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**Short Report**

# Knowledge, attitude and stigma experienced by leprosy patients in tribal concentrated Bastar district of Chhattisgarh, India

**Swapan Kumar Kolay[a], Samiran Bisai[b], Ranabir Pal[c], Pradip Kumar Mohanta[d], Debabrata Sarbapalli[e]**

[a] Assoc. Prof.,Head, School of Anthropology&TribalStudies, BastarUniversity, Dharampura, Jagdalpur, Bastar, India

[b]Deputy Director, Cultural Research Institute, BCW & TD Department, Govt. of West Bengal, Kolkata, India

[c] Additional Professor, Department of Community Medicine and Family Medicine, All India Institute of Medical Sciences (AIIMS), Jodhpur-342 005, Rajasthan, India

[d]Department of Surgery, College of Medicine & JNM Hospital, Kalyani, Nadia, West Bengal, India

[e]West Bengal University of Health Sciences, Salt Lake City, Kolkata, West Bengal, India

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## Abstract

**Objective:** To study leprosy patients in tribally concentrated Bastar district of Chhattisgarh, India in terms of their knowledge, attitudes and the stigma they have experienced. **Method:** This cross-sectional study included 101 registered Leprosy patients, in a single leprosy treatment centre between April, 2012 - June, 2013. The data collection tool (a pre tested close-ended questionnaire) was based on leprosy related socio-demographic variables, knowled geregarding different kinds of problems and issues experienced by the patients/participants. The investigators collected the data in face to face interviews and house hold visit. **Results:** Overall the majority of the respondents (85.1%) were between 16 and 60 years of age. 74.3% were males, 80.2% were married, and 54.5% were literate. The majority (67.3%) articulated positive knowledge about transmission of the disease, 75.3% knew that numbness of hands is an early symptom, 88.12% that it is curable, 91.1% had untreated deformities. Experiences reported included disturbed marital relationships (90.1%) orsocial life (94.1%), loss of employment (54.5%), isolation with the sitation to talk to people (29.7%), family members not sharing food (94.1%); being forced to leave the family (54.45%). Health

**Correspondingauthor: Samiran Bisai,** Deputy Director, Cultural Research Institute, Ambedkar Bhaban, P-1/4, Kankurgachi, Kolkata, West Bengal, India, 700054.,
E-mail: sbisai@hotmail.com

education interventions improved the knowledge of 91.1% of participants. Multi-Bacillary leprosy was higher in newly registered cases with higher disabilities in the hands and feet (60.4%), eyes (29.7%). 9.90 WHO grade-2 disabilities were due to a delayed diagnosis. 67.5% of thepatients/participants with some form of disability had experienced a delay in diagnosis of upto 12 months. **Conclusion:** The study noted that the tribal people were affected by leprosy not only in terms of the physical problems, but also by the stigmatization that affects their social participation. These need to be addressed by the progress of the national leprosyp rogram.

