

Stigmatization among disabled persons affected by leprosy

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In order to develop strategies for improving social image and restoring self-confidence of persons affected by leprosy (PAL) in the community, this study was conducted to identify social stigma among disabled persons and to differentiate stigmatization between persons disabled due to leprosy and not due to leprosy. The study is cross-sectional comparative design. Aunglan Township, one of the nine areas of JICA disability survey, was purposely selected. Out of registered 150 PALs with GI and II disability, 97 were interviewed during 2004 and 2005. Data collection method was face-to-face interviews using structured questionnaires. In comparison, 97 disabled persons affected by others than leprosy (Non-PAL) were also interviewed. Gender and education levels were not different between PALs and non-PALs. Proportion of married and divorced was higher among PALs than those of non-PALs (61% vs.40% and 7% vs. 3% respectively). Proportions of persons who had a job were not different. Among jobless, PALs gave reasons more with “depending on offspring” and “getting older” while non-PALs gave reasons more with “physically disabled”. Male PALs were getting more leadership role in the family comparing to non-PALs (87% vs. 49%). During the festive occasions, slightly higher proportion of “non-invited” among non-PALs than PALs was found. The responses shows obviously high level of self-stigmatization among both PALs and non-PALs but two groups were not significantly different. Similar patterns of stigmatization were found in the persons during social occasions and village affairs. About 10% higher in PALs than non-PALs on perceived being-discrimination shows that PALs might have self-stigmatization due to the disabilities affected by leprosy. Findings highlight stigma of PALs might not be caused by physical disabilities but by disfigurement or name of disease “*leprosy*”. And also, prevention of disfigurement and psycho-socio rehabilitation is crucial for improvement of quality of life of PALs.

INTRODUCTION

Leprosy is noted as an endemic disease in Myanmar for many centuries [1]. It has been depriving both patients and their families of leading a normal productive life. Leprosy is an ordinary disease with extraordinary social and economic implications. More numbers of studies do not adequately express the social and economic loss [2]. Leprosy and its consequences are a complex human

problem leading to discriminations, stigma and prejudices [3, 4].

Though the impact of social inequality on health conditions is widely known, its impact on the chronic and stigmatized disease, leprosy, has received little attention. Deformity sometimes leads to physical disabilities and to handicaps consequently causing problems to the patient and his family.

Stigma is a process of behavioural responses of community who are relating to an affected person. The process of stigmatization can be divided into two stages. The first stage describes how certain cognitive dimensions of leprosy lead to a variety of affective responses towards the disease. The second stage involves how these affective responses contribute to social devaluation of the leprosy patient and consequently, the adoption of negative behaviours towards them [5]. Stigma acts as a factor of socio-economic consequences of disabled persons affected by leprosy. Many studies pointed that leprosy is causing various socio-economic problems and many other problems due to the physical disabilities resulting from the disease. However, there is no clear determination that whether socio-economic consequences of persons affected by leprosy (PALs) are due to leprosy disease or physical disabilities. Low social image among PALs have to be approved whether it is due to disease itself or deformity. This study was conducted mainly to identify social stigma among disabled persons and to differentiate stigmatization between persons disabled due to leprosy and not due to leprosy (PAL and non-PAL).

These findings will be used as an input for Leprosy Control Program in order to develop strategies for improving social image and restoring self confidence of affected persons in the community. Integration between Prevention of Disabilities (POD) and Community Based-Rehabilitation (CBR) should be promoted to enhance the quality of lives of PALs and non-PALs in community.

