to:

- Stigma and disclosure of the disease
- Self-esteem
- Stigma affection of family members
- Psychological and social impact
- Illness-related problems and concerns

- Marriage and marital relations
- Stigma affection during occupation and/or job search
- Fear of ostracisation or exclusion from society

One part of the ‘EMIC’ is a stigma scale, which measures the level of perceived stigma (26).

This stigma scale was recently tested by Rensen et al. at two different locations in India (34). They compared levels of stigma in two different groups, leprosy-affected persons living in ‘Community Based Rehabilitation’ (CBR) areas and similar affected ones in non-CBR areas, functioning as leprosy control group. In addition a group of non-leprosy affected person was included, as non-affected control group, to provide reference data for calculation of cut-off values for ‘normal-’ values. The EMIC catalogue, which was used in this study, contained 17 Likert items for leprosy-affected persons and 13 Likert items for non leprosy-affected person. For each answer different points were given, for ‘‘yes’’ 3 points, for ‘‘possibly’’ 2 points, for ‘uncertain’’ 1 point and answer ‘‘no’’ gave 0 points. The total score was then calculated by adding the scores of each question and ranging it from 0-54 points for leprosy affected persons and from 0-39 points for non-leprosy affected persons (EMIC community-score). The higher the total score, the higher the level of perceived stigma. Crohnbach’s α was considered as good between 0.70 and 0.95. The test-retest reproducibility was 0.70and the internal consistency was 0.88. They observed the largest difference in median-EMIC score between the groups with- and without visible signs of leprosy. A further significant difference was found within the leprosy-affected group with visible signs between the CBR and the control group.

The EMIC was suggested as an effective part of a stigma assessment toolkit (34). The EMIC scale was used in several other studies in different developing countries and with a large variety of conditions, confirming its generic character (31, 33, 35, 36). It has furthermore been classified as instrument to measure perceived stigma in leprosy by ‘The International Federation of Anti-Leprosy Association’ (ILEP)(26).

2.8.6.1 EMIC-a & EMIC-c

This study uses both *EMIC-a (affected) and EMIC-c (community, non-affected)* for the assessment of perceived stigma in leprosy-affected persons and non-leprosy affected persons. Both questionnaires contain each 15 questions. All questions will be presented to the participant by a study investigator in form of a face-to-face interview. The questionnaires have been translated into Thai language and retranslated into English for validity.

1. ***EMIC-a*** **(for the 'affected' person)** -For each question, one mark will be given according to the right answer:

    - Yes (3 points)
    - Possibly (2 points)
    - Uncertain (1 point)
    - No (0 points)

    The scores will then be added up to get a sum score. Before calculation of the sum score, question 2 should be recoded to get the correct results (3→1, 2→1, 1→2, 0→3). The outcome score indicates the perceived stigma. The higher the score, the higher the level of perceived stigma.

2. ***EMIC-c*** **(for the 'community' or the non-affected persons).** This instrument analyses the attitude of the unaffected community (the potential 'stigmatizer') towards the affected persons. - For each question, one mark will be given according to the right answer:

    - Yes (2 points)
    - Possibly (1 points)
    - No (0 points)

The scores will then be added up to get a sum score. The higher the score, the more negative the attitudes from the community member towards the affected person.

2.8.7 Effects of stigma

Stigma has many different effects on the person, who gets stigmatized, as well as on their family and on the community. It may also affect the programs available to serve those affected. The effect of stigma may be psychological. For example, a stigmatized person can feel fear or shame, which can lead to anxiety and depression. Due to this, or because of discrimination or anticipated stigma, they may no longer take part in any social activities. This limits social participation and leads to social exclusion. Social exclusion or discrimination in turn may result in an economic burden for the affected person and their household and thus cause or aggravate poverty(6). Stigma or anticipation of stigma may cause affected people to conceal their condition. The burden of keeping this secret, of being ever watchful and careful, taking evasive actions and 'living a lie', takes an emotional toll. In addition, non-disclosure to family means loss of emotional and social support. Because of stigma, many persons with a stigmatized health condition do not seek help. This delays the diagnosis and treatment and may worsen the health condition. The risk of disability may also increase. Stigma thus hinders the effective treatment and care of the person.

In the case of infectious diseases, stigma can complicate efforts to control the disease. It can cause delay in diagnosis and treatment, which may prolong transmission in the community. Stigma may also be a barrier to preventive behavior, or instance proposing to use a condom being suggestive that one is HIV positive. This silence and denial inhibits prevention programs. People may not change their behavior, because doing so would expose them to stigma. In addition, patients may not adhere to treatment, if clinic attendance or regular medication leads to awkward questions and potential exposure to stigma. This increases the risk of further disease transmission, disability and drug resistance. Overall, stigma is likely to have a negative impact on the quality of life of affected persons, their family, health programs, and on society through the above mechanisms(26).

2.8.8 Stigma regarding leprosy

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English (1). Stigma has been defined variously since the beginning of its use and derived its meaning in different aspects of sociology and clinical science. The most common notion of stigma, however, still refers to people's fear of mingling with leprosy affected people, due to lack of scientific knowledge and suspicious ideas about the disease (2).

The fact that most of the untreated leprosy patients, or even those who underwent full treatment, often end up with severe visible deformities and disfigurements, has contributed to the stigmatization (3)

Stigma associated with leprosy has wide varieties of impacts on person's life ranging from mobility, interpersonal relationships, marriage, employment, leisure activities and attendance at social and religious functions (4).

Therefore, in terms of human suffering, the consequences of stigma often outweigh the burden of physical afflictions. Many people live happily with severe physical impairments, as long as they are accepted, respected, and loved by those around them and are able to function and participate meaningfully in the society in which they live (4).

2.8.9 Perceived stigma in leprosy

Perceived or felt stigma in leprosy is the perception or expectation of negative attitude or practice by the society towards the leprosy-affected person. Sometimes, an action by another person may be interpreted as stigmatizing, even though the intention was completely different. This means that the net outcome often depends on the perception but not necessarily on whether the perception was accurate.

Stigma is a dynamic process and can differ from person to person, depending on disease, culture, status, a person's character and the direction the condition develops. Some people may be stigmatized for more than one reason. For example a women of a low socio economic class with poor education could suffer the burden of multiple stigmatization, which then would be called as 'layered stigma' (26).

Therefore, stigma perception in an individual is a complex construct of anticipation that arises out of local culture, values, beliefs, ethnographical variation and the attitude prevalent in the community towards a particular illness, thereby setting a mirror of not only the disease but the whole society (33).

This study assesses two kinds of perceived stigma, one in the leprosy-affected person and the other one in non-leprosy affected person, the community or the potential stigmatizer. Perceived stigma in leprosy affected and non-affected persons is an assessment of perception of the disease based on his or her feeling and judgment (31).

Van Brakel recently performed a study in Indonesia assessing perceived stigma in the community by using the EMIC stigma scale. 931 community members responded to the EMIC questionnaire. The results showed that the main stigma-related problems perceived by the community were shame and embarrassment, problems finding a marriage partner and difficulties in finding paid work. The community perceptions regarding leprosy were consistent with the experiences of leprosy-affected persons living in the same community but implying the community's perceptions towards leprosy affected person. Concluding, reported severity of community stigma correlated with severity of the leprosy-affected person's restriction in the same districts (5).

In a study by Rao et al in India in 2006, perceived- and enacted stigma were assessed in both leprosy affected persons and the unaffected community. The study included 599 leprosy-affected and 2399 non-leprosy-affected persons from the community. Enacted- and perceived stigma was assessed in both subject groups. A special 'performa' was used to ascertain the perception and enactment of stigma at the family level, in the society and at the work place. On a 5-point scale the participants were asked about grade their agreement.

Within the group of leprosy-affected persons, the maximum stigma was noted for participation restriction in religious rituals. Further risk factors of stigma were higher age, lower education, belonging to a lower class and deformities. Within the community perceptions towards leprosy affected persons were assessed, which showed negative attitudes towards leprosy-affected persons in regard to class and status as well as occupation. The community showed furthermore severe stigma in concern of employment of leprosy-affected persons and towards affected persons selling food. Stigma from the community stigma was furthermore present in other socio-economic factors like lower socio-economic status, higher age and presence of deformities (37).

Tsutsumi et al. (38) performed a study in Bangladesh in 2003 assessing perceived stigma in leprosy affected persons. They used their own developed questionnaire for assessing perceived stigma. They found a rate of 50% of perceived stigma in leprosy-affected persons. Perceived stigma showed an association with low quality of life, deformities, lower income and lower education. Women with perceived stigma showed a lower quality of life than men.

In a study by De Stigter et al. (7) from 2000 in Nepal, community attitude towards leprosy affected persons was assessed. They found that stigma towards persons affected with leprosy was at 52%.

They grouped negative behavior into 5 groups: 1. Eating limitations, 2. Individual negative behavior, 3. Social-public, 4. Segregation and Group 5 with usual behavior. 186 community members were asked to elicit what other community members behave or pose attitude to the leprosy-affected persons.

2.8.10 Effects of stigma in leprosy

Leprosy and its stigma have a pervading affect on a patient’s life, affecting marriage, interpersonal relationships, employment, leisure activities as well as attendance at religious and social functions (4). In severe cases, stigma may even lead to complete rejection or banishment by communities, insults and hate (7). In many places where leprosy is prevalent, like SE-Asia, the family still plays an important part in personal identity and the recognition by society. For leprosy patients to loose the contact and care by their family is like loosing a large part of their own identity. Some people even describe this as worse than loosing fingers and toes, eyes and nose (6). Many studies show that women are more affected by the consequences of stigma as men. They suffer more isolation, loss of touch and rejection. They have more restrictions to live with than then men with the same level of disease (39).

In many cases leprosy leads to psychological problems, which are not caused by the disease itself, but by their rejection of society. In a study from South Africa, one third of black patients have contemplated suicide after diagnosis of leprosy (40). Stigma towards people with leprosy can severely harm the patient's psychological and social health but may affect them also physically. Shame of having leprosy can prevent people from seeking medical treatment until severe disfigurement and disabilities have occurred. This in turn makes the stigma worse and aggravates the circle (6).

2.8.11 Risk factors for stigma

'Last's dictionary of epidemiology' defines risk as the probability that an event will occur. Within the field of epidemiology it is widely used to describe the probability that a specific outcome will occur following a specific exposure (41). Nevertheless, there is little agreement on that very broadly generalized definition. It is uncertain whether a risk factor should be considered as truly causal or whether it can be more peripherally associated with an outcome. There is further disagreement on the strength of association, which is needed for an issue to be named a risk factor for a disease, and how directly it has to be associated with the outcome. There is also uncertainty whether a risk factor is something that can be modified, i.e. an eating habit or smoking, or whether it is immutable like gender(42).
Considering the definition that *Last's Dictionary of Epidemiology* gives for 'risk factor':

"…an aspect of personal behavior or lifestyle, an environmental exposure, or an inborn or inherited characteristic which on the basis of epidemiological evidence is known to be associated with health-related condition(s) considered important to prevent."(41)

This shows a rather loose definition of 'risk factor' not specifying the issues of strength of association, causal role and modifiability. In 1996, Beck presented a new definition in order to clarify this area better, which became the probably most commonly used term related to risk (42) :

"Risk factor: an environmental, behavioral, or biologic factor confirmed by temporal sequence, usually in longitudinal studies, which if present directly increase the probability of a disease occurring, and if absent or removed reduces the probability. Risk factors are part of the causal chain, or expose the host to the causal chain. Once disease occurs, removal of a risk factor may not result in a cure."(43)

Beck's definition is certainly more specific and contributes the following information to the definition:

1. The emphasis on the temporal sequence of exposure before outcome
2. Risk factors are accepted as a part of the causal chain
3. Risk factors are accepted to be involved in disease onset but not necessarily in its future progression or resolution.

2.8.12. Risk factors of stigma in leprosy

Factors that contribute to the process of stigmatization have been topic to several studies in the past. In identifying these factors it might be easier to recognize early stigmatization and intervene at an earlier stage. Different socio-demographic factors, superstition and beliefs as well as deformity and other factors have been linked to predispose to stigmatization of leprosy-affected persons. These risk factors may vary from country to country or even community to community, as each community can present a potentially different mix of reasons why leprosy is a feared and a shameful disease.

The following table presents different studies that have been performed to identify risk factors for stigma in leprosy.

Table 3: Risk factors associated with leprosy stigma

Author	**Location**	**Year**	**No. Subjects**	**% Stigma-affected**	**Measurement methods**	**Risk factors**
Perceived Stigma						
Myint et al.(44)	Myanmar	1992	251 affected 151 non-affected (community)	NA	Interview (KAP - interview schedule)	Low knowledge on leprosy (contraction, prognosis), social pressure – leprosy a shameful disease (community), deformities
Brouwers et al. (45)	Nepal	2011	100 Affected 100 non-affected (Community)	NA	Questionnaire (interview), Jacoby scale (perceived stigma), GPAS, Participation Scale,	Deformity (DG-I < DG II), activity limitations, female sex, beliefs that leprosy is a punishment for sinners (affected & non-affected)
Rao et al. (37)	India	2008	599 affected 2399 non-affected	NR	Questionnaires, interviews	Low education, low socio economic status, older age (46+), deformities (affected and non-affected).

Van Brakel et al. (5)	Indonesia	2012	1358 Affected (with disability) 931 Non-affected (community)	60% activity limitations and participation restrictions, 36% anticipated stigma	Questionnaires, face-to-face interview, Disability (WHO), SALSA scale, Participation Scale, Jacoby Stigma Scale, EMIC	Disability, female sex, reduced mobility, low education. Unemployment (non-affected)
Tsutsumi et al. (38)	Bangladesh	2007	189 affected 200 non-affected	50% Perceived stigma	Perceived Stigma Questionnaire (PSQ), disability grades (WHO classification)	Low quality of live, mental health, low socio economic status, deformities, male sex
De Stigter et al. (7)	Nepal	2000	300 Non-affected (Community)	57%	Interview (community behavior towards leprosy-affected person)	Deformity, fear of infection by germs, fear of curse of God, fear of germs and curse combined.
Enacted Stigma						
Lustosa et al. (46)	Brazil	2011	107 affected	70.1% Prejudice 27.1% Discrimination	Interview, questionnaire (socioeconomic data), SF 36,	Deformity, co-morbidity, mental health, low socio economic status
Kushwah et al. (47)	India	1981	344 affected	26.45%	Questionnaires	Middle age (45-55), male sex, low education (illiteracy), low socio economic status, housewives, laborer, joint family.
Mixed Stigma						

Primkaew et al. (48)	Thailand	2012	6 affected 31 non-affected (community) 4 health providers	NR affected 77%community (perceived) 100% health providers (enacted and perceived)	Interview, participant observation (PAL), document review	Low knowledge on leprosy (contraction), deformities, male sex, belief in destiny
Nagaraja et al. (49)	India	2011	NR, only affected	NR	Interviews, Modified Kuppuswamy Scale	Low socio-economic status, deformities, ignorance about leprosy, belief to be a curse/wrath/sin,
Ebenso (50)	Nigeria	2007	20 affected	Different kinds of stigma	Qualitative study	Deformity, activity limitation, belief in curse
Tsutsumi et al. (15)	Bangladesh	2004	140 affected 135 non-affected	87.9%	Questionnaires, CES-D, disability grades (WHO classification)	Isolation from society, low knowledge on leprosy in community
Nardi et al. (51)	Brazil	2011	223 affected	35.4% Social participation restriction	Participation Scale (PS), Disability (WHO), Eye-hand-foot score (EHF)	Low socio economic status, low education, single status, deformities, co-morbidity

- *Visible disfigurements* are probably the most important risk factors that predispose to stigma in advanced stages of the disease. Van Brakel confirms in his latest publication on ‘disability in people affected by leprosy', that persons with ‘leprosy-related disabilities are very likely to suffer from social stigma and discrimination(5). To prevent discrimination and stigma, affected people often try to hide their disfigurements and do not immediately seek for medical help when noticing the first signs and symptoms. This delay of treatment can lead to a progression of the disfigurement and eventually perpetuate the circle of stigmatization(52). Several further studies have confirmed visible disfigurements as an important risk factor for stigma in leprosy(5, 38, 44-46, 49, 51).

