

Leprosy Awareness, Knowledge and Attitude in the Community Across Three Endemic States in India: A Cross-sectional Study

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In India since the declaration of elimination of leprosy there has been a consistent increase in the proportion of grade 2 disability at the time of diagnosis, in spite of all efforts made by the program, indicating the delayed diagnosis of disease. The awareness about leprosy in the community is critical for early case detection. The objective of the study was to assess the level of knowledge regarding leprosy, and the attitude towards leprosy and affected people in the community. This cross-sectional study was a part of a larger research project - comparing three community-based interventions to enable early diagnosis of leprosy. A total of 10 blocks were surveyed across 5 districts from 3 endemic states (Uttar Pradesh, West Bengal and Chhattisgarh), 450 respondents, 45 from each block, were interviewed using a semi structured questionnaire in the local language. Regarding knowledge on leprosy, only 56.9% considered skin patches as a sign of leprosy, only 37% knew that leprosy is caused by a germ and only 30% knew, it spreads through coughing/sneezing from an untreated case. Regarding attitudes, 51% believed "Leprosy patients undergoing treatment should be in hospital" and 32% opined that "People should avoid seeking treatment from a centre where leprosy patients are being treated". According to respondents, the most preferred method to spread awareness about leprosy was a sensitization meeting at the community level (39.5%) by a staff of the public health program. The community, overall, had inadequate knowledge of and unfavourable attitudes towards leprosy, which may deter early detection of the disease.

Key words : Leprosy Knowledge, Attitude Towards Leprosy, Case Detection Methods, Leprosy

Introduction

As per WHO, during the fiscal year 2018, 120,334 new cases were detected in India which is about

57.7% of world's leprosy cases (WHO 2019). Although leprosy was declared as "eliminated" as a public health problem in India in December

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2005, new cases continue to occur without any significant decline in numbers, reflecting continued transmission of leprosy in the community. Since then there has been very little change in the number of new cases which hover between 120,334 and 135,485. In spite of effective coverage with Multi Drug Therapy (MDT), as per the National Leprosy Eradication Program (NLEP) report, as on 31st March 2016, there are 183 high endemic districts in India with the Annual New Case Detection Rate of >10 per 100,000 populations in these districts (NLEP 2016). However, the population based surveys from the endemic states of Uttar Pradesh and Maharashtra, report that the undetected cases in the community are much higher than the reported cases (Shetty et al 2009, Kumar et al 2013). In addition, as per the national report, since 2005 there is an increasing trend of patients with grade 2 disabilities at the time of diagnosis coupled with a similar trend in new child leprosy cases, which is an indication of delayed reporting and continued transmission of disease in the community.

Leprosy is one of the oldest diseases afflicting mankind (Pandya 2010) and yet it is still surrounded by lack of knowledge, misconceptions and superstitions about its causes, mode of transmission, development of deformity and treatment, which has been continuously fuelling the stigma associated with this disease (Rao et al 2008, John & Rao 2009, Thilakavathi et al 2015). The lack of knowledge and certainly the social stigma often lead those affected to delay seeking help for their symptoms (Muthuvel et al 2017). As a result, patients report to health care providers, often with established irreversible impairments, when the disease condition becomes too severe to ignore. Consequently, the infection-disease cycle of leprosy is perpetuated, at least in some regions of the country, which is perhaps reflected

in the burden of the disease in the high endemic districts, even more than a decade after "elimination". Therefore, if we are to reach the 'Zero Transmission' goal set by WHO, we need to make concerted efforts to increase community awareness, so that care-seeking by patients with symptoms of leprosy, at an earlier stages of their disease, become a common practice (WHO 2016). Therefore, this study aimed to assess the knowledge and attitude towards leprosy and people affected in the community. This study is part of a larger study on comparing three community-based interventions to promote early detection of leprosy, which is funded by the Leprosy Research Initiative. One of the interventions in this project was improving the awareness about the leprosy in the community to promote early detection of leprosy through Information, Education and Communication (IEC) activities. This data was collected to understand which aspects of leprosy needed to be focused on during the intervention phase of the study.

