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Original Article

Community Section

Perceived Stigma and Social Distance towards People Suffering from Leprosy: A Cross-sectional Study in Dibrugarh District of Assam, India

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ABSTRACT

Introduction: Leprosy presents as painless, hypopigmented, anaesthetic lesions on the body, which, when left untreated, progress to cause destructive and irreversible damage to the skin, nerves, eyes, and other body parts. The disease is often diagnosed late in its natural progression as it remains undetected as innocuous lesions. Additionally, the stigma and social distancing associated with leprosy further challenge its early diagnosis and control efforts.

Aims: To assess the perceived stigma and social distance towards people suffering from leprosy.

Materials and Methods: A community-based cross-sectional study was conducted among leprosy patients who were already undergoing Multi-Drug Therapy as well as new cases detected in the Leprosy Case Detection Camps (LCDC) in various locations of Dibrugarh district, Assam, India. A total of 42 leprosy patients were interviewed for the study over a six-month period from September 2024 to February 2025 to assess their fear of discrimination or perceived stigma. Additionally, 14 close contacts of the leprosy patients who accompanied them were also interviewed to assess their attitudes regarding maintaining social distance towards the leprosy patients. Analysis was performed and presented as frequencies, percentages, and proportions. Appropriate statistical tests, such as Chi-Square and Fisher's exact test, were conducted.

Results: Out of the 42 patients interviewed, the majority were male (32, 76.2%), with most patients belonging to the age group of 21-30 years (12, 28.6%). The majority of the patients were Multibacillary (MB) (23, 54.8%) and 19 (45.2%) were Paucibacillary (PB). Out of 42, 10 (23.8%) respondents reported experiencing stigma related to leprosy. Eight out of 14 respondents had a mean score for the Social Distance Scale (SDS) indicating an unwillingness to maintain closeness or social interactions with leprosy patients.

Conclusion: Intense active case finding needs to be conducted through grassroots-level frontline workers, and more cases should be detected at an early stage before the onset of deformity. Awareness campaigns, education, and improved healthcare access can reduce the stigma and social taboos associated with leprosy.

Keywords: Deformity, Multibacillary, Paucibacillary

INTRODUCTION

Leprosy (or Hansen's disease) is considered one of the oldest infectious diseases in human history. The disease affects the skin and nerves, leading to severe destructive effects and deformities. The physical impairments caused by the illness, along with its devastating effects on skin and nerves, have brought about prejudice, fear, and segregation in all societies since ancient times [1].

The World Health Organisation (WHO) has classified leprosy into Multibacillary (MB) and Paucibacillary (PB) forms based on the number of skin lesions, nerve involvement, and split skin smear [2]. With over 114,000 new leprosy cases detected in 2020, India accounts for more than 55% of the total cases reported globally, indicating active transmission in certain pockets of hyperendemicity [3]. According to data from 2023, Brazil, India, and Indonesia reported more than 10,000 new cases each [4]. The prevalence of leprosy in India, which accounts for more than half (60%) of the global disease burden, was 0.45 cases per 10,000 population in 2021-22 [5].

In some districts and blocks, the positivity rate is still more than 1 per 10,000 population, particularly in tea garden areas of upper Assam. In the financial years 2022-23 and 2023-24 (up to July 2023), a high percentage of MB cases and Grade-2 Disability (G2D) have been detected in Assam. This indicates that there are undetected hidden cases within the community. The G2D percentage was 12.9% in 2022-23 and 10.26% in 2023-24 (up to July 2023) among new cases in regular case detection activities [6]. These findings strongly indicate the need for increased efforts to identify the root causes, address them, and enhance early detection of cases to initiate treatment promptly, thereby preventing significant disability and the need for reconstructive surgeries.

While leprosy is completely treatable and curable, with medicines available free of charge at government health facilities, it remains a symbol of stigma and a social disease [7]. Assam achieved the goal of leprosy elimination (a prevalence rate of less than 1 case per 10,000 population) in 2005 [8]. However, new leprosy cases, predominantly MB, continue to be detected each year, suggesting that hidden cases still exist within the community [9].