MATERIALS AND METHODS

The study is a cross-sectional comparative design. After detailed discussion with the concerned health persons from Leprosy Control Programme, the study group should be in the area where the rehabilitation programme by JICA has being initiated. Therefore Aunglan Township, one of the

nine areas of JICA disability survey was purposely selected to integrate two projects (the present project and JICA project) so that the needs of the leprosy patients can be provided effectively in intervention phase. There were 150 registered GI and GII PALs at the township of study. Recruitment of the GI and II cases and identification of their social surroundings was done by the township leprosy control programme. Data collection was done during 2004 and 2005. Data collection method was face-to-face interviews using semi-structured questionnaires. Trained interviewers were used for interviews. Out of registered 150 PALs with GI and II disability, only 97 were interviewed due to difficulties in finding cases that were living in the forest, moving out and hospitalized for reconstruction. In comparison, 98 disabled persons affected by others than leprosy (non-PAL) were also interviewed.

RESULTS

Background characteristics of study subjects

Among the total 195 subjects, majority (63%) were males and remaining one-third were females. Male-female proportions were not different between PALs and non-PALs (male was 63% & female was 37% in both groups) ($P=0.956$).

Regarding educational status, majority (54%) were at middle school level. Nearly one-third (31%) were lower than middle school level. Distribution of persons with different educational levels was not significantly different between PALs and non-PALs ($P=0.297$).

There was a significantly different pattern of distribution of marital status between two groups ($P=0.001$). The proportion of “singles” was higher among non-PALs than PALs (39% vs.15%) while that of “married” was higher among PALs (61% vs. 40%). Proportion of “divorced” was two-folds higher among PALs than non-PALs (7% vs. 3%). Age distributions were not significantly different between two groups.

Type of disabilities

Differences of type of disabilities were observed between two groups. Skin disfigurement was obviously high between PALs (78.4%). Other organs affected (eye, hand and foot) were higher among non-PALs in comparing to PALs (29.6% vs 3.1% for eye, 13.3% vs 2.1% for hand, 37.8% vs 1.0% for foot respectively) (*Pearson Chi²(6) = 148.8671, P < 0.001*).

Occupational status

There was no different proportion of having job at the time of interview. The majority gave reason “due to physical disability” (55%). However, reasons for not having a job were found different among groups. Higher percentages of PALs gave reasons of “depending on offspring” and “getting older” are found (21% vs. 2% and 15% vs.6% respectively) (Table 1).

Table 1. Reasons for not having a job among PALs and non-PALs

Job status	Non-PALs		PALs		Total	
	Freq	%	Freq	%	Freq	%
Having a job*						
Yes	43	44.3	44	45.4	87	45.1
No	53	55.7	53	55.6	106	55.9
Total	96	100	97	100	193	100
Reasons for not having a job**						
Due to disability	37	68.5	21	40.4	58	54.7
Weakness/Fatigue	6	11.1	7	13.5	13	12.3
Offspring are earning	1	1.9	11	21.2	12	11.3
Getting older	3	5.6	8	15.4	11	10.4
Still schooling	4	7.4	2	3.9	6	5.7
Never worked	3	5.6	3	5.8	6	5.7
Total	54	100	52	100	106	100

* Pearson chi² (1) = 0.0063, Pr = 0.937

** Pearson chi² (5) = 15.7313, P = 0.008

Income

Although they were not statistically significant, mean and median income of PALs were higher than non-PALs (14450 kyats vs 12775 kyats and 10000 vs 9000 kyats respectively). Similarly, total family income in kyats per month was also higher in the families of PALs than that of non-

PALs (26367 vs 22007 kyats and 23146 vs 18124 kyats respectively).

Family leader role of persons

Getting “family leader role” of female persons in this study was higher among PALs than non-PALs (25% vs. 14%) but it was not statistically significant. However, among male persons PALs were getting more leader role in the family in comparing to non-PALs (87% vs. 49%) (P<0.001).

Social events in festive occasions

During the festive occasions, disabled persons might have some socially stigmatizing experiences. Three sequential questions were asked to the persons. Do they have invitations to such occasions like other people? Slightly higher proportion of “non-invitees” among non-PALs than PALs was not significant (P=0.429).

