

**Lights and shadows of people affected with leprosy
in Sittaung Area, Myanmar**

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The study was conducted with the general objective of exploring the effect of leprosy on social lives of persons affected by leprosy (PALs) so as to socially integrate them into local society in Sittaung Area. This was a multiple case study using individual as embedded unit of analysis. The analysis focused on how the PALs told their stories about their social lives in their community. Study population was PALs aged 18 years and above residing in Sittaung Area. The emphasis was on studying PALs from social group difference perspectives. A total of 38 PALs were included in the study. Among PALs of lower social group, economic difficulties were their concerns more than social problems emanating from their disability. The study highlighted that improvement in the economic status of PAL could bring the person out of shadow. It was also found that allowing PALs, especially of lower social group, participate in local social organizations by the community would discard away their feelings of being in shadows. Resilient spirit of each individual PAL was found as the key factor that could pull a PAL out of shadow. It is recommended that, especially for PALs of low social group, empowerment education approach complimented with socio-economic strategies could bring their lives out of shadows.

Prologue

“Taung-soke-a-kut-mae” (*a broken basket without lining*)

PAL spoke of being socially accepted or not depended to a great extent on their economic status in their community. It did not depend on their disease status. A female PAL from a lower social group encountered a serious discrimination by her community when the community came to know about her disease. Her family was not allowed to take water from the wells owned by her neighbors. She compared her poor life of that time to a broken basket without lining (*taung-soke-a-kut-mae*). However, after struggling and accumulating wealth,

her family’s status in the community changed. This woman, now a 59-year-old grade 2 PAL, of upper social group, and a released from treatment (RFT), said:

“Formerly, they told us not to take water from their wells. Now many people come to us to fetch water from our well.”

INTRODUCTION

Leprosy is a disease with social stigma. Social stigma has been defined as a physical, mental or social attribute of an individual or group that elicits an adverse or discriminatory response from others [1]. The ideology of the stigma of leprosy is strongly felt and expressed verbally in

the community [2]. Simultaneously, self-stigmatization exists among the patients with visible disfigurement: they withdraw from most social activities permanently. The impact of the disease clearly affected in the patient's everyday life. They considered leprosy as a constant threat to their lives.

Social prejudices contributed to emotional and physical suffering, abandonment, deformities and psychosocial problems [3]. Leprosy patients and their families reported encountering social, physical and mental problems. Some patients said they dared not walk around in the community that other people appeared disgusting them, which made them feel depressed and ashamed [4]. Some patients mentioned difficulties in their jobs after the onset of the disease. In addition to physical manifestation, indisposition, depression and worries limited their productivity. Therefore, many preferred to hide the disease in order to avoid being fired or given early retirement [3]. Children of several patients were not able to get jobs easily if the employers knew about their parent's condition [4].

Although the stigma of leprosy exists, there is a lack of knowledge about what it is like to be a person affected by leprosy (PAL) or how he or she adjusts his or her life with social ostracism in the society [2]. Health workers who fight against leprosy and those involved in health education and rehabilitation programmes for combating stigma of leprosy thus need to be aware of not only the significant impact that social and cultural constructions produce the stigma surrounding leprosy, but also how it is directly related to their service activities [2].

Understanding the effect of leprosy on social lives of persons affected by the disease and the way they cope and adjust their social lives in their communities could provide information to be taken into consideration in rehabilitation programmes for PAL. It is with these considerations that this study was undertaken because no similar previous study exists in Myanmar.

Aim and objectives

The study aimed to explore the effect of leprosy on social lives of persons affected by the disease so as to socially integrate them into local society in Sittaung Area.

Specific objectives

1. to determine the social group differences among PAL in Sittaung Area
2. to explore how the PAL cope and adjust their social lives in the community; and
3. to make recommendations on how to socially integrate the PAL in Sittaung Area.

MATERIALS AND METHODS

Study design

This is a multiple case study using individuals as embedded units of analysis. A case study is an empirical inquiry that investigates a complimentary phenomenon within its real life context especially when the boundaries between phenomenon and context are not clearly evident. This study relies mainly on qualitative data. The analysis focuses on how the PAL tell their story about their social lives in their community.

