

# Assessing the attitudes and perceptions of community members and health workers regarding leprosy stigma

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## ABSTRACT

**Aims:** To examine the attitudes and the perceptions of community members and health workers towards leprosy, to study possible determinants of stigma and to provide baseline data for those who are interested in launching de-stigmatizing interventions.

**Study design:** Cross-sectional survey using mixed methods

**Place and Duration of Study:** Raj PrachaSamasai Institute and Chaiyaphum province, Thailand, March- August 2011.

**Methodology:** The study was done using qualitative and quantitative methods in four districts. Interview guidelines, a predefined script and the Explanatory Model Interview Catalogue (EMIC) stigma scale were used as data collection tools. For qualitative data collection, community members were selected by maximum variation sampling based on sex, age and socio-economic status; health workers were selected by including those who were present at the sub-district health promotion hospital at the time of interviewing, and those who were responsible for leprosy and tuberculosis at the district hospital. Focus Group Discussions were conducted among health volunteers who were also community members and had people affected by leprosy in their responsible areas. For quantitative data collection, community members were selected by systematic sampling. Health workers were selected by convenience sampling. Content analysis was used for qualitative information. A t-test, a Chi square and multiple regressions were used for quantitative data. A p-value of <0.05 was considered indicative of a statistically significant difference or association.

**Results:** An equal number of community members and health workers was enrolled (n=236). There was significant difference at the 5% level (p=0.007, Chi2 test) between the proportion of community members and of health workers who perceived stigma related to leprosy in the community (75.4 % and

85.6 %, respectively). A statistically significant association was found between age, education, number of family members and type of house, and perceived stigma. All 24 community members, four health volunteers and two health workers in the qualitative sample linked leprosy with disability, while none of the community members or health volunteers knew the cause of leprosy. All thought it to be incurable. Fifteen community members thought leprosy is hereditary. Seventeen community members and two health workers linked leprosy with dirtiness. One out of the two health workers linked leprosy with oozy and smelling wounds. It was also found that people affected avoided social contact, attended health services as little as possible, and experienced negative interaction from people in community, health workers included.

**Conclusion:** In the perception of community members and health workers leprosy is a disabling disease that is incurable and hereditary, and is associated with dirtiness and oozy and smelling wounds. These negative perceptions may result in reduced quality of life for those affected and hamper their access to health care services. The authors propose that de-stigmatizing interventions be prioritised, taking local beliefs, attitudes, and perceptions into consideration.

## 1. INTRODUCTION

In Thailand, leprosy incidence has steadily declined, with only 405 newly detected cases in 2010. However, the proportion of new cases with grade 2 disability over the last five years fluctuated between 11.5 to 14.8% (Raj PrachaSamasai Institute, 2011, Unpublished report). This relatively high proportion suggests delayed presentation of new leprosy cases (1). Studies carried out to identify the causes of this delay revealed that stigma related to leprosy was partly to be held responsible (2;3). Stigma was defined by Weiss & Ramakrishna as "a social process or 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 identified with a particular problem"(4). We used this definition as our working definition of stigma in this study. Apart from contributing to delayed presentation, stigma also has a negative impact on the people concerned in terms of physical, psychological and socio-economic aspects. They may suffer mental stress and anxiety leading to depression and even attempt suicide in some cases (5). They may lose economic stability, their marriage, or opportunities for further education. To prevent stigma from occurring as well as to ameliorate the manifestations that cause so much suffering to individuals and their families, effective interventions are needed. Many attempts have been made to reduce stigma attached to leprosy. For instance, leprosy services have been integrated into the general health care system to reduce the differences between people affected by leprosy and those suffering from other health conditions (6). Alternative terms have been used instead of 'leprosy', such as 'Anaesthetic skin disease (Raj PrachaSamasai Institute, 2003, Unpublished workshop proceeding). Significant funds have been spent on the effort to reduce stigma attached to leprosy through information dissemination (Raj PrachaSamasai Institute, 2002-2010, Unpublished annual report). It is unclear whether stigma attached to leprosy actually decreased as a result of these efforts. Stigma is still

present. In recent years, leprosy-affected persons were still reported to be stigmatized by their neighbours and by health workers (7). Some leprosy patients were shunned and refused treatment of their ulcers by nurse aids, resulting in delay in diagnosis and poor compliance with treatment by many of them(8). **Before developing any interventions to address leprosy related stigma, more elaborated information is required.**

The aim of this study was to investigate the attitudes and perceptions of community members and health workers regarding leprosy stigma in the community, to study possible determinants of stigma, and to provide baseline data for those interested in launching de-stigmatizing interventions.

