

Original Research Article

Assessing the attitude and perception of community members and health workers regarding leprosy stigma

ABSTRACT

Aims: To measure the attitudes and the perception of community members and health workers towards leprosy and to provide baseline data for those who are interested in launching de-stigmatizing interventions.

Study design: Comparative study.

Place and Duration of Study: Raj Pracha Samasai Institute and Chaiyaphum province, Thailand, 14-17 August 2011.

Methodology: The study was done using qualitative and quantitative methods in four sub-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 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.

Results: There was significant difference at the 5% level ($p=0.007$, Chi2 test) in the proportion of community members and that of health workers who perceived stigma. An association was found between age, education, number of family members and type of house, and perceived stigma. Community members and health workers perceived leprosy as a disease characterised by dirtiness, bad odour, oozy wounds, unpleasant skin and impairments. Most community members thought leprosy was hereditary and incurable.

Conclusion: The stigma against leprosy may result in reduced quality of life for those affected and hampers their access to health care services. The authors propose that de-stigmatizing interventions be prioritised, taking local beliefs, attitudes, and perceptions into

consideration.

Keywords: assessment, attitude, perception, stigma, leprosy

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 Pracha Samasai 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 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 (4). 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 (5). Alternative terms have been used instead of 'leprosy', such as 'Anaesthetic skin disease' (Raj Pracha Samasai Institute, 2003, Unpublished workshop proceeding). Significant funds have been spent on the effort to reduce stigma attached to leprosy through information dissemination (Raj Pracha Samasai 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 (6). 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 (7). However, according to an intensive literature review, so far no study has been conducted to assess stigma towards leprosy in Thailand (8).

The aim of this study was to measure the perception 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. MATERIAL AND METHODS

This comparative research 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 19 persons affected by leprosy, 24 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. 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.

Another group of quantitative respondents were the 236 health workers who worked at the health units where people affected by leprosy attended health services. Those who were present at the time of data collection were interviewed. Those not willing to participate and those who were unable to answer the questions due to physical or mental problems were excluded. 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 Srisak and a desired width of the 95% confidence interval of $\pm 5\%$ (9;10).

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. 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 done by content analysis. Quantitative data entry and analysis was done using SPSS version 16. 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.

The EMIC scale 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 (11).

3. RESULTS AND DISCUSSION

3.1 Results

Qualitative results

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 disease with dirtiness, bad odour, oozy wounds, unpleasant skin, and impairments. The local term for leprosy is '*Khi thut*'. '*Khi*' translated as 'faces'. '*Khi thut*' 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.

With the exception of health workers and some health volunteers, all respondents, even persons affected by leprosy themselves, did not know the cause of leprosy. Most of them thought it is hereditary. An eighteen year-old woman said "*I saw an old man with clawed and*

118 *shortened hands. I asked my mother why he had hands like that. She told me it is*
119 *hereditary*". This belief was confirmed by a young man who was better educated than
120 general community members. He was deputy head of a village. He said "*I always share a*
121 *glass of whisky with my friend who has leprosy, but I am not infected because leprosy is*
122 *hereditary*". In addition, most villagers, even some persons affected by leprosy themselves,
123 thought leprosy is incurable. One male with leprosy-related disability who had already
124 completed treatment, kept asking for leprosy drugs as he thought he had not been cured yet.
125

126 In focus group discussions with health volunteers who knew the cause of leprosy through
127 training, they said leprosy is fearsome because they did not know how to protect people from
128 this disease. In our in-depth interview with one female villager, she said she feared leprosy
129 because she had no knowledge about leprosy.
130

131 **Stigma practices of people affected by leprosy**

132 After being diagnosed as having leprosy, people affected responded by keeping others from
133 knowing and avoiding social contact.
134

135 *Keep others from knowing*

136 If possible, people diagnosed as having leprosy would not let others know their disease
137 status. While collecting the data from health officers, we met a colleague from the national
138 leprosy organization, who had carried out a disability survey in another sub-district. She had
139 interviewed a woman affected by leprosy at the hospital, instead of at her house as planned,
140 because the interviewee did not allow her to visit her at home. The reason given was that
141 she did not want to damage the reputation of her relatives who were key members of the
142 community. People whose parents had leprosy were not able to accept this disease. We
143 were told by health officers and health volunteers that a female villager, wife of a local
144 policeman whose parents used to have leprosy, strongly refused to cooperate with the
145 process of contact examination. She announced that she would sue anyone who says she
146 has leprosy.
147

