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*Original Article*

# Self-stigma of leprosy affected persons in Jaffna District

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## Abstract

Leprosy new case detections are stagnant over the past 20 years and continue to be stigmatized in socially marginalized groups and the urban poor are less likely to seek care. There is a big gap in studies related to leprosy stigma in Sri Lanka. This study aimed to measure the stigma among leprosy affected persons in Jaffna District.

This was a cross sectional descriptive study done in dermatology clinic, teaching hospital, Jaffna using all 109 leprosy patients. The validated interviewer administered questionnaire with the tool (Internalized Scale of Mental Illness (ISMI) adapted for leprosy-affected persons) was used to measure the stigma. Average of mean scores (with SD) was calculated to demonstrate the level of stigma. The level of stigma to different domains/item responses were described by presenting compound bar diagrams/charts.

Mean age of the participants was 40.3±18.6yrs. Most of the participants were males (53.2%), Sri Lankan Tamils (97.2%), Hindus (77.1%), married (65.1%), from MOH Chankanai area (50.5%) and affected by MB type of leprosy (68.8%). Only 44% completed secondary education, 36.7% had no job and 32.1% were manual workers. The mean score of (ISMI) leprosy patients was 2.43 which mean high level of stigma. The response pattern to different components of ISMI was heterogeneous.

## Keywords

Leprosy, stigma, stigma-tool, Jaffna District.

## Introduction

Stigma is defined as the negative evaluation of a person as stained or discredited on the basis of attributes such as mental disorder, ethnicity, drug misuse or physical disability. There is no doubt that such prejudice has substantial negative social, political, economic and psychological consequences for stigmatized people. They may feel unsure of how 'normal' people will identify or receive them and become constantly self-conscious and calculating about what impression they are making(1).

In conceptualization, stigma is the result of a process in which a series of five interrelated components combine to generate stigma. "In the first component, people identify and label human differences. Although most human differences are socially irrelevant, differences such as skin colour, IQ, and sexual preferences are highly salient in many social contexts. The second component of stigma involves the process of stereotyping in which the labelled person is linked to undesirable characteristics. In the third component the group doing the labelling separates "them"—the stigmatized group—from "us". In the fourth component, stigmatized people experience discrimination and loss of status. We reason that when people are labelled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them. Finally, there can be no stigmatization without the fifth component of stigma, the exercise of power. The essential role of power is clear in situations where low power groups attempt a reverse stigmatization" (2).

According to Scambler's Extended Hidden Distress Model by categorizing 'felt stigma' further into internalized and anticipated stigma. In the case of internalized stigma, individuals accept the discriminating and exclusionary view of society, and stigmatize themselves; they internalize guilt and blame

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for having the disease, and tend to isolate themselves. On the other hand, anticipated stigma refers to the real or imagined fear of societal attitude because of the stigmatized condition. It has been suggested that some may even adopt anticipated stigma as a coping mechanism to protect against the possibility of enacted stigma (3)such as the pressure to respond to the challenge of stigma in environments of extreme poverty, the issues of scant resources and the requirements to adapt objectives accordingly, and the competing demands for relief and emergency aid. It is in such contexts that researchers have the responsibility of making evidence-based recommendations and yet, regarding stigma interventions, they are confronted by a domain almost devoid of reliable evidence. Without examples of comparable situations that can be reviewed, it may be possible to make progress only through recourse to theoretical concepts. Broad guidelines, based on respected theories, may prove to be a sound foundation on which intervention programmes can be designed. In this article, the discrete components of stigma that should be targeted in stigma intervention programmes are identified. It is also recommended that since stigma affects different levels in society simultaneously, stigma programmes should be multi-targeted and designed with an intention to adjust interactions between groups at different societal levels. This article lays the foundation for a companion article that presents a generally applicable method by which plans for stigma interventions can be assessed (Interventions for Stigma Reduction.

If a person is affected by a disease/condition and experiences the stigma, it is self-stigma. Personal experiences of the stigmatized individual, which reflect the internalized aspect of stigmatization, were first evaluated among homosexuals in the 1980s. Internalization of stigma is the devaluation, shame, secrecy, and withdrawal triggered by applying negative stereotypes to one's self. Internalization of stigma also has negative effects on coping with stigmatization within any given society. Internalization of stigma causes serious damage to the stigmatized individual. As members of a society, individuals with mental illnesses are faced with stereotyped judgments (4).

