

The Effectiveness of De-stigmatising Interventions

Silatham Sermittirong^{1*}, Wim H. Van Brakel^{2,3}, J. F. G. Bunders-Aelen²
Gomes Unarat¹ and Pojana Thanyakittikul¹

¹Department of Disease Control, Raj Pracha Samasai Institute, Thailand.

²Athena Institute, VU University, Amsterdam, The Netherlands.

³Netherlands Leprosy Relief (NLR), Amsterdam, The Netherlands.

Authors' contributions

This work was carried out in collaboration between all authors. Authors SS, GU and PT designed the study and collected and analyzed the data. Author SS wrote the paper, performed the statistical analysis and managed the literature searches author WHvB assisted with the analysis, read the draft paper and provided suggestions. Author JFGBA read and approved the final manuscript.

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ABSTRACT

Aims: This study on leprosy was conducted to assess the effectiveness of the de-stigmatising interventions which were launched by three different groups of people.

Study Design: Cross-sectional survey.

*Corresponding author: Email: silatham@health.moph.go.th;

Place and Duration of Study: Raj Pracha Samasai Institute and Chaiyaphum province, Thailand, May 2013.

Methodology: The study was done in three districts of Chaiyaphum province, Thailand. Community members and health workers were interviewed using the Explanatory Model Interview Catalogue (EMIC) scale. Frequency tables were used to describe the percentage of respondents who perceived stigma. A p-value of <0.05 was considered indicative of a statistically significant difference. A t-test was applied to compare between the mean EMIC score of community members and health workers before and after interventions.

Results: It was found that de-stigmatising interventions involving affected persons resulted in a measurable reduction of perceived stigma related to leprosy among community members and health workers. In the area of a self-help group (SHG) significant reductions were found in the mean EMIC score after interventions. There was no reduction of negative attitudes and perceived stigma either among community members or health workers in the area where de-stigmatising interventions were launched by a formal health care group. A high percentage of people with perceived stigma were still found in all areas (ranging from 77 to 85 %).

Conclusion: Involving the community and people affected themselves in de-stigmatising interventions, and tailor-made education are keys to success in reducing stigma related to leprosy. Sustaining of the intervention is important to ensure a gradual reduction of stigma in the long run.

Keywords: Assessment; attitude; effectiveness; interventions; leprosy; perception; stigma.

1. INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. The disease mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract and the eyes [1]. The disease has been treated with dapsone since the late 1940s and by the much more effective multidrug therapy, since 1982 [1]. Leprosy has afflicted humanity since time immemorial. It once affected every continent and it has left behind a terrifying image in history and in human memory of mutilation, rejection and exclusion from society [2]. It is estimated that there are between one and two million people with visible and irreversible impairments due to past and present leprosy [2]. Leprosy is no longer a public health problem in Thailand, defined as a prevalence of one case or more per 10 000 population [3] However, there are still approximately 6,000 people with leprosy-related disabilities living in 11 leprosy colonies and communities throughout the country [4].

Stigma related to leprosy is caused by visible manifestations in people affected by leprosy, beliefs regarding causes of the disease and its treatment, fear of transmission, association of those affected with groups of people perceived as 'inferior', and public health measures that treated leprosy differently from other diseases [5-10].

Stigmatising behaviors and measures have differed over time. Before the discovery of dapsone in the 1940s, stigma against leprosy manifested through compulsory identification of leprosy patients, which was accomplished through special clothing or ringing bells when approaching others, restriction to begging as the only means of survival, and forced segregation measures [11]. After the discovery of dapsone, a gradual shift to outpatient care was implemented [12,13]. In this latter phase, stigma manifested in less restrictive ways, such as people affected trying to conceal their disease and practicing self-isolation [5,14-17].

The community expressed their negative attitudes towards the patients by avoiding them or forcing them to leave home [5,18,19].

Stigma has an impact on people affected by leprosy in terms of mental health, economic status, marriage and education, and timely and regular treatment. A study from Bangladesh showed that people affected by leprosy experience significantly more depression than the control group [20]. The stress can even result in suicide as revealed by a study in South Africa, which reported that one third of patients contemplated suicide after learning their diagnosis of leprosy [21]. However, the manifestation of stigma may be different or change depending on visible signs, social status of people who have (had) leprosy, gender and social distance between affected persons and those who stigmatise [5,22-25].