## 2. METHODS

This survey was conducted using both qualitative and quantitative methods. The study areas were four sub-districts of four different districts of Chaiyaphum province in the North-eastern region of Thailand. They were selected as study areas because they have a higher number of people affected by leprosy than other sub-districts. Respondents for the qualitative interviews were persons affected by leprosy, community members selected by maximum variation sampling based on age, sex, and socio-economic status, and 6 health care workers who were present at the sub-district health promotion hospital at the time of data collection. Two health workers who were responsible for leprosy and tuberculosis at the district hospital were also included. Focus group discussions were done with health volunteers selected because of the people affected by leprosy living in the areas for which they were responsible. Quantitative respondents were community members who lived in the same village as people affected by leprosy. They were selected by systematic sampling, which was conducted by obtaining a list of names from a local health officer. This was done in confidential manner; no health information was included along with the names. The number of eligible people of each sub-district varied from 500 to 700. As the required number of respondents was 60 from each sub-district, every 8th-11th name in the list was selected. An equal number of community members from each of the four sub-districts was interviewed.

Exclusion criteria for all respondents were those not willing to participate and those who were unable to answer the questions directly themselves due to physical or mental problems were excluded. This is because the questionnaire used has only been validated for direct response interviews, not for interview by proxy. The sample size of quantitative respondents was calculated based on an estimated prevalence of community members who have negative attitudes towards leprosy of 96% found in the study of Srisakand a desired width of the 95% confidence interval of +/- 5% (9;10).

Another group of quantitative respondents were the health workers who worked at the health units at sub-district and district levels where people affected by leprosy attended health services. They were selected by convenience sampling; those who were present at the time of the data collection were interviewed until the required number was reached. As we had no estimated prevalence of health workers for sample size calculation, we applied that of community members to the health workers also.

Health workers who were responsible for district leprosy programme were approached by a research team, and asked to approach respondents who were health workers and health volunteers. Health volunteers known by a community were asked to approach persons affected by leprosy and community members.

The data collection process ensured the privacy of the respondents and started by explaining the study to a respondent by the interviewer, asking for informed consent, informing them about measures

to ensure confidentiality and the respondent's rights to refuse answering any specific questions if he/she wanted to.

Data collection tools comprised of interview guidelines for semi-structured interviews, a predefined script for focus group discussions and the EMIC stigma scale for the quantitative sample. The EMIC stigma scale derived from the Explanatory Model Interview Catalogue (11). The scale covers certain areas of life that are often affected by stigma. Its psychometric properties have been shown to be good in several studies (12;13). The strengths of this instrument are its simplicity and its utility, which has been demonstrated in different cultural settings and with different health conditions such as mental health and leprosy, depression and tuberculosis (11;14;15). It consists of 15 questions covering different aspects of stigma and has four answer options: 'yes', 'possibly', 'no', and 'don't know'. The score for each answer is 2,1,0,0 respectively. We chose EMIC cut-off point for perceived stigma at 8 which means that the respondents are considered to perceive existing stigmatization in the community when they answered at least 4 questions with 'yes', or 8 questions with 'possibly', or the combination of both answers with sum score at 8. The reason for choosing 8 is to increase the specificity of the cut-off point. If a respondent answer 'yes' or 'possibly' to fewer questions, there would be a high risk of false positives. A minimum of 0.70 was set as an acceptable reliability, and a ceiling or floor effect of 15% or less was set as an acceptable validity of the EMIC scale (16). Before using the EMIC scale, the questions were translated into Thai and then translated back into English language to check the correctness of the translation. The tools were piloted among 30 health workers and 30 community members with similar characteristics to the study groups.

Analysis of qualitative information was manually done by content analysis using open coding which was conducted by in-depth reading of the obtained information and giving similar data the same code, so that they could be grouped under the same heading. Quantitative data entry and analysis was done using SPSS version 16. Percentages and descriptive statistics were used to examine the frequency of answer options in the EMIC scale. To look for associations between the EMIC score and personal factors, multiple regression was performed. A p-value of <0.05 was considered indicative of a statistically significant difference or association. A T-test was applied to compare the mean EMIC scores of community members with those of health workers. Chi square was used to compare the proportion of community members and health workers who had negative attitudes and perceived stigma.

### 3. RESULTS AND DISCUSSION

#### 3.1 Results

##### *Qualitative results*

Information was collected in 19 people with leprosy related disability, 24 community members, 8 health workers and 6 health volunteers who were also community members. In this section, attitudes and perceptions about leprosy among community members and health workers are presented first.

This is followed by a description of the stigma practices, that is the way people behave in response to perceptions of stigma, first of people affected by leprosy and then of community members and health workers.