A study conducted by Rensen C et al., in India found that people affected by leprosy with visible signs experienced greater segregation and restrictions in participation than those without visible symptoms [10]. The stigma attached to leprosy is fueled by misconceptions regarding its causes, visible lesions or disfigurement, and people's fears of infection and exclusion [11]. The community has difficulty in accepting leprosy patients as one of the problems for leprosy patients is social isolation [12].

Stigma is a social process or personal experience characterised by exclusion, rejection, blame, or devaluation resulting from experiences or reasonable anticipation of adverse social judgment regarding a person or group associated with a particular problem [13].

Stigma has been defined by Goffman as "an attribute that is deeply discrediting," where the stigmatised individual is one who is not accepted and is not accorded the respect and regard of peers; one who is disqualified from full social acceptance [14]. The result of this stigma includes decreased social participation, lower employment prospects, marital issues, and societal exclusion [15].

Due to the severe societal consequences of leprosy infection, affected individuals often attempt to conceal their diagnosis, which can be viewed as an outcome of stigma within this framework. This behaviour leads to delays in treatment, increased risk of severe disability, and a heightened risk of community spread [16].

Regarding studies conducted to evaluate and assess stigma associated with leprosy, very few studies have been available from this part of the country. A study conducted in a tertiary care hospital in Tezpur, Assam, explores the qualitative aspects of the stigma associated with leprosy through qualitative tools such as in-depth interviews and focused group discussions [13]. Another study in the Kamrup district of Assam assesses the knowledge, attitude, and practices of healthcare providers concerning leprosy [17]. Neither of these studies used any scoring system to evaluate the presence of stigma associated with leprosy.

There is a felt need for more studies, preferably using standardised scales to measure stigma in leprosy, so that the assessment can be conducted objectively and within a short timeframe. Hence, the present study aimed to assess the perceived stigma and social distance towards people suffering from leprosy by using a validated Stigma and Social Distance Scale (SDS) in Dibrugarh, Assam, India.

MATERIALS AND METHODS

The study was a community-based cross-sectional study conducted over six months (September 2024 to February 2025) among leprosy patients who were already undergoing Multi-Drug Therapy, as well as new cases detected in the Leprosy Case Detection Camps (LCDC) conducted in various locations in Dibrugarh district. Cases were detected clinically based on physical examination, according to the WHO criteria for the detection of leprosy. Ethical clearance was obtained from the Institutional Ethics Committee (H) of Assam Medical College, Dibrugarh (No. 2023/AMC/EC/1395). Data was collected after obtaining written informed consent from the study participants, along with assent for participants under 10 years of age.

Inclusion criteria: Patients of any age and gender who were newly diagnosed with leprosy or who had been under treatment for leprosy within the last two years and who agreed to participate were included in the study.

Exclusion criteria: Persons unwilling to provide informed consent or not meeting the inclusion criteria were excluded from the study.

Sample size: Sample size was calculated using the formula:

$n=4pq/d^2$, where n=sample size, p=prevalence of stigma amongst Leprosy patients which was taken as 51.9% [18], q=1-p and d=allowable error which was taken as 15% absolute error and with 95% Confidence interval, the sample size was calculated to be 42.

A case of leprosy is defined as a person showing one or more of the following features who has yet to complete a full course of treatment:

1. Hypopigmented or reddish skin lesions with definite loss of sensation.
2. Involvement of the peripheral nerves, as demonstrated by definite thickening and loss of sensation.

WHO Classification:

- Multibacillary (MB):
  - More than 5 skin lesions
  - One or more nerve involvement
  - Split skin smear positive
- Paucibacillary (PB):
  - 1 to 5 skin lesions
  - No nerve involvement
  - Split skin smear negative [19]

A semistructured questionnaire was used to evaluate the demographic profile of the study subjects as well as other parameters related to treatment status. Additionally, the 15-item Explanatory Model Interview Catalogue - Community Stigma Scale (EMIC-CSS) [10] was used to measure perceived attitudes and behaviour towards individuals affected by leprosy. The EMIC stigma scale was developed by Weiss et al., and later adapted by the International Federation of Anti-Leprosy Associations (ILEP) specifically for leprosy.