Materials and Methods

Site : This report was a baseline study on level of awareness about leprosy of a large research project conducted in 40 blocks, in five districts from three states endemic for leprosy, West Bengal, Chhattisgarh and Uttar Pradesh. The research project tested three community-based education methods to promote early detection of leprosy; 1) Education of index case to identify cases among their contacts, 2) sensitization of non-formal health practitioners on early signs and symptoms of leprosy and referral to health facility for diagnosis and 3) to increase awareness about leprosy in the community. In this report, we will report the level of awareness about leprosy measured as part of baseline survey before the implementation of the third intervention mentioned above. The district and the blocks selected

for the baseline data collection is shown in the Table 1.

At each district, 2 blocks were assigned for IEC intervention and the survey was carried out in a total of 10 blocks with an average population of over 150,000 per block. All the study sites were in rural areas.

Subjects : The respondents were selected by stratified sampling which included community leaders, Village Health & Sanitation Committee members, teachers, school & college students, housewives, skilled & unskilled labourers, Village elders and people affected by leprosy. The community leaders were informed about the data collection in advance for their cooperation. The interview was conducted after obtaining an informed consent. A sample size of 450 was determined. A total of 90 respondents were included in each of five sites, 45 from each block.

The data was collected before the initiation of the intervention during the period October 2015 to February 2016.

Data collection tool : A semi-structured interview schedule was developed in English and translated into the local language at each site. The question-

naire was pilot tested in the field and minor modifications were made. The questions included socio-demographic details, awareness about leprosy, knowledge and attitude towards leprosy. The 'awareness' questions were related to knowledge about causes of leprosy, early signs, spread and, treatment. The attitude towards leprosy was assessed based on predefined questions and recorded on a five-point Likert scale as strongly agree, agree, don't know, disagree and strongly disagree. The questionnaire was administered by the Field Investigators of the project, who were given a standardized training on interviewing techniques.

Six questions were asked to assess the knowledge about leprosy. Correct response to each question were given a score of 1, maximum possible knowledge score was 6. The knowledge score was dichotomized as 'good' for those with score 3 and above and 'poor' for those below 3 of the total knowledge score. Six questions were asked to assess the attitude towards leprosy. Positive responses were given a score of 1 (Disagree and strongly disagree), other responses were considered as negative attitude and no score was

Table 1 : Name of the selected districts and blocks where IEC baseline survey was conducted

State	Districts	Blocks selected
West Bengal	Uttar Dinajpur	Raiganj
		Hemtabad
	Paschim Medinipur	Garhbeta II
		Garhbeta III
Chattishgarh	Bilaspur (36.49)	Biha
		Masturi
Uttar Pradesh	Deoria	Baitalpur
		Rampur karkhana
	Allahabad	Jasra
		Sankargarh

given, to obtain an attitude score. The attitude score was dichotomized as positive for those with score 3 and above and negative attitude for those with below 3 of the total attitude score. These scores were used to assess the association between various factors associated with knowledge and attitude.

Analysis : The data was entered in Microsoft Office Excel and analysed using SPSS 16. Descriptive statistics were used to describe the main results. Pearson's chi-square test was used

to understand the various factors associated with knowledge about leprosy and attitude towards leprosy and affected people.

Ethics approval from the study was approved by The Leprosy Mission Trust India Ethics Committee. The record number of the approval letter is EC070415 No: 6/15/a. Informed consent was obtained from all the study participants.

Results

As this is a study based in rural areas, all the 450 study participants were from a rural background.