### **Attitudes and perceptions about leprosy among community members and health workers**

In the perception of community members and health workers; leprosy is a disabling disease with disability, that is incurable and hereditary, and associated with dirtiness and oozy and smelling wounds. The local term for leprosy is '*Khithu*'. '*Khi*' translated as 'faces'. '*Khithu*' refers to disease or people with the mentioned characteristics, particularly with shortening of fingers and toes or contractures of hands and feet. When we mentioned the early signs of leprosy, they said that this is not leprosy it is merely a skin disease. All community members, four health volunteers and two health workers linked leprosy with disability.

With the exception of the health workers, none of the respondents knew the cause of leprosy and thought it is incurable. One female respondent told a researcher that leprosy could not be cured as she saw impairments of a person affected by leprosy in her village deteriorated little by little. One male with leprosy-related disability who had already completed treatment, kept asking for leprosy drugs as he thought he had not been cured yet. Fifteen community members thought it to be hereditary. An eighteen year-old woman said "*I saw an old man with clawed and shortened hands. I asked my mother why he had hands like that. She told me it is hereditary*". This belief was confirmed by a young man who was better educated than general community members. He was deputy head of a village. He said "*I always share a glass of whisky with my friend who has leprosy, but I am not infected because leprosy is hereditary*".

According to 17 community members and two health workers, leprosy is associated with dirtiness. A male health worker said "*these people are dirty, their families also dirty*". The same health worker mentioned oozy and smelling wounds as causes of stigmatizing behaviour of health workers. A 70 year-old woman commented "*villagers avoid these people because they are dirty. When you are dirty whatever disease you have, people avoid you*".

### **Stigma experiences of people affected by leprosy**

After being diagnosed as having leprosy, people affected responded by keeping others from knowing and avoiding social contact.

#### *Keep others from knowing*

If possible, people diagnosed as having leprosy would not let others know their disease status. While collecting the data from health workers, we met a colleague from the national leprosy organization, who had carried out a disability survey in another sub-district. She had interviewed a woman affected by leprosy at the hospital, instead of at her house as planned, because the interviewee did not allow her to visit her at home. The reason given was that she did not want to damage the reputation of her

relatives who were key members of the community. People whose parents had leprosy were not able to accept this disease. We were told by health officers and health volunteers that a female villager, wife of a local policeman whose parents used to have leprosy, strongly refused to cooperate with the process of contact examination. She announced that she would sue anyone who says she has leprosy.

#### *Avoiding social contact*

Uncle [M], the 76 year-old man with leprosy-related disability said *"I am afraid to talk with strangers because I fear that they will talk about my disability and talk behind my back"*. Because of fear of stigmatization, many affected persons dared not go outside their houses. They reported that they did not visit their relatives' houses, did not join celebrations organized by their neighbours or by the community, and did not join in religious events. When we asked for the reason for not doing so, a man with leprosy related disability said *"I don't want to go, I afraid they will find me disgusting"*. They said that sometimes they wanted to join the said events, but their families forbade them to do so, as they did not want other community members to talk or behave badly towards people affected by leprosy. However, there were some people with leprosy-related disability who managed to join the events as they lived alone and there was no one who forbade them. In the course of the events, people with leprosy-related disability did not mix with other community members. They ate separately or took food offered by the host or community members to be eaten at home. Uncle [O], a 76 year-old person with severe leprosy-related disability, said *"I understand them; if I were them, I would also feel disgust"*. This man was, like many others, unmarried. He said *"I dare not woo any woman, because my body is like this"*.

#### **Avoiding health care**

According to health workers and health volunteers, even children of people affected by leprosy did not accept household contact examination. People with suspected symptoms did not reveal themselves. A female health provider told us, *"Their children do not come for contact examination, because this area calls the disease Khi Thut. They are afraid of community rejection. I detected one suspected leprosy case, a 30 year-old man. I asked him to come back to get referral documents to the district hospital for diagnosis but he did not follow the appointment, he disappeared"*.

Health workers told us that many people seek leprosy treatment far from their homes. The reasons for this might include a good reputation for leprosy treatment in that place, but also that they did not want the community to know about their disease.

When they go to the health centre, people with leprosy-related disability reported they felt uncomfortable with a number of eyes staring at them negatively. They were the eyes of community members who came to visit health workers for their health problems or their relatives. Some people

talked badly to them. Uncle [X], a 70 year-old man with leprosy related disability, talked to a research assistant who was also affected by leprosy.

*Research assistant: "Are you ashamed because you have got this disease?"*

*Uncle [X]: "ashamed and afraid people would be disgusted with me".*

*Research assistant: "We do not like it when people stare at us. We are shy towards people, but not towards a doctor, aren't we?"*

*Uncle [X]: "Yes (laugh), staring with disgust".*

Uncle [Y], another person with leprosy-related disability, said *"doctors were not disgusted with us, but villagers were, they said we are disgusting"*.