The EMIC scale measures patients' fear of discrimination and awareness of negative attitudes, or perceived/anticipated stigma [19]. It also assesses the severity and widespread nature of stigma. The EMIC questionnaire contains 15 questions, with responses coded on a Likert scale ranging from 0 to 3, where:

- 0 = ‘No’
- 1 = ‘Don’t know’
- 2 = ‘Possibly’
- 3 = ‘Yes’.

The scores of all questions are summed to yield a total score that indicates perceived stigma. The higher the score, the higher the level of perceived stigma. The total obtainable score was 45, with a minimum score of 0. A score of 22.5 or higher was considered stigmatised [20].

The Bogardus Social Distance Scale (SDS) was used to assess caregivers and close contacts who accompanied leprosy patients regarding their willingness to maintain closeness or social interactions, serving as a proxy for their attitudes towards the leprosy patients. The SDS is a 7-point scale, with each point having 4 responses on a Likert scale: definitely willing (0), probably willing (1), probably not willing (2), or definitely not willing (3). The total SDS score ranges from zero (indicating no negative attitudes or fear) to 21 (indicating the most negative attitudes/fear) [21]. A higher score indicates a greater tendency on the part of the respondent to maintain social distance from the patient.

STATISTICAL ANALYSIS

Data were entered into Statistical Package for the Social Sciences (SPSS) version 25.0, and the analysis was presented as frequency, percentage, and proportions. Appropriate statistical tests, such as the Chi-square test and Fisher’s exact test, were performed to assess the association between stigma in leprosy and other categorical data, including the number of family members, Body Mass Index (BMI), educational status, occupation, marital status, treatment status, and category of leprosy (MB/PB). The p-value <0.05 was considered to be statistically significant.

RESULTS

[Table/Fig-1] shows that out of the 42 study participants (leprosy patients), the majority were male and belonged to the age group of 21-30 years. Only one patient was below 10 years of age. Regarding marital status, 27 (64.3%) of the patients were married. A considerable proportion of the patients were either illiterate or had only primary school education. In terms of occupational status, the majority of the patients were tea garden workers, followed by daily wage workers without organised employment, and many were unemployed. [Table/Fig-1] displays the distribution of leprosy patients concerning the number of family members, showing that most had 4-5 members in their families. It also indicates that the majority of patients were MB, with eight patients having single nerve involvement.

Parameters	Frequency (%)
Age group (years)	
0-10	1 (2.4)
11-20	6 (14.3)
21-30	12 (28.6)
31-40	10 (23.8)
41-50	8 (19)
51-60	2 (4.8)
61-70	3 (7.1)
Gender	
Male	32 (76.2)
Female	10 (23.8)
Education status	
Primary school	9 (21.4)
Middle school	7 (16.7)
High school	2 (4.8)
Higher secondary	3 (7.1)
Post graduate	1 (2.4)
Illiterate	20 (47.6)
Occupation	
Business	2 (4.8)
Carpenter	1 (2.4)
Daily wage worker	7 (16.7)
Farmer	1 (2.4)
Homemaker	3 (7.1)
Unemployed	10 (23.8)
Painter	1 (2.4)
Student	2 (4.8)
Tea garden worker	15 (35.7)
No. of family members	
<=3	11 (26.2)
4-5	20 (47.6)
>5	11 (26.2)
No. of skin lesions	
Paucibacillary (PB)	19 (45.2)
Multibacillary (MB)	23 (54.8)
BMI (kg/m^2)	
<18.5	22 (52.4)
18.5-24.9	18 (42.9)
25-29.9	2 (4.8)
Stigma	
No	32 (76.2)
Yes	10 (23.8)

[Table/Fig-1]: Distribution of the leprosy patients according to demographics.

As for BMI, the majority of patients were underweight, having a BMI<18.5 kg/m^2. [Table/Fig-2] shows that most patients responded that they did not believe a person with leprosy would try to keep others from knowing, and most did not think that if a family member had leprosy, that person would think less of themselves. Most patients indicated that leprosy did not cause shame or embarrassment.

