



## Addressing Stigma Related to Leprosy: Lessons from an Intervention Study in Thailand

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### Authors' contributions

This work was carried out in collaboration between all authors. Authors SS, NA and NC 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. All authors read and approved the final manuscript.

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### ABSTRACT

**Aims:** This study was conducted to develop de-stigmatising interventions aiming to reduce stigma related to leprosy; to improve the quality of life of the people affected; and to draw out lessons on how to set up such interventions elsewhere.

**Study Design:** Intervention study.

**Place and Duration of Study:** Raj Pracha Samasai Institute and Chaiyaphum province, Thailand, April 2011-December 2012.

**Methodology:** De-stigmatising interventions were carried out by 3 different groups, namely a formal health care group, a local volunteer group and a self-help group. A baseline survey was done using both qualitative and quantitative methods. Qualitative data collection was conducted

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through semi-structured interviews with people affected with leprosy (n=19), community members (n=24) and health workers who were responsible for leprosy and tuberculosis at a district hospital (n=2), and those who were present at a sub-district promotion hospital at the time of interviewing (n=6). One focus group discussion was conducted among health volunteers who had people affected by leprosy in the areas for which they were responsible (n=6). For the quantitative data collection, community members and health workers were interviewed using the Explanatory Model Interview Catalogue (EMIC) stigma scale. To track the course of the interventions, two sets follow-up enquiries were conducted. People affected by leprosy, people with other disabilities, health volunteers, local volunteers, nurses, health workers and administrative officers were interviewed. Focus group discussions were held with health volunteers, with local volunteers and with the self-help group members. Content analysis was used to analyse qualitative data. A T-test, a Chi-square test and multiple linear regression analysis were used to analyse quantitative data. Observation was also conducted to evaluate the outcomes of self-care practice of people affected by leprosy.

**Results:** Full participation of people affected by leprosy was found in interventions implemented by the self-help group, while little and no participation was found in those of the local volunteer and the formal health care group respectively. Self-esteem and social participation of the self-help group's beneficiaries changed more than that of the local volunteer group, while there was no change in those taking part in the formal health care group.

**Conclusion:** The findings support the study hypothesis that emphasises the importance of participation of different stakeholders. To maximise the likelihood of significant changes in attitudes, tailor-made education needs to be conducted to address negative attitudes and stigma perceptions found in the course of pre-intervention assessment.

*Keywords: Intervention; attitude; perception; stigma; leprosy; a self-help group; a local volunteer.*

## 1. INTRODUCTION

Stigma is a serious obstacle to identifying cases of leprosy and affects effectiveness of treatment, which are the major factors of controlling the disease [1-7]. It has been defined by different professionals in different ways. Sartorius has defined stigma as "characteristic of a person or an institution-the colour of skin, the type of work or a label, for example-that evokes negative attitudes and feelings (such as fear, disgust or hate) and usually results in discrimination of the person or institution in various walks of life" [8]. Sartorius further explained his stigma definition through a model which implies that a marker (a visible abnormality or a label) that allows the identification of a person can be loaded with negative contents by association with previous knowledge, with information obtained through the press or in personal contacts, with memories of things seen in movies or heard in the community. Once the marker is loaded in this way, it becomes a stigma. Stigmatization may lead to negative discrimination, which in turn leads to numerous disadvantages in terms of access to care, poor health service, marriage prospects and stability, educational and other social barriers [9]. These frequent setbacks can further damage self-esteem and cause additional stress that might worsen the condition of the marked person, and thus amplify the marker, this makes

it even more likely that the person will be identified and stigmatised [1,5,8,10-14].

Leprosy is a disease that may cause visible impairments. Visible impairments together with the local beliefs, fears or misconceptions construct stigma against those affected by leprosy leading to discrimination and other consequences [1,5,11,15-18]. Sartorius suggested that an intervention at any point might stop the vicious cycle of stigmatization [8]. As interventions addressing leprosy stigma were rare in Thailand, this study was conducted to develop the basis for interventions aiming to reduce stigma related to leprosy in order to improve the quality of life of people affected and to draw out lessons on how to set up such interventions elsewhere.

In the scientific literature, we found various de-stigmatising interventions against leprosy-related stigma for which there was evidence of effectiveness. These interventions were conducted in Sri Lanka, Nepal, and Nigeria [17,19,20]. Each of these interventions is briefly described below.

A social marketing campaign was launched in Sri Lanka in 1990 aiming to encourage people with possible leprosy skin lesions to seek diagnosis, and to change the negative attitude of the

general population towards leprosy [17]. The study results showed that the proportion of people who said they would not sit next to a leprosy patient decreased from 44% to 27%, as did the proportion of those who would not eat food prepared by leprosy patient (from 68% to 50%). The proportion of people who believed that leprosy was caused by bad deeds in a previous life fell from 37% to 12%. These successes are partly attributed to taking into consideration the community attitudes and perceptions, and to the participation of the community in the campaign [21].