People affected by leprosy did not use health care services as often as their neighbours. A female health provider said the outpatient cards of people affected by leprosy were thinner than those of other customers of their age. And if they have to go to see a doctor, they dared not to comment or ask a doctor about their health problems. They obeyed and followed a doctor's suggestions without objection or comment. Aunt [Z], a female people with leprosy-related disability told a research assistant *"I dare not go to see a doctor. I bought drugs from pharmacist when I was sick. I was afraid that they would be disgusted with me"*.

Most of people who had leprosy-related disability reported they developed their impairments little by little. When they had ulcers, some of them did not visit a doctor. They bought drugs from pharmacy and took care of their own wounds. Those who visited a sub-district hospital tried to avoid mixing with other community members as much as possible by visiting in the late afternoon and sitting separately. Some of them were afraid that health workers would be disgusted with them, so they just asked for wound cleaning materials to do wound care by themselves at home. At the time of our first visit, Uncle [M] had one large-size ulcer on his right sole and one large callous on the other. He had told a health provider that his daughter would take care of his wounds. The wound was worsening. Health workers at the peripheral health centre said they understood this situation. They said that for the sake of people with leprosy-related disability, they should separate the leprosy and tuberculosis clinic from those of other diseases. At the higher health care level, the district hospital, the leprosy and tuberculosis clinic had already been separated. The reason given for doing so was to let affected people talk and learn from each other about their problems. However, they found that the customers of this separated clinic tried to spend as little time as possible there. They just stopped by and told the health provider that they would come again to collect drugs to take back home. They did not wait while the health provider was running the drug dispensing process.

#### **Stigmatizing practices of community members and health workers**

Most health workers said that they did not have a negative attitude towards people with leprosy. This matches the information obtained from people with leprosy-related disability. However, there was still



one health care provider of a peripheral health centre who frankly admitted that stigmatizing behaviour was present in his workplace. Some health workers tried to move people with leprosy-related disability from their service spots as soon as possible by talking less or quickly terminating the conversation. The reasons given were that people with leprosy-related disability have poor hygiene, and that their wounds were oozy and smelling badly.

Community members did not show their negative feelings towards people with leprosy-related disability openly. They just ignored them, talked behind their backs, kept a distance, did not visit their houses, did not greet them or respond to their greetings and did not sit next to them. A 56 year-old man whose friend has suspected signs of leprosy said, *"if his hands become clawed and shortened, I will stay in a far distance. I am not disgusted, but I am afraid to be infected and transmit it to my grandchildren. If he has only skin symptoms, I am not disgusted, but a woman may be"*. Most community members said they did not want to share a meal with people with leprosy-related disability, but they did not refuse an animal hunted by people with leprosy-related disability. A majority of community members said they will forbid their children to marry someone whose parents had leprosy. A 56 year-old woman, who had one leg amputated because of diabetes, said the following *"People avoid people with leprosy, because they have disability and are dirty; even me. Because I have one leg, I dare not visit my daughter in Bangkok. I am afraid she will be ashamed because of having a disabled mother"*.

Uncle [N], a 75 year-old man affected by leprosy, told a researcher, *"I never fear anyone, but I want to die. People talk to me badly"*. Some people whose impairments had become worse as they got older had been abandoned by their family. A 55 year-old man told a researcher that his wife and his children moved away, because he could not feed a family.

### **Quantitative results**

#### *Characteristics of the community members*

Of the 236 community members, 153 (64.8%) were female, 163 (69.1%) completed only primary school, 186 (78.8%) were married, 186 (78.8%) were aged between 40-79 years.

#### *Characteristics of the health workers*

Of 236 health workers, 180 (76.3%) were female.

#### *Validity of the data collecting tool*

The internal consistency of the EMIC scale was good with an alpha score of 0.87, which indicates high internal consistency. (16) No floor or ceiling effects were found. Only 6.8% of respondents scored the lowest EMIC score, while only 4.7% scored the highest EMIC score.

#### *The EMIC score among community members and health workers*

The mean of the EMIC score of community members was 15.4 (95%CI 14.25-16.55; n=236), with a median of 16. The mean of the total EMIC score of health workers was 14.8 (95%CI 14.76-13.89; n=236) with a median of 15.5. The difference between the means was not significant (2-tailed p-value=0.387, t-test).

*Factors associated with the attitude and perception regarding leprosy stigma*

Multiple regression was used to investigate an association of personal data with EMIC score. A positive association was found among community members between the EMIC score and being over 80 years old, having had primary and secondary school education, and living in a family with more than 5 members. A negative association was found between the EMIC score and living in types of houses other than a cottage or shelter.

**Table 1.** Multiple regression for personal factors to investigate an association with EMIC score in community members.