- *False Beliefs and superstition* are further powerful risk factors for stigma in leprosy and have in many cases persisted in the affected person's community for a long time. Often these beliefs are based on false facts and passed on knowledge, but may also be based on religious ideas, as leprosy to be a curse by God(6, 7). Brouwers described in his study from 2011 in Nepal that many of the affected as well as un-affected study-participants belief that the disease was inflicted on the affected subjects as a punishment and that they are often considered as 'sinners'(45). A similar belief was also described in a study from India in 2001 (36) where leprosy was described as a curse by God for sinners and in a study from 2000 in Nepal (7) describing leprosy as a curse by God.

- *Insufficient knowledge and wrong information on leprosy*, which often comes with poor education, has been a further prominent risk factor for the development of stigma in leprosy in many studies and in multiple different settings(15, 44, 47, 49, 51). In a study from Myanmar in 1992, 81% of the participating subjects, affected and non-affected (community), knew that leprosy was caused by a bacterial infection, but 66% also believed that leprosy was caused by eating certain foods (44). Kushwah described in his study from 1981 in India, that the incidence of social stigma was highest in the illiterates and in the case of low socio-economic class, putting them in a low status in society, leading to neglect and hatred by the community (47). I a study from Thailand poor knowledge was even described among health workers working with leprosy affected persons who did not want to touch the patients, placed them on isolated seats away from other patients and expressed 'disgust', indicating a poor knowledge on the disease (48). Until today, lack of knowledge on leprosy causes fear of death to many people confronted with the disease. Historically, this is supported by the fact that until the 1940s there was no effective cure for leprosy and an infection with the disease was often considered a death sentence. For more then 6 decades now, leprosy is treatable and not a deadly disease anymore but many affected and non-affected people still belief in this deadly outcome (6).

- *Low socio-economic class,* a further factor for the development of stigma in leprosy. Kushwah describes in his study that the incidence of social stigma, stigma from the community, was highest towards lower classes in society with less income and less status in society (47). This was also supported by findings of an earlier study by Gussow and Tracy who observed that leprosy patients came largely from a low-income class with less prestigious occupational categories (53). Lustosa (46) classifies poor socioeconomic conditions as contributing factors to leprosy infection and spread. He describes low family income as resulting in poor housing conditions, hygiene, nutrition and access to health, which supports infection, spread and progression of the disease. Progression of the disease leads to more disfigurement and consequently to more stigmatization as described above.

- *Isolation and separation* of people with leprosy, as still reality in many countries worldwide, reinforcing the stereotype of high infectiousness and danger of leprosy. Separation and ostracisation are therefore further risk factors of stigma in leprosy(7, 15). De Stigter describes in his study from Nepal in 2000 that there are still persons affected by leprosy today who have to leave their village or get isolated from society. It is therefore understandable that affected persons try to hide their disease out of fear because of these negative community actions (7).

- *Gender* has been described as a further factor influencing stigmatization on leprosy affected persons (5, 38, 45, 47). I this case though, literature is not consistent on which sex has a stronger risk factor. It seems that location and culture have an important influence on this question. Kushwah described a higher prevalence of perceived stigma (social stigma) in males unless occupation was considered where housewives showed the highest rate (47). In a study from Bangladesh, Tsutsumi describes the negative social impact as worse in men than in women. He explains that with different cultural limitations that are placed on social relationships of women in Bangladesh, meaning they are less exposed to active relationships within society and therefore less exposed to negative social impacts (38). As opposed to that, a study from Nepal describes women with leprosy as more negatively impacted by society and family. He explains this with a different attitude of the family and the community towards disabled men and women. A woman with disabilities is often considered as a great burden to the family, as men would still get more encouraged to actively participating in the community and at home(45). Van Brakel underlines in his study from 2012 in Indonesia, that women with leprosy were disproportionally more affected by separation and divorce than men. They were also more affected by unemployment or unpaid work. He takes into consideration though, that the overall status of women in employment, in a society such as Indonesia, as well as the reported lower education may explain this observation (5). In contrast to that, a study from Brazil from 2011 did not show any association at all between the presence of restrictions in social participation and gender, which might be explained by a completely different cultural background of the participants (51).

- *Chronic ulcers and odor*, as found in some patients with leprosy, may have a distinctive odor caused by a bacterial infection. The smell can be very unpleasant and nauseating and can therefore trigger stigma and rejection by the community. This factor was described by Danlep et al. in a study performed in Madhya Pradesh in India in 2003 (54).

Even though several studies have been done to assess stigma, most studies have focused on the impact of stigma and not on risk factors contributing to the process of stigmatization. In Thailand, only one recent study by Primkeaw et al. (44, 48) has been performed to assess stigma in leprosy. This study assessed perceived- and enacted stigma among leprosy-affected persons, non-leprosy affected persons in the community and health workers. Unfortunately the sample size is very small and uneven and the type of stigma assessed is not clearly defined. Therefore, exploring the risk factors of perceived stigma in leprosy affected and non-affected persons in a large leprosy colony in Thailand, will add important information to the understanding of social aspects of Leprosy.

CHAPTER III

RESEARCH METHODOLOGY

3.1 Study design

The study had a cross-sectional study design to assess risk factors for stigma in leprosy affected persons living in the Non Somboon leprosy colony in Khon Kaen province, Thailand, and in non-affected persons from the community nearby. This study explored the affected persons' socio-demographic characteristics, knowledge on leprosy, assessed clinical characteristics and their relationship to stigma. The unaffected persons, or the community subjects, were also explored for socio-demographic characteristics and their relationship with stigma towards affected subjects.

3.2 Research Instruments

Interview questionnaires in Thai language were used for data collection. The face-to-face interviews were performed by study-investigators who had been trained prior to study start. There were two different questionnaires, one for the affected persons and one for the non-affected persons living in the community nearby. Both questionnaires contained 2 parts.

Questionnaire for the leprosy affected person

1. The first part collected data on:
    - Socio-economics: financial status, occupation, education
    - Demographics: Gender, age, religion, ethnicity, marital status, location
    - Knowledge on leprosy
    - Medical history of leprosy, clinical presentation, level of health institution
    - leprosy associated reactions
    - Disability grading (WHO)
2. The second part collected data to characterize perceived stigma, and to assess its severity, in the leprosy-affected person (EMIC-a).

Questionnaire for the non-leprosy affected person

1. The first part collected data on:
    - Socio-economics: financial status, occupation, education
    - Demographics: Gender, age, religion, ethnicity, marital status, location
    - Knowledge on leprosy

2. The second part collected data to characterize perceived stigma and to assess its severity in both the leprosy affected (EMIC-a) and non-leprosy affected person (EMIC-c).

3.3 Pre-testing of questionnaires

Pilot testing was done prior to study start. The questionnaires were tested on 15 leprosy-affected and 15 non-leprosy affected subjects. When problems or misunderstandings occurred, the questionnaires were changed accordingly. All questionnaires were translated into Thai language and retranslated for validity.

3.4 Study population and area

Study population:

1. The study population of leprosy-affected persons was living in Non Somboon leprosy colony, Khon Khaen province, Thailand. The people are locally called as ‘ people affected by leprosy’ (PAL). There were about 500 PAL living in the colony at the time of investigation. All PALs had completed multi-drug-treatment for leprosy.

2. The study population of leprosy unaffected persons was living around the colony, representing the community. There were about 750 people living in the community at the time of investigation. The community was approximately 1-2 kilometers away from the colony. The target community was distributed within a radius of 4 km from the colony. One person per household was chosen after systematic randomization, thereby accounting the number of household.

For both groups an approximately even amount of male and female participants were selected. Data collection was performed in the afternoon and evening to include persons both returning from work and those who were customarily at home during the day.

Study Area:

The study was carried out in- and around Non Somboon leprosy colony in Khon Khaen province, Thailand. This study location was chosen as it provides both a large number of affected subjects as well as close contact to a non-affected community nearby. Data of leprosy-affected persons was collected by house visits.

3.5 Duration of study

December 2012 to May 2013

3.6 Sample size

Sample size for leprosy affected subjects:

Sample size was dependent on the availability. At the time of investigation, Non Somboon leprosy colony had 633 households and about 500 persons with a medical history of leprosy. One person per household was selected. The sample size was calculated using a two-step process (Kish and Leslie 1965). The first step employed the Cochran formula, as below.

$$SS = Z^2 \times p \times q / d^2$$

SS = provisional sample Size
d = error allowance (0.05)
z^2 = critical value from normal distribution for 95% confidence interval
p = estimated prevalence
q = 1- p

Literature review did not show any specific information on the rate of stigma in leprosy-affected persons in Thailand. In view of this, a perceived stigma prevalence of 50% in the affected group was assumed, because this assumption yields the largest sample size requirement. Cochran formula calculated to 384 for prevalence = 0.50.

The second step was a correction for the total of households, in this case 633 total households. The correction was (provisional SS)(total households) / (provisional SS + total households), in this case (384)(633) / 1017 = 239. To account for incomplete data, 10% were added, for a sample size of 263.

Sample size for non-leprosy affected subjects:

Primkeaw et al. (48) described a rate of 77% of (undefined) stigma in the non-leprosy affected community. We furthermore knew that the community had a population of ca. 750 people. In view of this, a perceived prevalence of 70% in the unaffected persons was estimated. Cochran formula calculated to 323 for prevalence = 0.70. In the second, step a correction for total households was performed, in this case for 750 households in the community. The correction was (provisional SS)(total households) / (provisional SS + total households), in this case (323)(750) / 1073 = 225. To account for incomplete data, 10% were added, for a sample size of 250.

3.7 Sampling methods

Two stage sampling method was used. In the first stage, the colony was purposively selected. In the second stage, the sample frame was drawn from the colony´s housing-plan and simple random sampling was applied to select the colony subjects. Community subjects were also be selected by two stage sampling method. In the first stage, purposive selection of the community within 4 km radius of the colony was done. In the second stage, the sample frame was drawn from the community authority office and simple random sampling was applied to select the community subjects.

3.7.1 Inclusion and exclusion criteria

3.7.2.1 Leprosy affected persons

Inclusion criteria:

- Male and female persons affected by leprosy
- Age 18 or older

- History of medically diagnosed leprosy
- *Living in the colony for more than 1 year*
- Able to communicate with the study investigator and to understand and answer the questions adequately

Exclusion criteria:

- Patients with other non-stabilized diseases that can lead to similar clinical symptoms like diabetes mellitus or peripheral arterial disease.
- Not willing to participate in the study

3.7.2.2 Leprosy non-affected persons

Inclusion criteria:

- Male and female persons not affected by leprosy
- Age 18 or older
- *Living in the community nearby for more than 1 year*
- Able to communicate with the study investigator and to understand and answer the questions adequately
- One person from one household

Exclusion criteria:

- Not willing to participate in the study

3.8 Data collection

Data was collected by questionnaires using face-to-face interview. The disability-grade of all affected participants was analyzed according to the WHO classification by the study investigator. The questionnaires were translated into Thai language and re-translated into English for validity testing. Both questionnaires were pre-tested in a primer-study on 15 subjects of each group. If pre-testing showed difficulties or potential misunderstandings, they were changed accordingly. For the affected subjects, data was collected by house visits within the colony. Data for the unaffected persons was collected by house visits in the community within radius of 2 km around the colony.

All study investigators received a study I.D., which was written on the questionnaire. They furthermore underwent training before study start, as a 3 day seminar was performed. All participants were informed about the content and the objectives of the study prior to interview-start and signed informed consent was collected. After completion, the questionnaires were collected and stored in a safe location. All data analysis was performed at Chulalongkorn University Bangkok, Faculty of Public Health.

3.9 Measurement variables

1. **Leprosy affected persons:**

Independent variables (factors that may influence or cause stigma):

- Socio-economics: financial status, occupation, education
- Demographics: gender, age, religion, ethnicity, marital status, location, duration of stay in the colony
- Knowledge on leprosy: Information, cause of leprosy, infectiousness, transmission, treatment, signs and symptoms
- Medical history of leprosy, clinical presentation
- Disability grading (WHO)
- Leprosy associated reactions

Dependent variables (the outcome or the effect of these factors):

- Severity of perceived stigma in leprosy affected persons

2. **Leprosy non-affected persons:**

Independent variables (factors that may influence or cause stigma):

- Socio-economics: financial status, occupation, education
- Demographics: gender, age, religion, ethnicity, marital status, location, duration of stay

- Knowledge on leprosy: Information, cause of leprosy, infectiousness, transmission, treatment, signs and symptoms

Dependent variables (the outcome or the effect of these factors):

- Severity of perceived stigma in non-leprosy affected persons (community)

3.10 Data analysis

The goal of this study was to find associations between the respondents' perceived stigma (score of EMIC-a or c; Perceived Stigma Score) and her/his socio-demographic characteristics, knowledge on leprosy, leprosy medical history and WHO Grade of Disability.

All questionnaires were coded before entering the data into MS Excel and then analyzed in the statistical software 'SPSS version 16 for Windows. Demographic data was described using descriptive statistics. For continuous data, central tendency was reported as median with interquartile range (non-normally distributed data). Percentages and numbers of observation were reported for categorical variables. The distribution of continuous variables was assessed for normality by Kolmogorov-Smirnov test. Associations between dependent and independent categorical variables were assessed using Mann Whitney Test for 2 levels or Kruskal Wallis test for multiple level comparisons. Statistical significance was accepted as a p-value of < 0.05.

This analysis characterized associations between socio-demographic characteristics, knowledge on leprosy, 'WHO Disability Grade' (- higher Grade, more disability!) and perceived stigma in leprosy-affected subjects, and associations between socio-demographic characteristics, knowledge on leprosy and perceived stigma in non-leprosy affected persons.

3.11 Ethical consideration

1) The ethical committee of the College of Public Health at Chulalongkorn University assessed the study protocol before study-start.
2) All study participants received a full explanation about the study, its objectives and its benefits.

3) All study participants could withdraw from the study at any time and without giving any reason.
4) Informed signed consent was given by the investigators, considering

- Willingness to participate
- Freedom of withdrawal
- Confidentiality
- Access to final report or results of the study if desired
- Assurance of confidentiality of the collected data

3.12 Benefits of the study

The results provided important information on the development and severity of perceived stigma in leprosy-affected and non-affected persons. These may help to initiate and improve intervention programs against perceived stigma in leprosy. Thru a better understanding of the disease and its physical and psychological complications, the social aspects between the affected and the non-affected may improve and a successful process of re-integration may be easier.

3.13 Limitations of the study

As this study collected data from only one area in Thailand, it is not possible to generalize the results for the entire country. Certain regions in Thailand have recently started to integrate leprosy-affected persons into the community to improve stigmatization. These areas might have different results in perceived stigma both in the affected as well as in the non-affected person. As the design of this study was cross sectional, the results cannot reveal any definite cause and effect relationship. This study focused only on the assessment of ‘perceived stigma’ and does not give information on other aspects of stigma within the assessed population. As this study was performed in an urban location it might not represent the actual situation of perceived stigma in a rural location. Furthermore, chances of recall bias during the interviews cannot be excluded. Interviewer bias is also a possibility.

CHAPTER IV

RESULTS

This chapter gives descriptive and analytical results for the data, which was collected in March 2013.

The first section will give results of the leprosy-affected subjects living in the colony and the second section the results of the non-leprosy affected persons living in the community.

The first part of each section will present the descriptive statistics, such as frequencies and percentages, for all independent variables.

The second part of each section will present the analytical statistics to illustrate associations between the independent variables and the total EMIC scores.

A total of 522 questionnaires were collected, 265 for the group of leprosy-affected persons and 257 for the group of non-leprosy affected persons. In both groups, the number of subjects has reached the calculated necessary sample-size.

4.1 Leprosy affected persons:

4.1.1 Descriptive statistics:

4.1.1.1 Socio-demographics

Socio-demographic analysis shows that the group of subjects being older than 60 years had most participants (n=204). Gender was evenly distributed with 128 (51.7%) men to 137 (48.3%) women. Of all subjects, 99.2% were Thais and 2 subjects were of other nationality. Two confessions were represented with 135 (88.7%) Buddhist and 30 (11.3%) Christians. Considering marital status, 141 subjects (53.2%) were married and 85 (32.1%) were widowed, while 28 subjects (10.6%) were unmarried and 11 (4.2%) were separated.

226 subjects (85.3%) had lived in the colony for more than 20 years and 149 subjects (56.2%) were diagnosed with leprosy at an age of older than 40 years. 212 subjects (80%) were literate and of those did 22 subjects (10.3%) receive education longer than 4 years. Most of the participants were unemployed (59.6%), followed by 18.9%

working as farmers and 21.5% in different other professions. Only 85 subjects (32.1%) said that they have enough income to support the family.