To reduce stigma related to leprosy, de-stigmatising interventions were designed and launched in three different ways, through a formal health care group, a local volunteer group and a self-help group in three districts of Chaiyaphum province, Thailand. Three different groups of interventions were launched; one in each of three districts. The first intervention groups were conducted through the formal health care system in which a district health officer who worked at a district hospital acted as the head of the project, assisted by health officers of a health promotion sub-district hospital and health volunteers. The second intervention groups were conducted by a local volunteers group under the supervision of a health officer of health promotion at a sub-district hospital. The third was operated by a group of people with leprosy-related disability and by people with other disabilities. The third intervention groups were supported by a health officer and a local administrative officer who were responsible for the health and the welfare of the people in that area. Before launching the three groups of interventions, a community survey was done. It was found that community members and health workers perceived leprosy as a disabling disease with disability that is incurable and hereditary, and associated with dirtiness and oozy and smelling wounds. [Published elsewhere]. Most community members thought leprosy was hereditary and incurable. Each group formulated their own plan of action with the facilitation of a research team.

The formal health care group addressed two causes of leprosy-related stigma, impairments and personal hygiene, by training the health volunteers, who were responsible for home visits, on how to instruct and supervise people with leprosy-related disability in practicing self-care. During the same training course, people with leprosy-related disability were trained to do self-care and provided related materials. In terms of misconceptions and harmful beliefs, health volunteers were asked to disseminate the facts about leprosy to community members in the area under their responsibility.

In the second intervention group, local volunteers addressed causes of stigma in terms of impairments and personal hygiene by visiting people with leprosy-related disability to instruct and supervise their self-care practice and also to support them in case of mental suffering. They approached relatives of people affected and a local administrative organization to renovate and improve the houses of people with leprosy-related disability, who lived in poor unhygienic circumstances. To address misconceptions and harmful beliefs, they disseminated the fact that leprosy is curable and not hereditary through person to person communication and performed local drama with the participation of people with leprosy-related disability. Before carrying out related activities, local volunteers were informed by the research team and a community nurse about the facts regarding leprosy and self-care practices.

The self-help group (SHG) addressed the causes of stigma in terms of impairments and hygiene by practicing self-care and improve their personal hygiene. They also visited and taught self-care to people with leprosy-related disability who were elderly or unable to go out. In terms of misconceptions and harmful beliefs, they empowered each other by establishing income generation activities among group members. They participated in community events, taking part in a district health rally and organizing an exhibition to disseminate the facts about leprosy through display boards and games. Before carrying out these activities, the SHG members were trained on leprosy and self-care, and income generation activities.

Monitoring and evaluation was done twice, 5 and 10 months after the launching of the interventions. It was found that the self-esteem and social participation of the SHG beneficiaries had changed more than those of the volunteer group, while there was no change in those of the formal health care group. The attitudes of the community towards leprosy had changed slightly according to information obtained by in-depth interviews and focus group discussions [Published elsewhere]. To promote attitude changes, the research team decided to provide information about leprosy to the community.

Information about leprosy was provided to health workers and community members of all three study areas, except to the health workers of Tepsatit district hospital, because it was assumed that information displayed in leprosy campaign week would be enough to change stigma among health workers of this hospital. Leprosy information was given to health volunteers of Huay Yaijew sub-district of Tepsatit district using existing leprosy training materials designed by the national leprosy programme for use all over the country. In Nhong Bua Daeng and Bantan district, leprosy information was given using training materials that had been adjusted to focus on addressing negative attitudes and misperceptions of the community regarding leprosy.

This study was conducted to assess the effectiveness of de-stigmatising interventions, which were launched by three different groups of people.

2. MATERIALS AND METHODS

This study was part of a de-stigmatising interventions study, which was conducted to determine the effectiveness of the above mentioned three intervention strategies. We assessed the perceived stigma of community members and health workers regarding leprosy and compared the results with the baseline data obtained before the interventions were launched.

After 13 months an evaluation was done in May 2013 in the areas where the interventions were launched, which were Tepsatit, Nhong Bua Daeng and Bantan districts of Chaiyaphum province in the North-eastern region of Thailand.