In Southern Nepal, Cross & Choudhary launched the Stigma Elimination Project (STEP) in 2002 [19]. The project enabled and encouraged people affected by leprosy to establish self-care groups with the primary objective of controlling impairment. After one year, the groups took on the form of self-help groups focusing on credit union and micro enterprise development and expanding their criteria for membership to include other marginalized people. They became contributors to the development of their communities. The effectiveness of the programme was confirmed by measuring the level of social participation reported by the members of the group. It was found that STEP participants had significantly higher levels of participation compared with controls who had not been part of the intervention and that their levels of social participation were higher than would be expected even for the general population.

In 2006, Ebenso et al. [20] studied the impact of socio-economic rehabilitation (SER) on leprosy stigma in five northern states of Nigeria. It was found that SER improved self-esteem, financial independence, acquisition of new skills, and access to public institutions. SER also influenced the process of social integration resulting in positive attitudinal change towards SER participants.

Based on the lessons learnt from the above successful interventions, the hypothesis of this study was formulated. It was "participation of people affected by leprosy, community members, and local officers in leprosy de-stigmatising interventions will increase social participation and the self-esteem of people affected by leprosy as well as establishing the understanding of those involved, leading to a gradual positive change in attitudes and perceptions".

## 2. MATERIALS AND METHODS

This intervention study was started by conducting a pre-intervention baseline survey followed by launching of interventions and monitoring and evaluating the process and outcomes.

### 2.1 Pre-Intervention Survey

The study area included four districts in Chaiyaphum province which were Tepsatit, Nhong Buadaeng, Bantan and Bumnet Narong districts. They were selected because they had a higher number of people with leprosy-related disabilities than other districts. To obtain the reality of stigma situation in these areas, a baseline survey was conducted using mixed methods.

*Qualitative data collection* was conducted through 19 semi-structured interviews using interview guidelines with people affected by leprosy who lived in the study areas, and 24 community members who lived in the same villages as people affected. Eligible community members were selected by maximum variation sampling with regard to age, sex and socio-economic status. We sampled the informants among the community members by selecting a mix of men and women; three different age groups (15-24, 25-59, more than 60); and people with different socio-economic status which were poor, relatively poor, neither poor nor rich, relatively rich and rich. We asked health volunteers to identify the socio-economic status of eligible community members and seek consent from people affected by leprosy and chosen community members. The other groups of interviewees were six health care providers at the sub-district health promotion hospital who were present at the time of data collection; and two health workers with a leprosy-related role at the district hospital.

In addition, a focus group discussion took place with six health volunteers, responsible for villages where people affected by leprosy lived, using a predefined script.

The common theme of collected information was the attitudes and perceptions of the interviewees regarding leprosy, and the effect of stigma on the quality of life, including accessibility to health care of people affected by leprosy. Results of the interviews and the focus groups discussion were summarised and the summaries were sent back to participants for remember check.

Respondents of the *quantitative survey* were community members who lived in the same village as people affected by leprosy. They were selected by systematic sampling using a name list from a local health worker. 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 health workers who worked at health units which people affected by leprosy attended. Those who were present at the time of data collection were interviewed. The sample size for the quantitative survey was calculated based on a prevalence of community members with negative attitudes towards leprosy of 96% found in the study of Srisak, with a desired width of the 95% confidence interval of +/- 5% [22]. The sample size was calculated using OpenEpi.com. Rounded up, a sample size of 240 subjects was required [22].

The Explanatory Model Interview Catalogue (EMIC) stigma scale was used to collect the quantitative data. The EMIC scale consists of 15 questions covering different aspects of stigma with four answer options: 'yes', 'possibly', 'no', and 'don't know'. The scores for each answer are 2,1,0,0 respectively. We chose an EMIC cut-off point for perceived stigma of  $\geq 8$ , 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 would answer 'yes' or 'possibly' to fewer questions, there would be a high risk of a false positive classification. A minimum Cronbach's alpha of 0.70 was set as an acceptable level of internal consistency, and 15% or less was set as an acceptable ceiling or floor effect for the EMIC scale [23].

Content analysis was used to analyse qualitative data. A T-test was used to compare the difference between the mean EMIC score of community members and that of health workers. A Chi-square test was used to examine the difference between the percentage of community members who had perceived stigma and that of health workers. Multiple regression analysis was used to examine associations between personal factors and the EMIC stigma score among community members. The EMIC sum score was used as dependent variable and the

demographic variables shown in Table 3 as independent or explanatory variables. A backward stepwise procedure was used to eliminate variables from the regression model (with a threshold value of  $p \geq 0.10$ ). A p-value of  $< 0.05$  was used as cut-off for statistical significance. SPSS vs 17 was used to conduct the quantitative analysis.

## 2.2 Monitoring and Evaluation of the Intervention Study

De-stigmatising interventions were designed and carried out by three different groups. Each was formulated within a 10-month plan of action (POA) with a clear timeline (see Table 1).

Two monitoring and evaluation (M&E) rounds were conducted 5 and 10 months after the interventions were launched. The M&E framework was based on the framework of Swaans et al. [24]. The criteria comprise two main components, the process and the outcome. The aspects of process that were monitored consisted of 1) stakeholder representation, to know who are the participants and what are their roles in the interventions, 2) process structure, to know whether the participants were aware of the objectives of the interventions including their own tasks and roles, 3) process management, to know the competencies of the intervention coordinator, whether he/she was competent enough to lead the group, 4) capacity building, to see whether the participants had sufficient skills to perform their tasks, and 5) coalition building, to understand the supportive infrastructure, such as consultants, technical knowhow, and available funds. Two aspects of the outcomes of the interventions were evaluated, the direct and indirect outcome (see Table 2).