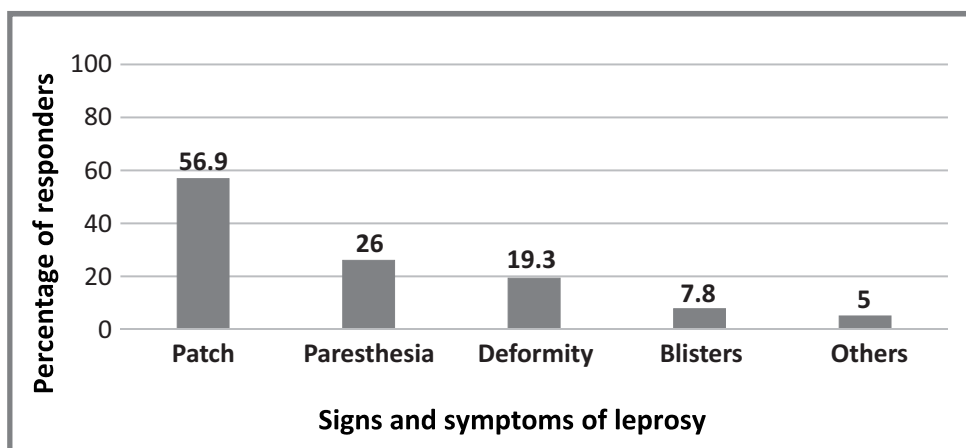


Fig. 1 : Knowledge on early signs and symptoms of leprosy (multiple response recorded), (n=450)

Table 2 : Characteristics of study participants

	Characteristics	N=450 (%)
Gender	Male	294 (65%)
	Female	156 (35%)
Education	Illiterate	51(11.3%)
	Primary	68(15.1%)
	Secondary	138(30.7%)
	Graduate & above	193(42.9%)
Marital status	Never married	114 (25.3%)
	Married& living with spouse	327 (72.7%)
	Divorced/Widow	9 (2%)

Table 3 : Knowledge about spread of leprosy (multiple response recorded), (n=450)

Spread of Leprosy	N	%
Through blood	190	42.2
Through coughing/sneezing	139	30.9
Sharing room with affected person	96	21.3
Mother to child	43	9.6

Table 4 : Attitude towards leprosy among community members (n=450)

Attitude related questions	Strongly agree (%)	Agree (%)	Don't know (%)	Disagree (%)	Strongly disagree (%)
1 Children should not play with other children from leprosy affected families	59 (13.1)	150 (33.3)	17 (3.8)	123 (27.3)	101 (22.4)
2 One should not share / food with person affected by leprosy	99 (22)	125 (27.8)	18 (4)	156 (34.7)	52 (11.6)
3 Leprosy patients undergoing treatment should be hospitalized	108 (24)	122 (27.1)	24 (5.3)	155 (34.4)	41 (9.1)
4 One should not mingle with persons affected by leprosy	80 (17.8)	78 (17.3)	16 (3.6)	221 (49.1)	55 (12.2)
5 One should avoid seeking treatment from a health centre where leprosy affected are being treated	43 (9.6)	59 (13.1)	43 (9.6)	237 (52.7)	68 (15.1)
6 Leprosy patients should not be allowed in social functions	71 (15.8)	79 (17.6)	19 (4.2)	221 (49.1)	60 (13.3)

The mean age of the participants was 37 (SD 14) years (age range, 14 to 68 years). Their characteristics are given in Table 2.

When asked about what the early signs of leprosy are, as shown in Fig. 1, about half the participants (56.9%) knew that patches on the skin could be an early sign of leprosy and about a quarter said that paraesthesia (tingling and numbness sensation)

as early sign. About 19% of respondents said that visible deformities such as claw fingers, foot drop as early sign.

When asked about cause of leprosy, less than 38% said that germs are the cause of leprosy. The majority (41.6%) believed that the disease causation was primarily blood-related and still some believe (10.4%) that it is an inherited disease.

Table 5 : The most common source of information about health (only one response was recorded)

Source of information	n=450	%
Health facilities	89	19.8
ASHA* / ANM**	77	17.1
Community health program	39	8.7
Other leprosy patients	17	3.8
Television / Radio	14	3.1
Doctor	11	2.4
Wall paintings / poster	7	1.6
Don't know	196	43.6
Total	450	100

*Accredited Social Health Activist, ** Auxiliary Nurse Midwifery

Table 3 shows the knowledge about transmission (spread) of leprosy. Majority (42.2%) said that the leprosy spreads through blood, while 30.0% of participants said that it spreads through coughing and sneezing; transmission was ascribed to sharing a room with affected person and from mother to child by, 21.3% and 9.6% respondents, respectively.

Attitudes towards leprosy is illustrated in Table 4. On positive attitude, 32% of participants opined that "people should avoid seeking treatment from a centre where leprosy patients are being treated". More than half the respondents, 51% believed that "patients undergoing medical treatment for leprosy should be in hospital".