Ancient societies in Indian subcontinent marginalized those with leprosy because of several factors: its chronic, potentially disfiguring nature; inconsistently effective therapy; association with sin; and the fear of contagion. This combination endowed leprosy with a unique stigma that persists today and resulted in its treatment with both seclusion and medical therapy. Initially, the colonial government accepted pressure from England and its colonial countries enacted the Leprosy Act in 19th century. This law institutionalized people with leprosy, using segregation by gender to prevent reproduction(5). This played a major role indirectly towards leprosy stigma. After governments began integrating leprosy care into their general health systems starting in , moving from vertical control programs to horizontal health services, an intervention shown to decrease the stigma associated with leprosy due to family counseling and community outreach activities(6).

The existence of stigma and fear of leprosy in Sri Lanka was documented in a news report. The report relates the incident at the Moneragala prison where the prison guards ensured the release of an inmate found to have leprosy by making a collection among them and paying the fine imposed on the inmate by the magistrate(7). In 2013 there was an incident of denying free education to the students from the leprosy affected pocket by a local school near to the area and some teachers were reluctant to work in a small school near to the area. These issues were solved with the involvement of several volunteer organizations with the help of higher officials(8). Leprosy new case detections are stagnant over the past 20 years and continues to be stigmatized in socially marginalized groups such as women, ''backward classes'' and the urban poor are less likely to seek care (9). There is a big gap in Sri Lanka about the studies related to stigma due to leprosy. This study aimed to measure the stigma among leprosy affected persons in Jaffna District.

**Methods**

This was a cross sectional descriptive study done in dermatology clinic, teaching hospital, Jaffna using all 109 leprosy patients (over 12 years of age) diagnosed within the past 3 years and visited to teaching hospital Jaffna for treatment/follow up during the study period.

Teaching hospital Jaffna is the only hospital providing diagnostic and treatment facilities to leprosy in the district. Persons, who stayed temporarily (live less than 6 months or frequent change of resident) and cannot give the information due to physical or mental status were excluded. The validated interviewer administered questionnaire with the tool (Internalized Scale of Mental Illness (ISMI) adapted for leprosy-affected persons) was used to measure the stigma quantitatively. Some patients were interviewed at their homes with the prior appointments to manage the time and comfort of the patients.

This tool was developed to measure the stigma of stigmatized patients/person (self-stigma or internalized stigma) of mental illness, leprosy, HIV / AIDS, disability, etc. The ISMI consists of four components namely alienation, stereotype endorsement, discrimination-experience and stigma resistance. This has 28 interview-based questions. For each question it has 4 options: Strongly disagree (1), disagree (2), agree (3), strongly agree (4). The five questions in the stigma resistance component are reverse coded (Item 24, 25, 26, 27, and 28 should be reverse coded by subtracting the score from 5). For the calculation, the five items should be recoded to get the correct results. Subsequently, the final score (mean) can be calculated by dividing the sum of all scores by the total number of answered questions. Higher mean scores indicate higher level of self-stigma(10). This interviewer administered tool was validated to Jaffna Tamil from English language (11).

Average of mean scores (with SD) was calculated to demonstrate the level of stigma of the patients. The level of stigma to different domains/item responses were described by presenting compound bar diagrams/charts.

Informed consent and assent if relevant were obtained from the participants. Ethical clearance was obtained from ethical review committee Faculty of Medicine, University of Jaffna.

## Results

### Characteristics of participants

Mean age of the participants (median-39) was 40.3(Std. Deviation-18.6, Minimum- 12.0 and Maximum-79.0). Most of the participants were males (53.2%), Sri Lankan Tamils (97.2%), Hindus (77.1%), ever married (65.1%), from MOH Chankanai area (50.5%) and affected by Multibacillary (MB) type of leprosy (68.8%). Among them only 44% had completed secondary education, 36.7% had no job and 32.1% were manual workers (Table 1).

