

Knowledge, Attitude and Practices Regarding Leprosy and its Management among Leprosy Patients, Their Relatives and the Medical Interns: An Institution Based Cross-Sectional Study

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Received : 13.06.2021

Accepted : 29.01.2022

The study aims at evaluating the knowledge, attitude and practices regarding leprosy and its management among patients, their caregivers (relatives), and future healthcare providers (medical interns). Questionnaire-based study was approved by Institutional Ethics Committee and participants were recruited after obtaining informed consent. Validated Questionnaire (face-validity and content-validity, content-validity-ratio cut-off 0.75) was used after pilot-testing for reliability (Chronbach's alpha>0.8 accepted). Vernacular-version of the questionnaire was developed by translation and back-translation. The questionnaire administered to clinically-diagnosed cases of leprosy, their caregivers (relatives), and future healthcare providers (medical interns) of BS Medical College Bakura, (a tertiary care rural medical college hospital). The calculated sample size was 88 for patients and their caregivers, considering 95% confidence interval, 10% allowable error and 35.67% response rate. The figures regarding knowledge about leprosy, and its treatment ranged between 71.6% to 26.1% among patients and between 85.2% to 37.5% among their caregivers for different knowledge domains. Lack of proper knowledge was also found in upto 52% of medical interns. Myths prevailed in upto 12.5% of patients, 23.9% caregivers, 6.7% of medical interns. There was attitudinal crisis and stigma in upto 45.5% of patients, 56.8% of caregivers, and 33.3% of medical interns. The stigma resulted in 33.4% of patients losing their job, 25% separated in their own home and 16.7% divorced. Awareness about leprosy is still lacking among patients and their caregivers despite repeated public health campaigns by NLEP. The absence of knowledge regarding leprosy among a few medical interns and even the presence of myths in their minds is an ominous sign. More effective awareness programmes and counseling involving the general population are necessary to eliminate stigma from the society.

Keywords: Leprosy, Knowledge, Attitude, Practice, Stigma

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Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, which, if left untreated, leads to progressive severe physical, psychological, and social disabilities (Joseph & Rao 1999). India has always been the country with the largest number of leprosy cases in the world, and in *Sushruta Samhita*, an ancient medical literature of India highlights that Indian people consider leprosy as a curse of God.

In the early days, leprosy patients were forced to leave their houses, and some of them were admitted to asylum or sanatorium. Today, however, they remain with their families, although they are often looked down upon and may receive little or no support (Wong 2004). Some years back leprosy patients were prevented from boarding a train and were ground for divorce (van Brakel 2003). Some believe leprosy is chronic and incurable. Most of the patients don't want to invest money in leprosy thinking as it is not life-threatening and harmless as most of them are from poor socio-economic status. Stigma against leprosy affects all aspects of leprosy control; the social consequences of the disease on the life of the patient are often severe and persist even after cure. Diagnosis and treatment of leprosy becomes easy and effective if patients present early and there is less chance of developing serious complications. Mostly the treatment is non-surgical and home-based; most important medicines are delivered free of cost from the governmental healthcare system under the NLEP. Therefore sufficient knowledge, proper attitude, and practice can prevent leprosy as well as can cure it early, reducing morbidity.

This study provides an insight regarding the attitude of rural Indian people towards leprosy and by knowing the healthseeking behaviour of patients, we can remove the missing links that prevent them from taking proper healthcare

services. Intending to make more effective communitybased strategies, and maximise the effectiveness of the health-education program, it needs to assess the current status of perception, attitude, and practices of patients and the factors influencing it. The finding of our study can help the policy-makers get an idea about the perception, prejudices, practices, and attitudes of patients and their care givers towards the most stigmatised disease to adopt appropriate changes accordingly.

The future doctors, i.e., the medical graduates serving interns, have got the role of counseling and treating the ailing patients and imparting the knowledge about the disease to the patient and their family members; thus, they need to have the correct attitude towards this disease. This study attempts to understand their knowledge and perception about the disease.

Materials and Methods

The study was an institution-based cross-sectional study and was initiated after obtaining due getting permission from Institutional Ethics Committee. The study was conducted at Dermatology Outdoor of Bankura Sammilani Medical College, Bankura, which is a rural-based tertiary-care hospital from February 2018 to July 2019.

The study population included all patients attending Dermatology OPD presenting with any signs or symptoms of leprosy or any reaction of leprosy or deformity due to leprosy; Relatives of leprosy patients (by law or by blood), and interns posted in their rotational duty schedule in dermatology clinic. Patients / relatives or medical interns who did not consent to participate and patients / relatives who did not understand the vernacular language were excluded.

