

**Assessment of social acceptance and self image
among Persons Affected by Leprosy in a community**

San Shwe, ** Kyaw Oo, *Le' Le' Win, ****Ye Win Than,
**** Kyaw Nyunt Sein, *Moe Thida & ****Kyaw Myint*

*Epidemiology Research Division
**Medical Statistics Research Division
***Health Systems Research Division
Department of Medical Research (Lower Myanmar)
**** Department of Health

A community-based, cross-sectional study was conducted in Aunglan Township, Magwe Division in collaboration with Leprosy Control Programme in 2003-4. A total of 97 Persons Affected by Leprosy (PAL) was interviewed face to face with structured questionnaires after pre-test. A total of 11 In-depth Interviews (IDI) was undertaken among health care providers, friends and relatives of PALs. Findings were triangulated. Social acceptance was assessed by marital status, change of jobs, social contact with relatives friends and involvement in occasions in the community. Divorce rate was more in grade II PALs. Change of jobs was found to be 33% which were mainly due to disfigurement of the body. Family support seemed to be strong as most of GII cases were heads of household i.e.63.9%. Low self image was found. Acceptance by the family was observed as a key factor and parents are main persons close to PALs. Social acceptance by the community was noted to some extent. But 26.7% of PALs were never accompanied by friends. Since the social death of the PALs with disability represents the biggest challenge for rehabilitation, this baseline information will serve as a useful input for launching strategy in community-based rehabilitation program in Myanmar.

INTRODUCTION

In Myanmar, Leprosy Control Programme (LCP) has been launched to achieve the prevalence rate below 1/10,000 population [1]. In LCP, national strategies have been launched and one important issue is rehabilitation of disabled leprosy cases. In Myanmar, Community Based Rehabilitation (CBR) has been initiated mainly based on physical and health grounds. Concentration on medical care of people affected by leprosy with Multi Drug Therapy (MDT), surgery, etc. though vastly beneficial, has led to highly inadequate psycho-socio-economic rehabilitation in a holistic manner resulting in poor quality of life. Many studies on epidemiology, drug trials and

operations research and health seeking behavior on leprosy have been documented but little is known about social factors which may intervene mainly in support and rehabilitation process [2-7]. Therefore, the attempt was made to explore the social acceptance and self image among grade 1 (GI) and grade 2 (GII) disabled Persons Affected by Leprosy (PAL). Based on this information, necessary measures will be taken by the family members and health care providers so that prevention of disability and rehabilitation can be achieved. The present project is an initial phase of three-phase project to explore social acceptance and self image of GI and II PALs in Aunglan Township, Magwe Division in late 2003 and early 2004.

MATERIALS AND METHODS

Study design

Community-based exploratory study design

Study methods

For quantitative, face-to-face interview with structured questionnaires was undertaken by trained interviewers. Semi-structured and open questions were included for assessing social acceptance and social image. For qualitative, Key Informant Interview (KII) with village female elders were done. For detailed information about social acceptance, self image, social stigma and needs, In-depth Interviews (IDI) to health care providers, relatives and friends of GI and II leprosy patients were performed by the investigators who have skill and experience in conducting qualitative research. All research tools were pre-tested.

Study area

Aunglan Township is located in Magwe Division, with a total population of 228,308. There are one 50 bedded hospital, two station hospitals and eight Rural Health Centers (RHC) for health care services. The township includes 92 village tracts with 240 villages. A total of 32 villages under three RHC areas namely (1) Aunglan Myoma Town proper (2) Kyaukpadaung (3) Pyalo and (4) Nyaungbinseik: were included in this study. The majority of villages are scattered and some areas are difficult to reach.