2.1 Selection Criteria and Sampling

The respondents consisted of 177 of community members who lived in the same village as people affected by leprosy. Subjects were selected by systematic sampling using a list of names from the local health officer. The number of eligible people for 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. In addition, 177 health workers were included who worked at health units where the people affected by leprosy included in the study were

registered. A convenience sample of those who were present at the time of data collection was interviewed. Those not willing to participate and those unable to answer the questions due to physical or mental problems were excluded. The sample size for the quantitative evaluation was calculated based on the estimated prevalence of community members who have negative attitudes towards leprosy of 96% found in a study of Srisak and a desired width of the 95% confidence interval of +/-5% [26,27].

2.2 Data Collection Methods

Respondents were interviewed using the Explanatory Model Interview Catalogue (EMIC) stigma scale, which was also used to measure the perceived stigma of community members and health workers before launching the de-stigmatising interventions.

The internal consistency of the EMIC scale in the baseline study was good, with an alpha score of 0.87, which indicates high internal consistency [28]. No floor or ceiling effects were found. The EMIC scale version we used consists of 15 questions covering different aspects of stigma, for instance, 'Does leprosy cause shame in your community?' There are four answer options: 'yes', 'possibly', 'no', and 'don't know'. The score options for each item are 2,1,0,0 respectively (Appendix 1). We chose an EMIC score cut-off point for perceived stigma of 8, which means that the respondents are considered to perceive stigmatization in the community when they answered at least 4 questions with 'yes', or 8 questions with 'possibly', or a combination of both with a sum score of 8 or more. The reason for choosing 8 was to increase the specificity of the outcome 'perceived stigmatisation'. If a respondent answered 'yes' or 'possibly' to fewer questions, there would be a high risk of false positives.

2.3 Data Analysis

Quantitative data entry and analysis was done using SPSS version 17. 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 score of community members and health workers before and after the de-stigmatising interventions. The pre and post-intervention sample was not the same, so confounding by other factors was a possibility, particularly in the sample of community members. We therefore conducted a multiple linear regression analysis with several demographic variables to examine the effect of these potential confounders. The model used the EMIC sum score as dependent variable and study area, age group, sex, marital status and education level of the respondents as independent variables.

3. RESULTS

Characteristics of the community members and health workers before implementing the de-stigmatising interventions.

Of the 177 community members, 111 (62.7%) were female, 122 (68.9%) completed primary school, 37(20.9%) completed secondary school, and 136 (76.8%) were married. The average age of the subjects was 55, with an age range from 18 to 84. Of 177 health workers, 136 (76.8%) were female.

Characteristics of the community members and health workers after implementing the de-stigmatising interventions.

Of the 177 community members, 136 (76.8%) were female, 104 (58.8%) completed primary school, 60(33.9%) completed secondary school, and 150 (84.7%) were married. The average age of the subjects was 49, with an age range from 19 to 76. Of 177 health workers, 151 (85.3%) were female.

The mean EMIC stigma score before and after de-stigmatising interventions was compared using a T-test. A significant difference was found between the before and after results of community members in Nhong Bua Daeng and Banten district, and of health workers in Banten district. Because of the demographic differences in the two samples, linear regression was used to obtain means that were adjusted for the main demographic variables (Table 1).

Table 1. The mean EMIC score, t-test results and linear regression results in the stigma reduction study in community members and health workers

		Community members			Health workers		
		Before	After	P-value	Before	After	P-value
Tepsatit							
N	Valid	59	59		59	59	
	Mean	15.31	15.24	0.96	14.29	16.31	0.90
	SD	6.25	7.99		6.09	6.69	
	Adjusted mean*	9.41	9.73	0.814			
Nhong Bua Daeng							
N	Valid	59	59		59	59	
	Mean	16.31	13.37	0.031*	14.75	12.73	0.12
	SD	8.22	6.19		7.24	6.64	
	Adjusted mean*	7.73	4.09	0.014			
Bantan							
	Valid	59	59		59	59	
	Mean	20.97	14.51	<0.001*	15.39	12.29	0.026*
	SD	8.75	6.84		7.82	7.14	
	Adjusted mean*	21.74	15.46	<0.001			

* Adjusted for the effect of age group, sex, marital status and education level of the respondents (full data not shown)

The frequency of community members and health workers scoring 8 or above on the EMIC scale was used to identify the percentage of community members and health workers who perceived stigma related to leprosy. While there was a slight reduction in the percentage after the interventions, but it was still over 70% (Table 2).