48 subjects (19.7%) had to change work because of leprosy. 125 subjects (47.2%) had other leprosy affected persons in their family and 95 subjects (35.8%) had other leprosy affected persons in close relationships, who are not connected to the family.

Numbers and percentages of all socio demographic variables are illustrated in Table 4.

Table 4:Socio-demographics (affected)

Characteristics	**Number**	**Percentage**
Age Groups (n = 265)		
60 years or below	61	23
61 years or older	204	27
Mean = 69.2, Median = 70.0		
SD = 11,51 Range = 31 - 92 (61)		
Skewness = -0.573		
Sex (n = 265)		
Female	128	51.7
Male	137	48.3
Nationality (n = 265)		
Thai	263	99.2
Religion (n = 265)		
Buddhism	235	88.7
Christian	30	11.3
Marital status (n = 265)		
Unmarried	28	10.6
Married	141	53.2
Separated	11	4.2
Widowed	85	32.1

Marital status combined (n = 265)		
Relationship	226	85.3
No relationship	39	14.7
Years living in colony (n = 265)		
≤ 20years	39	14.7
≥ 21years	226	85.3
Age at diagnosis, years (n = 265)		
≤ 20	32	12.1
21-40	84	31.7
41-60	131	41.4
≥ 61	18	6.8
Age at diagnosis, years combined (n = 265)		
≤40	116	43.8
≥41	149	56.2
Education (n = 265)		
Literate	212	80
Illiterate	53	20
Years of education (n = 213)		
Primary level (≤ 4years)	191	89.7
Secondary level (5-9years)	22	10.3
Tertiary level (≥10years)	0	0
Occupation (n = 265)		
Farmer	50	18.9
Laborer	28	10.6
Private business	8	3
Civil/office	3	1.1
Student	1	0.4
Housewife	10	3.8
Unemployed	158	59.6
Other	7	2.6
Occupation combined (n = 265)		

Farmer	50	18.9
Unemployed	158	59.6
Other	57	21.5
Enough income to support family (n = 265)		
Yes	85	32.1
No	180	67.9
Had to change work because of leprosy (n = 244)		
Yes	48	19.7
No	196	80.3
Affected person in family (n = 265)		
Yes	125	47.2
No	125	47.2
Don't know	15	5.7
Affected person in family, combined (n = 265)		
Yes	125	47.2
Not aware of	140	52.8
Affected person in close relationship, non-family (n = 265)		
Yes	95	35.8
No	127	47.9
Don't know	43	16.2
Affected person in close relationship, non-family, combined (n = 265)		
Yes	95	35.8
Not aware of	170	64.2

4.1.1.2 Knowledge on leprosy

150 subjects (56.6%) had received some kind of information on leprosy earlier, and of those, 68 subjects (54.8%) from a medical institution, 23 subjects (18.5%) from a friend or a family member and 33 subjects (26.6%) from other sources. 96 subjects (36.2%) said that they knew the cause of leprosy, but of those only 27 subjects (28.1%) chose the correct answer in the follow-up question assessing the specific cause of leprosy. 71 subjects (27.1%) thought that leprosy is very infectious

and 87 subjects (33%) said that they know how it is transmitted, but of these only 48 (55.2%) chose the right answer in the follow-up question. 139 subjects (52.7%) thought that leprosy is difficult to treat and 250 (94.3%) said that they have knowledge on the signs and symptoms of leprosy. The most individual prominent sign selected was patches on the skin (13.6%), followed by 'decreased sensitivity in skin areas' (7.2%). 185 subjects (69.8%) agreed to multiple answers in the follow-up questions. 179 subjects (67.5%) thought that leprosy is a severe disease and 113 subjects (42.8%) believed that leprosy is a punishment by God.

Numbers and percentages of the knowledge on leprosy variables are given in Table 5.

Table 5: Knowledge on leprosy (affected)

Characteristics	**Number**	**Percentage**
Received information on leprosy (n = 264)		
Yes	150	56.6
No	115	43.4
Source of information (n = 265)		
Local hospital	22	8.3
Local doctor	40	15.1
Health station	6	2.3
TV/radio/paper	17	6.4
Friend or family	23	8.7
Other	16	6
Multiple	26	9.8
Source of information, combined (n = 124)		
Medical institution	68	54.8
Friend or family	23	18.5
Other	33	26.6
Knowledge on cause of leprosy (n = 265)		
Yes	96	36.2
No	169	63.8

Source of leprosy cause (n = 96)		
Bacteria/microorganism	27	28.1
Curse by God	2	2.1
Karma	11	11.5
Other	56	58.3
Source of leprosy cause, combined (n = 96)		
Bacteria/Microorganism	27	28.1
Other	69	71.9
Leprosy very infectious (n = 262)		
Yes	71	27.1
No	191	72.9
Knowledge on leprosy transmission (n = 264)		
Yes	87	33
No	177	67
Leprosy transmitted from (n = 87)		
Air	4	4.6
Water/soil	2	2.3
Food	2	2.3
Animal	1	1.1
Mosquito	1	1.1
Close contact to persons	48	55.2
Other	29	33.3
Leprosy transmitted from, combined (n = 87)		
Right answer	48	55.2
Wrong answer	39	44.8
Leprosy difficult to treat (n = 264)		
Yes	139	52.7
No	125	47.3
Knowledge on symptoms of leprosy (n = 265)		
Yes	250	94.3
No	15	5.7

Specific symptoms answers (n = 250)		
Patches	34	13.6
Decreased sensitivity patches	18	7.2
Weakness had, feet, eyelids	7	2.8
Nerve pain	2	0.8
Swelling earlobes	1	0.4
Painless wounds	3	1.1
Multiple	185	69.8
Symptoms: multiple vs. one or no answer		
Multiple	185	69.8
One/No	80	30.2
Leprosy a severe disease (n = 265)		
Yes	179	67.5
No	86	32.5
Leprosy a punishment by God (n = 264)		
Yes	113	42.8
No	151	57.2

4.1.1.3 Leprosy medical history

When noticing first signs of leprosy, only 13 subjects (4.9%) immediately consulted a doctor. The main reasons for not seeking for medical advise was that they either did not think it was leprosy (16.3%), did not know where to go (8.7%) or awaiting self-cure (2.8%). 130 subjects (51.6%) gave multiple reasons why they did not go.

85 subjects (32.3%) received their first treatment at a local hospital, 46 subjects (17.5%) at a Primary Health Center and 40 subjects (15.2%) at their local doctor’s office. Combined, 210 subjects (79.2%) received their first treatment at a standard medical provider while 55 subjects (20.8%) were treated at a non-medical institution.

202 subjects (76.2%) had some form of disfigurement or deformity. Of those did 74 subjects (36.6%) develop these before treatment start, 77 subjects (38.1%) while under treatment and 51 subjects (25.2%) after treatment was completed. Of

those subjects who had disfigurements or deformities, 165 subjects (81.7%) said that they were visible. 153 (75.7%) subjects had first disfigurements or deformities on hands or feet while the rest in different regions all over the body. 146 subjects (55.1%) said that they have had ulcers before and of those did 82 subjects (56.2%) have them on the feet, 33 (22.6%) on the hands, 2 (1.4%) subjects in the facial region and 29 (19.9%) in different other regions of the body. Of all subjects who have had ulcers before, 86 (58.9%) said that these had some kind of foul smell.

The complete numbers and percentages of the leprosy medical history variables are given in Table 6.

Table 6: Leprosy medical history (affected)

Characteristics	**Number**	**Percentage**
Consult a doctor at first signs (n = 265)		
Yes	13	4.9
No	252	46.4
Did not consult a doctor – reasons (n = 252)		
Not think leprosy	41	16.3
Ashamed	5	2
Told not to	2	0.8
Awaited	7	2.8
Not know where go	22	8.7
No money	4	1.6
Multiple	130	51.6
Other	41	16.3
Where first treatment (n = 263)		
Primary Health center	46	17.5
Local doctor	40	15.2
Local hospital	85	32.3
Regional Hospital	39	14.8

Non-medical professional	21	8
Other	32	12.2
Where first treatment, combined (n = 265)		
Standard medical provider	210	79.2
Nonstandard medical provider	55	20.8
Have disfigurements or deformities (n = 265)		
Yes	202	76.2
No	63	23.8
When develop first disfigurements or deformities (n = 202)		
Before treatment	74	36.6
During treatment	77	38.1
After treatment	51	25.2
First disfigurements or deformities visible (n = 202)		
Yes	165	81.7
No	37	14
Where first disfigurement or deformity (n = 202)		
Facial region	11	5.4
Hand/foot	153	75.7
Eyes	2	1
Other body parts	36	17.8
Where first disfigurement or deformity, combined (n = 202)		
Hand/feet	153	75.7
Other region	49	24.3
Did ever have ulcers (n = 265)		
Yes	146	55.1

No	119	44.9
Where have ulcers (n = 146)		
Facial region	2	1.4
Hands	33	22.6
Feet	82	56.2
Other	29	19.9
Where have ulcers, combined (n = 146)		
Feet	82	56.2
Other locations	64	43.8
Did ulcers have foul smell (n = 146)		
Yes	45	30.8
No	60	41.1
Little bit	41	28.1
Did ulcers have foul smell, combined (n = 146)		
Yes/little bit	86	58.9
No	60	41.1

4.1.1.4 WHO Disability Classification

Of all 265 subjects, 183 subjects (69.1%) had a WHO Disability Grade Classification of Grade 2, 32 subjects (12.1%) a Grade 1 and 50 subjects (18.9%) a Grade 0.

The complete numbers and percentages of the WHO disability classification are given in Table 7.

Table 7: WHO disability classification (affected)

WHO disability	Number	Percentage
Grade 0	50	18.9

Grade 1	32	12.1
Grade 2	183	69.1
WHO disability, combined (n = 265)		
Grade 0&1	82	82
Grade 2	183	183

4.1.1.5 Total EMIC scores, affected

Comparing all EMIC questions by their highest number of ‘Yes’ selections, which is the highest contribution to the ‘total stigma score’ by adding 3 points (*except question 2, which was recoded into opposite direction*), EMIC question 4 places first with 194 subjects (73.2%). EMIC 4 asked whether the affected had ever felt ashamed or embarrassed because of her/his infection with leprosy.

Second most ‘Yes’ selections were received by EMIC question 14 with 184 selections (69.4%), assessing whether the affected had ever decided on her/his own to stay away from work or social groups because of leprosy.

EMIC question 3 ranks third with 145 ‘Yes’ selections (54.75%), assessing whether the affected does think less of her-/himself because of leprosy. EMIC question 2 closely followed this with 141 ‘Yes’ selections (53.2%), assessing whether the affected had ever talked about her/his leprosy problem with a close friend. EMIC question 1 was selected by 104 subjects (39.2%), assessing whether it would be preferred to keep other people from knowing about her/his leprosy history. EMIC question 10 was given 101 ‘Yes’ selections (38.1%), asking whether leprosy might have caused social problems for her/his family in the community. The last question, which was selected by 100 or more subjects, was EMIC question 7 with 100 selections (37.7%), assessing whether other people might have avoided them because of leprosy.

The highest score of ‘No’ selections, which was the lowest contributor to the total EMIC score with 0 points (*except question 2*), was received by EMIC question 9 with 44 selections (16.6%). This question assessed whether the affected subject believed that neighbors, colleagues or others in the community think less of her/his family because of leprosy. EMIC question 6 received 40 ‘No’ selections (15.1%), asking whether contact with the affected might have had bad effects on others around her/him. EMIC question 5 received 39 ‘No’ selections (14.7%), assessing whether the affected thinks that she/he is less respected among neighbors, colleagues or others in the community because of leprosy.

The highest score of ‘Possible’ selections, each contributing 2 points to the total EMIC score, was found in EMIC question 7 with 48 selections (18.1%), asking whether other people might have avoided her/him because of leprosy. 43 subjects (16.2%) said that leprosy might have caused social problems for their family in the community (EMIC 12) and 42 subjects (15.8%) selected ‘possible’ in both EMIC question 5 and question 8. EMIC question 5 asked whether neighbors, colleagues or others in the community might have less respect of her/him because of leprosy and EMIC question 8 assessed whether other people would refuse to visit their home because of leprosy.

Not knowing the answer (‘Don’t know’) contributed 1 point to the total EMIC score. Most subjects (65.3%) did not know whether leprosy had made it problematic for them to get married or if it had caused problems in their marriage (EMIC 11). This was followed by 171 subjects (64.5%) who did not know whether they have ever been asked to stay away from work or social groups (EMIC 13). The third most ‘Don’t know’ selections were given to EMIC question 12 with 132 subjects (49.8%), asking whether leprosy might make it difficult for someone else in her/his family to get married. The complete scores of all EMIC questions of the leprosy-affected subjects are given in Table 8.

Table 8: EMIC scores/total perceived stigma (affected)

‘n’ total= 265	**Yes** ***n (%)***	**Possibly** ***n (%)***	**Don’t know** ***n (%)***	**No** ***n (%)***
EMIC 1	104 (39.2)	26 (9.8)	106 (40)	29 (10.9)
EMIC 2	141 (53.2)	25 (9.4)	83 (31.3)	16 (6.0)
EMIC 3	145 (54.7)	22 (8.3)	81 (30.6)	17 (6.4)
EMIC 4	194 (73.2)	20 (7.5)	47 (17.7)	4 (1.5)

EMIC 5	88 (33.2)	42 (15.8)	96 (36.2)	39 (14.7)
EMIC 6	77 (29.1)	40 (15.1)	108 (40.8)	40 (15.1)
EMIC 7	100 (37.7)	48 (18.1)	99 (37.4)	18 (6.8)
EMIC 8	81 (30.6)	42 (15.8)	117 (44.2)	25 (9.4)
EMIC 9	79 (29.8)	35 (13.2)	107 (40.4)	44 (16.6)
EMIC 10	101 (38.1)	43 (16.2)	90 (34.0)	31 (11.7)
EMIC 11a&c	53(20.0)	16(6.0)	173(65.3)	23(8.7)
EMIC 12	68 (25.7)	30 (11.3)	132 (49.8)	35 (13.2)
EMIC 13	53 (20)	17 (6.4)	171 (64.5)	24 (9.1)
EMIC 14	184 (69.4)	13 (4.9)	61 (23)	7 (2.6)
EMIC 15	60 (22.6)	40 (15.1)	113 (42.6)	52 (19.6)

4.1.2 Associations between the independent variables and the total EMIC scores

Associations were calculated by using non-parametric testing methods, as EMIC scores (perceived stigma scores) were non-normally distributed. Mann-Whitney test was applied for independent variables with 2 levels and Kruskal Wallis test was applied for variables with 3 or more levels. The 'median' of total EMIC scores for each level is presented in the corresponding table. The 'median' was chosen, as the scores were non-normally distributed and has also been used by 2 further leprosy studies with non-normally distributed stigma scores before (5, 38).

4.1.2.1 Socio-demographics

Of all affected subjects, 61 were younger than 61years (23%) and the median age was 70.0 with a range between 31 to 91 years. Comparing the older 61 years group to the younger subjects in relation to their total EMIC scores, there was no significant difference (p=0.63).

Genders were represented with 128 (51.7%) females and 137 (48.3)% males. The total EMIC score of both genders showed no significant difference (p=0.079). Of all subjects, 235 (88.7%) were Buddhists and 30 (11.3%) were Christians. They showed no significant difference in total EMIC score (p=0.465).

Considering marital status, there was no significant difference in total EMIC score between 226 subjects who were in a relationship (85.3%) and those who were not (p=0.182).

Only 39 subjects (14.7%) were living in the colony for less than 20 years and those did not show a significant difference in total EMIC score to those subjects who lived there for longer. The age of diagnosis was equal or less to 40 years for 116 subjects (43.8%). There was no significant difference in total EMIC score to those subjects who were diagnosed with leprosy at an older age (p=0.866). Concerning education, 212 subjects (80%) considered themselves as literate. There was no significant difference in total EMIC score to those subjects who were illiterate (p=0.138). When asking for the years of education, 191 subjects (89.7%) had up to 4 years of education and 22 subjects (10.3%) up to 9 years. No subject had education, which was longer than that. There was no significant difference in total EMIC score between these groups (p=0.599).

Occupation was divided into farmers, unemployed and other professions for analytical reasons. 50 subjects (18.9%) were farmers, 57 (21.5%) were unemployed and 158 subjects (59.6%) did work in other professions. There was a significant difference in total EMIC score between these groups (p=0.013) with farmers having the highest score. Only 85 subjects (32.1%) said they had enough income to support their family. There was no significant difference in total EMIC score to those ones who did not have enough income (p=0.342).