For the data collection the approach of responsive evaluation was used. This is based on a constructivist theory [25,26]. It is assumed that human beings give meaning to their experiences and that this construction is influenced by personal background as well as socio-structural and stakeholder positions. Together the various, complementary, perspectives provide a more informed understanding of the intervention being evaluated. In this approach, information discovered in the course of data collection was raised and discussed among local participants and the research team to maintain good practice and address problems. Information was gathered by interviewing people affected by leprosy, a member of each group and their consultants.

Focus group discussions were conducted among the members and consultants of each group. The question guidelines and the predefined script were formulated based on the M&E framework. In the first M&E round, a meeting was held with a district hospital nurse and a SDHPH health worker to monitor and evaluate interventions launched by the formal health care group. 5 people affected by leprosy, 5 local volunteers and 1 SDHPH nurse were interviewed; Focus group discussions were conducted with 6 local volunteers to monitor and evaluate interventions launched by the local volunteer group. The members of the self-help group namely 4 people affected by leprosy and 4 people with other disabilities, 1 district hospital nurse, 2 administrative organization officers were interviewed; and conducted a focus group discussion was held with 8 self-help group members to monitor and evaluate interventions launched by the self-help group. In the second

M&E round of the formal health care group, 4 people affected by leprosy, 3 health volunteers and 2 SDHPH health workers were interviewed; and a focus group discussion held with 4 health volunteers and a SDHPH health worker. In the same M&E round with the local volunteer group and the self-help group, interviews and focus group discussions were conducted with similar numbers and groups of participants. Observation was done to compare the self-care outcomes of people affected by leprosy before and after each round of M&E by observing their personal hygiene such as bodily cleanliness and clothing and the condition of their impairments on the course of interviewing in each round. Content analysis using open coding was done to analyse data. An outcome that relates to the planned objectives of the interventions will be reported as a direct outcome. Other findings will be reported as indirect outcomes.

**Table 1. Activities planned by each group**

<b>Types of group</b>	<b>Activities</b>	<b>Persons in charge</b>
The formal health care group	- Providing the community with knowledge about leprosy by organizing a workshop; arranging a small exhibition on leprosy at the health service facilities and disseminating educational materials for village broadcasts	Health workers
	- Providing rehabilitation services to people with leprosy-related disability by training them, their care givers and families regarding leprosy and self-care	Health workers
	- Carrying out home visits	Health volunteers
	- Supporting persons with leprosy-related disability in income generation by coordinating organizations involved in seeking appropriate employment for them	Health workers
The local volunteer group	- Enabling the local volunteers to provide physical rehabilitation services to people with leprosy-related disability by training them in leprosy and prevention of disability (POD)	Health workers
	- Providing rehabilitation services to people with leprosy-related disability by conducting home visits to give instruction on and monitor self-care practice; to give psychological support and to assess the needs of people with leprosy-related disability.	The local volunteers
	- Coordinating with organizations concerned in helping people affected	The local volunteers and a nurse
	- Promoting positive attitudes towards leprosy by launching Information, Education, and Communication (IEC) activities	The local volunteers
The self-help group	- Narrowing the distance between people affected by leprosy and the community by promoting the contact between them	The members of the self-help group
	- Promoting income-generating activities by occupational training	Local related officer
	- Helping and supporting each other by meeting once a month and visiting each other at home	The members of the self-help group
	- Enabling SHG members to practice self-care as well as to instructing other members and their relatives to know how to do self-care by arranging related training	Health workers

**Table 2. Monitoring and evaluation criteria for effective de-stigmatising intervention**

Process	Stakeholder representation	Inclusion of local organizations
	Process structure	Inclusion of community key members Inclusion of people affected by leprosy Transparency on objectives, roles/tasks and procedures Structured decision making
	Process management	Facilitation of mutual respect, openness, and constructive interaction Competent facilitation and coordination
	Capacity building Coalition building	Competent participants Appropriate support Access to resources
<b>Outcomes</b>	Direct	Better self-care practice Reduction of stigma related to leprosy
	Indirect	Learning (leprosy knowledge, POD) Supporting (task of a local organization)

### 3. RESULTS

#### 3.1 Results of Pre-Intervention Survey

##### 3.1.1 Qualitative results

Community members and health providers perceived leprosy as a disease associated with disability, incurable, hereditary, dirtiness, oozy and smelling wound. People affected by leprosy tried to keep others from knowing about their disease. People with leprosy-related disability did not participate in community activities, and used health services less than other people. Community members stigmatised people with leprosy-related disability by avoiding them and by back biting. Health providers spent as little time as possible with people with leprosy-related disability. People with leprosy earned less income than other people of their sex and age resulting in poverty for most of them.