3.1 Differences in the Attitudes and Perceived Stigma Before and After the Interventions

(Fig. 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 before and after the interventions. The percentage of people who answered 'yes' was substantially reduced.

Table 2. The frequency of EMIC score by category among community members and health workers in the stigma reduction study in Thailand

		Community members				Health workers			
		Before		After		Before		After	
		N	%	N	%	N	%	N	%
Tepsatit									
Valid	Score 0-7	7	11.9	11	18.6	7	11.9	5	8.5
	Score ≥ 8	52	88.1	48	81.4	52	88.1	54	91.5
	Total	59	100	59	100	59	100	59	100
Nhong Bua Daeng									
Valid	Score 0-7	10	16.9	10	16.9	11	18.6	13	22
	Score ≥ 8	49	83.1	49	83.1	48	81.4	46	78
	Total	59	100	59	100	59	100	59	100
Bantan									
Valid	Score 0-7	7	11.9	11	18.6	10	16.9	16	27.1
	Score ≥ 8	52	88.1	48	81.4	49	83.1	43	72.9
	Total	59	100	59	100	59	100	59	100

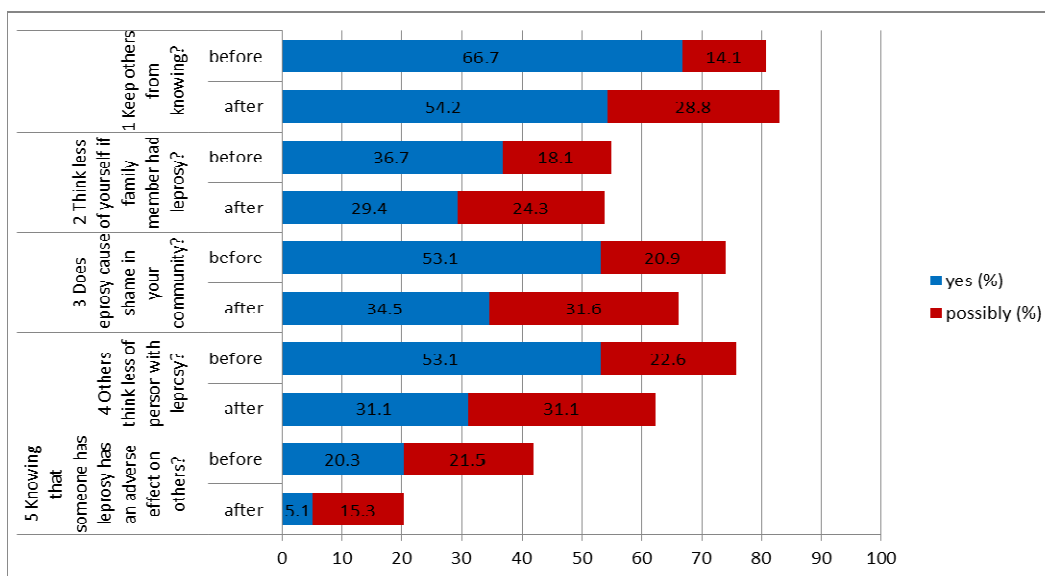


Fig. 1. Perceived stigma related to leprosy among CM (n=177) and HW (n=177) in North-East Thailand measured with the EMIC stigma scale. The graph shows items 1-5 of the scale

(Fig. 2) demonstrates the before and after views of community members and health workers regarding shame and avoidance behaviour of the family of persons affected by leprosy and community members. The percentage of people who answered ‘yes’ was significantly reduced.

(Fig. 3) demonstrates the before and after views of community members and health workers on how they and other people think about people affected by leprosy and their families in terms of marital and work prospects. Again, the percentage of people who answered ‘yes’

was reduced significantly. However, on most items the opinion of the respondents shifted from 'yes' to 'possibly', so the changes in the overall percentages were much smaller.