The targeted sample-size was 88 patients calculated by considering infinite population and 35.67% response-rate (Saha et al 2015) using

the formula $n = Z^2 pq / l^2$ Where n =sample-size, $Z=1.96$ (considering 95% confidence-level) $P=35.67$ (prevalence), $q=100-p=64.33$, l =allowable-error=10%

The relatives of the leprosy patients (88 in number) were also recruited for the study. All the medical interns (internship batch of 2018-2019) (150 in numbers) were also included. Purposive sampling technique was done to recruit the patient and their relatives till the targeted sample size is reached.

Development of Questionnaire and Translation to Vernacular

Experts identified the key areas, item format and item domain, from which the preliminary questionnaire was developed. The questions were then tested for validity and reliability before the development of a final questionnaire. Pilot interviews were conducted prior to the final data collection, and minor revisions to the interview guide were made. The vernacular-version was developed by forward translation and back translation, as shown in Fig. 1.

Testing the validity

The validity was tested on the parameter of face validity and content validity:

Eight experts were asked to comment on the item domain and item-pool of the questionnaire. They were asked:

- Whether the questions reflect the knowledge and attitude regarding leprosy, and treatment-seeking behavior in leprosy?
- Whether the questions were simple and unambiguous?
- Whether the questions were easily understandable?

Content validity

Eight experts were asked to comment on each item as "essential" and "non-essential".

The content validity ratio (CVR) for each item was calculated by the following formula (Lawshe 1975):

$$CVR = n_e - (N/2) / (N/2)$$

Where n_e = number of panelists indicating essential, N = Total number of panelists.

Those items whose minimum value of CVR was 0.75 (according to the cut-off value by Lawshe's critical value for 8 experts) were included in the final questionnaire.

Testing the Reliability

The reliability was tested by evaluating the internal consistency of items in each item domain. This was tested by determining Cronbach's alpha (Tsang et al 2017).

The Cronbach's alpha of the six item domains were as follows:

- Knowledge regarding leprosy: 0.8052 (95% lower Confidence-limit 0.7474)
- Knowledge regarding treatment of leprosy: 0.8749 (95% lower Confidence-limit 0.8403)
- Attitude towards leprosy: 0.9091 (95% lower Confidence-limit 0.8403)
- Feeling after being diagnosed with leprosy: 0.8499 (95% lower Confidence-limit 0.804)
- Myths regarding leprosy: 0.947 (95% lower Confidence-limit 0.9317)
- Experience after diagnosis: 0.8073 (95% lower Confidence-limit 0.8037)

Data-collection

To determine the knowledge and attitude practices regarding leprosy in patients, all patients attending dermatology-OPD were screened. After this initial screening, a thorough clinical evaluation was done and the diagnosis was made based on WHO field criteria and in doubtful cases, slit skin smear and skin biopsy was performed (World Health Organization, 2017). After confirmation of diagnosis, all cases were