Study population

There were 150 registered grade I (GI) and grade II (GII) PALs at the time of study. Recruitment of the GI and GII cases and identification of their social surroundings was done by the township leprosy control programme. Out of registered 150 PALs with GI and GII disability, only 97 could be interviewed due to difficulties in finding cases that are living in the forest, moving out and hospitalized for reconstruction. For qualitative approach, detailed information about self image, social stigma and needs,

were explored by 11 in-depth interview sessions with 4 health care providers, 3 relatives and 4 friends of GI and GII PALs.

Informed consent was provided to each interviewee and voluntary participation was made.

RESULTS

Age and sex

In the study group, male cases were found at 62.9% compared to female 37.1%. The age ranged from 10 to 84 years with the mean of 52.7 years.

Education

For educational status, majority of the respondents attained middle school (secondary) levels, few had university or graduates level. Illiterate persons accounted for 14%.

Marital status

Marital status was noted as an important indicator for assessing social acceptance. Out of 97 study patients, 90% were ever married and 10% were never married. Marital status by disability was observed that among GI cases, 66.6% were married, 16.7% were widow/widower and 16.7% were singles. For GII cases, 60.4% were found to be married 16.5% were widow/widower, 15.4% were single and 7.7% were divorced.

Regarding frequency of marriage among the currently married group i.e. (49/59), 83% had first time marriage followed by 13.6% had second marriage and 3.4% had third time marriage.

Of divorced persons, not many reasons were explored but social problems between husband and wife mattered most i.e. 42.8%, some 42.8 % did not want to respond and only 14.4% were due to health.

Occupation

Among the study group in both sexes, 45.4% have been occupied. Of 44 PALs who were working at the time of survey, 31.8% owned farms and 45.5% were doing

odd jobs like mat weaving and fortune telling, and working in construction sites. Only 11.4% were paid workers in the farms compared to watchman at farm i.e. 2.3%.

Table 1. Study group by type of job

Type of employment	Type of job	Freq.	Percent
Self	Farmer	14	31.8
	Odd jobs	20	45.5
	Trishaw driving	2	4.5
	Lottery ticket selling	2	4.5
	Paid worker	5	11.4
Employee	Watchman	1	2.3
	Total	44	100

Of 19 cases who had changed from one job to another, 18 (94.7%) were GII and only 1 (5.3%) was GI cases. The only GI case said that he changed to a new job to earn more money. Of 18 GII cases, 33.3% had changed jobs because they had some problems with health. Few 11.1% of GII cases did not want to do anymore and another 11% had other reasons like having problem at work.

Table 2. Reasons for changing job by type of disability

Reason for changing	Disability (%)		Total (n=19)
	GI (n=1)	GII (n=18)	
Need to get more earning	100	27.8	31.6
Health concern	0	33.3	31.6
Don't want to do	0	11.1	10.5
Problems at work*	0	11.0	10.5
Old age	0	5.6	5.3
No skill	0	5.6	5.3
No response	0	5.6	5.3
Total (n=19)	100	100	100

*Problems at work includes “problem with higher authority”, “problem with other co-workers”.

Main reasons for changing of work were desire to get more money, health reason and social problem. A total of 19 cases had changed from one job to another and 18 of them were GII cases. It was seen that disability was the main issue for changing jobs.

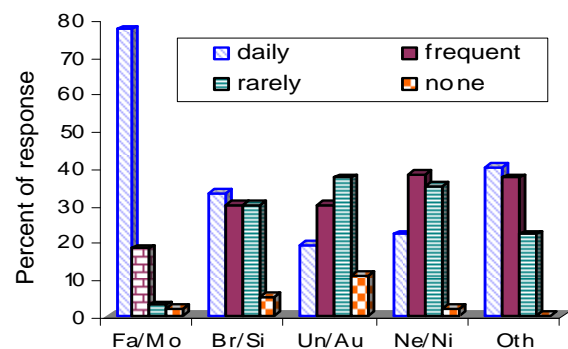
Status of PALs in the family

Identification of status of PALs in a family is assessing acceptance by the family. It was shown that majority of PALs 63.9% were heads of household.