Study area

Sittaung Area, situated in Kyaikhto Township, Mon State, was chosen purposely as the study area. Although it is not included in the six hyper-endemic leprosy regions, the registered prevalence rate of leprosy was 2.4 per 10,000 population in 2000 and disability grade 2 among new cases was 14% in 1999 [6].

After discussion with responsible persons from the Sittaung Area during the pilot trip, starting from Theinzayat Town, which is quite close to the Sittaung Bridge, we included 9 sites - towns/villages where there is a station hospital, a rural health centre (RHC) or a rural health sub-centre (RHSC). Two towns (Theinzayat and Kyaikhto) and seven villages (Mokepalin, Sittaung,

Inngapo, Thitseik, Kyaikhto, Kaukhtinn, Boyargyi, Kauksan and Kyaikkathar) were involved in this study. These study locations are situated along the east of the Sittaung River.

Study population and sampling

Study population was the PAL aged 18 years and above residing in Sittaung Area. We first made a visit to Sittaung Area and held informal interviews with basic health staff and community representatives (local leaders and local NGO members). We requested local basic health staff to make a list of PAL who were 18 years and above, each having different disability grades. WHO disability grade(1998) was used for this study. We inquired local job categories by which local people could be classified into different social groups. We did not define the sample size before the study and we planned to stop till we obtained saturated information which gave a total of 38 PAL.

Data collection

The interviewees were requested to describe their social lives emphasising on their lived experiences, implications of social stigma, coping with social stigma and adjusting their social lives in the community. We did not identify any theme in advance for interviews. We just followed the topics what they told us, but tried to obtain their changing lives before and after contracting the disease as much as we could. All the interviews were tape-recorded.

Data analysis

The dialogues were transcribed. The tapes were listened many times over and the transcripts were reread for several times to develop insights into the lived experiences of the PAL. Themes were extracted from the dialogue.

RESULTS

Social groups in Sittaung Area

Economic activities of the Sittaung Area are related to some extent on Kyaikhtiyoe

Pagoda. The festival of this pagoda begins in October and lasts till April every year. The economic activities also relate to fishing in Sittaung River.

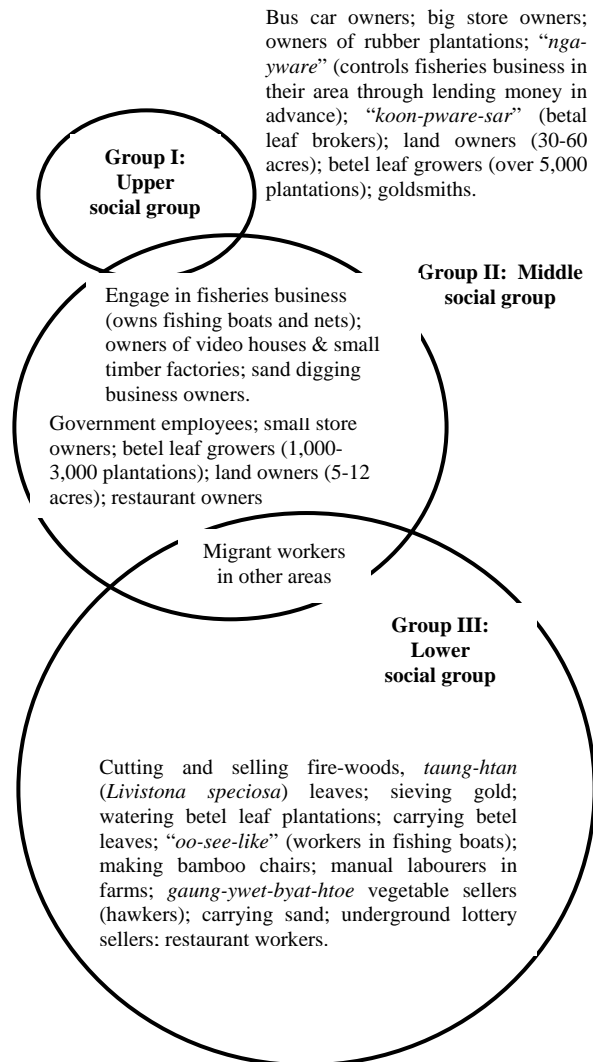


Fig 1. Social groups and their related economic structures in Sittaung Area (size of circles in relative proportions)

Social groups in Sittaung Area can be divided into three, basing economic activities of the local people: upper group, middle group, and lower group. This division into three social groups is in consonance with the study findings in Myanmar’s rural areas elsewhere [7, 8]. The relative proportions of the social groups and their related economic structures in Sittaung Area and population movements are graphically presented in Figure 1.

