

## Sociocultural Factors Affecting Diagnosis of Leprosy: A Cross-Sectional Study



### Medical Science

**KEYWORDS :** Sociocultural barrier, Kuppuswamy's index, cross-sectional study.

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### ABSTRACT

*Introduction: Sociocultural factors stand as barrier in the detection and treatment of leprosy. Misconceptions and myths, low literacy and knowledge about leprosy among patients were major socio-cultural barriers in its control. Socio-economic status of the patient plays an important role in acquiring leprosy and getting the treatment for the same. Most of the patient hide and conceal their symptoms which lead to delay in diagnosis and deformities. It has serious consequences on their social well-being. Methods: Cross sectional study to assess the socio-cultural barriers affecting treatment of leprosy patients. A total of 46 patients with leprosy attending Dermatology OPD were interviewed through semi-structured questionnaire during the period between June2015 to November2015. Results: In this study, ratio of male vs. female was 2:1. Mean and standard deviation of age of patients was 38 years and 14.5 years respectively. Majority [35(76%)] of the patients belong to lower class according to modified Kuppuswamy's index (2015). Out of these patients, 37 (80.4%) were old cases on follow up and 9(19.6%) were newly diagnosed cases. 19(41.3%) patients did not have any knowledge about the disease. 5(10.86%) knew only the name of the disease and the remaining 21(45.65%) had other views about the disease like curse, myth, allergy, trauma etc. Only 1(2.17%) patient who was well educated and belonging to upper middle class knew about the exact cause of the disease and its complications. 6 patients had family history of leprosy (13.04%). 17 patients faced social stigma (37%). Daily activities of 36 patients were affected (78.26%). Income of 27 patients got affected (58.7%). Education, care-taking and wellbeing of children were affected in 26 patients (56.52%). Conclusion: The major socio-cultural barriers in leprosy treatment are low socioeconomic status, myths, illiteracy, social stigmas and faith on alternative therapy.*

### INTRODUCTION

Leprosy has been around since ancient times, often surrounded by terrifying, negative stigmas and tales of leprosy patients being shunned as outcasts. Social stigma is associated mainly due to prevalent myths like its hereditary and contagious nature, divine curse along with the physical deformities caused. The affected people not only face physical impairments but also suffer psychosocial repercussion due to community's attitude.

According to NLEP 2001, prevalence rate in Bihar-Jharkhand was >10/10000 against whole country's prevalence of 3.74/10000. It declined to 0.68/10000 in 2011 in India<sup>[1,2,3]</sup>. However the state of Bihar-Jharkhand showed less decline with prevalence of >1/10000<sup>[1]</sup>. As per NLEP progress report 2014-15, 33 states /UT had attained the level of leprosy elimination except Bihar, Chhattisgarh and Dadar& Nagar Haveli.<sup>[4]</sup>

Sociocultural factors are customs, lifestyles and values that characterize a society such as religion, attitudes, economic status, class, language, politics and law. These factors stand as barrier in the detection and treatment of leprosy. Early diagnosis of leprosy and adequate therapeutic coverage reaching all individuals diagnosed are priorities in leprosy control program and essential condition for the interruption of transmission and the reduction of physical and social consequences of the disease<sup>[5&6]</sup>. These factors affect the quality of life and health. Stanley Brown had stated, "in no other disease do social and psychological factors loom so large as in leprosy"<sup>[7]</sup>. Due to the huge stigma attached to

leprosy most of the patient hide and conceal their symptoms which lead to delay in diagnosis and deformities. It has serious consequences on their social well-being.

This manuscript focused the socio-cultural barriers affecting treatment of leprosy patients attending Dermatology OPD in Rajendra Institute of Medical Sciences, Ranchi, Jharkhand. Outcome of this study will be strengthening the implementation in strategy of NLEP..

### MATERIALS and METHODS

A cross-sectional study was conducted on leprosy patients during a period between June2015 to November2015 attending the outpatient department of Dermatology, Venereology & Leprosy of a tertiary care centre. Informed consent was taken from patient or patient's relative. Ethical clearance was obtained from the Institutional Ethics Committee. A total 46subjects who were clinically diagnosed and had more than one cardinal features of leprosy (viz. hypo/ anaesthetic patches, nerve thickening, Positive AFB on ZN staining) and met the inclusion criteria of the study during our data collection period were recruited for this study.

Study Subjects were interviewed through semi structured questionnaire to assess the socioeconomic status according to modified Kuppuswamy's index (2015)<sup>\*</sup>, their first place of visit, reasons for preference, compliance of the patients to MDT, complications of leprosy and its consequences on patient's family and reasons for delay in diagnosis of leprosy.

**INCLUSION CRITERIA**

1. A newly diagnosed leprosy patient presenting with more than one cardinal features of leprosy.
2. Patients who were previously diagnosed as leprosy coming for follow up and taking anti-leprotic drugs/ MDT
3. Patients with severe deformity due to leprosy.
4. Patients who came after default treatment.

**EXCLUSION CRITERIA :**

Patients presenting with similar symptoms secondary to other cause like diabetic neuropathies, traumatic neuropathies, etc.