In Bantan sub-district, one man with leprosy-related disability expressed a desire to organize a group of people with disability to carry out activities that contribute to community development and that would help him re-gain his human dignity. In Nangdad sub-district; under the encouragement of Raj Pracha Samasai Institute (RPSI), which is responsible for the national leprosy programme, and the 5th Regional Office for Disease Prevention and Control (RODPC), a local volunteer group had been established to provide rehabilitation service for people with disability and other underprivileged groups. It was named 'Raj Pracha Samasai (RPS) local volunteer group'. The group had carried out some activities at the time of survey, but had not

paid much attention to people with leprosy-related disability. In Kokpet Pattana, the sub-district of Bumnet Narong district that we intended to use as a control, there had been the Leprosy Accreditation (LEA) Project supported by Raj Pracha Samasai Institute (RPSI). The Leprosy Accreditation (LEA) Project aimed to assure adequate standards of leprosy treatment and rehabilitation.

##### 3.1.2 Quantitative results

Of the 236 community members interviewed, nearly two thirds were female (64.8%), just over two thirds had only completed primary school (69.1%), 186 (78.8%) were married and an equal number was aged between 40-79 years. Of 236 health workers, 180 (76.3%) were female. The mean EMIC score of community members (n=236) was 15.4 (95%CI 14.3-16.6), with a median of 16. The mean EMIC score of the health workers (n=236) was 14.8 (95%CI 13.9-15.6) with a median of 15.5. The EMIC scores were normally distributed. The difference between the means was not significant (2-tailed p-value=0.387, t-test). Eight explanatory variables were included in the regression analysis. 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 better quality houses than a cottage or shelter (see Table 3). The percentage of community members with an EMIC score  $\geq 8$  was 75.4 (95%CI 69.9-80.9) while that of health workers was 85.6 (95%CI

81.1-90.1). This difference was significant at the 5% level ( $p=.007$ , Chi2 test).

### 3.2 Results of the Two Monitoring and Evaluation Rounds: The Process

#### 3.2.1 Activities

##### 3.2.1.1 The formal health care group of Huay Yaijew sub-district

In the first M&E round we found that the district hospital officers had organized a leprosy training course for key community members all over the district with the hope that they would transfer their knowledge to the communities in their

respective areas. The other planned interventions had not been conducted yet.

In the second M&E round, we found that the district hospital officer and his team had organized training for village health volunteers and people with leprosy-related disability on leprosy and prevention of disability (POD) to enable them to practice self-care. They also trained health volunteers to instruct and monitor people with leprosy-related disability regarding self-care. However; during home visits, the village health volunteers still focused only on general health, not on self-care or socio-economic aspects.

**Table 3. Multiple linear regression analysis to investigate an association between personal factors and the EMIC stigma score in the de-stigmatization study in Thailand**

Model	Coefficients		P-value
	B	SE	
Constant	22.335	7.524	.003
Sex	1.039	1.340	.439
<b>Age</b>			
- 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
- $\geq 80$	7.791	3.931	*.049
<b>Education</b>			
- Primary school	5.797	1.890	*.002
- Secondary school	6.596	2.456	*.008
Marital status	-0.307	1.624	.850
<b>Number of family members</b>			
- 2-4	3.193	2.035	.118
- $\geq 5$	4.285	2.146	*.047
<b>Types of house</b>			
- 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
<b>Income/Month (THB)</b>			
- 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
<b>Occupation</b>			
- Trading	-3.949	4.061	.332
- Agriculture	1.682	1.741	.335
- Unemployed	-2.497	2.421	.303
- Others	-1.819	3.116	.560

<sup>a</sup> Dependent variable: EMIC sum score

\* Predictor in the model

### *3.2.1.2 The local volunteer group of Nangdad sub-district*

In the first M&E round, we found that the local volunteers had carried out most of the planned activities, except the Information, Education and Communication (IEC). Most people affected by leprosy were in need of both physical and socio-economic support. Some of them gave priority to economic issues. For instance one person with leprosy-related disability who lived in a very poor and unhygienic house did not practice self-care and refused the offer of Nangdad sub-district administrative organization (SDAO) to renovate his house. He told the interviewer and the local volunteers that he needed a government leprosy allowance or micro-credit fund, not a better house. Some of them had a conflict with their relatives. At the end of the M&E round, the findings were discussed. The local volunteers group agreed to try and solve the problems that had been raised.

In the second M&E round, it was found that the problems encountered in the first round had been solved to some extent. The person with leprosy-related disability had accepted the offer of the sub-district administrative organization (SDAO) to renovate his house. The local volunteers had tried to establish an understanding between people affected and their relatives. However, the volunteers could not fulfil their wishes for a government allowance or micro-credit fund. Information, Education and Communication (IEC) activity had been carried out through traditional drama with the participation of people affected to inform the community members about leprosy.

### *3.2.1.3 The self-help group of Bantan sub-district*

In our first M&E round, we found that SHG members had jointly carried out income-generating earning activities through producing traditional handicrafts. The SHG chief was responsible for acquiring raw materials and selling the products, while the rest were responsible for making them. Bamboo weaving skills were transferred to the SGH members by an elderly man with one arm amputated. These active members also carried out home visits. They visited the elderly people with leprosy-related disabilities who stayed at home because of aging and stigma. They met at least once a month to talk and discuss any issues raised. The problems found in this first M&E round were the dominant behaviour of the SHG chief and the lack of leprosy knowledge and self-care skills of

the members. After the first round, the local health and administrative officers organized training on occupational and group working skills, leprosy knowledge and self-care practice.