At Kyaikhto Town, there is one very special social group that can be considered much higher than the upper social group categorized above. They are very rich people, about 40-50 families, but constituting a very small fraction of the total families in Sittaung Area. Their annual income is said to be Kyat 20-30 million. The Kyaikhtiyoe Pagoda festival business is said to be totally controlled by these families. People from middle and lower social groups work in their businesses as employees.

Some “Oo-see-like” workers migrate far to the south to a place known as Ahlat in Ye Township, Mon State, to be engaged in fisheries business there. Some families migrate to the same township to work at rubber plantations there. Some young people, especially girls (20-30 years age), migrate to border areas in the east to work as factory workers there.

Social characteristics of study samples

The social group characteristics and disability grades of the PAL included in our study are as shown in Table 1.

Table 1. Social group characteristics and disability grades of PAL

Social group	Disability grade 0	Disability grade 1	Disability grade 2	Total
High	4	0	2	6
Middle	5	0	3	8
Low	9	4	11	24
Total	18	4	16	38

Disability grade: a factor affecting social life?

It is clear that disability grade is a factor affecting social life. Generally, a PAL with low disability grade will have less social problems whether he or she comes from a low or high social group.

One 26-year-old married male PAL of lower social group with grade 0 deformity expressed his satisfaction in his social life. However, he spoke of economic difficulties as lacking in financial resources to invest in their Sittaung Area which was abundant with natural resources to be exploited. This

situation had no relationship of any kind to being a PAL. He was born and brought up in a poor family, he studied at a monastery because he could not go to a school, he earned as a manual laborer, he got married to a woman of the same social group when he was 23 years old and at the time of interview he had two children. He said:

“I came to know about my disease when I was 15 years old. At first I thought I was having some kind of skin allergy. The midwife staying in our village diagnosed the disease. I took treatment and was said to be cured after about a year I think ... I got married when I was 23 years old. Before I got married, my wife and her parents did not know that I was having this disease. After we got married, they knew about it but there was no problem.”

He spoke of his concerns for his children not because of his disease but because of their poor status and financial problems.

A 30-year-old male PAL of high social group with grade 0 deformity expressed his satisfaction in both his economic and social lives. He was also married and had one son who was now attending a nursery school. Both he and his wife were from rich families and they were neighbors. His wife knew about his disease before they were married and there was no problem. His younger brother and his aunty were also PALs with similar grades.

Having feelings of inconsequential within a PAL particularly with grade 2 disabilities could become one important factor for putting oneself into isolation from others. One 42-year-old female PAL, having shortened fingers and toes, and also having serious facial disfigurements (flattened nose and eye deformity) described about her feelings of inconsequential. She said: *“My daughter fell in love with a young man. I did not want my daughter to get married to anyone because I was afraid that people would look down at her. I told my daughter to bring the parents of the young man to me to make a request from me to get their son*

married to her. They came to me and they did. Even then, I did not feel comfortable. I personally met the boy at a billiard parlor and told him I did not agree him to marry my daughter. Three days later, he and my daughter eloped. I did not go to their wedding ceremony, because I felt ashamed to go out and meet people.”

The saying that “love is blind” might hold true. Disfigurement of a person might not deter away someone in love if an attachment between the two became too strong. However, love alone might not keep the attachment string strong in the long run. The following story revealed this issue.

The parents of a 35-year-old grade 2 PAL of low social group, sold rice and curry to train passengers at a railway station. His father got a second marriage, divorced his mother and took away their business. He had to leave school (third grade) to help his mother in their earning activities. His mother became a *gaung-ywet-byat-htoe* vegetable seller. He came to know that he was having skin patches when he was 14 years old; but he did not take treatment for two years. Later because of appearance of disfigurements he went to a health center and took treatment. When he proposed a girl who was also a *gaung-ywet-byat-htoe* vegetable seller like his mother, the girl refused because she detested him. He assisted the girl in carrying her goods, accompanied her to her house when it was late at night and proposed her quite often. Later, she became very sympathetic on him and they eloped because the girl’s side did not approve their love. He had already completed his treatment one year before eloping. After having four children, his wife started to have an affair with another man who was better looking compared to him. He said since they were very poor and sometimes they could eat only one meal for a day, he could understand the frustration of his wife towards him. His wife’s relatives stood on his side and persuaded his wife to stop the affair. She changed her behavior and was now staying with him.