**Table and figures-Table 1: Characteristics of participants (n-109)**

| Characteristics | Number | Percentage |
|---|---|---|
| **MOH area** | | |
| Chankanai | 55 | 50.5 |
| Point-Pedro | 2 | 1.8 |
| Sandilipay | 5 | 4.6 |
| Thellipalai | 6 | 5.5 |
| Uduvil | 4 | 3.7 |
| Velanai | 4 | 3.7 |
| Chavakachcheri | 7 | 6.4 |
| Jaffna | 8 | 7.3 |
| Karainagar | 6 | 5.5 |
| Karaveddy | 2 | 1.8 |
| Kayts | 1 | 0.9 |
| Kopay | 3 | 2.8 |
| Maruthankerny | 1 | 0 .9 |
| Nallur | 5 | 4.6 |
| **Sex** | | |
| Male | 58 | 53.2 |
| Female | 51 | 46.8 |
| **Ethnicity** | | |
| Sri Lankan Tamil | 106 | 97.2 |
| Others | 3 | 2.8 |
| **Religion** | | |
| Hindu | 84 | 77.1 |
| Christians | 23 | 21.1 |
| Others | 2 | 1.8 |
| **Educational status of the patient** | | |
| No schooling | 8 | 7.3 |
| Grade 1-5 | 35 | 32.1 |
| Grade 6-11 | 48 | 44.0 |
| O/L passed | 12 | 11.0 |
| A/L passed | 5 | 4.6 |
| Degree | 1 | 0.9 |
| **Occupation of the participants** | | |
| Student | 18 | 16.5 |
| Professional/technical/managerial | 2 | 1.8 |
| Clerical/Sales and services | 6 | 5.6 |
| Manual worker | 35 | 32.1 |
| Market oriented farmers and fishery workers | 8 | 7.3 |
| Not working | 40 | 36.7 |
| **Current marital status of the participants** | | |
| Ever Married | 71 | 65.1 |
| Single | 38 | 34.9 |
| **Type of leprosy** | | |
| MB | 75 | 68.8 |
| PB | 34 | 31.2 |

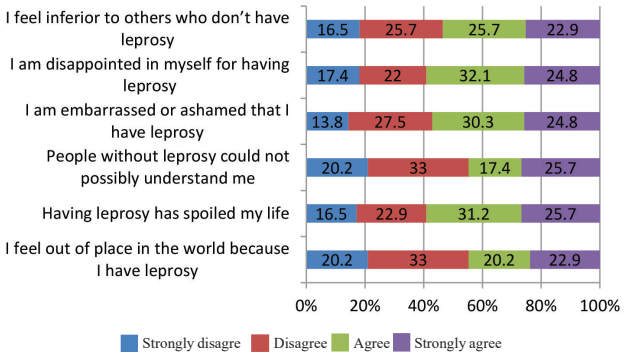
## Level of stigma

The mean score of (ISMI) the leprosy patients, was 2.43 (SD-0.77, minimum-1.00 and maximum-4.00) which means high level of internal stigma. The response pattern to different components of ISMI was heterogeneous.

## Alienation

Responses to this section were heterogeneous and participants were in different levels of stigma (fig. 1).

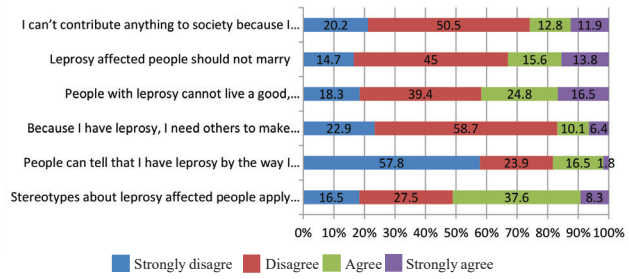
**Figure 1: Response pattern to different items of Alienation**




## Stereotype Endorsement

Majority of the respondents either strongly disagreed or disagreed to most of the items of this section except the item "Stereotypes about leprosy affected people apply to me" (fig.2). This means relatively low level of stigma due to stereotype endorsement.