**Keywords:** Leprosy, socialstigma, disabilitygrading, India

# Hindistan'da ChhattisgarhBastar Bölgesinde bir köyde lepra hastalarının bilgi, tutum ve damgalama durumu

## Özet

**Amaç:** Bu çalışmanın amacı Hindistan'da Chhattisgarh Bastar Bölgesinde bir köyde lepra hastalarının bilgi, tutum ve damgalama ile ilgili durumlarını incelemekti. **Yöntem:** Kesitsel tipteki bu çalışma bir köyde bulunan lepra tedavi merkezine kayıtlı lepra hastalarında, yaş ve cinsiyetlerine bakılmaksızın Nisan 2012-Haziran 2013 tarihleri arasında yürütüldü. Veri toplama aracı (kapalı uçlu sorulardan oluşan) lepra ile ilgili sosyo-demografik değişkenlere ve hastaların/katılımcıların karşılaştıkları farklı tür problemler ve konular halkındaki bilgilerine dayanmaktaydı. Araştırmacılar veriyi yüz yüze görüşmelerle ve ev ziyaretleri ileelde etti. **Bulgular:** Katılımcıların %85.1'ü 16-60 yaş aralığındaydı, %74.3'ü erkekti, %80.2'si evliydi ve %54.5'i okuryazardı. Katılımcıların %67.3'ü hastalığın bulaşma yolu hakkında doğru bilgiye sahipti, %75.5'i ellerde uyuşmanın erken belirti olduğunu, %88.1'si tedavi edilebildiğini biliyordu ve %91.1'unun tedavi edilmemiş deformasyonları mevcuttu. Bildirilen problemler evlilik ilişkilerinde (%90.1) veya sosyal yaşamda (%94.1) bozulma, işini kaybetme (%54.5), insanlarla konuşmaktan kaçınarak izole olma (%29.7), aile bireylerinin gıdalarını paylaşmaması (%94.1), aileden ayrılmaya zorlanmaydı (%54.5). Sağlık eğitimi müdahale çalışmaları katılımcıların %91.1'inin bilgi durumunu iyileştirdi. Multibasiller lepra ellerde ve ayaklarda (%60.4), gözlerinde (%29.7)daha fazla deformasyonları olan, yeni kayıtlı olgularda daha yüksekti. Ayrıca, bu hastalarda DSÖ'ye göre evre-2 bozukluklar geç tanıya bağlı olarak daha fazlaydı (%9.9). Bir tür deformasyonu olan hastaların %67.5'inde tanıda 12 aya kadar gecikme mevcuttu. **Sonuç:** Bu çalışma, köy halkının sadece fiziksel problemler açısından değil, aynı zamanda topluma katılımlarını etkileyen damgalamayla da cüzzamdan etkilendiğini ortaya koydu. Bu bulguların ulusal Lepra programı yürütülürken ele alınması gereklidir.

**Anahtar kelimeler:** Lepra, sosyal damga, deformasyon evresi, Hindistan

## Introduction

Leprosy still remains endemic in many countries, especially affecting poor rural people. Leprosy affects the peripheral nerves and skin, leading to deformities ranging from loss of eye brows to paralysis of muscles. It produces injury and infection to hands and feet due to loss of sensation, affecting activities of daily living producing serious deformities and disabilities that lead to stigmatization and psychosocial suffering[1,2] Global efforts to eradicate leprosy by multidrug regimens in a closely monitored system were introduced in fourth quarter of last millennium with a notable drop in the incidence and prevalence, although it is still diagnosed from certain endemic areas in the South Asian Association for Regional Cooperation (SAARC) countries including India and also South America[1] Leprosy affects weaker and marginalized sections of society, exposing patients to social stigmas and prejudices associated with leprosy. These still remain major obstacles for its eradication as global phenomenon.[3]

The stigmas remain prevalent basically at the grassroots levels even within families and household circles. These social effects of leprosy devalue the patients, causing patients to run from the homes for mental peace and to beg, or to form peer groups for their basic livelihood.

As a consequence citizens are compelled to hide this curable disease, avoiding diagnosis and early treatment, thus allowing a completely curable disease to worsen to the point of disfigurement with other correlated risks.[4]World leprosy day is observed to promote awareness of the curability if treated, and recognition that, if untreated progressive and permanent damage to the skin, nerves, limbs and eyes occurs. It stresses that leprosy is not highly infectious – transmission being limited to close and frequent contacts with untreated cases.[5]The present study was conducted in order to ascertain the socio-demographic and socio-economic conditions, and the social stigmas attached to the disease as experienced by the leprosy patients in order to recommend optimal policies for dealing with the disease.

## Methods

The participants in this study were receiving curative health care services from the Maharani Hospital, Jagdalpur, which provides medical care for people of Bastar district. According to the latest census (2011) the total population in the district was enumerated as 14, 13,199. Among these 9,31,780 were documented as a tribal population, which formed 65.9 percent of the total population of the district.[6]

In this cross-sectional study the investigators collected data from the registered patients in the hospital for the treatment of leprosy. The study was conducted over fifteen months with collection of the data from April, 2012 to June, 2013.

The participants were identified and selected on the following inclusion criteria:

*1.* The Leprosy patients who had been registered in the hospital.

*2.* The patients had been under medication for the past one year

*3.* They had continued treatment without break.

*Exclusion criteria:* One non-consenting, three non-co-operative and three severely ill patients were excluded from study for ethical reasons.