Of all working subjects, 48 (19.7%) had to change work at least once because of leprosy. Analysis showed that the EMIC score was significantly higher (p=0.016) in the group of those subjects who had to change work.

Of all subjects, 125 (47.2%) had one or more leprosy-affected persons in their family. 125 (47.2%) subjects did not and 43 subjects (16.2%) said that they do not know whether they have. There was no significant difference in total EMIC score between these groups (p=0.848). 95 subjects (35.8%) had leprosy-affected persons, who were not family members, in some form of closer friendship, 127 (47.9%) subjects said they do not have and 43 subjects (16.2%) said that they do not know whether they have. There was no significant difference in total EMIC score between these groups (p=0.184).

The complete numbers and percentages, median- and p-values of the socio-demographic variables are illustrated in Table 9.

Table 9: Associations between socio-demographic variables and total EMIC scores

Characteristics	**Number (%)**	**Median EMIC score**	**P-value**
Age Groups (n = 265)			
60 years or below	61 (23.0)	25	0.63
61 years or older	204 (77.0)	22	
Mean = 69.2, Median = 70.0			
SD = 11,51 Range = 31 - 92 (61)			
Skewness= 0.417			
Sex (n = 265)			
Female	128 (51.7)	20	0.079
Male	137 (48.3)	24	
Nationality (n = 265)			
Thai	263 (99.2)		
Other	2 (0.8)		
Religion (n = 265)			
Buddhism	235 (88.7)	23	0.465
Christian	30 (11.3)	19.5	
Marital status (n = 265)			
Unmarried	28 (10.6)	27.5	0.071
Married	141 (53.2)	22	
Separated	11 (4.2)	16	
Widowed	85 (32.1)	22	
Marital status combined (n = 265)			

Relationship	226 (85.3)	22	0.182
No relationship	39 (14.7)	25	
Years living in colony (n = 265)			
≤ 20years	39 (14.7)	22	0.949
≥ 21years	226 (85.3)	23	
Age at diagnosis, years (n = 265)			
≤ 20	32 (12.1)	23.5	0.753
21-40	84 (31.7)	23.5	
41-60	131 (49.4)	21	
≥ 61	18 (6.8)	24	
Age at diagnosis, years combined (n = 265)			
≤40	116 (43.8)	23.5	0.866
≥41	149 (56.2)	22	
Education (n = 265)			
Literate	212 (80)	22	0.138
Illiterate	53 (20)	26	
Years of education (n = 213)			
Primary level (≤ 4years)	191 (89.7)	22	0.599
Secondary level (5-9years)	22 (10.3)	20.5	
Tertiary level (≥10years)	0 (0)	0	
Occupation (n = 265)			
Farmer	50 (18.9)	26	0.089
Laborer	28 (10.6)	22.5	
Private business	8 (3)	26.5	
Civil/office	3 (1.1)	33	
Student	1 (0.4)	30	
Housewife	10 (3.8)	26	
Unemployed	158 (59.6)	20	
Other	7 (2.6)	23	

Occupation combined (n = 265)			
Farmer	50 (18.9)	26	**0.013**
Unemployed	158 (59.6)	20	
Other	57 (21.5)	25	
Enough income to support family (n = 265)			
Yes	85 (32.1)	23	0.342
No	180 (67.9)	23	
Had to change work because of leprosy (n = 244)			
Yes	48 (19.7)	27	**0.016**
No	196 (80.3)	21.5	
Affected person in family (n = 265)			
Yes	125 (47.2)	21	0.848
No	125 (47.2)	23	
Don't know	15 (5.7)	26	
Affected person in family, combined (n = 265)			
Yes	125 (47.2)	21	0.643
Not aware of	140 (52.8)	23.5	
Affected person in close relationship, non-family (n = 265)			
Yes	95 (35.8)	22	0.184
No	127 (47.9)	25	
Don't know	43 (16.2)	20	
Affected person in close relationship, non-family, combined (n = 265)			
Yes	95 (35.8)	22	0.906
Not aware of	170 (64.2)	23	

4.1.2.2 Knowledge on leprosy

150 (56.6%) of participants had received information on leprosy before. There was no significant difference in total EMIC score to those ones who did not (p=0.479).

Of these, 68 subjects (54.8%) received it from a medical institution, 23 subjects (18.5%) from a friend or the family and 33 subjects (26.6%) from other sources. There was no significant difference in total EMIC score between these groups (p=0.372).

Of all 265 subjects, 96 (36.2%) said that they have knowledge on the cause of leprosy, but of those, only 27 (28.1%) picked the correct answer in the follow-up question on asking for the specific cause. There was no significant difference in total EMIC score between those subjects who meant to have knowledge on the cause of leprosy and those who did not (p=0.883). There was neither a significant difference between those subjects who picked the correct answer in the follow-up question and those who did not (p=0.448).

71 of all subjects (27.1%) believed that leprosy was very infectious. These subjects had a significantly higher total EMIC score than those who believed that leprosy was not very infectious (p=0.001). Concerning leprosy transmission, 87 subjects (22%) said that they know how leprosy is transmitted and of those did 48 (55.2%) pick the correct answer in the follow-up question. Nevertheless, there was no significant difference in total EMIC score between both groups (p=0.693) and there was neither a significant difference between those subjects who picked the correct answer in the follow up question and those who did not (p=0.544).

139 subjects (52.7%) believed that leprosy was difficult to treat. These had a significantly higher total EMIC score than those subjects who believed that leprosy was not difficult to treat (p=0.001).

Asking whether the participants have knowledge on the signs of leprosy, 250 subjects (94.3%) answered with ‘yes’. Nevertheless, there was no significant difference in total EMIC score between those who said that they have knowledge on the signs and those who did not (p=0.352). Of those subjects who believed to have knowledge on the signs of leprosy, 34 (13.6%) selected ‘skin-patches’ and 18 subjects (7.2%) selected ‘decreased sensitivity in skin areas’ in the follow-up question as typical signs, while 185 subjects (69.8%) selected more than one given answer. Comparing these groups, there was no significant difference in total EMIC score (p=0.992).

179 subjects (67.5%) believed that leprosy is a severe disease and these had a significantly higher total EMIC score than those who did not believe that (p=0.045). Finally, 113 subjects (42.8%) believed that leprosy is a punishment by God and these had a significantly higher total EMIC score than those who did not believed that (p=0.018). The complete numbers and percentages, median-values and p-values of the knowledge on leprosy variables are presented in Table 10.

Table 10: Knowledge on leprosy

Characteristics	**Number (%)**	**Median**	**P-value**
Received information on leprosy (n = 264)			
Yes	150 (56.6)	24	0.479
No	115 (43.4)	21	
Source of information (n = 265)			
Local hospital	22 (8.3)	24	0.899
Local doctor	40 (15.1)	25.5	
Health station	6 (2.3)	24.5	
TV/radio/paper	17 (6.4)	26	
Friend or family	23 (8.7)	20	
Other	16 (6.0)	22.5	
Multiple	26 (9.8)	23	
Source of information, combined (n = 124)			
Medical institution	68 (54.8)	24.5	0.372
Friend or family	23 (18.5)	20	
Other	33 (26.6)	24	
Knowledge on cause of leprosy (n = 265)			
Yes	96 (36.2)	11	0.883
No	169 (63.8)	23	
Source of leprosy cause (n = 96)			
Bacteria/microorganism	27 (28.1)	24	0.835
Curse by God	2 (2.1)	24	
Karma	11 (11.5)	21	

Other	56 (58.3)	22	
Source of leprosy cause, combined (n = 96)			
Bacteria/Microorganism	27 (28.1)	24	0.448
Other	69 (71.9)	22	
Leprosy very infectious (n = 262)			
Yes	71 (27.1)	27	**0.001**
No	191 (72.9)	20	
Leprosy transmission (n = 264)			
Yes	87 (33)	22	0.693
No	177 (67)	23	
Leprosy transmitted from (n = 87)			
Air	4 (4.6)	16	0.577
Water/soil	2 (2.3)	18	
Food	2 (2.3)	31	
Animal	1 (1.1)	32	
Mosquito	1 (1.1)	19	
Close contact to persons	48 (55.2)	23	
Other	29 (33.3)	21	
Leprosy transmitted from, combined (n = 87)			
Right answer	48 (55.2)	23	0.544
Wrong answer	39(44.8)	21	
Leprosy difficult to treat (n = 264)			
Yes	139 (52.7)	24	**0.001**
No	125 (47.3)	19	
Knowledge on signs of leprosy (n = 265)			
Yes	250 (94.3)	22	0.352
No	15 (5.7)	24	
Signs and symptoms, answers (n = 250)			
Patches	34 (13.6)	22.5	0.989
Decreased sensitivity patches	18 (7.2)	21	

Weakness had, feet, eyelids	7 (2.8)	19	
Nerve pain	2 (0.8)	21	
Swelling earlobes	1 (0.4)	27	
Painless wounds	3 (1.1)	19	
Multiple	185 (69.8)	23	
Signs and symptoms: multiple vs. one/none			
Multiple	185 (69.8)	23	0.992
One/None	80 (30.2)	22.5	
Leprosy severe disease (n = 265)			
Yes	179 (67.5)	24	0.045
No	86 (32.5)	20.5	
Leprosy punishment by god (n = 264)			
Yes	113 (42.8)	25	**0.018**
No	151 (57.2)	21	

4.1.2.3 Leprosy medical history

When noticing first signs of leprosy, only 13 participants out of 265 (4.9%) consulted a doctor. Of the given reasons in the follow-up question for those who did not go, 41 subjects (16.3%) did not think it was leprosy, 22 subjects (8.7%) did not know where to go and 130 subjects (51.6%) gave multiple answers. There was no significant difference in total EMIC score between these groups (p=0.139). When asking for the location of first treatment, 210 subjects (79.2%) chose a standard medical provider as opposed to 55 subjects (20.8%) who consulted a non-medical source. The total EMIC score between these two groups was not significantly different (p= 0.469).

210 subjects (79.2%) had some kind of disfigurement or deformity. These subjects did not have a significantly higher total EMIC score than those ones who did not have deformities (p= 0.063). There was neither a significant difference (p= 0.349) in total EMIC score in relation to different times of treatment initiation. Those subjects who had visible first disfigurements or deformities had a significantly higher

total EMIC score than those ones who did not (p= 0.008). The location of the first disfigurement was nevertheless not significant in relation to the total EMIC score (p= 0.919). Those subjects who said that they have had ulcers before 146 (55.1%) showed a significantly higher EMIC score than those ones who did not (p= 0.009) The location of the ulcers nevertheless did not significantly seem to influence the total EMIC score (p= 0.346). Foul smell though, seemed to have a significant influence on the total EMIC score as those subjects with smelly ulcers had a significantly higher total EMIC score (p=0.001). The complete numbers and percentages, median-values and p-values all leprosy medical history variables are illustrated in Table 11 below.

Table 11: Leprosy medical history

Characteristics	**Number (%)**	**Median**	**P-value**
Consulted doctor at first sign (n = 265)			
Yes	13 (4.9)	21	0.629
No	252 (95.1)	23	
Not consult doctor - reasons (n = 252)			
Not think leprosy	41 (16.3)	24	0.139
Ashamed	5 (2.0)	32	
Told not to	2 (0.8)	12.5	
Awaited	7 (2.8)	16	
Not know where go	22 (8.7)	22	
No money	4 (1.6)	25	
Multiple	130 (51.6)	21.5	
Other	41 (16.3)	23	
Where first treatment (n = 263)			
Primary health center	46 (17.5)	25	**0.004**
Local doctor	40 (15.2)	26	
Local hospital	85 (32.3)	21	
Regional hospital	39 (14.8)	17	
Non-medical professional	21 (8.0)	24	
Other	32 (12.2)	24.5	

Where first treatment, combined (n = 265)			
Standard medical provider	210 (79.2)	22.5	0.469
Nonstandard medical provider	55 (20.8)	24	
Have disfigurements or deformities (n = 265)			
Yes	202 (76.2)	23.5	0.063
No	63 (23.8)	20	
When develop first disfigurements or deformities (n = 202)			
Before treatment	74 (36.6)	23.5	0.349
During treatment	77 (38.1)	21	
After treatment	51 (25.2)	25	
First disfigurements or deformities visible (n = 202)			
Yes	165 (81.7)	25	**0.008**
No	37 (14)	19	
Where first disfigurement or deformity (n = 202)			
Facial region	11 (5.4)	22	0.919
Hand/foot	153 (75.7)	24	
Eyes	2 (1)	24	
Other body parts	36 (17.8)	21	
Where first disfigurement or deformity, combined (n = 202)			
Hand/feet	153 (75.7)	24	0.523
Other region	49 (24.3)	21	
Did ever have ulcers (n = 265)			
Yes	146 (55.1)	25	**0.009**
No	119 (44.9)	20	
Where have ulcers (n = 146)			
Facial region	2 (1.4)	12.5	0.346
Hands	33 (22.6)	24	
Feet	82 (56.2)	25	
Other	29 (19.9)	21	
Where have ulcers, combined (n = 146)			
Feet	82 (56.2)	25	0.353

Other locations	64 (43.8)	24	
Did ulcers have foul smell (n = 146)			
Yes	45 (30.8)	29	**0.002**
No	60 (41.1)	19	
Little bit	41 (28.1)	25	
Ulcer-smell, combined (n = 146)			
Yes/little bit	86 (58.9)	26	**0.001**
No	60 (41.1)	19	

4.1.2.4 WHO disability classification

The different WHO Disability Grades had a significant influence on the total EMIC score. The higher the grade of ‘disability’ the higher the total EMIC score. Comparing the combined total EMIC scores of Grade 0 and Grade 1 (‘non-visible deformity grades’) with the total EMIC score of Grade 2, analysis found a significant difference (p=0.031). The complete numbers and percentages, median-values and p-values of the WHO Disability Classification are given in Table 12.

Table 12: WHO disability classification

WHO Disability Classification (n = 265)	**Number (%)**	**Median**	**P-value**
Grade 0	50 (18.9)	19	0.051
Grade 1	32 (12.1)	23	
Grade 2	183 (69.1)	24	
WHO disability classification, combined (n = 265)			
Grade 0&1	82 (30.9)	19.5	**0.031**
Grade 2	183 (69.1)	24	

4.2 Leprosy non-affected persons

4.2.1 Descriptive statistics

4.2.1.1 Socio-demographics

Analysis showed that of the two age groups, those ‘younger than 61 years’ had most participants with 178 subjects (69.3%). The genders were unevenly distributed with 183 (71.2%) females to 74 (28.8%) males. Of all subjects, 248 (96.5%) were Thai and 8 subjects (3.1%) were of other nationality. Two religious confessions were represented with 247 Buddhists (96.9%) and 8 Christians (3.1%). Considering marital status, 193 subjects (75.1%) were married and 29 (11.3%) were widowed, while 30 subjects (11.7%) were unmarried and 5 (1.9%) were separated from their partner.

Of all subjects, 224 (87.2%) have lived in the community for more than 20 years. 251 subjects (97.7%) were literate and of those received 171 subjects (68.1%) education for up to 4 years, 53 subjects (21.1%) between 5 to 9 years and 27 subjects (10.8%) were educated for 10 years or more. The most presented profession among the community members was ‘farmer’ with 75 subjects (29.2%). Laborer and private business owners followed with 57 (22.2%) respectively 38 subjects (14.8%). 44 subjects (17.1%) were unemployed.

Of all subjects, 120 (46.7%) said that they have enough income to support the family. 58 subjects (22.7%) had leprosy affected persons in their family and 30 subjects (11.7%) had leprosy affected persons in a close friendship, with no connection to the family. The complete numbers and percentages of the socio demographic variables are given in Table 13.