The second question was “Did they go to this occasion?” to the persons who received invitation. The answer “no” was noted as “self-stigmatized”. Like the first question, PALs and non-PALs were not significantly different (P=0.246). However, the third question “Did they experience social problem during their presence in the occasion?” figured out non-PALs have more problem than PALs (P=0.017). Among three questions, the responses show obviously high level of self-stigmatization among both PALs and non-PALs. Among those who did not go to the occasion although invited, the reason for not going were explored. Proportion of not willing to go to social occasions was 74.5% among PALs and 8.2% among non-PALs. Some 9.3% of PALs and 7.1% of non-PALs said they were not feeling well at the time of occasion. Reason of “low esteem” was given by 9.3% of PALs and 1.2% of non-PALs (Fig. 1).

Social events in social occasions

To explore stigmatization on social occasions, similar questions were asked. The responses showed that non-PALs were less invited than PALs (P=0.017). For

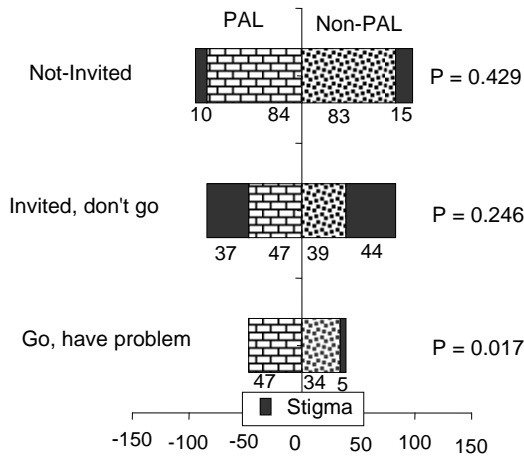


Fig.1. Comparison of PALs and non-PALs having stigma events on festive occasions

the next two questions the responses were not different among two groups. Self-stigmatization was also pronounced like in festive occasions. About 30% of PALs felt “reluctant to go to the social occasion” while 44% of non-PALs gave such reason. “Low esteem” was given as a reason for not going by 14.8% of PALs but no non-PALs said like this (Fig. 2).

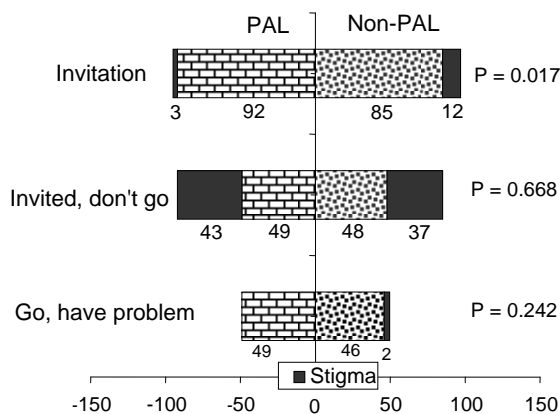


Fig. 2. Comparison of PALs and non-PALs having stigma events on social occasions

Social events on village activities

To explore stigmatization on village occasions, similar questions were also asked. The responses show that PALs were not less stigmatized than non-PALs on all three questions. Self-stigmatization was also pronounced like in festive occasions. Although majority, both PALs and non-PALs said they were not free to participate,

15% of PALs and 22% of non-PALs said they did not want to go there. Another 15% of PALs and 22% of non-PALs also responded that they did not go to avoid people. Feeling low esteem was also given as a reason for not going by 8% of PAL and 17% of non-PALs (Fig.3).