In our second M&E round, there was progress in the group activities. The SHG chief had moderated his dominant behaviour while the others were more confident in expressing their views. During the course of the home visits, SHG members had instructed the elderly persons with leprosy-related disabilities and their care givers in practicing self-care. The group expanded their income-generating activities by investing in a small fish farm. They had joined district health campaigns by joining in a procession, and by organizing an exhibition booth to distribute leprosy knowledge to the community through posters and games. These activities were conducted with the support of the local officers and a research team.

## **3.2.2 Stakeholder representation**

### *3.2.2.1 The formal health care group of Huay Yajew sub-district*

The members were 4 health workers from the district and sub-district level, and 5 village health volunteers who were responsible for villages where persons affected by leprosy resided. There was no involvement of people affected by leprosy or the local administrative organization. The district hospital officer (a nurse responsible for the district leprosy programme) acted as the chief of the intervention with the support of health workers at sub-district level or sub-district health promotion hospital (SDHPH) and health volunteers of the villages in which people with leprosy-related disability resided.

### *3.2.2.2 The local volunteer group of Nangdad sub-district*

The group involved representatives of different stakeholders. There were village health volunteers who were close to people affected by leprosy as some of them lived in the same village as people affected; the SDHPH nurse responsible for community health; the officer of the SDAO responsible for the well-being of community members. People affected by leprosy were invited to participate in the process of intervention design and formulation of plans. The local volunteer group consisted of 81 members of whom 8 were assigned to implement the leprosy-related POA under the support of the SDHPH



nurse and SDAO officer. The SDHPH nurses and the chief of Nangdad sub-district administrative organization (SDAO) acted as the group consultants who supervised interventions. They also provided support for managerial and organisational processes such as accessing vehicles and meeting rooms, drafting proposals etc. The 8 local volunteers provided physical rehabilitation services to people with leprosy-related disability by conducting home visits to give instruction on and monitor self-care practice, to give psychological support, to assess the needs of people with leprosy-related disability; coordinating with organizations concerned in helping people affected; and promoting positive attitudes towards leprosy by launching Information, Education, and Communication (IEC) activities.

### *3.2.2.3 The self-help group of Bantan sub-district*

The group also involved representatives of different stakeholders similar to the local volunteer group. The group members were 5 persons affected by leprosy residing in Bantan sub-strict and 6 people with other disabilities. Village health volunteers, a nurse of the district hospital (responsible for the district leprosy programme), and the local administrative officer (responsible for the community well-being) acted as the group consultants who supervised interventions launching and, like their counterparts in the volunteer group, provided managerial and organisational support. The group members actively formulated a POA facilitated by a researcher with additional comments from the consultants. The POA was carried out by the group members with strong support from the consultant team particularly the nurse from the district hospital.

Researchers who were health workers at provincial, regional, and central levels acted as consultants and supervisors of the interventions launched by these three different groups.

## **3.2.3 Process structure**

### *3.2.3.1 The formal health care group of Huay Yajew sub-district*

All members of the group knew the objective of the interventions, the POA and their roles. A nurse of the district hospital, who was also a district leprosy programme manager, was responsible for making decisions and for launching the POA with the additional comments

and support of sub-district health workers and village health volunteers.

### *3.2.3.2 The local volunteer group of Nangdad sub-district*

The process was transparent. The 8 members of the group understood the interventions and the POA. Some of them had participated in the process of designing the interventions and the plan was formulated together with a nurse of the SDHPH. The chief of SDAO had not participated, but he was informed of the interventions, their objectives and the POA by a SDHPH nurse. All 8 members and the consultants knew their roles and understood the decision-making process that was made through group discussion.

### *3.2.3.3 The self-help group of Bantan sub-district*

All SHG members and consultants were aware of and understood the intervention and POA. They knew their roles and that the decision making process was done through group discussion.

## **3.2.4 Process management**

### *3.2.4.1 The formal health care group of Huay Yajew sub-district*

Coordination was done through telephone conversations or face to face meetings among health workers at district and sub-district levels. Planned activities were organized by a nurse of the district hospital with the cooperation of sub-district health workers and village health volunteers. The leader of the group, a nurse of district hospital, was competent enough to lead the group as he had been responsible for leprosy and tuberculosis related tasks for many years.

### *3.2.4.2 The local volunteer group of Nangdad sub-district*

The chief of the group, a local volunteer, facilitated the group work by arranging a meeting at least once a month to discuss their POA and any related issues. The meeting atmosphere was friendly and enjoyable. All members admired the chief who acted as a chairman for the way she facilitated the group process. She respected the members and gave them equal opportunity to express their views. The group rules were written by group members. Activities mentioned earlier were carried out according to the plan.

#### *3.2.4.3 The self-help group of Bantan sub-district*

A meeting was organized at least once a month to monitor the plan of action, to talk and discuss about the members' health condition and any other issues raised. A person with leprosy-related disability acted as a chairman for the meeting. He was competent enough to lead the group. Health volunteers, the nurse of the district hospital and the administrative officer, who acted as group consultants, observed the meeting and added their points of view when needed. The group rules were written by group members.