Furthermore, many patients were uncertain whether knowing that someone has leprosy would have an adverse effect on others; half of them did not believe that community members would avoid a person with leprosy. It was observed that most patients did not believe leprosy causes problems in the family. However, many were unsure if leprosy could cause issues in an ongoing marriage, and 4 (9.4%) patients believed that leprosy could be a hindrance to marriage. The majority responded that having leprosy would not make it difficult to find work.

S. No.	Questions	No Score-0 (n (%))	Don't know Score-1 (n (%))	Possibly Score-2 (n (%))	Yes Score-3 (n (%))
1.	Would a person with leprosy try to keep others from knowing?	20 (47.6)	12 (28.6)	7 (16.7)	3 (7.1)
2.	If a member of your family had leprosy, would you think less of yourself?	18 (42.9)	16 (38.1)	6 (14.3)	2 (4.8)
3.	In your community, does leprosy cause shame or embarrassment?	23 (54.8)	11(26.2)	5 (11.9)	3 (7.1)
4.	Would others think less of a person with leprosy?	19 (45.2)	19 (45.2)	3 (7.1)	1 (2.4)
5.	Would knowing that someone has leprosy have an adverse effect on others?	12 (28.6)	24 (57.1)	6 (14.3)	0
6.	Would other people in your community avoid a person affected by leprosy?	21(50)	16 (38.1)	4 (9.5)	1 (2.4)
7.	Would others refuse to visit the home of a person affected by leprosy?	26 (61.9)	11 (26.2)	3 (7.1)	2 (4.8)
8.	Would people in your community think less of the family of a person with leprosy?	20 (47.6)	18 (42.8)	4 (9.5)	0
9.	Would leprosy cause problems for the family?	16 (38.1)	12 (28.6)	13 (30.9)	1 (2.4)
10.	Would a family have concern about disclosure if one of their members had leprosy?	12 (28.6)	18 (42.9)	10 (23.8)	2 (4.8)
11.	Would leprosy be a problem for a person to get married?	3 (7.1)	26 (61.9)	9 (21.4)	4 (9.5)
12.	Would leprosy cause problems in an ongoing marriage?	10 (23.8)	25 (59.5)	5 (11.9)	2 (4.8)
13.	Would having leprosy cause a problem for a relative of that person to get married?	10 (23.8)	24 (57.1)	6 (14.3)	2 (4.8)
14.	Would having leprosy cause difficulty for a person to find work?	14 (33.3)	14 (33.3)	7 (16.7)	7 (16.7)
15.	Would people dislike buying food from a person affected by leprosy?	18 (42.9)	14 (33.3)	8 (19.4)	2 (4.8)

0= No, 1= Do not know, 2= Possibly and 3= Yes * Question 2 is reverse coded.

[Table/Fig-2]: Summary of EMIC stigma scale questionnaire for perceived stigma.

Out of the total EMIC score of 45, the average EMIC score was 13.3±9.6. Out of 42, 10 (23.8%) respondents were found to experience stigma related to leprosy. Among the 42 patients interviewed, 26 (61.9%) were newly diagnosed and had yet to start MDT treatment, while the remaining 16 were already undergoing MDT.

[Table/Fig-3] shows that the majority of illiterate patients suffered from stigma. Regarding treatment status, seven out of ten patients who were already receiving treatment also suffered from stigma, and this association was found to be statistically significant (p-value <0.05). Patients with more than five family members also experienced stigma, and this too was statistically significant (p-value <0.05). Furthermore, The majority (nine out of ten) patients with stigma were underweight with a BMI <18.5 kg/m^2,which was