Table 13: Socio-demographic characteristics (non-affected)

Characteristics	**Number**	**Percentage**
Age Groups (n = 257)		
60 years or below	178	69.3
61 years or older	79	30.7
Mean = 51.62, Median = 52		

SD = 17.161 Range = 19-96 (78)		
Skewness = -0.016		
Sex (n = 257)		
Female	183	71.2
Male	74	28.8
Nationality (n = 257)		
Thai	248	96.5
Other	8	3.1
Religion (n = 255)		
Buddhism	247	96.9
Christian	8	3.1
Marital status (n = 257)		
Unmarried	30	11.7
Married	193	75.1
Separated	51	1.9
Widowed	29	11.3
Marital status combined (n = 257)		
Relationship	222	86.4
No relationship	35	13.6
Years living in comunity (n = 257)		
≤ 20years	33	12.8
≥ 21years	224	87.2
Education (n = 257)		
Literate	251	97.7
Illiterate	6	2.3
Years of education (n = 251)		
Primary level (≤ 4years)	171	68.1
Secondary level (5-9years)	53	21.1
Tertiary level (≥10years)	27	10.8
Years of education, combined (n = 251)		

≤ 4years	171	68.1
≥5years	80	31.9
Occupation (n = 257)		
Farmer	75	29.2
Laborer	57	22.2
Private business	38	14.8
Civil/office	4	1.6
Student	4	1.6
Housewife	19	7.4
Unemployed	44	17.1
Other	16	6.2
Occupation combined (n = 257)		
Farmer	75	29.2
Other	138	53.7
Unemployed	44	17.1
Enough income to support family (n = 257)		
Yes	120	46.7
No	136	52.9
Affected person in family (n = 256)		
Yes	58	22.7
No	194	75.8
Don't know	4	1.6
Affected person in family, combined (n = 256)		
Yes	58	22.7
Not aware of	198	77.3
Affected person in close relationship, non family (n = 256)		
Yes	30	11.7
No	175	68.4

Don't know	51	19.9
Affected person in close relationship, non family, combined (n = 265)		
Yes	30	11.7
Not aware of	226	88.3

4.2.1.2 Knowledge on leprosy

123 subjects (47.9%) had received some form of information on leprosy earlier and of those, 47 subjects (38.2%) from a medical institution, 23 subjects (18.7%) from a friend or family and 53 subjects (43.1%) from other sources. 79 subjects (30.7%) said that they know the cause of leprosy, but of those only 20 subjects (25.7%) chose the correct answer in the follow-up question assessing the specific cause of leprosy. 105 subjects (41.5%) thought that leprosy is very infectious and 83 subjects (32.3%) said that they know how it is transmitted. Of those, only 32 subjects (38.6%) chose the right answer in the follow-up question on way of transmission. 136 subjects (52.9%) think that leprosy is difficult to treat and 106 (41.2%) said that they have knowledge on the signs and symptoms of leprosy. The most individually selected sign was skin patches, chosen by 21 subjects (19.8%), followed by ‘decreased sensitivity in skin areas’ selected by 10 subjects (9.4%). 70 subjects (66.0%) agreed to multiple answers in the follow-up question on specific signs and symptoms. 138 subjects (53.7%) thought that leprosy is a severe disease and 72 subjects (28.0%) believe that leprosy is a punishment by God. The complete numbers and percentages of the knowledge on leprosy variables are illustrated in Table 14.

Table 14: Knowledge on leprosy

Characteristics	Number	Percentage
Received information on leprosy (n = 257)		
Yes	123	47.9
No	134	52.1

Source of information (n = 123)		
Local hospital	31	25.2
Local doctor	8	6.5
Health station	8	6.5
TV/radio/paper	9	7.3
Friend or family	23	18.7
Other	5	4.1
Multiple	39	31.7
Source of information, combined (n = 123)		
Medical institution	47	38.2
Friend or family	23	18.7
Other	53	43.1
Knowledge on cause of leprosy (n = 257)		
Yes	79	30.7
No	178	69.3
Source of leprosy cause (n = 79)		
Bacteria/microorganism	20	25.7
Curse by God	1	1.3
Karma	1	1.3
Other	57	72.2
Source of leprosy cause, combined (n = 79)		
Bacteria/Microorganism	20	25.3
Other	59	74.7
Leprosy very infectious (n = 253)		
Yes	41.5	41.5
No	58.5	58.5
Leprosy transmission (n = 257)		
Yes	83	32.3
No	174	67.7
Leprosy transmitted from (n = 83)		
Air	12	15.5

Water/soil	1	19
Food	1	21
Animal	0	0
Mosquito	0	0
Close contact to persons	32	16.5
Other	37	16
Leprosy transmitted from, combined (n = 83)		
Right answer	32	38.6
Wrong answer	51	61.4
Leprosy difficult to treat (n = 257)		
Yes	136	52.9
No	121	47.1
Knowledge signs of leprosy (n = 257)		
Yes	106	41.2
No	151	58.8
Signs and symptoms answers (n = 106)		
Patches	21	19.8
Decreased sensitivity patches	10	9.4
Weakness had, feet, eyelids	1	0.9
Nerve pain	1	0.9
Swelling earlobes	0	0
Painless wounds	3	2.8
Multiple	70	66
Leprosy severe disease (n = 257)		
Yes	138	53.7
No	119	46.3
Leprosy punishment by god (n = 257)		
Yes	72	28
No	185	72

4.2.1.3 Total EMIC scores

When comparing all EMIC questions by their highest number of ‘Yes’ selections, which is the highest contribution to the ‘total stigma score’ by adding 3 points, EMIC question 3 received most “Yes” selections by 140 subjects (54.5%). This question assessed whether the participant believed that leprosy causes shame or embarrassment in their community.

Second most agreements in form of ‘Yes’ selections was received by EMIC question 15 with 128 (49.8%), asking whether other people would dislike buying food from a person affected by leprosy. EMIC question 14 ranked third with 121 ‘Yes’ selections (47.1%), assessing whether leprosy would cause difficulty to a person in finding work. EMIC question 2 was selected by 108 subjects (42%), asking whether the participant would think less of her/himself if a member of the family had leprosy. EMIC question 4 followed closely with 106 ‘Yes’ selections (41.2%), assessing whether the subject believed that others would think less of a person with leprosy. The same number of selections was given to EMIC question 13, asking whether she/she thought that leprosy would cause a problem for a relative of an affected to get married. 105 selections (40.9%) where received by EMIC 11, assessing whether leprosy would cause a problem to get married, followed by EMIC question 9 with 103 ‘Yes’ selections questioning whether leprosy would cause problems for the family of an affected person.

Comparing all EMIC questions by their highest number of ‘No’ selections, which together with ‘Don’t know’ is the lowest contributor to the ‘total stigma score’ with 0 points, EMIC question 9 received the highest number of 44 selections (16.6%). This question asked whether the affected believed that neighbors, colleagues or others in the community think less of her/his family because of leprosy. EMIC question 6 was selected by 40 subjects (15.1%) with ‘No’, assessing whether contact with an affected persons might have bad effects on others around. EMIC question 5 received 39 ‘No’ selections (14.7%), asking whether an affected person would be less respected among neighbors, colleagues or others in the community.

The highest score of ‘Possible’ selections, contributing each 1-point to the total EMIC score, was found in EMIC question 4 with 80 selections (31.1%), which asked whether the participant believed that others would think less of a person with leprosy. 76 subjects (29.6%) chose 'Possible' on EMIC question 8, asking whether people in the community would think less of a person with leprosy. EMIC question 14 received 75 'Possible' selections (29.2%), questioning whether leprosy would cause difficulty for a person to find work. Only one 'Possible' selection less, with 74 (28.8%), was given to EMIC question 6, assessing whether other people in the community would avoid a person with leprosy.

Most 'Don't know' selections, 23 (8.9%) were given to EMIC question 1, asking whether a person with leprosy would rather keep others from knowing about the disease. This was closely followed by EMIC question 11 with 22 subjects (8.6%), questioning whether leprosy would be a problem to get married. The third highest number of 'Don't know' selections was received by EMIC question 12 and EMIC question 13 with each 20 selections (7.8%). EMIC 12 was assessing whether leprosy would cause problems in an ongoing marriage and EMIC question 13 whether leprosy would cause a problem for a relative of an affected to get married. The complete scores of all EMIC questions of the non-affected subjects are illustrated in Table 15 below.

Table 15: EMIC scores (non-affected)

'n' total= 265	**Yes** ***n (%)***	**Possibly** ***n (%)***	**Don't know** ***n (%)***	**No** ***n (%)***
EMIC 1	75 (29.2)	55 (21.4)	23 (8.9)	104 (40.5)
EMIC 2	108 (42.0)	63 (24.5)	11 (4.3)	75 (29.2)
EMIC 3	140 (54.5)	58 (22.6)	5 (1.9)	54 (21.0)
EMIC 4	106 (41.2)	80 (31.1)	10 (3.9)	61 (23.7)
EMIC 5	80 (31.1)	58 (22.6)	9 (3.5)	110 (42.8)
EMIC 6	97 (37.7)	74 (28.8)	9 (3.5)	77 (30.0)
EMIC 7	92 (35.8)	68 (26.5)	5 (1.9)	92 (35.8)
EMIC 8	88 (34.2)	76 (29.6)	6 (2.3)	87 (33.9)
EMIC 9	103 (40.1)	53 (20.6)	6 (2.3)	95 (37.0)

EMIC 10	106 (41.2)	67 (26.1)	11 (4.3)	73 (28.4)
EMIC 11	105 (40.9)	59 (23)	22 (8.6)	71 (8.6)
EMIC 12	93 (36.2)	67 (26.1)	20 (7.8)	77 (30)
EMIC 13	106 (41.2)	64 (24.9)	20 (7.8)	67 (26.1)
EMIC 14	121 (47.1)	75 (29.2)	11 (4.3)	50 (19.5)
EMIC 15	128 (49.8)	63 (24.5)	9 (3.5)	57 (22.2)

4.2.2 Associations between the independent variables and the total EMIC scores

Associations were calculated by using non-parametric testing methods, as EMIC scores (perceived stigma scores) were non-normally distributed. Mann-Whitney test was applied for independent variables with 2 levels and Kruskal Wallis test was applied for variables with 3 or more levels. The ‘median’ of total EMIC scores for each level is presented in the corresponding table. The ‘median’ was chosen, as the scores were non-normally distributed and has also been used by 2 further leprosy studies with non-normally distributed stigma scores before (5, 38).

4.2.2.1 Socio-demographics (Non-affected)

Of all non-affected subjects, 178 were younger than 61years (69.3%). The median age was 52.0 years with a range between 19 to 96 years. Comparing the subjects of older than 61 years to younger ones, the older ones had a significant higher total EMIC- or stigma score (p= 0.021).

Genders were represented with 183 (71.2%) females and 74 (28.8%) males. There was no significant difference between their total EMIC scores (p= 0.748).

Considering marital status, there was no significant difference in total EMIC scores between the 222 subjects (86.4%) who were in a relationship and those who were not. Only 33 subjects (12.8%) were living in the community for less than 20 years but those did show a significant lower total stigma score than those ones who lived there for longer (p=0.001).

Concerning education, 251 subjects (97.7%) considered themselves as literate. There was no significant difference in total stigma score to those ones who were illiterate (p=0.851). Looking at the years of education, 171subjects (68.1%) had up to

4 years of education, 53 subjects (21.1%) were educated for up to 9 years and 27 subjects (10.8%) had more or equal to 10 years of education. There was a significant difference in total EMIC scores between these groups (p=0.024), with those with up to 4 years of education having the highest stigma score. Occupation was divided into farmers, unemployed and other professions for analytical reasons. 75 subjects (29.2%) were farmers, 44 (17.1%) were unemployed and 138 subjects (53.7%) worked in other professions. There was a significant difference in total EMIC scores between these groups (p=0.013), with the unemployed subjects having the highest score.

120 subjects (46.7%) said they had enough income to support their family and analysis showed that there was no significant difference in total EMIC score to those subjects who did not obtain enough income (p=0.874).

Of all subjects, 58 (22.7%) had leprosy-affected persons in their family, 194 (75.8%) said they do not and 4 subjects (1.6%) said that they do not know whether they have. There was no significant difference in total EMIC scores between these 3 groups (p=0.882). 30 subjects (11.7%) had leprosy-affected persons in closer friendships, 175 (68.4%) said that they do not and 51 subjects (19.9%) said that they do not know if they have. There was no significant difference in total EMIC scores between these groups (p=0.598). The complete numbers and percentages, median-values and p-values of the socio demographic variables are given in Table 16.

Table 16: Analysis for associations between socio-demographic variables and total EMIC scores (Non-affected)

Characteristics	Number (%)	Median	P-value
Age Groups (n = 257)			
60 years or below	178 (69.3)	14	**0.021**
61 years or older	79 (30.7)	18	
Mean = 51.62, Median = 52			
SD = 17.161 Range = 19-96 (78)			
Skewness = -0.016			
Sex (n = 257)			
Female	183 (71.2)	16	0.748

Male	74 (28.8)	15	
Nationality (n = 257)			
Thai	248 (96.5)		
Other	8 (3.1)		
Religion (n = 255)			
Buddhism	247 (96.9)	16	
Christian	8 (3.1)	15.5	
Marital status (n = 257)			
Unmarried	30 (11.7)	12	0.108
Married	193 (75.1)	16	
Separated	5 (1.9)	24	
Widowed	29 (11.3)	18	
Marital status, combined (n = 257)			
Relationship	222 (86.4)	16	0.288
No relationship	35 (13.6)	14	
Years living in community (n = 257)			
≤ 20years	33 (12.8)	10	**0.001**
≥ 21years	224 (87.2)	16.5	
Education (n = 257)			
Literate	251 (97.7)	16	0.841
Illiterate	6 (2.3)	16.5	
Years of education (n = 251)			
Primary level (≤ 4years)	171 (68.1)	17	**0.024**
Secondary level (5-9years)	53 (21.1)	16.5	
Tertiary level (≥10years)	27 (10.8)	16	
Years of education, combined (n = 251)			
≤4years	171 (68.1)	17	**0.049**
≥5years	80 (31.9)	14	

Occupation (n = 257)			
Farmer	75 (29.2)	17	**0.002**
Laborer	57 (22.2)	13	
Private business	38 (14.8)	13	
Civil/office	4 (1.6)	14.5	
Student	4 (1.6)	5	
Housewife	19 (7.4)	19	
Unemployed	44 (17.1)	20	
Other	16 (6.2)	17	
Occupation combined (n = 257)			
Farmer	75 (29.2)	17	**0.003**
Unemployed	44 (17.1)	20	
Other	138 (53.5)	13.5	
Enough income to support family (n = 257)			
Yes	120 (46.7)	15.5	0.874
No	136 (52.9)	16	
Affected person in family (n = 256)			
Yes	58 (22.7)	16	0.846
No	194 (75.8)	15	
Don't know	4 (1.6)	18.5	
Affected person in family, combined (n = 256)			
Yes	58 (22.7)	16	0.882
Not aware of	198 (77.3)	15	
Affected person relationship, Non-family (n = 256)			
Yes	30 (11.7)	14.5	0.598
No	175 (68.4)	16	
Don't know	51 (19.9)	16	

Affected person relationship, Non family, combined (n = 256)			
Yes	30 (11.7)	14.5	0.312
Not aware of	226 (88.3)	16	

4.2.2.2 Knowledge on leprosy

123 participants (47.9%) had received information on leprosy before. There was no significant difference in total EMIC score to subjects who did not (p=0.98). Of those who had received information, 47 subjects (38.2%) received it from a medical institution, 23 subjects (18.7%) from a friend or the family and 53 subjects (43.1%) from other sources. There was no significant difference in total EMIC scores between these groups (p=0.654).

Of all 257 subjects, 79 (30.7%) said that they have knowledge on the cause of leprosy, but of those ones only 20 persons (25.7%) picked the correct answer in the follow-up question on the specific cause. There was no significant difference in total stigma score between those subjects who meant to have knowledge on the cause of leprosy and those who did not (p=0.896). There was neither a significant difference between those subjects who picked the right answer in the follow-up question and those who did not (p=0.148). 105 (41.5%) of all subjects believed that leprosy was a very infectious disease. There was no significant difference in total EMIC score to those subjects who believed that leprosy was not very infectious (p=0.054). Concerning leprosy transmission, 83 subjects (32.3%) said that they know how leprosy is transmitted and of those did 32 (38.6%) pick the right answer in the follow-up question on specific transmission. There was no significant difference in total stigma score to those subjects who picked the wrong answer (p=0.389). 136 subjects (52.9%) believed that leprosy was difficult to treat and this group had a significantly higher total EMIC score than those who believed that leprosy was not difficult to treat (p=0.015).