### **3.2.5 Capacity building**

#### *3.2.5.1 The formal health care group of Huay Yaijew sub-district*

The district health worker organized leprosy training for the health worker of the SDHPH and the village health volunteers to enable them to transfer their knowledge to the community and to support self-care practices of people with leprosy-related disability. Two persons with disabilities also attended the same training. They were trained how to do self-care and received prevention of disability (POD) materials distributed by health unit to practice self-care at home.

#### *3.2.5.2 The local volunteer group of Nangdad sub-district*

To enable and support people with leprosy-related disability to practice self-care, 2 group members and 3 people with leprosy-related disabilities attended the small group training on leprosy and POD, which was organized by Bantan sub-district. The group members also attended a national workshop to present their work and exchange experiences with other local volunteer groups all over the country.

#### *3.2.5.3 The self-help group of Bantan sub-district*

The SHG members needed capacity building in terms of income generation, group working process, and POD. Capacity building activities were arranged accordingly by the consultant team. Apart from that, SHG members also had a chance to attend the SHG training organized by the RPSI.

### **3.2.6 Coalition building**

#### *3.2.6.1 The formal health care group of Huay Yaijew sub-district*

It was not difficult to get financial support for the intervention as a district hospital nurse, the leader of this intervention, was involved in the district health promotion fund. However, the micro-credit fund was not easy to access since this was available only at the provincial level and required a complicated process in terms of application and selection.

#### *3.2.6.2 The local volunteer group of Nangdad sub-district*

The small fund was established through donations from the group members, the national leprosy foundation or Raj Pracha Samasai (RPS) Foundation, and fund raising activities. This fund was used for acquiring some materials needed by people affected by leprosy and other underprivileged groups, such as the poor, the elderly and people with physical challenges. There was a complaint from the group about the fact that the fund was insufficient to support the group activities. Although there was micro-credit fund available at provincial level, neither the first line consultant of the group nor the SDHPH nurse attempted to support the group to gain access to this fund, because of the complicated and difficult process with only a small chance of a favourable response. However, the nurse supported the group to contact the chief of the SDAO to help improve the house condition of one man affected by leprosy who had lived under poor hygienic circumstances.

#### *3.2.6.3 The self-help group of Bantan sub-district*

The group's first small fund was obtained through donations from the group members and the consultant team. Additional funds were obtained through selling the group products. They used this fund to invest in their small income-earning activities. The group wanted to have more funds to expand their business. The first line consultant, a nurse of the district hospital, was willing to help them to go through the application process, but could not because two group members were not able to pay their previous debt back to the provincial micro-credit fund before applying for a new loan. The group then decided not to apply for the loan, but to collect the money obtained from their income-generating

activities little by little to be used as a business-expansion fund in the future.

For home visits, training, and Information, Education and Communication (IEC) activities, the group received support for one year from an overseas non-government organization. Even though the funds were limited, there was still a chance in the future for the group to seek funds from SDAO to run their activities.

### **3.3 Results of the Two Monitoring and Evaluation Rounds: The Outcomes**

The results of the monitoring and evaluation of the outcomes of the interventions are given below.

#### **3.3.1 Direct outcomes**

##### *3.3.1.1 The formal health care group of Huay Yaijew sub-district*

In the first M&E round, we did not visit people affected by leprosy because we had been informed by a district hospital nurse and a SDHPH health worker that they had not launched interventions that targeted people affected by leprosy yet.

In the second M&E round, we compared the self-care outcomes of people affected by leprosy with that of pre-intervention survey and found that their hygiene was a bit improved in terms of cleanliness of body and clothing but that the conditions of their impairments were no better.

##### *3.3.1.2 The local volunteer group of Nangdad sub-district*

In the first M&E round, we found no change in terms of physical or socio-economic aspects. Even though the group members, who said that they were no longer afraid of leprosy and were willing to help, had visited and assessed the needs of persons affected by leprosy, there was no appreciation expressed by the persons affected. Most of them still isolated themselves and did not want to talk to other people. There were comments made by some community members that the group should not help persons affected by leprosy as some of them were anti-social, drank alcohol, gambled, and did not work. Some community members commented that people affected should be assisted by their relatives, not by other people. One health volunteer told a researcher that

*'It is difficult to ask community members to help uncle [X] as he is lazy, aggressive, scolds people, drinks alcohol, and gambles. His relatives are rich, but they don't help him. If he has money, he will gamble.'*

In the second M&E round, we found improvement of impairments and hygiene of some affected people as a result of regular self-care practice and house renovation with the support of their relatives, the local volunteers and the SDAO. People affected were more confident in meeting people. However, some of them had not practiced self-care and were not satisfied with the group assistance as their wishes for a leprosy allowance and micro credit fund had not been fulfilled. A person with leprosy related disability told an interviewer that

*'I don't want a new or a clean house. I can not eat it. I want money to buy food.'*

##### *3.3.1.3 The self-help group of Bantan sub-district*

In the first M&E round, some persons with leprosy-related disabilities did not practice self-care. Some of them did, but their technique was not technically correct. In terms of social aspects, people with leprosy-related disabilities contacted more people than before. This was demonstrated by their willingness to visit other people and to join the monthly meeting. They were more confident to talk and express their views than before. During the first M&E round there were no signs of cooperation from the families of the self-help group members. The wife of the group leader told a research team that