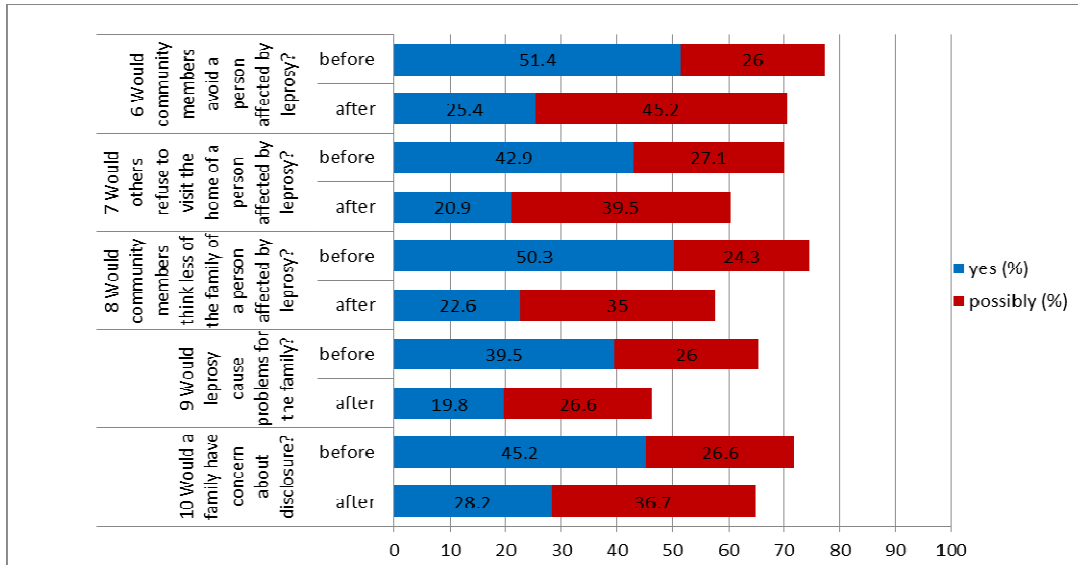


Fig. 2. Perceived stigma related to leprosy among CM (n=177) and HW (n=177) in North-East Thailand measured with the EMIC stigma scale. The graph shows items 6-10 of the scale

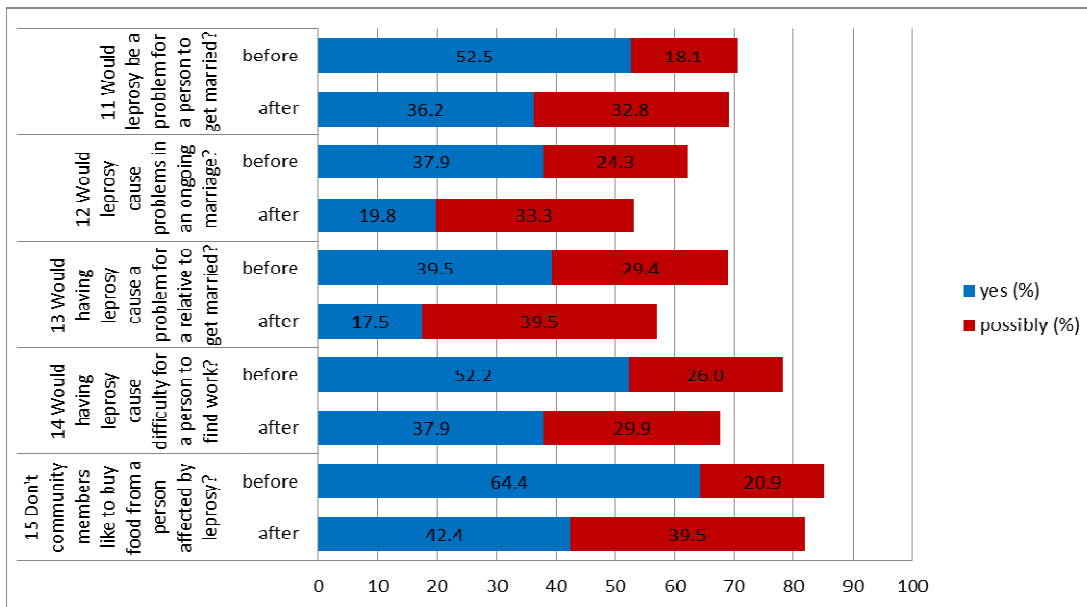


Fig. 3. Perceived stigma related to leprosy among CM (n=177) and HW (n=177) in North-East Thailand measured with the EMIC stigma scale. The graph shows items 11-15 of the scale