148 According to health workers and health volunteers, even children of people affected by
149 leprosy did not accept household contact examination. People with suspected symptoms did
150 not reveal themselves. A female health provider told us,
151 "*Their children do not come for contact examination, because this area calls the disease Khi*

152 *Thut. They are afraid of community rejection. I used to detect one suspected leprosy case, a*
 153 *30 year-old man. I told him to be back again to get referral documents to the district hospital*
 154 *for diagnosis but he did not follow the appointment, he disappeared”.*

155

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

159

160 *Avoiding social contact*

161 Uncle [M], the 76 year-old man with leprosy-related disability said *“I am afraid to talk with*
 162 *strangers because I fear that they will talk about my disability and talk behind my back”.*

163 Because of fear of stigmatization, many affected persons dared not go outside their houses.

164 They reported that they did not visit their relatives’ houses, did not join celebrations

165 organized by their neighbours or by the community, and did not join in religious events.

166 When we asked for the reason for not doing so, a man with leprosy related disability said *“I*

167 *don’t want to go, I afraid they will find me disgusting”.* They said that sometimes they wanted

168 to join the said events, but their families forbade them to do so, as they did not want other

169 villagers to talk or behave badly towards people affected by leprosy. However, there were

170 some people with leprosy-related disability who managed to join the events as they lived

171 alone and there was no one who forbade them. In the course of the events, people with

172 leprosy-related disability did not mix with other villagers. They ate separately or took food

173 offered by the host or villagers to be eaten at home. Uncle [O], a 76 year-old person with

174 severe leprosy-related disability, said *“I understand them; if I were them, I would also feel*

175 *disgust”.* This man was, like many others, unmarried. He said *“I dare not woo any woman,*

176 *because my body is like this”.*

177

178 When they go to the health centre, people with leprosy-related disability reported they felt

179 uncomfortable with a number of eyes staring at them negatively. They were the eyes of

180 villagers who came to visit health workers for their health problems or their relatives. Some

181 people talked badly to them. Uncle [X], a 70 year-old man with leprosy related disability,

182 talked to a research assistant who was also affected by leprosy.

183

184 *Research assistant: “Are you ashamed because you have got this disease?”*

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

186 *Research assistant: “We do not like it when people stare at us. We are shy towards people,*

187 *but not towards a doctor, aren’t we?”*

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

189

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

192

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

200

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

219

220 **Stigma practices of community members and health workers**

221 Most health workers said that they did not have a negative attitude towards people with
222 leprosy. This matches the information obtained from people with leprosy-related disability.
223 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 smelling badly. The same health provider said *“these people are dirty, their families also dirty”*. According to the comment of a 70 year-old woman, *“villagers avoid these people because they are dirty. When you are dirty whatever disease you have, people avoid you”*.

Villagers 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 villagers 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 informants 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 (11). 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.

263

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).

269

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.

276

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

279

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

280

281

Table 1. (continued)

Model	Unstandardized Coefficients	Sig
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	B	SE	
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

283

284 ^a Dependent variable : Total leprosy EMIC score

285 *Predictor in the model

286

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

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

291



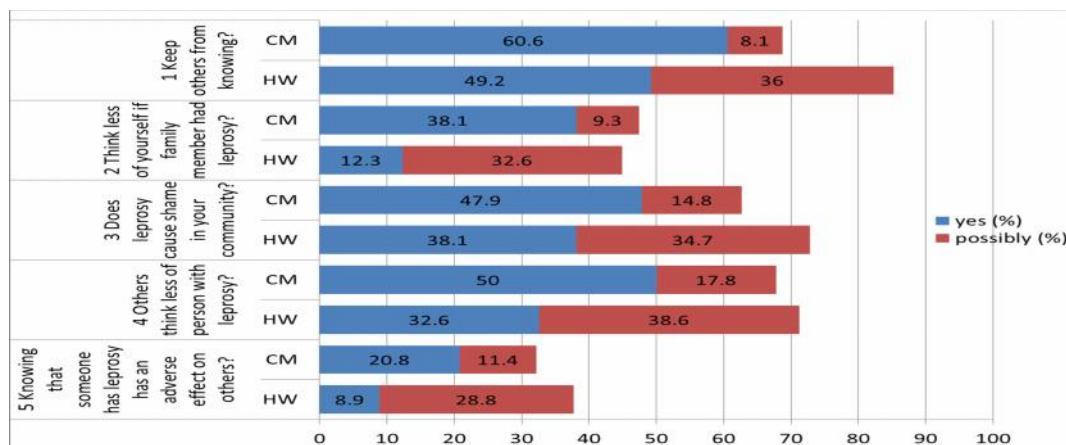
292 **Graph 1** demonstrates the views of community members and health workers on how they
 293 and other people feel about having people affected by leprosy in their family or community.
 294 Respondents were 236 community members, and 236 health workers of 4 districts in

295 Chaityaphum province. More than 60% thought that people with leprosy would keep others
 296 from knowing their condition, that leprosy would cause shame, and that others think less of
 297 people with leprosy.