Model	Unstandardized Coefficients		Sig
	B	SE	
Sex	1.039	1.340	.439
Age			
- 30-39	-1.113	3.121	.722
- 40-49	-0.852	2.911	.770
- 50-59	2.012	2.984	.501
- 60-69	2.339	3.199	.465
- 70-79	4.857	3.376	.152
- ≥80	7.791	3.931	*.049
Education			
- Primary school	5.797	1.890	*.002
- Secondary school	6.596	2.456	*.008
Marital status	-0.307	1.624	.850
Number of family members			
- 2-4	3.193	2.035	.118
- ≥5	4.285	2.146	*.047
Types of house			
- Small house with weed roof	-21.362	7.727	*.006
- Small house with tile and zinc roof	-17.012	6.452	*.009
- Concrete house	-18.674	6.654	*.005
- Others (Wooden house with high lifted floor)	-19.855	6.544	*.003
Income/month (THB)			
- 2 001-5 000	1.067	1.768	.547
- 5 001-10 000	-.786	1.990	.693
- >10 000	1.213	2.869	.673
- Do not answer	-1.649	3.167	.603
Occupation			
- Trading	-3.949	4.061	.332
- Agriculture	1.682	1.741	.335
- Unemployed	-2.497	2.421	.303
- Others	-1.819	3.116	.560

<sup>a</sup> Dependent variable : Total leprosy EMIC score

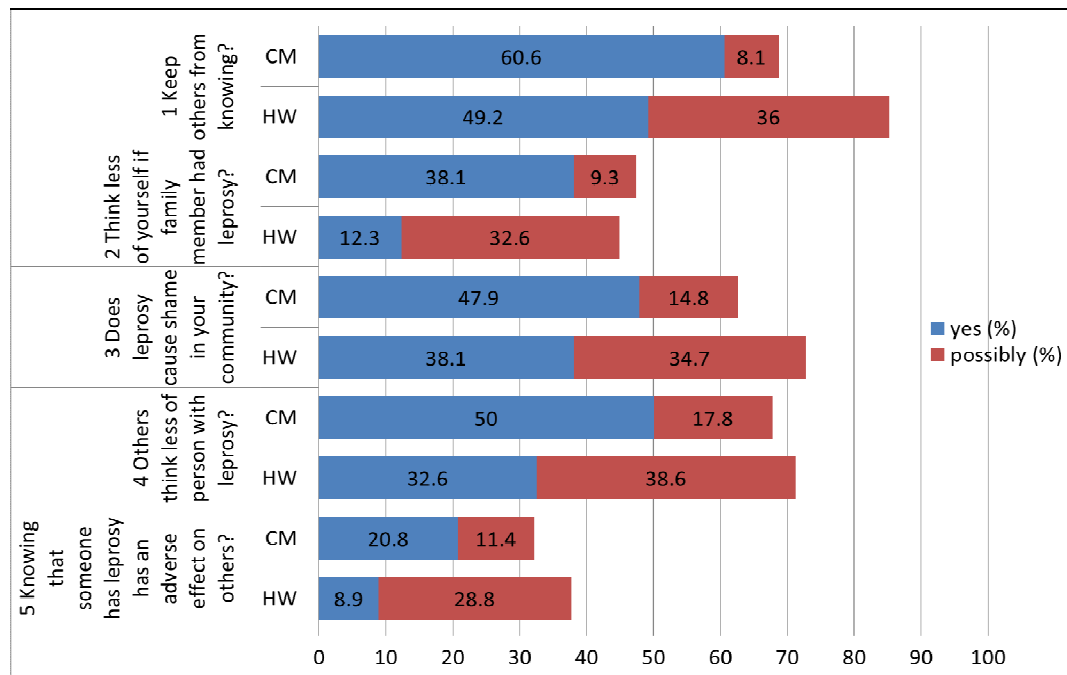
\*Predictor in the model

*Community members and health workers' perception on leprosy stigma*

The percentage of CM with EMIC score  $\geq 8$  was 75.4 (95%CI=69.9-80.9), while that of HW was 85.6(95%CI=81.1-90.1). This difference was significant at the 5% level ( $p=0.007$ , Chi2 test).