Did the disease drive PAL into poverty?

In our study we discovered that PAL of different social groups were in their respective social groups long before getting the disease. There were exceptional few. One finding for this exception is described as “a broken basket without lining” on how a female grade 2 PAL from a poor family struggled to become rich. Some might be from well-to-do families who encountered economic failures and became poor before becoming a PAL.

Changing jobs because of disfigurements might, in some cases, drive a PAL and his or her family to become poor. Whether families of those PALs of lower social group remained in the vicious cycle of poverty in the same way as in other poor families or not would depend on existence of opportunities for creeping out of the cycle in their local context.

The family of a 51-year-old grade 2 PAL of low social group, became very poor when he was 13 years old. His parents had to sell their cows and belongings to pay back debts because of crop failures. Since then, they were involved in odd jobs. He got married when he was 22 and both husband and wife did odd jobs to earn their living. Although not rich, they had no debts and were able to survive. However, they encountered more hardship in their economic life as they began to have children and the wife was unable to participate much in earning activities. He discovered that he was suffering from the disease in 1984 and at that time they had four children. As he dared not go out while he was taking treatment, his wife had to do odd jobs. A story was heard where the chance to get out of poverty cycle seemed dim because children could not continue schooling.

A 42-year-old male PAL with grade 2 disability from a lower social group said: *“I am not lu-yar-win (able to socialize) not because of my disease. It is because I am poor. There are others who are also like me (with some disfigurements) but they are*

lu-yar-win because they are rich. Money is very important. I will continue working hard to earn money. I have sons and I want to perform shin-pyu ceremony (ceremony where young boys are put into novice-hood) for them”.

Sometimes this might not hold true for some social groups and this was found among educated people. A 57-year-old married male grade 2 PAL of high social group was an educated person (passed 10th grade) and was working as a sub-division manager in a paper factory. He narrated how he was forced to retire from his job by a female factory manager in 1986. When he retired, the tables and chairs he used in his office were said to have been burnt. His sister, a school teacher, and his brother, a university graduate working as a government official, also cut off contacts with him. When he went to a meditation center, some of the mediators did not want to stay in the same room with him.

Resilient spirit: a pull factor out of shadows?

Although discriminated by the community and discarded by husband, a female PAL (with grade 2 deformity) struggled hard for the survival of her family consisting of a daughter and her mother. Her mother fried Myanmar snacks and her daughter sold these around the village. After saving some money, they bought rice from merchants and sold back to local villagers and villagers from hill tracts in the eastern part of Sittaung Area. Gradually their family’s economic status started to rise. Her family even started saving gold. Now, because of this social status, her family is included in the high social group of their village.

A 42-year-old male PAL with grade 2 disability from a lower social group described how he and his family worked hard to improve their living conditions. He said: “my friends told me that in my situation (with disabilities) I should have died. However, I do not want to die. I will do whatever possible while I am still alive.

Even my wife sometimes told me that some of my wishes were not practical for me to do. But, still I do not easily give up my hopes.”

The strong driving forces for such a hard work were his strong desires to perform a *shinpyu* ceremony and also to get his children married.

There were also stories revealing lack of resilient spirit leading to encountering failures in their lives. A 30-year-old male, grade 0 PAL of high social group, said he discovered that he was suffering from the disease when he was 13-14 years old while attending 8th grade and he failed in the final examination. He did not relate the failure in examination to discovery of the disease. He said he got “*seight-lay* (drifting of mind)” because of the failure and he discontinued his schooling although his parents could afford for continuing his schooling. A 52-year-old female, a divorcee, grade 0 PAL of middle social group, attempted suicide two times after coming to know about the disease.