4. DISCUSSION

In Tepsatit district where formal health care structures were used to reduce stigma related to leprosy, there was no reduction in EMIC score, a measure of perceived stigma among either community members or health workers. The likely reason for the lack of effect on the stigma perceived by health workers was that there were few leprosy-related activities organised in the hospital. Only information regarding leprosy was displayed at the hospital outpatient department during the leprosy campaign week organised once a year. The fact that stigma was not reduced among community members is disappointing as this formal intervention was carried out in a leprosy prevalent area in Thailand. Health volunteers carried out home visit to supervise self-care practice of persons with leprosy-related disabilities. Leprosy knowledge was provided to key community members, including health volunteers, with the hope that these people would disseminate the obtained knowledge to the community and influence the attitudes and perceptions of the rest of the community. This result supports the review of Wong who mentioned that the results of many studies revealed that knowledge about the curability of leprosy did not change negative attitudes towards leprosy patients [29]. For instance, a study in Tanzania did not find a substantial improvement in knowledge or attitudes of the adult population or health workers in community where intensive health education was launched [30]. A study in India did not find change in expressed prejudice towards people with leprosy after a community health education campaign [31]. The study of Jacob et al. [32] in South India showed that IEC activities in the form of providing leprosy knowledge did not change the attitudes of the target group. Instead, after a health education session about leprosy in school, the attitudes of some children towards leprosy actually worsened.

In Nhung Bua Daeng district, where the stigma reduction intervention was launched by a volunteer group, stigma had reduced significantly among community members, but not among health workers. Leprosy information developed on the basis of the community attitudes and perception regarding leprosy was provided to both community members and health workers. The de-stigmatising activities were launched by a volunteer group in the community, 27 kilometres away from the hospital where most of health workers worked and lived. The non-awareness and the fact that most health workers did not participate in the de-stigmatising intervention may be the reason that there was no change in their attitudes and perception regarding leprosy. On the other hand, community members did have a chance to participate in this intervention, which was launched in their own place. This may be the reason why the level of perceived stigma was reduced significantly among them. The lack of reduction of stigma among health workers and the significant reduction among community members might indicate that providing focused information to the health workers only is not enough to significantly reduce stigma related to leprosy among health workers. They need to be specifically targeted as a separate group. In the successful social marketing approach used in Sri Lanka, apart from targeted IEC, they also trained health workers to recognise leprosy and refer persons with suspect lesions to the leprosy staff [33]. In addition, they improved the network of clinics. These thorough preparations were in accordance with the suggestion of Bollinger, who conducted a study on stigma associated with HIV/AIDS [34]. He suggested that IEC should be considered a component of stigma reduction interventions, but that dissemination of information as a sole strategy would not be adequate.

In Bantan district, we observed a significantly reduction of stigma among both community members and health workers. Most of the health care workers worked in the district hospital, which was only one kilometre away from an area where the SHG launched the de-stigmatising interventions. The SHG consisted of people with leprosy-related and other

disabilities who actively carried out socio-economic rehabilitation (SER) by themselves. There was also participation of key community members and health volunteers who acted as group supporters and consultants under the close supervision of a district hospital health officer and a local administrative officer. The significant reduction in stigma may be attributed to the contribution of the beneficiaries themselves, together with the key community members and health volunteers. In addition, there was awareness of the SHG activities among community members and health workers, who worked and lived near or in the same area as the SHG members. This study confirms the results of studies done in Nepal and Nigeria that reported success in helping people affected by leprosy regain their dignity by involving them as participants in SER [35,36]. As in our study, this resulted in positive attitude changes in the community and reduced internalized stigma of people affected by leprosy [Published elsewhere].