**STATISTICAL ANALYSIS**

Proper template for data entry was generated in MS Excel. Data were randomly checked to assure the quality of the data. Descriptive analysis was done through SPSS software.

**RESULTS**

A total of 46 patients were assessed of which 31(67.4%) were male and 15(32.6%) female. Mean age of male was 39 years and of female was 36 years. Socioeconomic status according to modified Kuppuswamy's index (2015) was as follows:- Lower class(LC):- 13(28%), upper lower class(ULC):- 22(47.8%), Lower middle class(LMC):- 6(13%), upper middle class(UMC) :-5(10.9%). There were no patients from upper class(UC). Out of these patients, 37 (80.4%) were old cases on follow up and 9(19.6%) were newly diagnosed cases.

**KNOWLEDGE ABOUT THE DISEASE:-** 19(41.3%) patients did not have any knowledge about the disease. 5(10.86%) knew only the name of the disease and the remaining 21(45.65%) had other views about the disease like curse, myth, allergy, trauma etc. Only 1(2.17%) patient who was well educated and belonging to upper middle class knew about the exact cause of the disease and its complications.

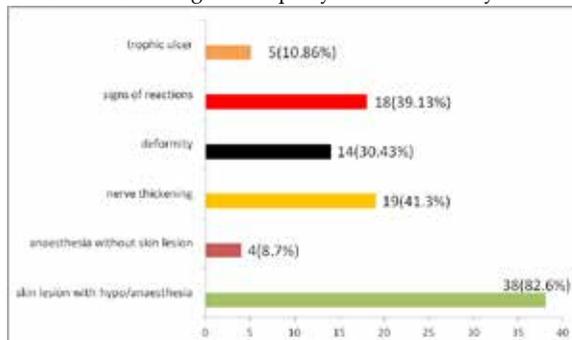
**Table 1: Socio-demographic profile of the patients (n=46)**

Variables	Category	Numbers(%)
Sex	Male	31(67.4%)
	Female	15(32.6%)
Socio Economic Status(SES) As modified Kuppuswamy index(2015)	LC	13(28%)
	ULC	22(47.8%)
	LMC	6(13%)
	UMC	5(10.9%)
	UC	0(0%)
Education Status	Illiterate	20(43.47%)
	Literate	16(34.78%)
Sex	Mean Age(yrs.)	Standard Deviation Age(yrs.)
Male	38	15
Female	36	14
Total	38	14.5

**Table 2: DURATION OF DISEASE**

Duration of disease	No. of patients(n=46)	Percentage
<1 month	2	2.17%
1-6 months	2	2.17%
6m-1 year	5	10.86%
1-5 years	27	58.7%
>5 years	10	37%

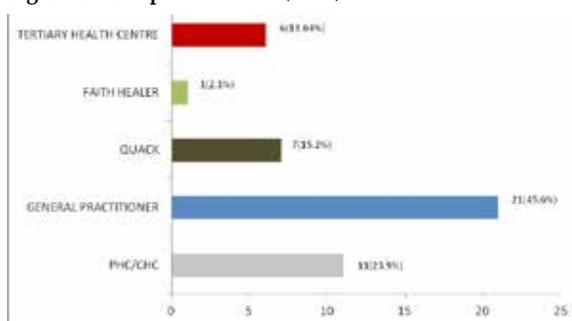
Above table 2 shows that majority (80% of 46) of the patients were suffering from leprosy more than one year.



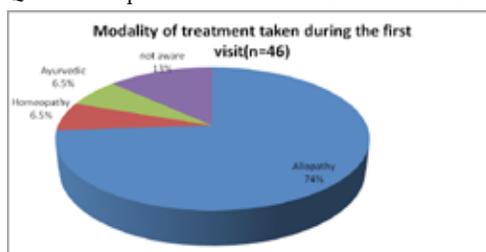
**Figure 1: Clinical Presentation [multiple response] (n=46).**

Above figure 1 shows majority of the patients had skin lesion with hypo/anesthesia followed by nerve thickening, signs of reaction, deformity, trophic ulcer and anesthesia without skin lesion.

**Figure 2: First place of visit (n=46)**

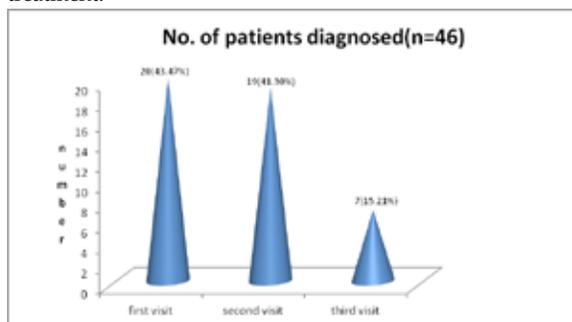


Above figure 2 shows that most of the patients were visited first time to General Practitioner followed by govt. hospital, Quack. One patient was visited faith healer at first time.



**Figure 3: Modality of treatment taken during the first visit.**

Above figure 3 shows that majority (74% of 46) the patients had taken mainly allopath medicine. Few patients had taken homeopath and ayurvedic medicine along with allopath treatment.