101 registered leprosy patients who were apt for the inclusion criteria participated in this study. Pre-tested close-ended questionnaires contained questions linking to correlates of stigmas, of the impact and the effects of the stipulated leprosy morbidities in relation to the patients' socio-demographic situation and their knowledge about the disease. This knowledge was based on the efforts of the present National Leprosy Eradication Programme being implemented by the Government of India. The questionnaire was developed at the institute by the investigators with the help of the experts and the questionnaire was pre-tested in ten subjects as a pilot regarding its validity and reliability. Institutional Ethical Committee approved the study. The principal investigator then collected the data by face to face interview through door to

doors visit by using the questionnaire. The purpose of the study was explained to all the patients or their caregivers and they were assured of strict confidentiality. Written informed consents were taken from each participant prior to study, with the option not to participate.

*Data analysis:*

After collection of data through the primary source the data were thoroughly cleaned and meticulously entered into a master chart. Thereafter, it was processed through MS Excel package and the results were presented as percentages. The contingency chi-square statistic was employed to test the differences between groups.

## Results

Among 101 Leprosy patients majority of them were males (74.3%), and married (80.2%). In age group distribution, among 16-30 years was 14.9%, 31-45 years 24.8%; 45.5 % and 8.9% respectively were in the age group of 46-60 years and above 60 years. Of all cases, the majority (54.5%) were literate, and of these 31.9% had completed primary education and 26.7% could only read and write. The corresponding rate for having passed middle school was identical (26.7%). 8.9 and 5.9 percent patients had completed the 10th and 12th years of school respectively. As regards the different occupations of the respondents, 40.6 percent had started working inside the leprosy center as fruit sellers, vegetable sellers or as cobblers while 20.8 percent had started working as welfare workers inside the leprosy center. 28.7% of the families had an annual income of more than Rs.1,00,000 ($1500), and 24.8% patients had an income from Rs. 50,001 to 1,00,000 ($750-1500), whereas 17.8% of families had an annual income of less than Rs. 12,000 ($200). 29.7 percent had an annual family income ranging between Rs. 12,001 - 50,000 ($200-750)/year.

Regarding the knowledge of the participants about leprosy, 61.4% stated that leprosy is transmitted by touching, whereas 8.9 percent considered leprosy as a hereditary disease; 23.8% knew it as a communicable disease. About 75.3% of the patients had noticed numbness of the hands as an early symptom of leprosy, while 11.9% noticed a discolored skin patch. 88.1% had satisfactory knowledge regarding the curability of Leprosy; 91.1% knew that leprosy causes deformities and that there is no vertical transmission (91.1%). On enquiry 85.2% of the respondents replied that they did not have any proper knowledge about leprosy before they contracted the disease (Table 1).

94.1% of the respondents stated that, after they were diagnosed with leprosy they noticed that their social life was affected, 54.5% lost their jobs an 29.8% hesitated to talk to people. Other social problems reported were isolation in the form of hesitation to go people (75.3%) and attending social gatherings (87.1%); 90.1% reported that even their marital life was affected after they contracted the disease. Family members refusing to eat with the patients were reported by 94.1%. About 54.5% were forced to leave their family. An overwhelming majority (98.0%) expressed their satisfaction with the treatment; while of 91.1% felt that the Health education imparted by the National Leprosy Eradication Programme had improved their knowledge of the disease (Table 2).

Leprosy cases were clinically classified into Paucibacillary and Multibacillary leprosy by the WHO study group on chemotherapy of leprosy. In our study population Multi bacillary (MB) Leprosy was higher in newly registered patients. Overall 85.1%were between 16-60 years of age; only 15 (14.9%) cases were either below 16 years or above 60 years of age (Table 3).

**Table 1.** Knowledge of respondentsregardingLeprosy of 101 respondents

| Variables (n=101) | Responses | Number | % |
|---|---|---|---|
| Transmission of leprosy | Touching (correct) | 62 | 61.4 |
| | Sneezing (correct) | 6 | 5.9 |
| | By foodstuffs | 13 | 12.9 |
| | Hereditary | 9 | 8.9 |
| | Divine effect | 8 | 7.9 |
| | Unknown | 3 | 3.0 |
| Early symptom | Numbness of hand (correct) | 76 | 75.3 |
| | Discolored skin patch (correct) | 12 | 11.9 |
| | Auto-amputation | 6 | 5.9 |
| | Deformed nasal bridge | 3 | 2.9 |
| | Thickened nerves under skin (correct) | 2 | 2.0 |
| | Thickened ear lobes (correct) | 2 | 2.0 |
| Communicable disease | Yes (correct) | 24 | 23.8 |
| | No | 77 | 76.2 |
| Curable disease | Yes (correct) | 89 | 88.1 |
| | No | 12 | 11.9 |
| Deform body parts | Yes (correct) | 92 | 91.1 |
| | No | 9 | 8.9 |
| Develop numb skin patch | Yes (correct) | 21 | 20.8 |
| | No | 80 | 79.2 |
| Vertical transmission | Yes | 9 | 8.9 |
| | No (correct) | 92 | 91.1 |
| Transmission through breast feeding | Yes | 5 | 5.0 |
| | No (correct) | 96 | 95.1 |
| Knowledge before diagnosed with disease | Yes (correct) | 15 | 14.9 |
| | No | 86 | 85.2 |