Variables		Stigma		Total	p-value
		Yes	No		
No. of family members	<=3	3	8	11	0.007
	4 to 5	1	19	20	
	>5	6	5	11	
BMI category (kg/m_2)	<18.5	9	13	22	0.008
	18.5-24.9	0	18	18	
	25-29.9	1	1	2	
Treatment started	No	3	23	26	0.027
	Yes	7	9	16	
Marital status	Married	8	19	27	0.468
	Unmarried	2	12	14	
	Widow	0	1	1	
Education	High school	0	2	2	0.48
	Higher secondary	0	3	3	
	Illiterate	6	14	20	
	Middle school	3	4	7	
	Post graduate	0	1	1	
	Primary school	1	8	9	
Occupation	Business	0	2	2	0.459
	Carpenter	0	1	1	
	Daily wage worker	3	4	7	
	Farmer	0	1	1	
	Homemaker	2	1	3	
	Tea garden worker	2	13	15	
	Painter	0	1	1	
	Student	0	2	2	
	Unemployed	3	7	10	
Category	Paucibacillary (PB)	1	18	19	0.013
	Multibacillary (MB)	9	14	23	

[Table/Fig-3]: Factors associated with stigma in leprosy.

statistically significant (p-value <0.05). Additionally, nine out of ten patients who suffered from stigma had MB leprosy, and this association was statistically significant (p-value <0.05).

[Table/Fig-4] presents the socio-demographic profile of the close contacts of the leprosy patients in the study, with the majority being in the age group of 41-50 years and predominantly female. Most of them were married and had education levels up to middle school. A majority were homemakers by profession, followed by daily wage workers.

The SDS was applied to 14 respondents who were close contacts. Out of a total SDS score of 21, the average score for the SDS was 9.8±4.9. The majority, i.e., eight out of fourteen respondents, had scores higher than the average mean for the SDS, indicating unwillingness to maintain closeness or social interactions with leprosy patients [Table/Fig-5].

Variables		Frequency (%)
Age group (years)	11-20	2 (14.3)
	21-30	3 (21.4)
	41-50	4 (28.6)
	51-60	3 (21.4)
	61-70	2 (14.3)
Gender	Female	10 (71.4)
	Male	4 (28.6)
Marital status	Married	11 (78.6)
	Unmarried	2 (14.3%)
	Widow	1 (7.1)
Educational status	High school	1 (7.1)
	Higher secondary	2 (14.3)
	Secondary school	1 (7.1)
	Middle school	5 (35.7)
	Primary school	4 (28.6)
	Illiterate	1 (7.1)
Occupation	Daily wage worker	5 (35.7)
	Homemaker	6 (42.9)
	Hotel worker	1 (7.1)
	Unemployed	2 (14.3)

[Table/Fig-4]: Socio-demographic details of close contacts of leprosy patients.

S. No.	SDS questions	Definitely willing	Probably willing	Probably not willing	Definitely not willing	Total
1.	How would you feel about renting a room in your home to someone with leprosy?	3	4	2	5	14
2.	How about being a worker on the same job with someone with leprosy?	4	4	2	4	14
3.	How would you feel having someone with leprosy as a neighbor?	3	4	3	4	14
4.	How about having someone who had leprosy earlier as care taker of your children for a couple of hours?	1	3	2	8	14
5.	How about having one of your children marry someone who had leprosy earlier?	4	0	5	5	14
6.	How would you feel about introducing someone who had leprosy earlier to your friend?	9	2	2	1	14
7.	How would you feel about recommending someone who had leprosy earlier For a job working for a friend of yours?	9	2	3	0	14

[Table/Fig-5]: Summary of SDS responses of close contacts of leprosy patients.

DISCUSSION

In this study, the majority of the participants (32 or 76.2%) were male, with a mean age of 32.6±13.7 years. In contrast, a study conducted by Arudchelvam et al., found that 71.6% of participants were male, with a mean age of 45.93±12.8 years [22].

In the present study, 22 (52.4%) of the patients were underweight, with a BMI<18.5 kg/m^2, while 18 (42.9%) had a normal BMI (18.5-24.9 kg/m^2). Conversely, in a study by Jindal R et al., 7 (14%) had a low BMI (underweight), and 30 (60%) had a normal BMI. It is important to note that nutritional status significantly contributes to regulating immune response against *Mycobacterium leprae*. Undernutrition has been identified as an important risk factor predisposing individuals to develop leprosy, and it may also affect treatment response [23].