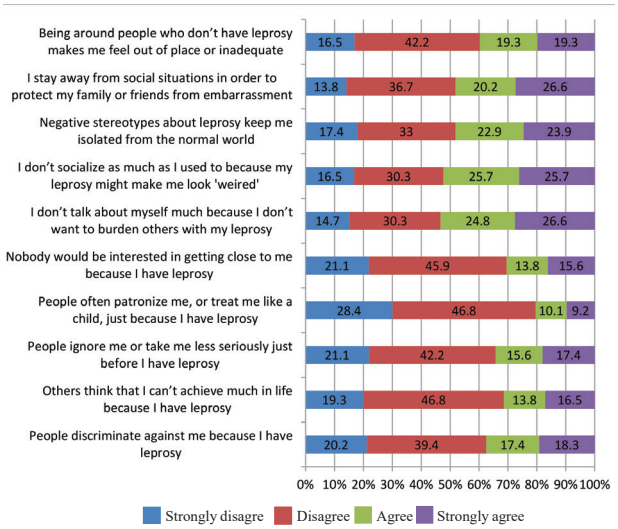
**Figure 2: Response rates to different items of Stereotype Endorsement**




## Discrimination Experience

Except 2 items, Majority of the respondents either strongly disagreed or disagreed to most of the items of this section also. But the differences were small (fig.3). Therefore this components may be shared a significant level of stigma to the total score.

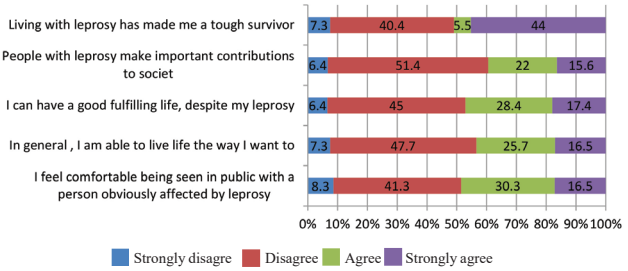
**Figure 3: Response rates to different items of Discrimination Experience**




## Stigma resistance

The differences between agree and disagree components were marginal (fig.4). Therefore this components may also be shared a significant level of stigma to the total score.

**Figure 4: Response rates to different items of Stigma resistance**




## Discussion

Both over-all score and responses to sub-components had shown a significant level of stigma among the participants. Though the study instrument consisted of validated tool to measure the level of stigma, still there were possibilities of information bias as it is a subjective reflection of the participants. So, measures were taken to minimize the bias from different sources. For the measurement by ISMI only the one particular pre-intern doctor did the interview with adequate information about the study and the tool to the patients to make them comfort to answer without internal conflicts when selecting the responses or options of the Likert scale. To prevent the chronological monotonous answers she made a cross check in the completion of interview when the respondent's answer was doubtful. She gave some parallel explanation in addition to the direct wording or read out of the items when they puzzled.

As the sample size was limited every effort was made to recruit all patients fulfilling the inclusion criteria, visited to the clinics. The patients who visited for the follow up review or collecting the Slit Skin Smear reports at the end of treatment had chance to be missed easily as their waiting time was less. They were asked to wait if possible or no other commitments during the particular visits with the help of clinic in-charge nursing officer. In the event of lack of time on the particular day, detailed contact information including mobile number was collected after giving adequate information about the study and they were followed at their home in a convenient time of the patient with advance notice.

The results of a study done in Nigeria using same tool also found higher level of stigma among leprosy patients with different backgrounds. But their study have done comparatively less number of patients than our study (12). Similar findings were observed in a qualitative study done in Nepal (13). Significant level of high stigma was found similarly in a study done in Bangladesh but used a different tool to measure the level of stigma and the situation in early part (14). In West Bengal and Tamil Nadu States of India, a study had been done using the same instrument to measure the stigma with a larger sample size resulted in similar findings as our study. In addition, they have found significantly higher level of stigma among patients with visible signs of leprosy compared to patients without visible signs of leprosy(15). This suggests that our study is more consistent as the Tamil Nadu and Jaffna share more common social and cultural components from historical time compare to other countries.

Mean score and component analysis demonstrated the higher level of stigma among leprosy patients. Further, community education and medical knowledge of the disease over the years does not immediately dispel stigma. More studies are needed to better understand the causes of stigma and to assess the effect of interventions to decrease it. Future studies for the demonstration of this, will facilitate further reduction in case load and sustain a leprosy free nation.

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