*'I don't want disabled people to come to my house. They drink alcohol when they meet. I don't like.'*

In the second M&E round, most of the persons with leprosy-related disabilities practiced self-care, with the exception of the SHG chief, who tended to focus on the group activities instead of his own health. There were more contacts between the SHG members and people in the community, including decision makers of different organizations, on many occasions. A nurse of district hospital told a researcher about a woman with leprosy related to disability that

*'Aunt [Y] never goes to a temple since she has a disability, now she goes'.*

The group members were proud of themselves as they had a group, had a chance to support one another, and to join community events. Not only persons affected by leprosy benefited from this self-help group, but also people with other disabilities joined the group. They learned how to work as a team. Nuttapol, a young man who has disability related to poliomyelitis said

*'My life has become meaningful. I have a group to do activities together. I have someone to talk with, instead of sitting and thinking only about myself, lonely at home'.*

The other community members were interested and admired the SHG for their contribution to community's activities. There was more cooperation from the families of the self-help group members. For instance the wife, the daughter, the son in law, and two nieces of the leader of the group, the mother of another group member, a man with another disability and the daughter of an old woman with leprosy-related disability all became involved. The house of the leader became a place used for some group activities with the participation of his family.

### **3.3.2 Indirect outcomes**

As a result of the interventions; we found that people involved such as those affected by leprosy, people with other disabilities, health volunteers and local volunteers had acquired knowledge about leprosy and POD. Local administrative and health workers in the areas where local volunteers and self-help group operated told the research team that the groups helped them with their home visits and other tasks.

The qualitative results or the outcomes showed indications of positive changes of stigma and attitudes among people affected by leprosy and community members in the areas where interventions were launched by the local volunteer and the self-help group.

## **4. DISCUSSION**

The baseline survey showed a high proportion of community members and health workers who perceived stigma against persons affected by leprosy (mean EMIC scores, 15.4 and 14.8, respectively). This is consistent with the recent study of Adhikari et al. [27] in Western Nepal, who found high median EMIC score of 12 (range 0-30) among community members. Seventy-five

percent of community members and 86% of health workers scored equal to or above the cut-off of 8, indicating a definite perception of negative attitudes. This shows there was ample justification for designing and launching de-stigmatising interventions.

Even health workers had higher stigma than community members, interventions focused on community members as it was thought that stigma among community members was more urgent to be addressed because people affected had interaction with community members in their daily life.

The conceptual model of Sartorius implies that there are multiple points at which the vicious cycle of stigma can be interrupted [8]. The scanty evidence regarding effectiveness of de-stigmatising interventions shows that simultaneous use of multiple strategies is likely to be the most effective approach [28]. The de-stigmatising interventions launched in the three areas were similar in terms of promoting positive attitudes towards leprosy, providing rehabilitation services to people with leprosy-related disability, and supporting people with leprosy related disability in income generation. They were conducted by different groups: the formal health care group, the local volunteer group, and the self-help group. As there were different factors involved in the different groups, we could not make formal conclusions as to which kind of intervention was the best. However, some lessons can be drawn for future interventions, based on the results of the responsive evaluation.

### **4.1 The Formal Health Care Group**

This represents the conventional approach to launching any health intervention in Thailand, where health units at provincial, district and sub-district level are responsible for all health-related conditions under the supervision and technical guidance of specialized technical organizations at regional and central level. At the most peripheral or sub-district level, there are village health volunteers who help health workers with simple health care services, such as measuring blood pressure or body weight monitoring. Providing knowledge about leprosy to the community and providing rehabilitation services to people with leprosy-related disability were tasks supposed to be carried out by health services at district and sub-district levels where people affected by leprosy resided to promote

their early diagnosis and good quality of life. The interventions carried out by the formal health care group in this study represent the formal health care system in Thailand in general, in which there is no participation of people affected by leprosy, their community or family members. The people affected were not empowered or given a chance to contribute to the activities that directly related to them. The community members were not aware of the problem of people affected and had no sense of responsibility and ownership. Training was conducted in a blanket fashion, not addressing local attitudes and perception regarding to leprosy.

Based on our observations, comparing the findings of the first and second M&E rounds, there was some evidence of improved hygiene in greater cleanliness of body and clothes. However, there was no evidence of improved daily self-care practice. Economic rehabilitation had not been conducted even though it was one of the specified interventions. This phenomenon is common in the health care services in Thailand, where health organizations do not pay attention to the socio-economic problems of their target groups because they consider this to be the task of other organizations. Moreover, they are already overwhelmed with the workload of other health conditions. Because the quality of life of people does not include only physical health, but also socio economic aspects of life, health providers should liaise with local administrative authorities, who have the mandate to promote the well-being of the community, to address the problems of people affected. The low level of participation of people affected by leprosy, their community and family members may be reasons why no changes were found in terms of attitudes and stigma among people affected and community members in this area.