Asking whether the participants have knowledge on the signs of leprosy, only 106 subjects (41.2%) answered with ‘yes’. Analysis showed no difference in total stigma score between these two groups (p=0.929). When asking more specifically for the typical signs and symptoms of leprosy, 21 subjects (19.8%) selected ‘skin-patches’ and 10 subjects (9.4%) chose ‘decreased sensitivity in skin areas’. 70 subjects (66.0%) selected more than one given answer. Comparing these 2 groups, there was no significant difference in total EMIC score (p=0.861). 138 subjects (53.7%) believed that leprosy is a severe disease and analysis showed a significant higher total EMIC score in this group (p=0.004). 72 subjects (28.0%) believed that leprosy is a punishment by God and those had a significant higher total stigma score than those subjects who did not believe leprosy being a punishment by God (p=0.011). The complete numbers and percentages, median-values and p-values of the knowledge on leprosy variables are given in Table 17.

Table 17: Knowledge on leprosy (non-affected)

Characteristics	**Number (%)**	**Median**	**P-value**
Received information on leprosy (n = 257)			
Yes	123 (47.9)	15	0.98
No	134 (52.1)	16	
Source of information (n = 123)			
Local hospital	31 (25.2)	16	0.921
Local doctor	8 (6.5)	14	
Health station	8 (6.5)	18.5	
TV/radio/paper	9 (7.3)	18	
Friend or family	23 (18.7	14	
Other	5 (4.1)	18	
Multiple	39 (31.7)	16	
Source of information, combined (n = 123)			
Medical institution	47 (38.2)	16	0.654
Friend or family	23 (18.7)	14	
Other	53 (43.1)	16	
Knowledge on cause of leprosy			

(n = 257)			
Yes	79 (30.7)	15	0.896
No	178 (69.3)	16	
Source of leprosy cause (n = 79)			
Bacteria/microorganism	20 (25.7)	14.5	0.417
Curse by God	1 (1.3)	21	
Karma	1 (1.3)	17	
Other	57 (72.2)	15	
Source of leprosy cause, combined (n = 79)			
Bacteria/Microorganism	20 (25.3)	14.5	0.148
Other	59 (74.7)	15	
Leprosy very infectious (n = 253)			
Yes	105 (41.5)	17	0.054
No	148 (58.5)	14	
Leprosy transmission (n = 257)			
Yes	83 (32.3)	16	0.439
No	174 (67.7)	15	
Leprosy transmitted from (n = 83)			
Air	12 (14.5)	15.5	0.766
Water/soil	1 (1.2)	19	
Food	1 (1.2)	21	
Animal	0 (0)	0	
Mosquito	0 (0)	0	
Close contact to persons	32 (38.6)	16.5	
Other	37 (44.6)	16	
Leprosy transmitted from, combined (n = 83)			
Right answer	32 (38.6)	16.5	0.389
Wrong answer	51 (61.4)	16	

Leprosy difficult to treat (n = 257)			
Yes	136 (52.9)	17	**0.015**
No	121 (47.1)	14	
Knowledge signs of leprosy (n = 257)			
Yes	106 (41.2)	16	0.929
No	151 (58.8)	15	
Signs and symptoms answers (n = 106)			
Patches	21 (19.8)	14	0.861
Decreased sensitivity patches	10 (9.4)	14	
Weakness had, feet, eyelids	1 (0.9)	15	
Nervepain	1 (0.9)	21	
Swelling earlobes	0 (0)	16	
Painless wounds	3 (2.8)	16	
Multiple	70 (66.0)	17	
Leprosy severe disease (n = 257)			
Yes	138 (53.7)	17.5	**0.004**
No	119 (46.3)	14	
Leprosy punishment by god (n = 257)			
Yes	72 (28.0)	18.5	**0.011**
No	185 (72.0)	14	

4.2.2.3 Independent variables that had a significant impact on the total EMIC either in the group of affected subjects, non-affected subjects or in both.

In the colony, occupation had a significant impact on the total EMIC score when comparing farmers with unemployed subjects and those in other professions (p=0.013). Famers had a higher median of total EMIC score than both other groups.

Amongst those subjects living in the community, occupation also had a significant impact on the total EMIC score, both in the individual comparison (p=0.002) as well as in the combined analysis (p= 0.003). Significantly higher total EMIC scores were also seen in those subjects who thought that leprosy was very infectious (p=0.001), those who thought that leprosy was very difficult to treat (p=0.001) and those who thought that leprosy was a punishment by God (p=0.018). Amongst the community members, age had a significant impact on the total EMIC score, by showing that those above or equal to 60 years of age had a higher total EMIC score than the younger subjects. 'Years living in the community' was another variable that turned out to be significant, showing that those who lived in the community for more or equal to 21 years had a significantly higher total EMIC score. Years of education also impacted the EMIC score significantly by showing that the groups with longer education had a lower total EMIC scores (p=0.049). The variables assessing knowledge on leprosy, showed almost similar outcomes to those of the affected group. Those community subjects who thought that leprosy was difficult to treat had a significant higher EMIC score (p=0.015) than those who did not. Persons who thought that leprosy was a severe disease (p=0.004) and those who thought that leprosy was a punishment by God (p=0.011) had significant higher EMIC scores, as well. Only the group of subjects who thought that leprosy was very infectious turned out to be just borderline significant (p=0.054). All independent variables that had a significant impact on the total EMIC score either among the affected group; the un-affected group or both are given in Table 18.

Table 18: Independent variables with significant impact on the EMIC scores, either among the affected-, the non-affected or both

Independent variables	**Colony:** 'Median' of total EMIC score	**Community:** 'Median' of total EMIC score
Age groups (p-value)	0.63	**0.021**
60 years or below	25	14

61 years or older	22	18
Years living in colony/community (p-value)	0.949	**0.001**
≤ 20years	22	10
≥ 21years	25	16.5
Years of education (p-value)	0.599	**0.024**
Primary level (≤ 4years)	22	17
Secondary level (5-9years)	20.5	16,5
Tertiary level (≥10years)	0	16
Years of education combined (p-value)	0.599	**0.049**
≤4years	22	17
≥5years	20.5	14
Occupation (p-value)	0.089	**0.002**
Farmer	26	17
Laborer	22.5	13
Private business	26.5	13
Civil/office	33	14.5
Student	30	5
Housewife	26	19

Unemployed	20	20
Other	23	17
Occupation, combined (p-value)	**0.013**	**0.003**
Farmer	26	13.5
Unemployed	20	20
Other	25	13
Leprosy very infectious (p-value)	**0.001**	0.054
Yes	27	17
No	20	14
Leprosy difficult to treat (p-value)	**0.001**	**0.015**
Yes	24	17
No	19	14
Leprosy a severe disease (p-value)	**0.045**	**0.004**
Yes	24	17.5
No	20.5	14
Leprosy punishment God (p-value)	**0.018**	**0.011**
Yes	25	18.5
No	21	14

CHAPTER V
DISCUSSION

5.1 Discussion structure

The main objective of this study was to determine risk factors for perceived stigma in leprosy affected and non-leprosy affected persons in- and around Non Somboon leprosy colony, Khon Kaen province, Thailand. The affected subjects were living in the colony, the non-affected subjects in the community.

Literature review has shown that certain risk factors support the process of stigmatization. This study has specifically looked for risk factor that support the development of perceived stigma within leprosy-affected persons living in a leprosy colony, as well as in leprosy unaffected persons living in the nearby community. A deeper analysis for further understanding or the relative importance of risk factors would require multiple regression analysis, which is beyond the scope of this study.
The Discussion Chapter is divided into the following sections:

1. Leprosy affected persons, colony
    1.1. General discussion on the socio-demographics characteristics of the colony population
    1.2. Discussion on the key findings
2. Non-leprosy affected persons, community
    1.1. General discussion on the socio-demographics characteristics of the community population
    1.2. Discussion on the key findings
3. Conclusions of the study
4. Benefits of the study
5. Recommendations

5.1.1 Leprosy affected persons, colony

5.1.1.1 General discussion on the socio-demographic characteristics

The colony population had a median age of 70 years and the majority of participants fell into the age bracket of 61 years or older. This may be explainable by the fact that the incidence rate of leprosy has fallen tremendously over the last 3 to 4 decades due to effective 'Multi Drug Treatment'; hence the majority of leprosy-affected persons today can be found among the older generations. The genders were evenly distribution with 128 females (51.7%) to 137 males (48.3%). Confessions were present with 235 (88.7%) Buddhists and 30 (11.3%) Christians. The percentage of Christians was higher than in the general population of Thailand (0.6%) (55), and this might be due to the attraction of Christian Aid Organizations working in 2 Christian communities within the colony. The literacy rate was 80% and lower than in the general Thai population with 92.6% (56). Analysis of occupation showed, that 18.9% of subjects were working as famers, 10.6% as laborers and 9.9% were divided into different other professions. The majority of subjects (59.6%) were unemployed. 67.9% of subjects said that they did not have enough income to support their family, which may be in contrast to a 2010 published rate describing 7.75% living below poverty in Thailand (57). It is to mention though, that this information is just a perception and may therefore go in contrast to solid facts. As poverty is a major burden for many residents, extra income from common agricultural and fishing projects is now divided through all needy persons living within in the colony.

These general findings suggest that the population in the colony is not representative for the general population of Thailand, but may be more a result of isolation and rejection by the general population.

5.1.1.2 Discussion on the key findings

Different aspects of socio-demographics, knowledge on leprosy and personal medical affection of leprosy have been assessed for their relation to perceived stigma in leprosy.

Age has been identified as a risk factor for stigma in several other studies (37, 47). A study from India in 2008 by Rao et al. found that perceived stigma was significantly higher in persons of more than 46 years of age (37). As opposed to these findings, our study could not reveal a significant difference in perceived stigma between older subjects (61years+) and those who were below that age (p=0.63). Nevertheless, as 77% of our subjects belonged to the group of subjects above 61years, we cannot exclude that this might have had an impact on the outcome.

Sex was identified as a further risk factor for perceived stigma in several other articles that have been reviewed. Brouwers et al., for example, found that women in Nepal had a significant higher rate of perceived stigma than men (45) and this was confirmed by a study from Van Brakel in Indonesia in 2012 (5). Opposed to that, Tsutsumi described in his study from Bangladesh in 2007(38), that male sex had a significant higher rate of perceived stigma. In contrast to the described findings did our study not show a significant difference in perceived stigma between women and men at all. Nevertheless, as most mentioned studies were performed in different countries, nationality and different cultures might have had a significant impact on the outcome.

Problems of leprosy-affected people regarding work have been discussed in several other studies before. It may be difficulties to find work, because of social exclusion and discrimination based on stigma against leprosy-affected people as described in 2 articles by Van Brakel in 2003 and 2012 (4, 5), or may be caused by the individual’s comprising work capacity due to their physical disabilities (5, 46). When looking at the results of this study, those people who had to change work because of leprosy, self-decided or forced, had a significant higher total EMIC score (p=0.016), representing a higher level of perceived stigma, than those who did not. This qualifies ‘change of work because of leprosy’ as a risk factor for perceived stigma in this study.

Socio-economic status, which is generally connected to the profession and income of a person, has been described as a further potential risk factor for perceived stigma in several publications. All studies that were reviewed, assessing socio-economic status in relation to stigma in leprosy, identified low-socio eco-economic status as a significant risk factor for perceived stigma (37, 38). This study has assessed the level of perceived stigma of different professions in the colony. The results nevertheless show that there was a very disproportional outcome in quantity of subjects doing different jobs. Being a farmer was most common with 18.9%, which was followed buy a variety of different other professions too small in numbers of workers to compare. For analytical reasons, three groups of occupations were constructed for better comparison. The first group was ‘farmers’ (18.9%), the second group was a combination of ‘other’ professions (21.5%) and the third group consisted of the ‘unemployed’ subjects (59.6%). Analysis showed a significant difference in perceived stigma between these groups (p=0.016). Farmers, which are generally considered of low-economic status in this region (58), had the highest level of perceived stigma, which was in correspondence with the findings of earlier studies (37, 38). The combination of ‘other professions’ followed closely with the second highest stigma level. Nevertheless, as opposed to findings of other studies, the group of ‘unemployed’ subjects, generally connected to a very low socio-economic status, had a much lower stigma score than both other groups. This might be caused by the fact that many unemployed subjects hardly ever get to leave the colony, because of their physical disabilities. This consequently may lead to less exposition to potential stigma by community subjects outside the colony.

Similar to ‘low economic status’ was ‘low education’ found to be an outstanding risk factor for stigma in leprosy (5, 37, 44, 48, 51). This study in contrary did not show a significant difference (p=0.599) in perceived stigma between two defined groups of education, the first group with subjects up to 4 years of education (89.7%) and second one with subjects with education between 5-9 years (10.3%). Neither was there a significant difference between those who were literate (80%) and those who were not (p=0.138). As almost 90% of subjects were part of the group with education of up to 4 years, an impact on the result cannot be entirely excluded.

'Knowledge on leprosy' was a further potential risk factor for perceived stigma, which was found as significant in several other articles. Especially knowledge on the 'cause of leprosy', the 'way of transmission' and the perceived outcome seemed to be far away from reality in several studies ((7, 44, 48). Our study did not reveal any significant difference in perceived stigma between those subjects who had received general information on leprosy before and those who had not (p=0.479). Neither did the source of the information have a significant impact on the stigma score (p=0.889). Nevertheless, the analysis of certain subcategories of 'knowledge on leprosy' showed significant higher stigma scores among those subjects who thought that leprosy was very infectious (p=0.001), those who thought that leprosy was difficult to treat (p=0.001) and those who thought that leprosy was a punishment by God (p=0.018). Especially superstition and religious believes were confirmed by earlier studies, like leprosy as a punishment for sinners (45) or a curse by God ((7, 49, 50) .

This study has furthermore analyzed the medical history of the affected subjects in regard to the severity of perceived stigma. When considering the early period of the affected subjects' leprosy-medical-history, there were no significant differences between those who were seeking for medical help at an early stage and those who did not (p=0.629). Neither did the sub-question on the reasons why so many subjects did not consult a doctor (95.1%) show a significant difference in stigma scores (p=0.139). It should be mentioned though that the majority gave multiple reasons (51.6%) and 26.3% did not think it was leprosy at all, corroborating possible low knowledge on leprosy and it's signs and symptoms.

When focusing on disfigurements, this study did not revel any significant difference in perceived stigma between those who had disfigurements and those who had not (p=0.063). This in in contradiction to several other studies who found disfigurements to be an important risk-factor for perceived stigma (37, 38, 44) or stigma in leprosy in general (46, 48, 51). Nevertheless, when asking more specifically whether the 'first disfigurements' were visible, those ones who confirmed visible deformities had a significantly higher stigma score score than those subjects who had non-visible deformities (p=0.008). This difference may be explained by the fact that the question specifically asked for 'first disfigurements' and whether these were visible or not. This was in opposition to many other studies, which assessed the relation of stigma and disfigurements in general. These included later stages of leprosy, where deformities and disfigurements are more common (5).

When looking at ulcers, this study found a significant higher rate of perceived stigma in affected persons who had ulcers before than in those who did not (p=0.009). The result of the sub-question, whether these ulcers had a foul smell, presented a significant higher rate of perceived stigma in subjects who had bad smelling ulcers than those who did not (p=0.002).

Finally, considering the WHO disability qualification in respect to perceived stigma, this study found a significant higher stigma score in subjects with Grade 2 disability than those with Grade 0 and Grade 1 combined (p=0.031). For better comparison, Grade 0 and Grade 1 were combined, as none of these grades contain visible affections as opposed to Grade 2. This is supported by many articles that have been reviewed, showing that visible affections and deformities have a significant impact on stigma in leprosy (7, 37, 38, 44, 45).

5.1.2 Leprosy non-affected persons, the community

5.1.2.1. General discussion on the socio-demographics characteristics

The community population had a median age of 52 years, which was above the median age of Thailand with 35.7 years (56). The majority of participants (69.3%) fell into the age bracket of 60 years or younger, which is in agreement with official statistics on Thailand (56). The sex distribution was unevenly distributed with 71.2% females and religion was presented with 96.9%

of Buddhists and 3.1% of Christians. The percentage of Christians was slightly higher than in the general Thai population (0.7%) and there were no Muslims present. The literacy rate was 97.7%, which was slightly higher than in the general Thai population with 92.6% (56) and clearly higher than in the colony with 80%. Analysis of occupation showed, that 29.2% were working as famers, 22.2% as laborers and 14.8% had private businesses. 17.1% of the community subjects were unemployed and the rest was divided into different other professions. The unemployed rate (17.1%) was lower than in the colony (59.6%), but still higher than in the general population (0.6%). 52.9% of subjects said that they did not have enough income to support the family, which was higher than a published 'below poverty-rate' of 7.75% from 2010 (57). The studies' information is nevertheless a perception and may go in contrast to solid facts.