We noted that the disability rate was 60.4 percent for hands and feet while ophthalmic disabilities were found in 30 patients (29.7%). Unfortunately among all the cases, WHO grade-2 disabilities were observed among 9.90 percent in our series. The disability rate was higher in the Multi-Bacillary patients (11.3%) than in the Pauci-Bacillary patient (8.3%) (Table 4).

During our study we noted a regrettable event among the population in this tribal remote area: 40 patients confessed that although they had noted some patches on their body they did not care to get medical help as long as this was a painless morbidity. This was noted irrespective of gender. Majority (67.5%) of the patients with some form of disability had delayed in diagnosis of leprosy cases byup to 12 months. Subjects with delayed diagnosis longer than 12 months had 40 percent grade-2 disabilities (Table 5).

**Table 2.** Reportedattitudes of thecommunitytowardsleprosypatients

| **Variables (n=101)** | **Response** | **Number** | **%** |
|---|---|---|---|
| Leprosy affected social life | Yes | 95 | 94.1 |
| | No | 6 | 5.9 |
| Fired from the job | Yes | 55 | 54.5 |
| | No | 46 | 45.6 |
| Hesitation to talk with the people | Yes | 30 | 29.7 |
| | No | 71 | 70.3 |
| Not to go near to others | Yes | 76 | 75.3 |
| | No | 25 | 24.8 |
| Hesitation to attend social gathering | Yes | 88 | 87.1 |
| | No | 13 | 12.9 |
| Affected marital life | Yes | 91 | 90.1 |
| | No | 10 | 9.9 |
| Refusal to eat with the patient | Yes | 95 | 94.1 |
| | No | 6 | 5.9 |
| Forced to leave the family | Yes | 55 | 54.5 |
| | No | 46 | 45.6 |
| Satisfaction of the patient with the treatment | Yes | 99 | 98.0 |
| | No | 2 | 2.0 |
| Health education has improved the knowledge regarding leprosy* | Yes | 92 | 91.1 |
| | No | 9 | 8.9 |

*: From National Leprosy Eradication Programme by Government of India

**Table 3.** Distribution of Leprosyrespondentsaccordingtoage, genderandtype of Leprosy

| Age (Year) | Paucibacillary (PB) Leprosy | | | | Multibacillary (MB) Leprosy | | | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | Total | | | | Total | | | |
| | Male | Female | Number | % | Male | Female | Number | % | Number | % |
| Less than 15 | 1 | 2 | 3 | 6.3 | 2 | 1 | 3 | 5.7 | 6 | 5.9 |
| 16 – 30 | 9 | 1 | 10 | 20.8 | 4 | 1 | 5 | 9.4 | 15 | 14.9 |
| 31 – 45 | 2 | 4 | 6 | 12.0 | 17 | 2 | 19 | 35.9 | 25 | 24.8 |
| 46 – 60 | 19 | 7 | 26 | 54.2 | 16 | 4 | 20 | 37.7 | 46 | 45.5 |
| Above 60 | 2 | 1 | 3 | 6.3 | 3 | 3 | 6 | 11.3 | 9 | 8.9 |
| Total | 33 | 15 | 48 | 47.5 | 42 | 11 | 53 | 52.5 | 101 | 100.0 |

**Table 4.** Distribution of Leprosyrespondentsaccordingto WHO grades of disability

| Grade of disability | Paucibacillary (PB) | | Multibacillary (MB) | | Total | |
|---|---|---|---|---|---|---|
| | Number | % | Number | % | Number | % |
| Grade – 0 | 33 | 68.8 | 28 | 52.8 | 61 | 60.4 |
| Grade – 1 | 11 | 22.9 | 19 | 35.9 | 30 | 29.7 |
| Grade – 2 | 4 | 8.3 | 6 | 11.3 | 10 | 9.9 |
| Total | 48 | 47.5 | 53 | 52.5 | 101 | 100.0 |