**Figure 4: Patients diagnosed in different visits**

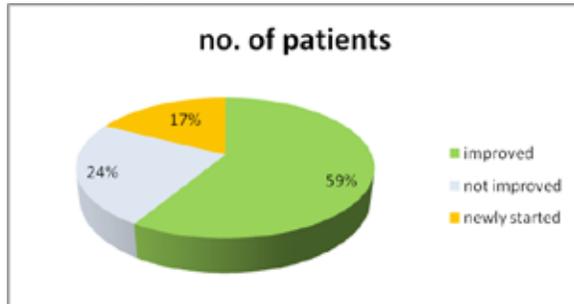
Above figure 4 shows that 20(43.7%) patients had diagnosed during the first visit. 26(56.5%) patients had diagnosed in second visit and third visit.

**Table no. 3: Total No. of patients who took Multi Drug Therapy(MDT)**

MDT taken	No. of patients	Percentage
Regularly	26	56.52%
Irregularly	11	23.91%
Newly started	09	19.56%

Out of 46 patients, 44 were multibacillary and only 2 were paucibacillary.

Above table 3 shows that out of 46 patients, 26 patients had taken MDT regularly, 11 irregular and 9 patients were just started the MDT.



**Figure5: Improvement of Patients**

Above figure shows that 59% patients were improved after taking MDT. Most of them had taken MDT regularly, 24% patients were not improved due to irregularity in taking of medicine.

**Table no. 4: Socio-cultural Barrier in treatment among Leprosy patients (N=46)**

Socio-cultural Barrier	No. of response*by 46 patients	Percent
Myth & misconception	21	21.21%
Social Stigma	17	17.17%
Belief on alternative therapy( Ayurvedic, homeopathic and Faith Healer)	6	6.06%
Illiteracy	20	20.20%
Low socio-economic Status	35	35.35%
Total response	99	100%

\*Multiple responses

Above table 4 reveals that main reason for delay in treatment was due to socio-cultural barriers i.e., low socio-economic status, myth & misconception, illiteracy and social stigma. Some patients had believed on alternative therapy.

- Consequences of leprosy:
- 6 (13.04%) patients had family history of leprosy.
- 17 (37%) patients faced social stigma.
- Daily activities of 36(78.26%) patients were affected.
- Income of 27(58.7%) patients got affected.
- Education of children was affected in 26(56.52%) patients.

**DISCUSSION:-**

In our study, 19(41.3%) patients did not have any knowledge about the disease. 5(10.86%) knew only the name of the disease and the remaining 21(45.65%) had other views about the disease like curse, myth, allergy, trauma etc. Only 1(2.17%) patient who was well educated and belonging to upper middle class knew about the exact cause of the disease and its complications. Socioeco-

nomical status according to modified Kuppuswamy's index (2015) was as follows: Lower class:- 13(28%), upper lower class:-22(47.8%), Lower middle class:- 6(13%), upper middle class :-5(10.9%). There were no patients from upper class. Most of the patients belonged to lower and upper lower class justifying the old notion that the prevalence of leprosy in people of lower economic status is high. A similar finding in context of socioeconomic condition reported by N Majumder (2015)<sup>[8]</sup> conducted in Potka block of East Singhbhum district of Jharkhand was community based study however our study is hospital based study.

AssefaAmenu et al., (2000) also stated misconceptions and myths about the disease and the stigma that goes with it not only causes untold misery to the patient, but to his family as well. Low literacy and knowledge about leprosy among patients were major socio-cultural factors found to leprosy control. Socio-economic status of the patient plays an important role in acquiring leprosy and getting the treatment for the same. Apart from that there are different beliefs about leprosy mostly in rural areas that the disease is a curse, it is due to consumption of pig/fish, allergic reaction to certain things etc<sup>[9]</sup>.

In our study, 17(37%) patients suffered social stigma. Daily activities of 36(78.26%) patients got affected. Income of 27(58.69%) patients got affected. 26(56.52%) patients could not provide proper care and education to their children. Due to the chronicity of this grave disease, income of the family is affected and hence the normal upbringing of the children takes a toll. Most of our patients complained that they could not carry out their daily activities which earned them money. Even after they were diagnosed with leprosy, most of them did not know the actual cause, course and complications of the disease. The knowledge of the disease was not transferred to their children. Society considered them an outcast and never supported them socially and financially. Neighbors even misguided the persons affected to approach quacks and faith healers resulting in delay in diagnosis and complications.

We consider the effective involvement of various segments of society, particularly the integration and partnership of public health services and health education centers to be valuable tool for the planning and execution of educational activities directed at risk groups and community.

**Conclusion:**

This manuscript highlighted the major socio-cultural barriers in leprosy treatment were low socioeconomic status, myth, illiteracy, social stigmas and faith on alternative therapy.

**Recommendation:**

Socio-cultural barriers which are affecting the leprosy treatment must be addressed in National leprosy Eradication Programme (NLEP). There is a need for educational activities in primary schools and colleges. Mass media tools need to be adequately utilized. Mobile phone which has revolutionized mass communication is a wonderful tool in spreading awareness about the disease through social media.

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