The general findings suggest that the population in the community was not representative for the general population in Thailand, but might be representative for the region around the colony. .

5.1.2.2 Discussion on the key findings

This study has identified age as a significant factor for perceived stigma among the non-affected subjects by showing that older subjects of more than 61 years had a higher stigma score than the younger subjects (p=0.021). This was in correspondence with other studies that also identified age as being a risk factor for stigma (37, 47). Focusing on perceived stigma, Rao et al. described in a study form 2008, that perceived stigma was significantly higher in persons of more than 46 years of age than in younger subjects and that was observed in both the leprosy-affected and non-leprosy affected subjects (37).

Genders in this study did not show a significant difference in perceived stigma score between women and men and that was in contrast to several other studies that have identified sex as a potential risk factor for perceived stigma (5, 38, 45). Nevertheless, none of these studies specifically described this observation in non-affected subjects and it is therefore unclear whether this is valid for that group, as well. In addition, most of these studies were performed in different countries and it is unclear whether that might have had a significant impact on the outcome.

A further observation that had a significant impact on the stigma score was the time persons had already lived in the community. Subjects who lived in the community for more than 21 years showed a significantly higher stigma score than those subjects who lived there for a shorter period of time (p=0.001). It is to speculate whether a former and strong negative attitude against leprosy-affected people might have influenced the community-residents so permanently that have never changed their mind again.

Low education was a further prominent risk factor to have a significant impact on stigma in leprosy in several other studies (5, 37, 44, 48, 51). This was in correspondence with the results of our study, which showed that subjects with less than 5 years of education had a significant higher stigma score than those with longer education (p=049).

Van Brakel described in a study from 2012 (5), that unemployment was a significant risk factor for perceived stigma among community members, which was in correspondence with our results, showing unemployed subjects with the highest stigma score among all given professions.

For better comparison, three groups of different professions were constructed. The first group was ‘farmers’, the second group ‘other’ professions and the third group was ‘unemployed’. Analysis showed that there was a significant difference in perceived stigma between these groups (p=0.003), with the group of ‘unemployed’ still having the highest stigma score.

Low ‘knowledge on leprosy’ was a further potential risk factor for perceived stigma, which was found in several other studies ((7, 44, 48). Especially knowledge on the ‘cause of leprosy’, the ‘way of transmission’ and the ‘prognosis or outcome’ of leprosy were found as often times far from facts in these studies. Our study did not reveal any significant difference in perceived stigma between those subjects who had received general information on leprosy before and those who had not (p=0.98). Neither did the source of the information have a significant impact on the total stigma score (p=0.921). The analysis of subcategories on ‘knowledge on leprosy’ nevertheless showed significantly higher stigma scores among those subjects who thought that leprosy was very infectious (p=0.054), those who thought that leprosy was difficult to treat (p=0.015), those who thought that leprosy was a severe disease (p=0.004) and those who believed that leprosy was a punishment by God (p=0.011). Interestingly, the outcomes of these sub-categories were quite similar to the subjects living in the colony, with the addition that those community subjects, who believed that leprosy is a severe disease, had a significantly higher stigma score, as well (p=0.045).

It seems that independent of received information on leprosy, certain stereotypes and false ideas just keep persisting in a significant number of subjects, leading to higher levels of stigma. Religious beliefs like leprosy being a punishment by God (p=0.001) or prominent stereotypes like leprosy being very infectious (p=0.054) and a severe disease (p=0.004) have been found in several other studies, independently of nationality and confession ((7, 49, 50).

5.1.2.3 Comparison of variables with significant impact on total EMIC scores in both the affected and non-affected

When comparing the results of the socio-demographic assessment of the leprosy-affected persons with that of the non-affected, only one variable among tuned out to have a significant impact on the ‘total stigma score’ in both groups, which was occupation. Nevertheless, closer assessment of the Median-scores reveals disagreement in the profession, which showed the highest level of perceived stigma. In the group of leprosy-affected subjects, ‘farmers’ showed the highest stigma score with a Median EMIC score of 26, followed by ‘other’ professions Median 25 and the group of ‘unemployed’ subjects with a Median stigma score of 20. As opposed to that, the non-leprosy affected subjects showed the highest stigma score among the ‘unemployed’ subjects with a Median of 20, followed by ‘farmers’ with a Median score of 13.5 and ‘other’ professions with a Median score of 13.

Nevertheless, the scores among the working subjects go into the opposite direction. The working subjects in the group of affected persons have high stigma scores (Median 26 for 'farmers' and Median 25 for 'other' professions), while the working subjects in the non-affected group, have the lower stigma scores (Median 13.5 for 'farmers' and 13 for 'other' professions). It is to speculate whether this is based on a higher risk for exposition to potential stigma among those who work, as opposed to unemployed subjects.

Interestingly, 'knowledge on leprosy' had in several sub-categories a significant impact on the total stigma score in both the affected and non-affected subjects. Poor knowledge on the disease in combination with 'superstition' and 'false believe' are still dominating factors that persist, independent whether the person is leprosy-affected or not.

5.2 Conclusions and recommendations

This study results can confirm certain risk factors of perceived stigma in leprosy that have been described in earlier studies before. Among the leprosy–affected persons those were low social status, poor knowledge on leprosy, religious- and non-religious superstition and visible disfigurements. As new or more specified risk factors the study found significant higher stigmas scores in certain sub-categories on the knowledge on leprosy. Those were among people who thought that leprosy was very infectious, difficult to treat or a punishment by God. The study could not confirm age or sex as being significant risk factors for perceived stigma, neither was general education a significant risk factor among the leprosy-affected persons.

Concerning the community subjects, this study could confirm age as a significant risk factor for perceived stigma. General education and specific professions, often connected to a certain socio-economic status, could also be conformed as having a significant impact on perceived stigma in leprosy. Poor knowledge on leprosy, superstition and religious believes also been proved to be significant risk factors for perceived stigma in this study.

When comparing the results of the colony with those of the community, poor knowledge of leprosy with its many significant sub-categories was probably the most impacting category on both the affected and non-affected side. Based on this studies result it is therefore suggestible to improve knowledge on leprosy with emphasis on the cause and source of leprosy, on the way of transmission, the infectiousness and the seriousness of the disease. This should be done on both the affected- and unaffected side. As the information provided might be partially difficult to understand, the possibility of direct interaction between the informing and the informed subject would be suggestible. This way potential questions and misunderstandings could be resolved immediately and the spread of misunderstood information may be reduced. For quality assurance the training personal should be well educated and qualified on knowledge in leprosy and should have good pedagogical skills to assure the best possible learning effect. Repetitive sessions to assure and test for long-term effect may be suggested. An affective improvement on poor knowledge on leprosy may then eventually reduce the burden of perceived stigma in both the leprosy-affected and non-affected person and even increase the chances of a successful reintegration and acceptance of leprosy affected persons into the ‘normal’ society.

REFERENCES

(1) Harris K. Pride and prejudice--identity and stigma in leprosy work. Lepr Rev. 2011 Jun;82(2):135-46.

(2) Poestges H. Leprosy, the key to another kingdom. Lepr Rev. 2011 Jun;82(2):155-67.

(3) Navon L. Beggars, metaphors, and stigma: a missing link in the social history of leprosy. Soc Hist Med. 1998 Apr;11(1):89-105.

(4) Van Brakel WH. Measuring leprosy stigma--a preliminary review of the leprosy literature. Int J Lepr Other Mycobact Dis. 2003 Sep;71(3):190-7.

(5) Van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, et al. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. Global health action. 2012;5.

(6) Rafferty J. Curing the stigma of leprosy. Lepr Rev. 2005 Jun;76(2):119-26.

(7) De Stigter DH, de Geus L, Heynders ML. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. Lepr Rev. 2000 Dec;71(4):492-8.

(8) ILEP. Facts about Leprosy [online]. 2012; Available from: http://www.ilep.org.uk/facts-about-leprosy/. [2012]

(9) National Institute of Allergy and Infectious Diseases U. Leprosy (Hansen's Disease) [online]. 2011; Available from: http://www.niaid.nih.gov/topics/leprosy/Understanding/Pages/history.aspx. [2011]

(10) WHO. Leprosy [online] . 2012 [2012]; Available from:

http://www.who.int/mediacentre/factsheets/fs101/en/index.html. [2012]

(11) SEARO. Leprosy Fact Sheet [online]. 2012; Available from: http://www.searo.who.int/en/Section10/Section20/Section2293.htm [2012].

(12) WHO. Leprosy situation in the WHO South East Asia Region [online].2005; Available from: http://www.who.int/lep/situation/se_asia/en/index.html [2005].

(13) WHO. Leprosy elimination: Elimination of leprosy FAQ 2000 [online]; Available from: http://www.who.int/lep/strategy/faqs/en/index.html [2000].

(14) WHO. Diagnosis of leprosy [online]. 2012; Available from: http://www.who.int/lep/diagnosis/en/index.html [2012].

(15) Tsutsumi A, Izutsu T, Akramul Islam MD, Amed JU, Nakahara S, Takagi F, et al. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. Lepr Rev. 2004 Mar;75(1):57-66.

(16) Jacob JT, Kozarsky P, Dismukes R, Bynoe V, Margoles L, Leonard M, et al. Five-year experience with type 1 and type 2 reactions in Hansen disease at a US travel clinic. Am J Trop Med Hyg. 2008 Sep;79(3):452-4.

(17) ILEP. How to Recognise and Manage Leprosy Reactions. 2002.

(18) ILEP. How to recognize and manage leprosy reactions. 2002.

(19) Kahawita IP, Lockwood DN. Towards understanding the pathology of erythema nodosum leprosum. Trans R Soc Trop Med Hyg. 2008 Apr;102(4):329-37.

(20) Srinivasan. Management of ulcers in neurologically impaired feet in leprosy

affected persons. Management of ulcers? ILEP. [Book]. (Surgical Reconstruction & Rehabilitation in Leprosy), 2012.

(21) Gahalaut P, Pinto J, Pai GS, Kamath J, Joshua TV. A novel treatment for plantar ulcers in leprosy: local superficial flaps. Lepr Rev. 2005 Sep;76(3):220-31.

(22) Goffman. Stigma: Notes on the Management of Spoiled Identity, 1963.

(23) Neylan TC, Nelson KE, Schauf V, Scollard DM. Illness beliefs of leprosy patients: use of medical anthropology in clinical practice. Int J Lepr Other Mycobact Dis. 1988 Jun;56(2):231-7.

(24) Van Brakel WH. Measuring health-related stigma--a literature review. Psychol Health Med. [Review]. 2006 Aug;11(3):307-34.

(25) Wagener DK, Schauf V, Nelson KE, Scollard D, Brown A, Smith T. Segregation analysis of leprosy in families of northern Thailand. Genet Epidemiol. 1988;5(2):95-105.

(26) ILEP. Guidelines to Reduce Stigma [online] . 2012; Available from: http://www.ilep.org.uk/technical-advice/guidelines-to-reduce-stigma/ [2012].

(27) Luka. Understanding the stigma of leprosy. SSMJ. 2010;3(3).

(28) Bainson KA, Van den Borne B. Dimensions and process of stigmatization in leprosy. Lepr Rev. 1998 Dec;69(4):341-50.

(29) Heijnders ML. The dynamics of stigma in leprosy. Int J Lepr Other Mycobact Dis. 2004 Dec;72(4):437-47.

(30) Van Brakel WH, Anderson AM, Mutatkar RK, Bakirtzief Z, Nicholls PG, Raju MS, et al. The Participation Scale: measuring a key concept in public health. Disabil Rehabil. 2006 Feb 28;28(4):193-203.

(31) Weiss MG, Doongaji DR, Siddhartha S, Wypij D, Pathare S, Bhatawdekar M, et al. The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. Br J Psychiatry. 1992 Jun;160:819-30.

(32) Pike. Language in relation to a unified theory of the structure of human behavior. The Hague, Mouton. (2. edition), 1976.

(33) Weiss. Explanatory Model Interview Catalogue (EMIC). transcultural psychiatry. 1997;3(2).

(34) Rensen C, Bandyopadhyay S, Gopal PK, Van Brakel WH. Measuring leprosy-related stigma - a pilot study to validate a toolkit of instruments. Disabil Rehabil. 2011;33(9):711-9.

(35) Chowdhury AN, Sanyal D, Bhattacharya A, Dutta SK, De R, Banerjee S, et al. Prominence of symptoms and level of stigma among depressed patients in Calcutta. J Indian Med Assoc. 2001 Jan;99(1):20-3.

(36) Vlassoff C, Weiss M, Ovuga EB, Eneanya C, Nwel PT, Babalola SS, et al. Gender and the stigma of onchocercal skin disease in Africa. Soc Sci Med. 2000 May;50(10):1353-68.

(37) Rao PS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and correlates of leprosy stigma in rural India. Indian J Lepr. [Research Support, Non-U.S. Gov't]. 2008 Apr-Jun;80(2):167-74.

(38) Tsutsumi A, Izutsu T, Islam AM, Maksuda AN, Kato H, Wakai S. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. Soc Sci Med. 2007 Jun;64(12):2443-53.

(39) Zodpey SP, Tiwari RR, Salodkar AD. Gender differentials in the social and family life of leprosy patients. Lepr Rev. 2000 Dec;71(4):505-10.

(40) Scott J. The psychosocial needs of leprosy patients. Lepr Rev. 2000

Dec;71(4):486-91.

(41) Last. A dictionary of epidemiology. (4th edition), 2001.

(42) Burt BA. Definitions of risk. Short report. [Short Report for the Consensus Development Conference on Diagnosis and Management of Dental Caries Throughout Life]. 2001.

(43) Beck JD. Risk revisited. Community Dent Oral Epidemiol. 1998 Aug;26(4):20-5.

(44) Myint T, Thet AT, Htoon MT, Win M. A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships. Indian J Lepr. 1992 Jul-Sep;64(3):313-24.

(45) Browers. Quality of life, perceived stigma, activity and participation of people with leprosy-related disbilities in South-East Nepal. dcidj. 2011;22:16-34.

(46) Lustosa AA, Nogueira LT, Pedrosa JI, Teles JB, Campelo V. The impact of leprosy on health-related quality of life. Rev Soc Bras Med Trop. 2011 Oct;44(5):621-6.

(47) Kushwah SS, Govila AK, Upadhyay S, Kushwah J. A study of social stigma among leprosy patients attending leprosy clinic in Gwalior. Lepr India. 1981 Apr;53(2):221-5.

(48) Primkaew. Stigma in leprosy affected persons in Nadoon district, Mahasarakham, Thailand. Office of Disease Precention and Control 5th Nakhonratchasima Journal. 2012 February 2012;18.

(49) Nagaraya Vea. Stigma among the leprosy patients of urban leprosy centres in mysore: a field study. J Epidemiol Community Health 2011 August;65.

(50) Ebenso B. Impact of socio-economic rehabilitation on leprosy stigma in northern Nigeria: Findings of a retrospective study. Asia Pacific Disability Rehabilitation Journal. 2007;18(No. 2).

(51) Nardi SM, Paschoal VD, Zanetta DM. Social participation of people affected by leprosy after discontinuation of multidrug therapy. Lepr Rev. 2011 Mar;82(1):55-64.

(52) Bekri W, Gebre S, Mengiste A, Saunderson PR, Zewge S. Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia. Int J Lepr Other Mycobact Dis. 1998 Mar;66(1):1-9.

(53) Gussow Z, Tracy GS. The phenomenon of leprosy stigma in the continental United States. Lepr Rev. 1972 Jun;43(2):85-93.

(54) Danlep. Combating leprosy. WHO Special Ambassador's Newsletter No 3. 2003.

(55) US-Department-of-states. Thailand. 2010.

(56) CIA. Factbook Thailand. 2010.

(57) CIA. Factbook Thailand. 2013.