298 

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

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302 

303 **Graph 2** shows that more than a half of community members and health workers believed
 304 that community members would avoid a person with leprosy, refuse to visit their homes, and
 305 think less of the family of a person with leprosy. They also thought that a family of a person
 306 with leprosy would be concerned about disclosure. More than 60% of health workers thought
 307 that leprosy would cause problems for the family, while 46.6% of community members
 308 viewed in the same way.

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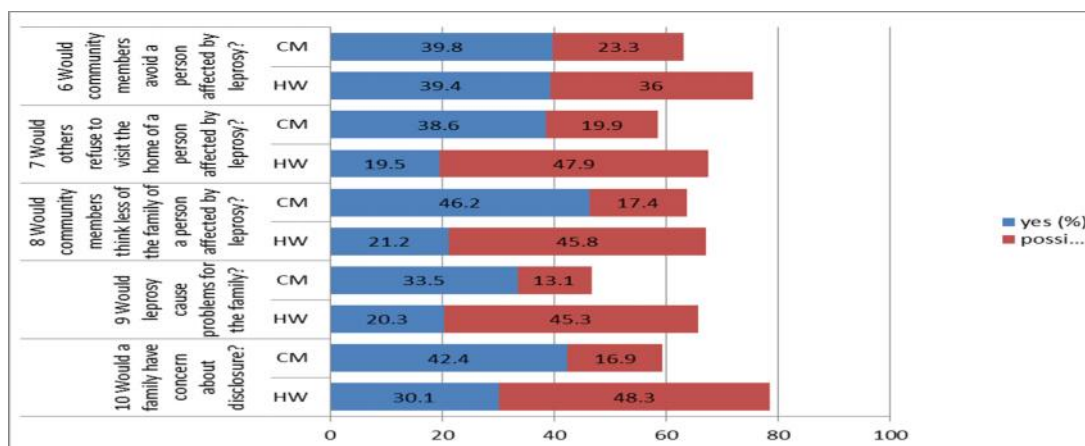
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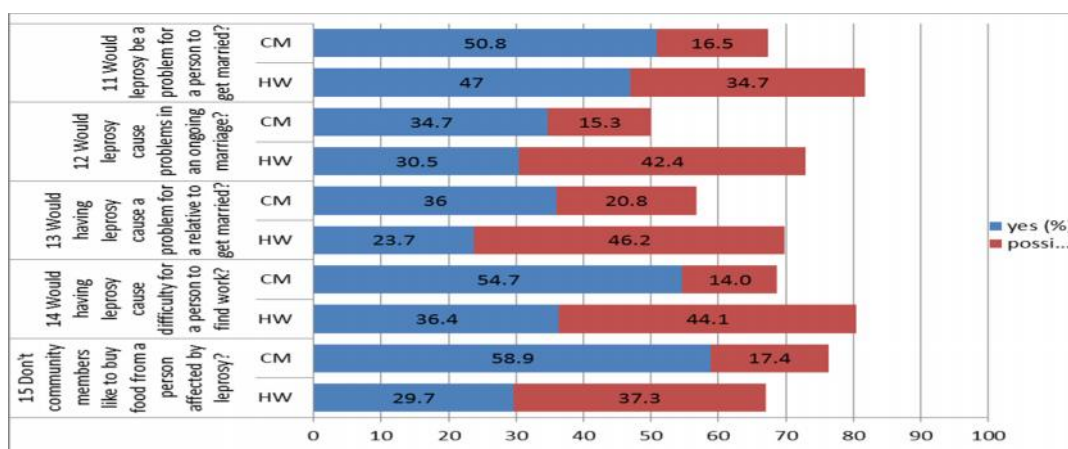
319 **Graph 2.** Perception of stigma among CM and HW; item 6-10

320



Graph 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.