$X^2$ = 2.702, df=2, p=0.259

**Table 5.** Leprosyrespondentswithdisabilitiesaccordingtodelay in diagnosis.

| Delay in diagnosis | Disability grading | | | | | |
|---|---|---|---|---|---|---|
| | Grade – 1 | | Grade – 2 | | Total | |
| | Number | % | Number | % | Number | % |
| Less than 12 months | 21 | 70.0 | 6 | 60.0 | 27 | 67.5 |
| 12 months and more | 9 | 30.0 | 4 | 40.0 | 13 | 32.5 |
| Total | 30 | 75.0 | 10 | 25.0 | 40 | 100.0 |

$x^2$ =0.333, df=1, p=0.5637.

## Discussion

Three million people worldwide are estimated to be disabled by the consequences of this chronic, debilitating disease, with much co-morbidity and many personal implications.[7] India still has a huge load of Leprosy cases with a prevalence rate of 0.69 per 10,000 populations (2011). Furthermore, the Leprosy cases were not evenly distributed between states in the India. The highest rates have been reported from Chhattisgarh state where the prevalence rate was 1.69 per 10,000 population. This was the reason that we were interested to find reasons to seek solutions.[8] The government of India has taken many steps to eliminate Leprosy through expand the coverage as well as improve the quality of services in the inaccessible regions.[9]

WHO has recommended that multi-drug therapy (MDT) treatment completion rates should be maintained at around 90-95 percent with a patient friendly system for delivery of MDT that should be flexible with regular contacts between patient and the health workers.[10] In a retrograde cohort study done in the Kamrup district of Assam, India, different socio-demographic variables affected the success of the delivery of treatment. In registered causes ranged from loss of occupational hours to fear of social stigma affected the patients' search for treatment.[11]

The definition of the International Classification of Functioning, Disability and Health not only considers disability in medical terms but also recognizes the social context of disability as a negative factor where leprosy patients with grade 2 disability fear about stigmatization and discrimination, and experience serious psychosocial and economic problems.[12] Investigators from Nepal have suggested that there is an urgent need of rehabilitation for the patients who have already developed irreversible disabilities and have emphasized the legal, social, religious, medical and occupational aspects.[13]The strategy of WHO for leprosy elimination encourages self-reporting and early treatment by promoting community awareness and changing the image of leprosy. This includes increased empowerment of people affected by the disease, together with their greater involvement in services and community, which will bring us closer to a world without leprosy.[7]

In our series the disability rate was 60.40 percent for hands and feet while ophthalmic disability was less (29.7%); WHO grade-2 disabilities were 9.9% and more in Multi-Bacillary cases. Leprosy is a leading cause of permanent disability among communicable diseases globally with an estimated three million people living with disabilities due to leprosy. It is expected that up to one million people will continue to suffer from this disability in the next decades.[14]

Overall 85.1 percent of the patients were between 16-60 years of age, the economically productive age group in this subcontinent. Multi bacillary leprosy was higher in the newly registered patients and they had higher numbers of grade 2 disabilities. An analytic cross-sectional study carried out in the Dhanusha district of Nepal has also noted similar observations, males with 68.3% having MB-MDT) and females with 61.1% having MB-MDT.[15] The male preponderance may be explained by lesser health care of women in the underdeveloped SAARC countries for which there is a dire need of women empowerment.

The causes and manifestations of stigmas may differ among different cultures, but the effects of stigmas on individuals and families are remarkably similar across cultures. The same is true for interventions for stigma reductions; although these may need to be culturally adapted to the local context before implementation.[16] We appeal to the human rights community around the world to remind citizens of all countries of their obligations at every opportunity under human rights law to ensure a world free of stigmas and prejudices regarding Leprosy even where the disease does not exist.

A multipronged strategy should be initiated with Behavioral Change Communication (BCC) as the mainstay to remove this curable disease from the globe, which should be possible since so far no resistance has been reported to the anti-leprosy drugs. Future phases of our research should involve a larger community based study, which will, we hope, incorporate self-stigma as a matter of priority and use a comprehensive assessment of self-stigma regarding other diseases as well.

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