

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

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ABSTRACT: Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English. 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. This study investigated risk factors of perceived stigma and severity in leprosy affected persons living in Non Somboon leprosy colony in Khon Kaen province, Thailand. This was a cross-sectional study design to assess risk factors for stigma in leprosy-affected persons in Non Somboon, Thailand. Two hundred sixty-five leprosy-affected subjects were studied via questionnaire and interview. The results of this study could confirm certain associations between independent variables and the level of perceived stigma as found in earlier studies. As risk factors for perceived stigma, this study could confirm occupation ($p=0.013$), low knowledge on leprosy (several sub-categories) and visible disfigurements ($p=0.008$). The study found new or more specific factors like a significant association between the 'initial location of treatment' ($p=0.004$) or the 'presence of ulcers' ($p=0.009$) and perceived stigma. In conclusion, major factors that were associated with perceived stigma were poor knowledge on leprosy and visible or noticeable disfigurements. Strategies to reduce perceived stigma should primarily focus on the improvement of health educational programs on leprosy and make these easily available to the leprosy-affected person.

Keywords: Leprosy, Stigma, Explanatory Model Interview Catalogue, Thailand

INTRODUCTION

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].

This study looked for risk factors of perceived stigma in leprosy-affected persons living in Non Somboon leprosy colony in Khon Kaen province, Thailand.

RESEARCH DESIGN

This was a cross-sectional study to assess risk factors for perceived stigma in leprosy-affected persons living in the Non Somboon leprosy colony in Khon Kaen province, Thailand. The study explored the affected persons' socio-demographic characteristics, knowledge on leprosy, medical

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history, clinical characteristics and their relationship to perceived stigma.

STUDY POPULATION

The study population was leprosy-affected persons living in Non Somboon leprosy colony, Khon Kaen province, Thailand. There were about 600 affected persons living in the colony at the time of investigation. All subjects had completed multi-drug-treatment for leprosy.

DATA COLLECTION AND INSTRUMENTS USED

Data were collected by questionnaires using face-to-face interview. The disability-grade of all participants was analyzed according to the WHO classification by the investigator. The questionnaires were translated into Thai language and re-translated into English for accuracy testing. The questionnaire was pre-tested in a primer-study on 15 subjects. Data was collected by house visits. For subject sampling, 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 subjects. All study investigators underwent training before study start. The participants were informed about the content and the objectives of the study prior to interview-start and signed informed consent was collected.

The questionnaire consisted of 2 parts, the first part assessed socio demographic characteristics, knowledge on leprosy and the subjects' leprosy medical history. The second part consisted of the Explanatory Model Interview Catalogue (EMIC) questionnaire, which measured perceived stigma. The EMIC questionnaire assesses the subject's perception of the disease, beliefs and potential effects of leprosy and has originally been developed to elicit illness-related perceptions, practices and beliefs [5]. It has been classified as the instrument to measure perceived stigma in leprosy as recommended by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010 [6, 7].

ANALYSIS

This study was looking for associations between the respondents' perceived stigma (score of EMIC; 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 17 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 .

ETHICAL CONSIDERATION

The Ethical Review Committee for Research Involving Human Research Subjects, Health Sciences Group, Chulalongkorn University assessed the study protocol before study-start. All study participants received a full explanation about the study, its objectives and its benefits and could withdraw from the study at any time and without giving any reason. Informed signed consent was given by the investigator and signed by both the participant and the study investigator.

RESULTS

A total of 265 questionnaires were collected, satisfying the necessary sample size of 263 subjects.

'Socio-demographic characteristics' and their association to the total EMIC scores

Of all affected subjects, 61 were younger than 61 years (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 ($p=0.079$). 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 ($p=0.138$).

Occupation was divided into farmers, unemployed and other professions for analytical reasons. Fifty 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. 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. One hundred twenty five (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 ($p=0.848$).

‘Knowledge on leprosy’ and its association with the total EMIC scores

One hundred fifty (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 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 ($p=0.883$).

Seventy one 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 ($p=0.544$).

One hundred thirty nine 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 ($p=0.352$).

One hundred seventy nine 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 believe that ($p=0.018$).

‘Leprosy medical history’ and its association with the total EMIC scores

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 ($p=0.469$). Two hundred ten 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 ($p=0.063$). 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 ($p=0.001$).

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.

Table 1 WHO disability classification (n = 265)

WHO disability	Number	Percentage
Grade 0	50	18.9
Grade 1	32	12.1
Grade 2	183	69.1

The numbers and percentages of the WHO Disability Classification are given in Table 1.

DISCUSSION

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.

Literature review has shown that certain risk factors support the process of stigmatization. This study has specifically looked for risk factors that support the development of perceived stigma within leprosy-affected persons living in a leprosy colony.

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%) [8], 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% [9]. 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. Many subjects (67.9%) 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 [10]. 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.

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 [11, 12]. A study from India in 2008 by Rao et al. [11] found that perceived stigma was significantly higher in persons of more than 46 years of age. 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. [13], for example, found that women in Nepal had a significant higher rate of perceived stigma than men and this was confirmed by a study from Van Brakel in Indonesia in 2012 [14]. Opposed to that, Tsutsumi described in his study from Bangladesh in 2007 [15], that male sex had a significant higher rate of perceived stigma. In contrast to the described findings our study did 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, 14], or may be caused by the individual's comprising work capacity due to their physical disabilities [14, 16]. 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 [11, 15]. 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 by 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 [17], had the highest level of perceived stigma, which was in correspondence with the findings of earlier studies [11, 15]. 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 [11, 14, 18-20]. 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 [18, 19, 21]. 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 [13] or a curse by God [21-23].

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 in stigma score 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 reveal any significant difference in perceived stigma between those who had disfigurements and those who had not ($p=0.063$). This is in contradiction to several other studies who found disfigurements to be an important risk-factor for perceived stigma [11, 15, 18] or stigma in leprosy in general [16, 19, 20]. Nevertheless, when asking more specifically whether the 'first disfigurements' were visible, those ones who confirmed visible deformities had a significantly higher stigma 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 [14].

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 [11, 13, 15, 18, 21].

CONCLUSIONS AND RECOMMENDATIONS

Some of the study's results were consistent with risk factors of perceived stigma in leprosy that have been described in earlier studies before. 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.

Poor knowledge of leprosy with its many significant sub-categories like leprosy-infectiousness, cause, transmission, severity and others was probably the most impacting category influencing the level of perceived stigma. 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. 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 effective improvement of poor knowledge on leprosy may eventually support the reduction of perceived stigma in the affected persons and may lead to a reduction of the psychological burden that many leprosy affected persons suffer with.

STUDY LIMITATIONS

As this study collected data from only one location in Thailand, it is not possible to generalize the results for the entire country. The design of this study was cross sectional, meaning 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. Examples of other forms of stigma would be 'enacted stigma' or 'internalized stigma', which require other methods of assessment. As this study was performed in an urban location it might not represent the actual situation of perceived stigma in a rural location. A deeper analysis for further understanding or the relative importance of risk factors would require multiple regression analysis, which was beyond the scope of this study.

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