The most common source of information is from health facility nearest their homes and health worker in the community including ASHA and ANM. Television and Radio had minimal reach. More than 40% of respondents said "not heard about leprosy", shown in Table 5.

Participants were asked about where they usually get information related to health to understand the source of information. Majority of them said that they received information from ASHA and ANM (32.7%) through health talk in their

respective village, followed by health facilities (23.1%), through medical officer (9.1%), through television and radio (8.9%) and from fellow villagers (6.7%). Around 15.3% were not sure about the source of information related to health.

Study participants were asked to indicate the most preferred mode of education to spread awareness about leprosy in the community. Sensitization about leprosy at the community level through health talks at village meetings, involving members from Panchayat Raj Institutions (PRI) was reported to be the most preferred mode of imparting awareness (39.5%), followed by posters (9%), and rallies with school children (8.4%). The less preferred mode was through ASHA (1.3%), followed by health camps 2.9% and door to door information sharing (6%).

Association of demographic factors with Knowledge and Attitude : Education was found to be associated with the level of knowledge and attitude towards leprosy. Monthly income was taken as a proxy indicator for socio-economic status of the responder, which was strongly associated with knowledge and attitude. Those from better socio-economic backgrounds had a good level of knowledge about leprosy and a

Table 6 : Factors associated with knowledge and attitude

	Factors	Knowledge on leprosy		Attitude towards leprosy	
		Good	Poor	Positive	Negative
Gender	Male	153 (52%)	141 (48%)	187 (64%)	107 (34%)
	Female	92 (59%)	64 (41%)	113 (72%)	43 (28%)
		$\chi^2=1.975$, p-value=>0.05		$\chi^2=3.576$, p-value=0.059	
Age	35 and below	131 (57%)	101 (43%)	163 (70%)	69 (30%)
	36 and above	114(52%)	104 (48%)	137 (63%)	81 (37%)
		$\chi^2=0.789$, p-value=>0.05		$\chi^2=2.780$, p-value=>0.05	
State	UP	97 (54%)	83 (46%)	116 (64%)	64 (36%)
	Chhattisgarh	43 (48%)	47 (52%)	64 (71%)	26 (29%)
	West Bengal	105 (58%)	75 (42%)	120 (67%)	60 (33%)
		$\chi^2=2.733$, p-value=>0.05*		$\chi^2=1.200$, p-value=>0.05*	
Education level	Up to primary	45 (38%)	74 (62%)	63 (53%)	56 (47%)
	Secondary & above	200 (60%)	131 (40%)	237 (72%)	94 (28%)
		$\chi^2=18.038$, p-value=<0.001		$\chi^2=13.715$, p-value=<0.001	
Socio-economic status	Low	110 (48%)	121 (52%)	140 (61%)	91 (39%)
	High	135 (62%)	84 (38%)	160 (73%)	59 (27%)
		$\chi^2=8.915$, p-value=<0.05		$\chi^2=7.846$, p-value=<0.05	

*df=2

positive attitude towards leprosy affected person. Other factors such as gender, age and state from where the study participants were included were not associated with knowledge and attitude about leprosy, shown in Table 6.

Association between knowledge and attitude : Those with good level of knowledge about leprosy had positive attitudes towards leprosy. However, 25% of people among those with good level of knowledge about leprosy had negative attitudes towards leprosy, indicating that the knowledge doesn't always change the attitude.

Discussion

After the declaration of elimination of leprosy as a Public Health problem, the National Leprosy Eradication Programmes was integrated and

leprosy work became the responsibility of general health care staff. The general health staff were already involved in multiple programmes, and were not as skilled or experienced in leprosy, as the NLEP staff had been, neither did they have specific training on leprosy. Active case finding was discontinued, and it was hoped that community awareness activities would encourage people to report to health providers if they had any suggestive signs of leprosy. Unfortunately, due to the drastic reduction in NLEP staff the awareness campaigns, which were part of the NLEP also declined, so public awareness of early signs, curability and availability of free treatment gradually faded (Barkataki et al 2006, Grewal et al 2013, Singh et al 2012).