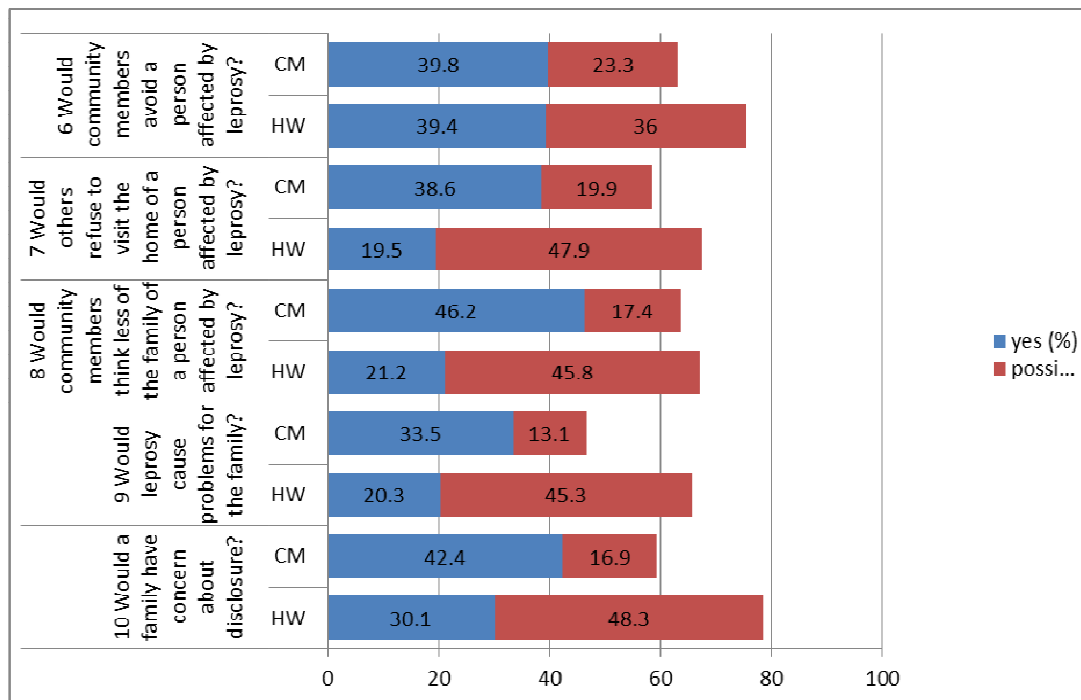
**Figure 1** demonstrates the views of community members and health workers on how they and other people feel about having people affected by leprosy in their family or community. Respondents were 236 community members, and 236 health workers of 4 districts in Chaiyaphum province. More than 60% thought that people with leprosy would keep others from knowing their condition, that leprosy would cause shame, and that others think less of people with leprosy.

**Figure 1.** Perception of stigma among CM and HW; item 1-5



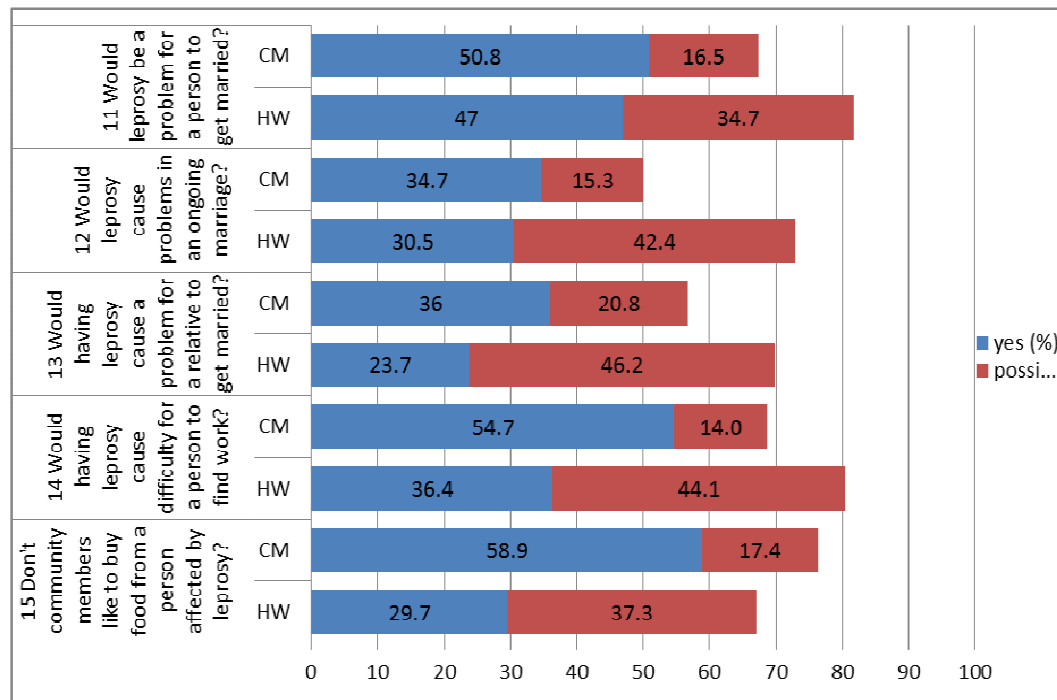
**Figure 2** demonstrates the perceptions of community members and health workers regarding the way the community treat people affected by leprosy and their families. More than a half of community members and health workers believed that community members would avoid a person with leprosy, refuse to visit their homes, and think less of the family of a person with leprosy. They also thought that a family of a person with leprosy would be concerned about disclosure. More than 60% of health workers thought that leprosy would cause problems for the family, while 46.6% of community members viewed in the same way.