DISCUSSION

A PAL with low disability grade could be considered to have less social problems whether he or she comes from a low or high social group. In our study we found that among PAL of lower social group, economic difficulties were their concerns more than social problems emanating from their disability grade. Sittaung Area is rich with natural resources - for fishing, rubber plantation and betel leaf plantation. However, for poor people, opportunities to improve their socio-economic lives in Sittaung Area seem to be quite dim. Young people migrate out of Sittaung Area to nearby border areas in search of jobs and this is no exception for the sons and daughters of PAL in the area. Some PAL could not send their children to schools not because their children encountered discrimination, but they could not afford for their children’s educational expenses.

Although isolation was imposed on oneself by some PAL because of feeling ashamed over disfigurements, disfigurement might not always deter away someone in love when attachment bindings became very strong. A PAL with grade 2 could get married if he could show his tenderness to a woman of the same social group and could make her become bounded to him. In the long run, “love” and “attachment” might not ensure stability of the union. Financial problems were the key factors that could hurt this binding. Several social problems came in with economic problems than with the disease problem itself.

We did not find any case in our study that was driven into poverty after being affected with leprosy. PAL of low or high social groups were in the respective groups long before getting the disease. On the other hand, our study findings highlighted that improvement in the economic status of a PAL could bring the person out of shadow. PAL of low social group were said to be like “broken baskets without linings (*taung-soke-a-kut-mae*)” and they are not *lu-yar-win* (able to socialize others). If the economic status of a PAL is good, they become *lu-win-sant* (able to socialize others).

Our study findings indicate the need for including socio-economic rehabilitation (SER) programmes for people cured of leprosy as a complement to health education programmes. The respect accorded to wealth counters the stigma associated with leprosy. Through SER programmes, PAL would be helped to regain their place in the community as opportunities are developed to help them find productive employment. We would recommend that such SER programmes for PAL of low social group, although specific individual needs may also have to be considered for those PALs with physical disabilities, should be part and parcel of poverty alleviation programmes for poor people as a whole.

For most of poor women who are economically and socially dependent, their inferiority status in their family and

community could be heightened by the social stigma associated with leprosy. One of the female PAL in our study who was divorced by her husband and was discriminated by her community, became socially accepted by the community when her economic conditions improved. This indicates the importance of economic empowerment of poor women including those affected with leprosy.

It was found that allowing PAL, especially of lower social group, to participate in local social organizations by the community would discard away their feelings of being in shadows. This change is found to be taking place in Sittaung Area and PAL interviewed said this change was due to health education efforts made by local basic health staff.

Stigma is one important factor in the vicious cycle of leprosy persistence and spread among the community. In order to get rid of the existing stigma, health education needs to be carried out continuously and unremittingly in the form of a long-term programme of health education on leprosy among various social groups in a community.

For behavioural change to occur and be accompanied by destigmatization, knowledge must not remain abstract. Instead, knowledge should be actively generated by regular interaction with the people who form part of one’s immediate social world [8]. This concept is based on the participatory model of development communication.

Changes in attitudes and behaviour depend on several factors - the accuracy and understanding of the information disseminated and whether the information is presented in a way that recognizes local beliefs and attitudes about illness and healing. For behavioural change to take place and de-stigmatization to be followed, health education programmes should put emphasis on behavioural involvement between the group that is suffering from stigma and the wider community [9].

Myanmar has tried to disseminate key messages on leprosy to the community through volunteers of Maternal and Child Welfare Association (MMCWA) members after providing training to these members. However, the approach fell short of involving PAL in the same group education sessions with other community members. And, an assessment study made on the approach showed that using MMCWA volunteers as communicators needed further reinforcement [12].

We found in our study that resilient spirit of each individual PAL is one of the key factors that could pull a PAL out of shadow. We encountered many stories told by PAL of lower social group how they struggled hard to improve the lives of their families. Religious beliefs and related practices were found to be driving forces for some PAL for the resilient spirit - strong desire to make donations for the religion, strong desire to perform *shin-pyu* ceremony, staying single and working hard to take care of their mothers.

While studying PAL in a selected area of Sittaung from social group difference perspectives, we tried to elicit individual and contextual factors that push PAL into or pull out of shadows. We would like to recommend that, especially for PAL of low social group, empowerment education approach complimented with SER strategies could bring their lives out of shadows.

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