#### **4.2 The Local Volunteer Group**

This group was similar to the formal health care group in terms of its structure, and also included volunteers as group members. However, the process management was different. The local volunteers worked as a team and ran the intervention independently, while under the formal health care system, the village health volunteers worked individually following the order of the SDPH officer. It was shown that some people with leprosy-related disability showed reduced signs of self-stigma, such as more contact with other community members in a

positive manner, better hygiene, and better self-care practice. These results were partly attributed to the home visits and the drama performed by the local volunteers, who were no longer afraid of leprosy as they had been trained in leprosy and POD. Moreover, the relatives of people with leprosy-related disability gradually became involved in the rehabilitation process, such as in supporting self-care practices and accompanying them to attend care for complicated wounds. It would be shameful for the relatives if they let the local volunteers, who were considered outsiders, help their family members without their involvement. There was no involvement of relatives in the area of the formal health care group, because the village health volunteers did not take care of people with leprosy-related disability beyond their routine duty. The village health volunteers in the formal health care group did not pay attention to the wishes of the people with leprosy-related disability to get micro-credit, since this was a wish of all poor villagers who did not have access to micro-credit either, not only of people affected by leprosy. Resources were insufficient to provide micro-credit to all.

In the stigma reduction intervention in the area of the local volunteer group, community members who acted as volunteers were involved in the process right from the beginning of the intervention. They were gradually empowered and built a sense of responsibility and ownership by participating in every step of the activities ranging from formulating a plan of action, implementing the plan, and presenting results at a national workshop. The families of people affected also gradually took part in the rehabilitation process. A local organization also took part in the rehabilitation process by providing funds for renovating houses of people affected.

As a result, there were some changes in terms of social participation of people affected who had more positive contact with their relatives and community members. The volunteers of the group who were also community members were not afraid of leprosy anymore. This change may be because they had knowledge and were in contact with people affected by leprosy. This finding supports the studies of Arole et al. and Awofeso who considered that education should be part of any strategy aimed at reducing leprosy-related stigma [4,29]. It also supports the report of World Health Organization, which mentions that contact between people living with

HIV and community helps in addressing misinformation and establishing empathy [30]. However, no qualitative evidence was found in terms of changes of attitudes and perceptions among other community members. More time may be needed for information transmission from health volunteers to others.

### 4.3 The Self-Help Group

This group was quite different from the others, as it was run by people with leprosy-related or other disabilities under close supervision of a local health worker and the officer of the local administrative organization. The self-esteem of people with leprosy-related disability increased as they could make decisions by themselves, for instance which activities should or should not be done. They had a chance to show their ability in carrying out the group activities, join community events, gain new experiences and knowledge, and earn more income. As a result of more contact between the community and the SHG members, there were signs that the community's attitudes changed, such as that other community members showed interest in and admired the group's activities. These outcomes support the study of Ebenso et al. [20] in Nigeria, who found a positive impact of socio-economic rehabilitation on the self-esteem of people affected by leprosy. They also support the findings of Apinundecha et al. [31] who carried out HIV/AIDS de-stigmatising interventions in Thailand, and suggested that community interventions that empower the community, combined with a financial contribution to reduce resource constraints, are a useful and effective means of increasing interaction between people living with HIV/AIDS (PLWHA) and other community members, increasing tolerance and reducing HIV/AIDS stigma.

Our findings show that there was a notable improvement of self-esteem and social participation of SHG members, who were people with disability related to leprosy and other health conditions. This may be because they had fully participated in the group activities and community events that also lead to the changes in the community's attitudes.

These three strategies of delivering de-stigmatising interventions: by formal health care system, by local volunteers, and by SHG had the same main objective, to reduce stigma related to leprosy. Specific interventions were also similar. The differences were in how the activities were

conducted, and the type of people who took part in each activity. Results seem to indicate that the more people affected, their families and community members participated, the more positive the changes in attitudes and behaviours occurring among them. The findings support the hypothesis of this study, which was that involving different stakeholders, particularly the beneficiaries themselves, in conducting de-stigmatising interventions would increase their social participation and self-esteem and would gradually lead to changes of attitude and perception in the community. However, tailor-made IEC activities are still needed to address the negative attitudes and perceptions of the wider community regarding leprosy.

During the first two rounds, the M&E was done qualitatively. This gives good insight into the perceived changes and the possible reasons. However, some aspects of stigma had not been addressed sufficiently during the first 10 months, for instance the attitudes and perceptions on leprosy among community members and health providers, to show a quantitative difference in stigma. We therefore decided to extend the de-stigmatising interventions for another four months. The activity expected to be conducted during this time was providing community members and health workers with education based on information obtained from the pre-intervention stigma assessment. The quantitative results, of the interventions using the EMIC stigma scale were measured after the extended four months. The results of this third M&E round will be presented in a separate paper.

## 5. CONCLUSION

This intervention study, analysing three different approaches to de-stigmatization, showed that the most effective de-stigmatising interventions were those that actively involved local stakeholders, including the beneficiaries themselves. Their involvement helps to facilitate the improvement of self-esteem and social participation of people affected by leprosy and the contact between people affected and other stakeholders. This results in a reduction of community's negative attitude. Quantitative follow-up research will analyse the extent to which this could eventually interrupt the vicious cycle of stigmatization.

## 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 to.

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## COMPETING INTERESTS

The answers to the questions on competing interest are all 'no', and therefore we have nothing to declare.

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