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



3.2 Discussion

339 Most informants and respondents linked leprosy with disability and dirtiness because in their
340 community they had only noticed those people affected who also have disability and poor
341 hygiene. People who have never seen people affected by leprosy themselves perceived this
342 image from their parents and the media. Disability and dirtiness are stigmatised in
343 themselves according to one woman whose leg was amputated. She did not have leprosy
344 but was ashamed of her disability. Another woman said that people who are dirty are
345 stigmatized whatever disease they have. Therefore, it is not surprising that the quantitative
346 result showed that a large majority of both community members and health workers
347 perceived people affected by leprosy to be stigmatized. This finding supports the results of 2
348 different studies of Peedaswat and Poopook conducted in different areas of Thailand,
349 showing that people affected by leprosy who had disability were more likely to be
350 stigmatized than those who did not (7;12). In any stigma reduction attempt, it is important to
351 address the community's perception that links leprosy with dirtiness and disability.

352

353 The belief of the community that leprosy is hereditary and incurable may be another reason
354 for stigmatization (13). Because leprosy occurs in one particular family and because
355 disability cannot be restored, people thought leprosy was hereditary and incurable. The
356 belief that leprosy is hereditary was found also by Leerapun, Idawani, and de Stigter in
357 Thailand, Indonesia, and Nepal, respectively (14-16). The qualitative data showed that the
358 current respondents also believed that leprosy is hereditary.

359

360 In our in-depth interviews, we found that people do not want other villagers to know that they
361 have leprosy. This finding was supported by the results gathered with the EMIC scale
362 showing that more than 60% of respondents thought that people with leprosy would keep
363 others from knowing their condition. They also thought that leprosy would cause shame, and
364 that others would think less of people with leprosy. Because of these attitudes and
365 perceptions, some people who have leprosy preferred getting treatment far away from home.
366 In addition, some household contacts of people affected by leprosy refused to cooperate in
367 the examination of contacts. People affected by leprosy showed evidence of internalised (or
368 self-) stigma by not participating in community activities. Stigma studies by other researchers
369 yielded similar findings. In Nigeria, Alubo found that people affected preferred to get
370 treatment from a place that they did not know (17). In Indonesia and in Nepal, the studies of
371 Idawani and of Heijnders found that people affected avoided certain social contact (15;18).
372 Idawani found that villagers in Indonesia thought that people affected by leprosy would
373 remain indoors (15). An extreme form of self-stigma was described in Nonthanum's study in
374 Thailand, who found a woman affected by leprosy who had hidden herself in a house more

375 than 60 years (Nonthanum B, 2008, Unpublished study report). Self-stigma may result in
376 delayed treatment, which may in turn lead to disability and further stigma (19).

377

378 More than 50% of the community members and health workers believed that community
379 members would avoid a person with leprosy. This is supported by information from a villager
380 who said he would keep a distance if it is confirmed that his friend has leprosy. In-depth
381 information from health officers also revealed that health officers tried to spend as little time
382 as possible in providing care to people with leprosy-related disabilities. These findings are
383 similar to the study of Primkaew in Thailand who found that health workers told people
384 affected by leprosy to sit outside the clinic away from other people and failed to provide ulcer
385 care to people with leprosy-related disability (20). These stigmatizing behaviours of
386 community members and health workers may be the main reason for people affected by
387 leprosy to internalize stigma and to start behaving accordingly. This in turn may lead to
388 further deterioration of their impairments.

389



390 Over 60% of community members and health workers thought that leprosy would be a
391 problem for a person affected in terms of marital prospects and relationships, and also in
392 work prospects. More than 50% and 70% of community members and health workers,
393 respectively, believed that leprosy would cause problems in an on-going marriage of people
394 affected, and that having leprosy would make it difficult for a relative to get married. These
395 quantitative findings were confirmed by the information from the in-depth interviews that men
396 affected by leprosy dare not start a relationship with women. One affected husband was left
397 by his wife because of not being able to earn enough income to feed his family. The belief
398 that leprosy is hereditary may be a reason for respondents to think that having leprosy would
399 affect the marriage prospects of relatives. However, from our observations and in-depth
400 interviews, the children of people affected did not seem to have a problem finding a spouse.

401

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

407

408 It is also important to note that there was significant difference in the proportion of
409 community members and health workers who have negative attitudes and perceived stigma.

410 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 (21). 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 (22).

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. This 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.

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 (4;23). 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 (24-26).

4. CONCLUSION

Both people in leprosy-endemic communities and health workers associated leprosy with disability and dirtiness and thought leprosy was incurable and hereditary. 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. After explaining the study, the participants were asked to give informed consent. The participants could refuse to answer any specific questions, if they wanted to.

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