Table 3. Role of PALs in the family

Head of household	Freq.	Percent
Respondent (PAL)	62	63.9
Spouse	16	16.5
Father	6	6.2
Mother	6	6.2
Brother / sister	4	4.1
Son / daughter	2	2.1
Grandfather	1	1.0
Total	97	100.0

Figure 1 indicates how frequent PALs contacted with their relatives by types. It was found that initial contact was made mainly by parents 77%, brothers and sisters 34% but 40% had contacts with other relatives who were not closely related. Among them parents made more contacts on a daily basis. Family members and relatives seemed to be close contacts for GI and GII cases in this study.



Fa/Mo =Father/Mother (29 cases)
 Br/Si =Brother/Sister (78cases)
 Un/Au = Uncle/Aunt (42cases)
 Ne/Ni = Nephew/Niece (72 cases)
 Oth = Others ((28 cases)

Fig. 1. Frequency of contact with relatives by PALs

Social contact with friends

The attitudes of friends on social contact with the PALs were studied. Most PALs (86.1%) felt that they are well accepted by the friends – always treated with good manner (93%), listened to what they said (90.7%), can talk to them friendly (89.5%) and can discuss with them always (50%). Some 10.5% have never discussed with friends and 26.7% said they did not accompany their friends.

Respondents perceived that although relatives and friends were socially accepting them as usual, they might be reluctant to chat and go out together.

Social occasions

Participation in outgoing social occasions was explored on religious affairs, festive occasions and other ceremonies like seeing patients, going to funeral and village affairs. They had been invited always for religious festivals and 44% did not go. For festive occasions, usually 54.6% of PALs were invited always but 5.2% said they were never invited. More than half i.e.53% participated in festive occasions. More than 50% of PALs had always been invited for social occasions like seeing relatives or friends while sick or death. Many of respondents who were invited did not involve with those occasions (44% to religious fairs, 47% to fun fairs and 32% ill/funerals). Activities for development of community in the village were participated by 67.5%.

DISCUSSION

Marital status was explored to check whether there is a link between disease and social issue. Remarriage, second or third times, was found and the main reason given was “PALs could not perform daily household chores”. This might be their bad feeling towards deformity. Changing from one job to another was found in GII PALs for health and social reasons and it was a challenge for social acceptance by the community. It was approved by seeing the number of changing jobs was 19 and of them 18 were GII cases. Instead of saying deformity they chose the word “**health concern**”. Majority (63.9%) of PALs were heads of households. This was found to be positive factor of social image of PALs in the family. Social acceptance by the family was high. It coincided with the findings by Kyaw Myint *et al.* [8], in which the authors stated “*most patients were accepted either by their families or community*”. Leprosy

and in turn, deformity and disability bring about deeper and fundamental changes in character, personality and attitude of people. These changes remain even after cured [9]. It needs to explore relationship among PALs, with their environment, family members, relatives, friends and community so that socio economic loss by the disease can be assessed. Parents and close relatives have more contacts than other relatives.

Without any reasons the majority of PALs did not go to festive or ceremonial occasions but they used to go to funerals or seeing sick persons. It showed they have low self image and confidence in this study. Although they showed low self confidence and image majority believed that they were helpful to family, friends and community. It was positive attitude towards social rehabilitation. Family is considered as the main support for disabled cases. Family members never devaluate the status of the cases and they pay more sympathy to the disabled ones. Therefore family members should be involved in training for self care and POD.

This study highlighted social acceptance and self image of PALs especially GII. Changing jobs indicates the insight feelings of PALs on social acceptance by the community. It is the high time to consider to implement social rehabilitation for PAL especially GII cases. Empowerment of PALs by proper counseling and self-care training to prevent complication and more damage to the affected sites are important. Reconstruction of deformity to gain self-confidence by PALs should be extended. Strategies for improving social acceptance and restoring self image were highly recommended to improve quality of life of PALs with deformity in the community.

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