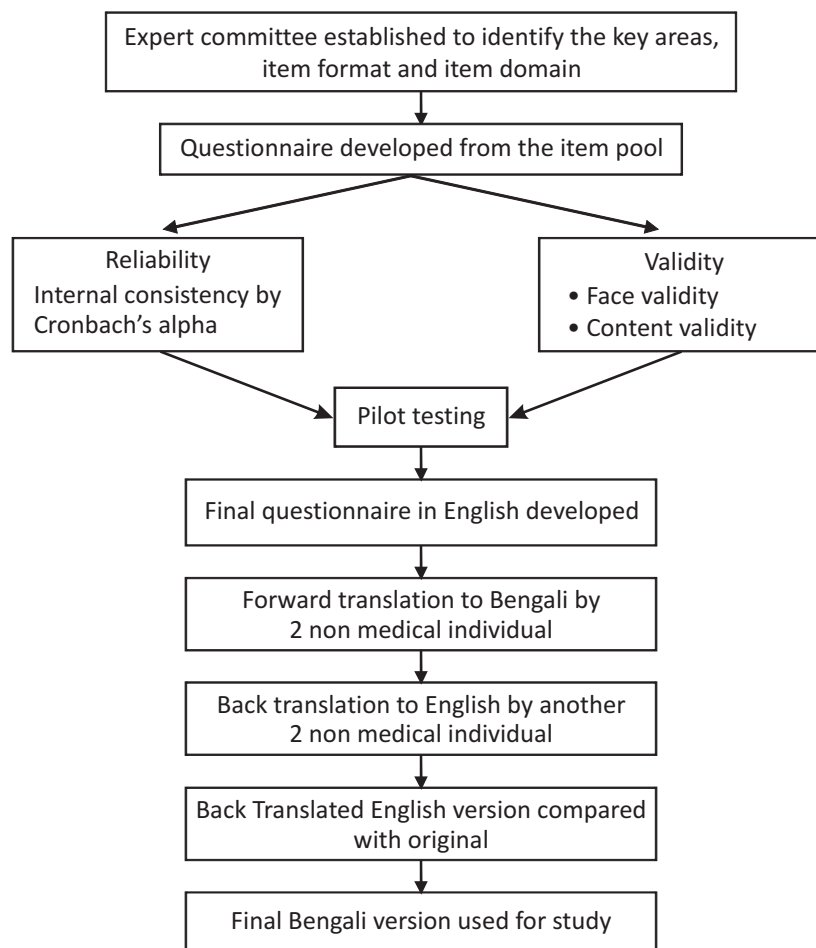


Fig. 1 : Development of Questionnaire and Translation to Vernacular

enlisted. Informed consent was taken & only those who gave the consent, were included in the study. Pre-designed, pre-tested, interviewer-administered semi-structured questionnaires on knowledge-attitude-practice regarding leprosy was administered to each patient. The clinical profile of the patients was recorded in the pre-designed case record form.

For relatives, informed consent was obtained, demographic profile noted and a questionnaire was administered to be filled by them with the help of the investigator if required.

For medical interns, informed consent was obtained, demographic profile noted, and the questionnaire was supplied to each to be filled by them.

Data-analysis

The descriptive data were expressed as mean \pm SD, median, inter-quartile range, 95% CI of mean for numerical data; ratio proportion and percentage for categorical data. Kolmogorov-Smirnov test was used to find the normal distribution. The numerical data were analysed by using an unpaired t-test or Mann Whitney *U*

test (as applicable), and the categorical data was analysed by using the chi-square test. MedCalc® version 12.5.0.0-64-bit (<http://www.medcalc.org>) for Windows XP/Vista/7/8 was used for statistical-analysis and P -value ≤ 0.05 was considered statistically significant.

Results

Among 326 participants, 88 were leprosy patients, and 76.1% of them were male. Most of the patients and their relatives were from tribal (81.3%) populations and from lower socio-economic society (73.3% were BPL) and illiterate (62.5%). Most of them (38.6%) were farmers by occupation, followed by house-wife (21.6%) and manual-labourer (19.9%), students (8.5%), businessmen (6.2%), Government jobs (4.5%).

Among the 88 leprosy patients, most of them had borderline-tuberculoid (BT) Hansen (49, 55.7%) followed by pure-neuritic (16, 18.2%), borderline-lepromatous (11, 12.5%), lepromatous (9, 10.2%), Mid-borderline (2, 2.2%) and tuberculoid Leprosy (1, 1.1%). Nine (10.2%) patients have had a definite contact history with other leprosy patients. 18(20.5%) patients presented with lepra-reaction, among them 11(61.1%) presented with Type 1 reaction and 7 (38.9%) with Type 2 reaction.

Among patients, 31.8% presented along with disability, of which 28.6% was grade 1 disability, and 71.4% was grade 2 disability. Both types of disabilities were more common in the pure-neuritic variety (53.6%) followed by borderline

Table 1 : Knowledge regarding treatment of leprosy

		Patient (n=88)	Relative (n=88)	Intern (n=150)	p-value
Whether leprosy is treatable	Yes	40(45.5%)	51(58.0%)	143(95.3%)	<0.0001 (chi-square)
	No	0(0.0%)	2(2.3%)	2(1.3%)	
	Don't know	48(54.5%)	35(39.6%)	5(3.3%)	
Whether leprosy is curable	Yes	39(44.3%)	52(59.1%)	126(84.0%)	<0.0001 (chi-square)
	No	1(1.1%)	2(2.3%)	12(8.0%)	
	Don't know	48(54.5%)	34(38.6%)	12(8.0%)	
Preferred treatment option	Modern medicine	40(45.5%)	51(58.0%)	148(98.7%)	<0.0001 (chi-square)
	Ayurvedic	0	0	1(0.7%)	
	Yoga and naturopathy	0	0	1(0.7%)	
	Don't know	47(53.4%)	37(42.0%)	0	
Whether medicine is available free of cost	Yes	47(53.4%)	58(65.9%)	145(96.7%)	<0.0001 (chi-square)
	No	0	1(1.1%)	2(1.3%)	
	Don't know	41(46.6%)	29(33.0%)	3(2.0%)	
Duration of treatment	6 months	7(7.9%)	13(14.8%)	42(28%)	
	1year	17(19.3%)	14(15.9%)	56(37.3%)	
	Don't know	66(75.0%)	61(69.3%)	47(31.3%)	