**Figure 2.** Perception of stigma among CM and HW; item 6-10



**Figure 3** shows the views of community members and health workers on how leprosy affects people and their families in terms of marital and work prospects. Over 60% thought that leprosy would be a problem for a person affected in terms of marital and work prospects. The same percentage thought that community members would not like to buy food from a person affected by leprosy. In addition, around 50% of community members believed that leprosy would cause problems in an on-going marriage of people affected, and having leprosy would cause problems for a relative wanting to get married. Around 70% of the health workers had a similar view.

**Figure 3.** Perception of stigma among CM and HW; item 11-15



### 3.2 Discussion

Most respondents linked leprosy with disability and dirtiness because in their community they had only noticed those people affected who also have disability and poor hygiene. People who have never seen people affected by leprosy themselves perceived this image from their parents and the media. Disability and dirtiness are stigmatized in themselves according to one woman whose leg was amputated. She did not have leprosy but was ashamed of her disability. Another woman said that people who are dirty are stigmatized whatever disease they have. Therefore, it is not surprising that the quantitative result showed that a large majority of both community members and health workers perceived people affected by leprosy to be stigmatized. This finding supports the results of 2 different studies of Peedaswat and Poopook conducted in different areas of Thailand, showing that people affected by leprosy who had disability were more likely to be stigmatized than those who did not

(8;17). In any stigma reduction attempt, it is important to address the community's perception that links leprosy with dirtiness and disability.

The belief of the community that leprosy is hereditary and incurable may be another reason for stigmatization (18). Because leprosy occurs in one particular family and because disability cannot be restored, people thought leprosy was hereditary and incurable. The belief that leprosy is hereditary was found also by Leerapun, Idawani, and de Stigter in Thailand, Indonesia, and Nepal, respectively (19-21). The qualitative data showed that the current respondents also believed that leprosy is hereditary.

In our in-depth interviews, we found that people do not want other community members to know that they have leprosy. This finding was supported by the results gathered with the EMIC scale showing that more than 60% of respondents thought that people with leprosy would keep others from knowing their condition. They also thought that leprosy would cause shame, and that others would think less of people with leprosy. These attitudes and perceptions may help to explain why some people who have leprosy preferred getting treatment far away from home. In addition, some household contacts of people affected by leprosy refused to cooperate in the examination of contacts. People affected by leprosy showed evidence of internalised (or self-) stigma by not participating in community activities. Stigma studies by other researchers yielded similar findings. In Nigeria, Alubo found that people affected preferred to get treatment from a place that they did not know (22). In Indonesia and in Nepal, the studies of Idawani and of Heijnders found that people affected avoided certain social contact (20;23). Idawani found that community members in Indonesia thought that people affected by leprosy would remain indoors (20). An extreme form of self-stigma was described in Nonthanum's study in Thailand, who found a woman affected by leprosy who had hidden herself in a house more than 60 years (Nonthanum B, 2008, Unpublished study report). Self-stigma may result in delayed treatment, which may in turn lead to disability and further stigma (24).

More than 50% of the community members and health workers believed that community members would avoid a person with leprosy. This is supported by information from a villager who said he would keep a distance if it is confirmed that his friend has leprosy. In-depth information from health officers also revealed that health officers tried to spend as little time as possible in providing care to people with leprosy-related disabilities. These findings are similar to the study of Primkaew in Thailand who found that health workers told people affected by leprosy to sit outside the clinic away from other people and failed to provide ulcer care to people with leprosy-related disability (25). These stigmatizing behaviours of community members and health workers may be the main reason for people affected by leprosy to internalize stigma and to start behaving accordingly. This in turn may lead to further deterioration of their impairments.

Over 60% of community members and health workers thought that leprosy would be a problem for a person affected in terms of marital and work prospects. More than 50% and 70% of community

members and health workers, respectively, believed that leprosy would cause problems in an on-going marriage of people affected, and that having leprosy would make it difficult for a relative to get married. These findings support the study of Kaehler who found that over 60% of community members thought that leprosy would be a problem for a person affected in terms of marital and work prospects. He found a similar percentage of community members who believed that leprosy would cause problems for people affected in terms of their on-going marriage and for their relatives to get married (26). These quantitative findings were confirmed by the information from the in-depth interviews that men affected by leprosy dare not start a relationship with women. One affected husband was left by his wife because of not being able to earn enough income to feed his family. The belief that leprosy is hereditary may be a reason for respondents to think that having leprosy would affect the marriage prospects of relatives. However, from our observations and in-depth interviews, the children of people affected did not seem to have a problem finding a spouse.