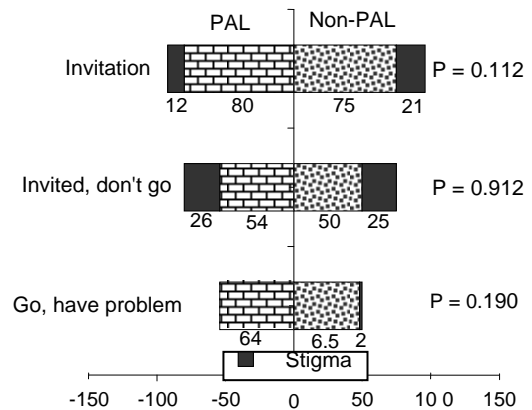


Fig. 3. Comparison of PALs and non-PALs having stigma events on village activities

Perceptions of PALs and non-PALs on response of villagers

PALs and non-PALs were also compared on their self-stigmatization with perceived discrimination of other people on them. Forty-eight percent of non-PAL and 58% of PALs noticed that other peoples’ behaviour on them which looked discriminating. About 10% higher in PALs than non-PALs on perceived being-discrimination shows that PALs might have self-stigmatization due to the disabilities affected by leprosy (Chi square 17.95, p=0.001). However, second question “What is the response of villagers towards them?” was asked to highlight discrimination. A non-response rate on this question was high (about 40%). No difference was found between PALs and non-PALs (P=0.287) (Table 2).

Table 2. Responses of villagers on disabled persons

Response of villagers	Non-PAL		PAL		Total	
	Freq	%	Freq	%	Freq	%
As usual	30	30.61	42	43.30	72	36.92
Friendly	8	8.16	5	5.15	13	6.67
Discriminate	9	9.18	8	9.28	18	9.23
Not answer	51	52.04	41	42.27	92	47.18
Total	98	100.00	97	100.00	195	100.00

Pearson Chi² (2) = 3.7742, P = 0.287

DISCUSSIONS

Proportion of ever-married among PALs was higher than non-PALs since leprosy might not affect them at their early age of marriage. However, higher divorce rate among PALs may have some explanation to be uncovered. It highlights leprosy might be a factor for marital problems among disabled persons.

Family income or personal income of PALs was not different from that of non-PALs. Major disability for PALs might not be due to physical disablement but due to disfigurement which may affect them socially disabled. Having social disablement was noted among both PALs and non-PALs. Rejections from environment and reluctance to environment of the affected persons were carefully analysed. Intra-family role of PALs was not lower than that of non-PALs. It means that PALs could lead their family by generating income. They get acceptance of their family.

A high level of self-stigmatization among leprosy patients was also observed in India and equally a high level of social stigma was found in their communities, which led to reduced interaction between the leprosy patients and their communities [6]. That study did not mention discrepancy of stigma between PALs and non-PALs. In a study of community perception in high and low endemic region in Myanmar, about 44% of community had positive attitudes towards PALs showing leprosy was still a social stigma [7]. That study did not mention that whether those who had negative attitudes towards leprosy were due to leprosy disease or disability of the patients. In a study on social aspect of leprosy in Hmawbi Township, Myanmar, about 8% of patients felt that they were outcasted by society [8]. The study did not describe the differential of outcasting among the patients with and without disability. In our study, getting invitation, participation and discrimination at extra-familial environment were not significantly different between PALs and

non-PALs. Higher percentage of self-stigmatization (refusing invitation to participate) was noted among PALs at social occasions and community activities but this was not much. It shows that stigma among PALs might be not due to "leprosy" but due to disfigurement (consequence of disease). This statement was supported by qualitative findings from another part of this study [9]. PALs do not want to be known as leprosy cases. Community acceptance is an issue for leprosy cases and mentioned that leprosy patients especially disabled cases used to stay away from people and they have low self esteem. The patients fear that neighbors might know of taking treatment for leprosy.

Prevention of disfigurement of PALs will be more important in future because decreasing incidence and improved case management programme including POD and POWD would minimize physical disablement among PALs remaining main cause of social disablement and stigma of PALs as disfigurement. There is lack of complete understanding about global needs for rehabilitation in current situation.

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 (Multidrug therapy MDT, surgery, etc) will be vastly beneficial. However, psycho-socio-economic rehabilitation is a holistic manner which will reduce self-stigmatization among disabled persons thus resulting in improvement of quality of life.

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