Regarding the respondents' perceptions of stigma related to leprosy, it was shown that there was a strong positive change in views regarding marital and work prospects, in particular item 13 and 22 regarding problems of relatives wanting to get married and problems of people affected by leprosy selling food. These changes may be attributed to the awareness of the respondent that leprosy is not hereditary and not always related to disability. Most respondents said they would buy food from people affected by leprosy if they did not have a disability and were not dirty. However, there were only slight changes in their feelings about having people affected by leprosy in their family or community (particularly item 1, 2 and 4 regarding keeping others from knowing, thinking less of themselves if a family members has leprosy, and thinking less of persons with leprosy). The reason that only minor changes were seen may be because, for a long time, leprosy has been linked with people perceived to be inferior, such as a beggars or people who are poor, out of work, uneducated, or of a lower social class [25]. It is difficult to completely change such deep-rooted attitudes in a matter of months.

Even though we found evidence that the level of stigma had decreased, negative attitudes were still perceived by a majority of respondents. Even after the interventions, the percentage of respondents with an EMIC score equal or greater than 8 – interpreted as evidence of perceived stigma – was still over 70%. In his study in Paraguay, Nicholls found that some community leaders suggested that changing attitudes was a huge task, because leprosy remains a taboo subject. They considered it to be a disease of society, not of people [37]. This may be true in Thailand also. Therefore, it is important to sustain the de-stigmatising interventions.

This study did not simultaneously assess the attitudes and perception of people affected by leprosy along with those of the wider community. However, according to the qualitative monitoring and evaluation conducted twice in-between the interventions, the SHG members showed a bigger increase in self-esteem and social participation than the beneficiaries of the local volunteer intervention, while there was no change in the beneficiaries of the formal health care intervention [Published elsewhere]. This could be attributed to the opportunities that SHG members had in exercising their capabilities to the utmost by contributing to the activities of the community as a whole. In addition, we also found in the interventions launched by the local volunteers and the SHG that the relatives of people with leprosy-related disability and of SHG members gradually participated in the rehabilitation process and in group activities. This is likely to be because the activities launched by local volunteers and SHG gradually changed their attitudes in a positive direction.

In Heijnders & van der Meij's study, they grouped de-stigmatising interventions into four levels, intrapersonal; interpersonal; organizational/institutional; community and governmental/structural [38]. Looking at which of these levels were targeted in our interventions, the local volunteer group succeeded in addressing stigma at intrapersonal, interpersonal and community levels, while SHG also succeeded at targeting the organizational level. The formal health care group did not appear to have succeeded at any level.

Interventions that were found to be effective were those launched in a participatory manner and using mixed methods at different levels. The people involved at each level, namely community members and health workers, play an important role in the leprosy affected people's local world, a somewhat circumscribed domain within which daily life take place [39]. Addressing leprosy-related stigma among community members and health workers may help to alleviate the difficulties faced by people affected.

5. LIMITATIONS OF THE STUDY

Unfortunately, the characteristics of health workers such as age, education level, marital status, etc., were not collected. In a future intervention study such baseline data should be collected, because it is important to be able to investigate factors that may contribute to the effectiveness of the de-stigmatising interventions.

6. CONCLUSION

In our attempts to reduce stigma related to leprosy, apart from involving the community, a key to success was involving people affected themselves. Tailor-made education should be carried out as part of de-stigmatising interventions, taking attitudes and perceptions of the community into consideration. Importantly, such interventions should be sustained to facilitate a gradual reduction of stigma in the long run.

CONSENT

All authors declare that verbal informed consent was obtained from the respondents of this study.

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.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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APPENDIX 1

EMIC stigma scale

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

Appendix 1. EMIC scale continued.....

	Yes	Possibly	No	Don't know	score
	2	1	0	0	
8. Would people in your community think less of the family of a person with leprosy?					
9. Would leprosy cause problems for the family?					
10. Would a family have concern about disclosure if one of their members had leprosy?					
11. Would leprosy be a problem for a person to get married?					
12. Would leprosy cause problems in an ongoing marriage?					
13. Would having leprosy cause a problem for a relative of that person to get married?					
14. Would having leprosy cause difficulty for a person to find work?					
15. Do the people in your village don't like (reject) to buy food from people affected by leprosy?					
total					

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