It is important to note that, even though there was no difference between the attitudes and perception of community members and health workers, the percentages of health workers who answered "possibly" to every question were much higher than those of community members. This may be because some of health workers were not sure about the attitudes and perception of community members as they lived in the town far from their workplace.

It is also important to note that there was significant difference in the proportion of community members and health workers who have negative attitudes and perceived stigma. A higher proportion of health workers had negative attitudes and perceived stigma than community members. Stigma in health services was also reported in the literature review of Heijnders and Van Der Meij(27). This is important, since health workers are expected to lead by example when it comes to behaviour towards people with illnesses. It also indicates that specific interventions are needed to address stigma among health workers.

There was a positive association between age and perceived stigma. The people who were over 80 years old may have known people affected by leprosy for a long time, possibly since the early stages of their disease. At that time, there was no effective treatment. They may have seen people affected gradually developing impairments. They may have observed that leprosy occurred in particular families. They were familiar with the stigmatizing behaviour of the community that may have also included themselves. This impression may be an explanation for this association. This result support the study of van Brakel et al in Indonesia who also found an association between age and stigma (28).

Some other personal factors were also associated with perceived stigma. People who lived in a better quality dwelling perceived less stigma than those who lived in a shelter or cottage. The type of house as well as income may be used as proxy indicators of a respondent's economic status. In this study, there was no association between income and perceived stigma which may be interpreted that there



is no association between economic status and perceived stigma. The fact that less perceived stigma was found among those living in a better quality dwelling may be because they have a better chance to access information related to disease or health than those who lived in a cottage or a shelter. From our observation, cottages or shelters were often situated in more remote areas of the community or in the rice fields, far from daily sources of information such as neighbours, a village broadcasting post, or a visiting mobile education team. Access to recent education or information regarding the disease may have contributed to less perceived stigma. However, the effect of the level education appears to show the opposite: we found that people with primary and secondary level education scored higher on perceived stigma than those with a lower education level. This may be because people with higher education have a higher level of general awareness of the stigma of leprosy as they have more chance than those with lower education to hear about stigma related to leprosy from other sources. For instance, they may be reading newspapers that often use stigmatized terms concerning leprosy.

People who lived in a family with more than five members perceived more stigma than those lived in a smaller family. In the community's perception, leprosy may affect other family members in terms of shame and marriage opportunities. This may mean that the bigger the family, the more leprosy may be perceived as a threat to the family integrity. This notion may reinforce the stigma perception of those with many family members. The findings support the study of Rodchan in the west region of Thailand. She found positive association between the number of family members and perceived stigma (29).

Stigmatization resulted in a reduced quality of life of people affected as they avoided social contact, attended health services as little as possible, and experienced negative interaction from people in community including health workers. These negative effects were also found in the study of Tsutsumi et al. in Bangladesh and the study of Joseph & Rao in India (5;30). Leprosy-related stigma needs to be addressed in order to improve the quality of life of those affected. A tailor-made de-stigmatizing approach has been shown to be effective in reducing stigma towards leprosy, for example using a social marketing campaign in Sri Lanka and socio-economic rehabilitation in Nepal and Nigeria (31-33).

## **LIMITATIONS OF THE STUDY**

The limitations of this study include the language used in the course of interviewing. Most of elderly community members used only dialect in communication that would cause misunderstanding between them and interviewers. This limitation was addressed by arranging interviewers who could fluently use the dialect to interview the elderly.

#### **4. CONCLUSION**

In the perception of community members and health workers alike, leprosy is a disabling disease that is incurable and hereditary, and associated with dirtiness and oozy and smelling wounds. This resulted in a majority expressing negative attitudes and perceptions regarding leprosy. This stigmatization in turn affects the quality of life and the access to health care services of persons affected. To prevent the occurrence of this phenomenon, local beliefs, attitudes, and perceptions need to be taken into consideration in designing de-stigmatizing interventions.

#### **ETHICAL APPROVAL**

The study was approved by the ethics committee of the Department of Disease Control, Ministry of Public Health of Thailand.

#### **ACKNOWLEDGEMENTS**

We would like to thank all respondents who are community members and health officers of Bantan, NhongBuaDaeng, Tebsatit, BumnetNarongdistricts for their valuable information. Our thanks go to Dr SompongJaroongjittanusonti, the Provincial Chief Medical Officer of Buriram and his staff for supporting us in conducting the pilot of the instrument in Satuek District. We also thank Dr ChooratKoosakulrat, the Provincial Chief Medical Officer of Chaiyaphum for allowing his staff to assist our study process. Last but not least, we would like to thank Dr RuchWongtrungkapun, Director, Raj PrachaSamasai Institute, for the resources and support given to our study team.

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