In this study, 33.3% of patients indicated that having leprosy would not cause difficulty in finding work. This finding was similar to that of Marahatta SB et al., which revealed that participants perceived that individuals affected by leprosy would not face employment issues if they were skilled and physically capable [24]. However, this perception depended on both the physical status of the patient and the extent of deformity. A study by Sharma L et al., also mentioned that participants in their in-depth interviews noted there was no discrimination in workplace policies during recruitment or employment. They were hired based on their proficiency at work; however, they reported taking more leave and being absent from work due to treatment-related reasons, particularly during periods of reactions, which affected their daily wages and monthly income [13]. In this study, the majority of the participants were married (27, 64.3%), which was similar to the findings in the study by Murphy-Okpala N et al., where it was 63.9% [25].

The EMIC-SS and SDS Scale have been validated for assessing perceived stigma among leprosy patients in various studies. The EMIC-CSS questions are phrased more generally (for example, “In your community, does leprosy cause shame or embarrassment?”), while the SDS questions are directed personally at the respondent (for example, “How would you feel about having someone with leprosy as a neighbor?”). Using both the EMIC-CSS and SDS allows for the exploration of community and personal attitudes towards individuals affected by leprosy as well as the perceived stigma experienced by the patients suffering from leprosy [21].

The average EMIC score found in the current study was 13.3±9.6, while the SDS score was 9.8±4.9. In contrast, the study by Murphy-Okpala N et al., reported an EMIC score of 18.96±7.73 and an SDS score of 9.39±7.03. These scores are comparable, indicating that the level of stigma towards leprosy patients is prevalent regardless of geographical location [25]. This also suggests similar attitudinal preferences or willingness to maintain closeness or social interactions with patients suffering from leprosy.

In the current study, the perceived stigma measured by the EMIC scale was found to be 23.8% among the leprosy patients. Conversely, a systematic review conducted by Adhikari B et al., reported that out of seven studies focusing on perceived stigma, one study conducted in Indonesia found that 35.5% of participants affected by leprosy experienced perceived stigma. In the same study, community perceptions of stigma towards leprosy were assessed, revealing a range from 18% to 50% [26].

In this study, factors such as the number of family members, the BMI of the patient, treatment status, and the category of leprosy (i.e., MB/PB) were found to be statistically significantly associated with the presence of perceived stigma, resulting in higher mean EMIC scores among the patients. However, the factors of educational status, marital status, and occupation of the leprosy patients were not statistically significant regarding stigma. This finding was supported by a study conducted by Adhikari B et al., where it was observed that there was a significant difference in EMIC scores among participants with disfigurement or deformities (p-value=0.014), ulcers (p-value=0.022), and odorous ulcers (p-value=0.043) compared to those who did not, indicating that MB leprosy patients with deformities were at greater risk of experiencing stigma. The same study also found that occupation was not associated with stigma, which aligns with the findings of the current study. However, the factor of educational status was found to be significantly associated, while treatment status was not significantly associated, unlike in the current study [27].

Limitation(s)

The sample size of the study was small, and certain categorisations of the participants regarding specific parameters, such as place of residence (rural/urban) and socio-economic status, could not be included. The diagnoses were based on clinical criteria, and split skin smears were not used, as the district Leprosy Team relied on clinical diagnosis for treatment initiation.

CONCLUSION(S)

The present study provides important insights regarding the perceived stigma associated with leprosy. Factors such as a larger number of family members, nutritional status indicated by BMI, and treatment status were found to be significantly associated with stigma. It is well recognised that with holistic improvements across sectors, including social, educational, and economic areas, along with behavioural change initiatives and advancements in management (such as multidrug therapy and reconstructive surgery), the stigma and prejudice long associated with leprosy have been significantly reduced.

With the effective implementation of the National Leprosy Eradication Programme, the eradication of leprosy in the country is on track. However, there still remain pockets with a high incidence and prevalence of leprosy, especially in the Tea Garden areas of Assam, which symbolise a lack of awareness, education, healthcare access, and social taboo in those regions. Such areas need to be mapped, and more intense active case finding should be implemented to detect cases early.

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