(58) Nations U. Thailand Info, Socio-economic Situation. 2013

APPENDICES

Appendix A

1. Leprosy research questionnaire, affected

Interviewer i.d.:

<u>Part I:</u>
A. Demographic characteristics
B. Natural history of disease, clinical presentation and disability
C. Disability according to the WHO classification

<u>Part II:</u>
"Explanatory Model Interview Catalogue" (EMIC-a)

- <u>CASES:</u>

Inclusion criteria:

- Male and female persons affected by leprosy
- Age 18 or older
- History of medically diagnosed leprosy
- Living in the colony for more than 1 year
- Able to communicate with the study investigator and to understand and answer the questions adequately

Exclusion criteria:

- Patients with other non-stabilized diseases that can lead to similar clinical symptoms like diabetes mellitus or peripheral arterial disease.
- Not willing to participate in the study

<u>Part I:</u>

A. Demographic entities:

1. Age: ………. years
2. Sex: ☐ female ☐ male
3. Ethnicity: ☐ Thai ☐ Other (………………..)
4. Village/Community: ☐ Non Somboon ☐ Other
5. How many years lived in the colony? ………. years
6. How old were you when diagnosed with leprosy? …….... years
7. Religion:
    a. ☐ Buddhism
    b. ☐ Christian
    c. ☐ Muslim
    d. ☐ Hindi
    e. ☐ other

8. Marital status:

   a. ☐ Unmarried
   b. ☐ Married
   c. ☐ Separated
   d. ☐ Widowed

9. Family medical history: family member diagnosed with leprosy (before own infection)?
   a. ☐ yes
   b. ☐ no
   c. ☐ don't know

10. Anybody in close relationship, non-family, diagnosed with leprosy (before own infection)?
    a. ☐ yes
    b. ☐ no
    c. ☐ don't know

11. School education:
    a. ☐ yes (literate)
    b. ☐ no (illiterate)

    If yes, up to which level?
    I. Primary level (< 5 years)
    II. Secondary level (5-10 years)
    III. Higher education (> 10 years)

12. Occupation
    a. ☐ farmer
    b. ☐ Laborer
    c. ☐ private business
    d. ☐ civil/office
    e. ☐ student
    f. ☐ house-wife/man
    g. ☐ unemployed
    h. ☐ other

13. Is your financial income enough to support your family sufficiently (total income)?
    a. ☐ yes
    b. ☐ no

14. Did you have to change your work because of leprosy?
    a. ☐ yes
    b. ☐ no

B. Knowledge and natural history of the disease, clinical presentation and disability:

1. Did you ever receive information on leprosy?
   a. ☐ Yes
   b. ☐ No

   If yes, where did you get the information (several selections possible)?

   I. ☐ hospital

    II. ☐ health station
    III. ☐ local doctor
    IV. ☐ TV/newspaper/radio
    V. ☐ friend or family
    VI. ☐ other

2. Do you know what causes leprosy?
    a. ☐ yes
    b. ☐ no

   If yes, please choose one of these:
    I. ☐ Bacteria or any micro-organism
    II. ☐ Curse by god
    III. ☐ Karma
    IV. ☐ Other: specify (______________)

3. Do you think leprosy is very infectious?
    a. ☐ yes
    b. ☐ no

4. Do you know how leprosy is transmitted?
    a. ☐ yes
    b. ☐ no

   If yes, how is it transmitted?

    I. ☐ air
    II. ☐ water soil
    III. ☐ food
    IV. ☐ animal
    V. ☐ mosquito
    VI. ☐ close contact to infectious persons
    VII. ☐ other

5. Do you think leprosy is difficult to treat?
    a. ☐ yes
    b. ☐ no

6. Do you know any signs and symptoms of leprosy?
    a. ☐ Yes
    b. ☐ No

   If yes, which of the following are signs and symptoms of leprosy (multiple answers possible!)?
    I. ☐ Pale or reddish patches on the skin
    II. ☐ Low or decreased sensitivity in these skin patches
    III. ☐ Weakness in hands, feet or eyelids
    IV. ☐ Pain in the nerves
    V. ☐ Swelling or lumps in the face or earlobes

        VI. ☐ Painless wounds or burns on hands and feet

7. Do you think leprosy is a very severe disease?
    a. ☐ yes
    b. ☐ no

8. Do you think leprosy is a punishment (by God, etc.) for having done something bad in life?
    a. ☐ yes
    b. ☐ no

9. Did you go to a doctor/hospital as soon as you noticed first signs/symptoms of leprosy?
    a. ☐ yes
    b. ☐ no

    If no, why did you not seek for medical help (several selections possible)?
        I. ☐ Did not think it was leprosy
        II. ☐ felt ashamed
        III. ☐ I was told not to go yet
        IV. ☐ Awaited for self-cure
        V. ☐ Did not know where to go
        VI. ☐ Did not have money for treatment

10. Where did you get your first treatment?
    a. ☐ Primary Health center
    b. ☐ Local doctor
    c. ☐ Local hospital
    d. ☐ Tertiary hospital
    e. ☐ Non-medical professional/healer/witch-doctor etc.
    f. ☐ Friend
    g. ☐ Other

11. Have you finished your treatment for leprosy (MDT)?
    a. ☐ Yes
    b. ☐ No

12. Do you have disfigurements or deformities?
    a. ☐ Yes
    b. ☐ No

13. When did you develop first disfigurements or deformities?
    a. ☐ Before the first visit to a health center
    b. ☐ During the treatment at a health center
    c. ☐ After the treatment at a health center

14. Was the first disfigurement or deformity visible to others/could other people see them?
    a. ☐ Yes
    b. ☐ No

15. Where was the first disfigurement or deformity?
    a. ☐ Face
    b. ☐ Hand and/or foot
    c. ☐ Eyes
    d. ☐ Other body parts

16. Did you ever have ulcers?
    a. ☐ Yes
    b. ☐ No

    If yes, at which part of the body did you have ulcer?
      I. ☐ Face
      II. ☐ Hands
      III. ☐ Feet
      IV. ☐ other

    If yes, did it have a foul smell?
      I. ☐ Yes
      II. ☐ No
      III. ☐ A little bit smelly

C. Disability according to the WHO classification: *(To be done by interviewer)*

“Grade 0” ☐	- **No disability found**.
“Grade 1” ☐	- **Loss of sensation** noted in the hand or foot, this does not include the loss of sensation in the skin patch (Eyes are not given grade 1).
“Grade 2” ☐	- **Visible damage or disability.** For the eyes, this includes the inability to close the eye fully or obvious redness of the eye, visual impairment or blindness. - For the hands and feet, visible damage includes wounds and ulcers as well as deformity due to muscle weakness, such as foot drop or claw hand. Loss or partial reabsorption of fingers or toes.

Part II: “Explanatory Model Interview Catalogue” (EMIC-a) stigma scale for the leprosy-affected, adjusted for leprosy

No.	Question	Yes 3	Possible 2	Uncertain 1	No 0	Score
1.	If possible, would you prefer to keep people from knowing about your leprosy?					
2.	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?					
3.	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?					
4.	Have you ever been made to feel ashamed or embarrassed because of this problem?					
5.	Do your neighbors, colleagues or others in your community have less respect for you because of this problem?					
6.	Do you think that contact with you might have any bad effects on others around you, even after you have been treated?					
7.	Do you feel others have avoided you because of this problem?					
8.	Would some people refuse to visit your home because of this condition even after you have been treated?					
9.	If they knew about it would your neighbors, colleagues or others in your community think less of your family because of this problem?					
10.	Do you feel that your problem might cause social problems for your family and children in the community?					
11A	Do you feel that this disease has caused problems in getting married? *(Unmarried only)*					
11B	Do you feel that this disease has caused problems in your					

	marriage? *(Married only)*					
12.	Do you feel that this disease makes it difficult for someone else in your family to marry?					
13.	Have you been asked to stay away from work or social groups?					
14.	Have you decided on your own to stay away from work or social group?					
15.	Because of leprosy, do people think you also have other health problems?					

2. Leprosy research questionnaire, unaffected

Interviewer i.d.:

Part I:
A. Demographic characteristics
B. Natural history of the disease, clinical presentation and disability

Part II:
"Explanatory Model Interview Catalogue" (EMIC-c)

- CASES:

Inclusion criteria:

- Male and female persons not affected by leprosy
- Age 18 or older
- Living in the community nearby for more than 1 year
- Able to communicate with the study investigator and to understand and answer the questions adequately

Exclusion criteria:

- Not willing to participate in the study

Part I:

A. Demographic entities:

15. Age: ………. years
16. Sex: ☐ female ☐ male
17. Ethnicity: ☐ Thai ☐ Other (………………..)
18. Village/Community: ☐ Non Somboon ☐ Other
19. How many years lived in the community? ………. years
20. Religion:
    a. ☐ Buddhism
    b. ☐ Christian
    c. ☐ Muslim
    d. ☐ Hindi
    e. ☐ other

21. Marital status:
    a. ☐ Unmarried
    b. ☐ Married
    c. ☐ Separated
    d. ☐ Widowed

22. Family medical history: family member diagnosed with leprosy?
    a. ☐ yes
    b. ☐ no
    c. ☐ don't know

23. Anybody in close relationship, non-family, diagnosed with leprosy?
    a. ☐ yes
    b. ☐ no
    c. ☐ don't know

24. School education:
    a. ☐ yes (literate)
    b. ☐ no (illiterate)

    If yes, up to which level?
    I. Primary level (< 5 years)
    II. Secondary level (5-10 years)
    III. Higher education (> 10 years)

25. Occupation
    a. ☐ farmer
    b. ☐ Laborer
    c. ☐ private business
    d. ☐ civil/office
    e. ☐ student
    f. ☐ house-wife/man
    g. ☐ unemployed
    h. ☐ other

26. Is your financial income enough to support your family sufficiently (total income)?
    a. ☐ yes
    b. ☐ no

B. Knowledge on leprosy:

17. Did you ever receive information on leprosy?
    a. ☐ Yes
    b. ☐ No

    If yes, where did you get the information (several selections possible)?

    VII. ☐ hospital
    VIII. ☐ health station
    IX. ☐ local doctor
    X. ☐ TV/newspaper/radio
    XI. ☐ friend or family
    XII. ☐ other

18. Do you know what causes leprosy?
    a. ☐ yes
    b. ☐ no

    If yes, please choose one of these:
    I. ☐ Bacteria or any micro-organism
    II. ☐ Curse by god
    III. ☐ Karma
    IV. ☐ Other: specify (______________)

19. Do you think leprosy is very infectious?
    a. ☐ yes
    b. ☐ no

20. Do you know how leprosy is transmitted?
    a. ☐ yes
    b. ☐ no

    If yes, how is it transmitted?

    VIII. ☐ air
    IX. ☐ water soil
    X. ☐ food
    XI. ☐ animal
    XII. ☐ mosquito
    XIII. ☐ close contact to infectious persons
    XIV. ☐ other

21. Do you think leprosy is difficult to treat?
    a. ☐ yes
    b. ☐ no

22. Do you know the signs and symptoms of leprosy?

a. ☐ yes
b. ☐ no

If yes, which of the following are signs and symptoms of leprosy (multiple answers possible!)?

I. ☐ Pale or reddish patches on the skin
II. ☐ Low or decreased sensitivity in these skin patches
III. ☐ Weakness in hands feet or eyelids
IV. ☐ Pain in the nerves
V. ☐ Swelling or lumps in the face or earlobes
VI. ☐ Painless wounds or burns on hands and feet

23. Do you think leprosy is a very severe disease?
    a. ☐ yes
    b. ☐ no

24. Do you think leprosy is a punishment (by God, etc.) for having done something bad in life?
    a. ☐ yes
    b. ☐ no

Part II: "Explanatory Model Interview Catalogue" (EMIC-c) stigma scale for the community/non-affected, adjusted for leprosy

No.	**Question**	**Yes** **3**	**Possibly** **2**	**Don't know** **1**	**No** **0**	**Score**
1.	Would a person with leprosy keep others from knowing, if possible?					
2.	If a member of your family had leprosy, would you think less of yourself, because of this person's problem?					
3.	In your community, does leprosy cause shame or embarrassment?					
4.	Would others think less of a person with leprosy?					
5.	Would knowing that someone has leprosy have an adverse effect on others?					
6.	Would other people in your community avoid a person affected by leprosy?					

7.	Would others refuse to visit the home of a person affected by leprosy?					
8.	Would people in your community think less of a family of a person with leprosy?					
9.	Would leprosy cause problems for the family?					
10.	Would a family have concerns about disclosure if one of their members had leprosy?					
11.	Would leprosy be a problem for a person to get married?					
12.	Would leprosy cause problems in an on-going marriage?					
13.	Would leprosy cause a problem for a relative of that person to get married?					
14.	Would leprosy cause difficulty for a person to find work?					
15.	Would people dislike buying food from a person affected by leprosy?					

Appendix B

Form of Informed Consent Form

Address ……………………………………………
Date ………………………………………………..

Code number of participant ……………………………………………….

I who have signed here below agree to participate in this research project

Title: "Risk factors of stigma in leprosy-affected persons and non-affected persons in Non Somboon, Khon Kaen province, Thailand"

Principle researcher's name: Dr. Nils Kaehler

Contact address: College of Public Health Sciences, Chulalongkorn University, building 2-3, Soi Chulalongkorn 62, Bangkok 10330, Thailand.

Telephone: 086-0244250

I have **(read or been informed)** about rationale and objective(s) of the project, what I will be engaged with in details, risk/harm and benefit of this project. The researcher has explained to me and I **clearly understand with satisfaction**.

- *This study is assessing for risk factors of stigma in leprosy affected and non-affected persons. The procedure of participation will be in form of an interview, which will take between 30-40 minutes.*

I willingly **agree** to participate in this project and consent the researcher to response to the questionnaires. After the end of the project personal data will be deleted.

I have **the right** to withdraw from this research project at any time as I wish with no need to **give any reason**. This withdrawal **will not have any negative impact upon me (e.g. still receive the usual services).**

Researcher has guaranteed that procedure(s) acted upon me would be exactly the same as indicated in the information. Any of my personal information will be kept confidential**.** Results of the study will be reported as total picture. Any of personal information which could be able to identify me will not appear in the report.

If I am not treated as indicated in the information sheet, I can report to the Ethics Review Committee for Research Involving Human Research Subjects, Health Sciences Group, Chulalongkorn University (ECCU). Institute Building 2, 4 Floor, Soi Chulalongkorn 62, Phyat hai Rd., Bangkok 10330, Thailand, Tel: 0-2218-8147 Fax: 0-2218-8147 E-mail: eccu@chula.ac.th,

I also have received a copy of information sheet and informed consent form

Sign …………………………………	Sign …………………………………
(……………………………………)	(……………………………………)
Researcher	Participant

Appendix C

Budget

S.N.	Activities	Unit Price (THB)	Quantity	Total (THB)
1	**Hotel**	**500**	**14**	**12.000**
2	**Food for staff**	**100**	**12d x 14**	**16.800**
3	**Data collection** Photocopy Quest	**20**	**500 sets**	**10,000**
	Translator/Co-ordinator	**20.000**	**1**	**20.000**
	Interviewers per diem	**250**	**14 x 12 D**	**42.000**
	Transportation cost	**1500**	**2 trips**	**15,000**
4.	**Document printing** Paper + printing	**4**	**6000 pages**	**14,000**
	Photocopy (exam + final submit)	**0.5**	**12 x 400 pages**	**2,400**
	Stationary	**2000**	**1 set**	**500**
	Binding Paper (exam)	**150**	**7 set**	**1,050**
	Binding Paper (submit)	**150**	**7 set**	**1,050**
	Total			**134.800**

Appendix D

Schedule of activities

Work Plan	**Time Period in months**									
	Aug	**Sept**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**
Literature Review	🟦	🟦	🟦							
Writing Thesis Proposal			🟦	🟦						
Validity testing of Questionnaires					🟦					
Field testing of Questionnaires							🟦			
Thesis Proposal Submission					🟦					
Ethical Consideration by CPH					🟦	🟦	🟦			
Data Collection							🟦	🟦		
Data Analysis								🟦	🟦	
Thesis Writing									🟦	
Thesis examination										🟦
Thesis submission										🟦

VITAE

A. Personal Details

Full Name: Dr. Nils Kaehler

Address: Phahonyotin Soi 3, 10400 Bangkok

Email: dr.nils.kaehler@gmail.com

Date of birth: 07th February, 1974.

Nationality: German

Sex: Male

B. Education/Qualification

Course Completed	**Institution**	**Date of Completion**
Qualified Medical Doctor	University Goettingen	2002
DTM&P	BNI Hamburg, Germany	2010
DTM&H and MCTM	Mahidol University,	2012

C. Professional Work Experience

1. General Medicine, Emergency Medicine and Sport Medicine, 2002-2011, Trondheim, Norway
2. Chief Medical Officer, Sangklaburi Medical Polyclinic, Thailand. 2011-ongoing.