These facts have been reported in a number of studies which show the paucity of knowledge about leprosy among community members as well as persons affected by leprosy and community members. A study from Tamil Nadu, reported that there was poor awareness about the signs, symptoms and transmission of the disease, and considerable levels of misconception about transmission among community members. The fear of stigma and discrimination was prevalent among study participants (Thilakavathi et al 2015). Consistent with their findings, in this survey, over 40% of participants ascribed to blood related cause and 10% still believe in hereditary aetiology. About 42% said that the leprosy spread through blood. The situation was not different in Kolkata, a major metropolis, among the urban population, where the members of the community hardly knew of early signs or symptoms of leprosy, where to go for diagnosis and treatment (John & Rao 2009, John et al 2013). In Uttar Pradesh, less than half of the participants were able to say something about signs and symptoms and treatment of leprosy (Barkataki et al 2006). We found that around 56% of participants were able to say that skin patches could be an early signs of leprosy, which is slightly better than their findings, yet inadequate. Seshadri et al (2014) compared knowledge and attitude about leprosy between affected individuals, their family members and the general population. The knowledge score was poor among the general population, as compared to patients with leprosy, but even among the patients themselves knowledge was not satisfactory (Seshadri et al 2014). These findings emphasize the need for continuous education about leprosy in the community.

The time-honoured methods for raising awareness for leprosy have been wall paintings, banners and posters, rallies with school children, health

talks on the radio and occasional slots on the television. This study demonstrates the poor reach of some of the methods using TV and Radio, and wall painting (especially outside health facility premises). It is evident that newer and more effective methods are required if the situation is to be improved.

The results from our study show that poor knowledge and negative attitudes are prevalent across all the study sites in different states, and though the females and the younger generation show slightly better figures these were not statistically significant (Barkataki et al 2006, Grewal et al 2013, Seshadri et al 2014) and the results were similar across the 5 sites where the survey was done. The misconceptions observed in this study about cause and spread of leprosy as blood related and hereditary is perhaps reinforcing the stigma narrative in the community and resulting in the negative attitude about leprosy. It is to be noted that around 25% participants with better knowledge score had negative attitude about leprosy, emphasizing that there is more to be done to bring the positive attitude towards leprosy than the awareness program to improve the knowledge about leprosy. The main reason this survey was undertaken in the larger project was to find out what the important aspects of leprosy that most needed to be communicated to the population were and what channels of communication would be most effective for this purpose. The findings from this survey were taken into consideration in preparing the content of the sensitization program that was implemented in the study area, as part of the main study.

The respondents felt that 'Community Awareness campaigns' through sensitization program were the most effective method to improve awareness about leprosy. They preferred to have the meetings at their own Panchayats Raj Institutions

(PRI, a village council, elected by a voting system, also called local government), where the PRI members are present, and the talk/health education on leprosy is given by a senior leprosy worker, so that the community feels more responsible towards leprosy.

Though ASHAs (Accredited Social Health Activists) are the pillars of the National Rural Health Mission and are familiar with and accepted in their own communities, as the first person to be called for health-related problems, but it appears that many participants were not aware that she could be approached for leprosy related signs and symptoms. But probably this is due to the fear of stigma, because the ASHA is from the same community and so closely connected to their community, and the respondents would not want anyone in the community to know if they were suspected to have leprosy. This hesitation could also be the reason for the number of cases undetected in the community. For improving the access to services it would be important to understand these reasons.

Regarding the community's ideas about appropriate methods of spreading awareness about leprosy, the most innovative suggestion was involving the members of PRIs, in the community awareness program on leprosy. As far as we were able to ascertain this has not been tried before so we are planning to use the PRIs as our major tool for awareness in the next phase of the study.

Limitations of study : The study participants were from rural area and the findings cannot be generalized for urban area. In this study, the questions on knowledge about and attitude towards leprosy were asked by an interviewer in a local language and participants understanding of the exact meaning of the questions may not be same for all study participants.

Conclusion

In the post-elimination scenario of leprosy, when services are provided through an integrated setup, knowledge about leprosy is very important for voluntary reporting. The community, overall, had inadequate knowledge of and unfavourable attitude towards leprosy, which may deter early detection of the disease. There is a need to test and implement new innovative health education methods to educate community members, including Panchayat Raj Institutions (PRIs) about leprosy and it is advisable to design target specific affective material for different populations such as urban/rural groups and students to improve community awareness regarding leprosy.

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