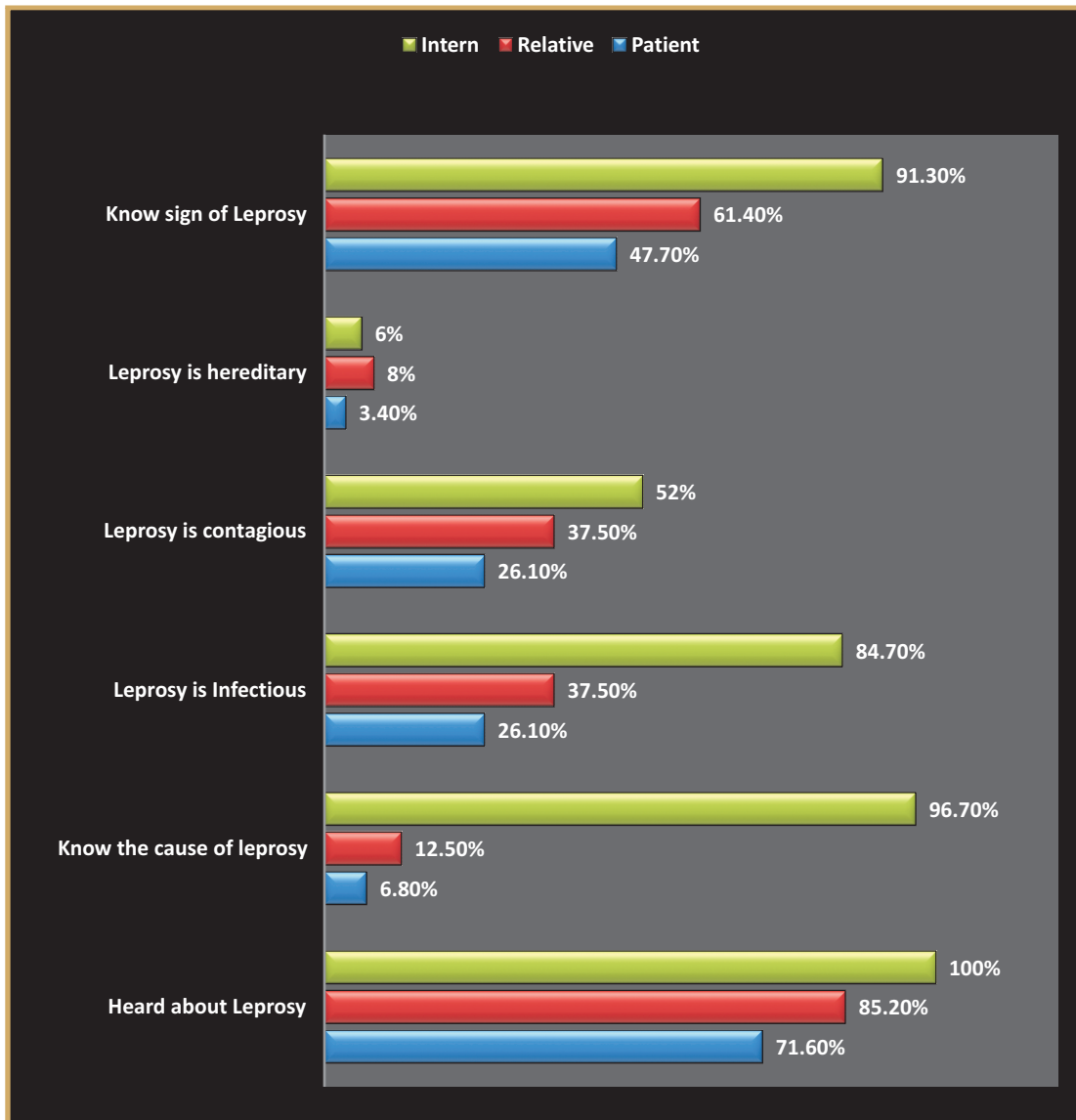


Fig. 2 : Bar diagram showing knowledge regarding Leprosy

tuberculoid (25.0%) leprosy. Most common form of disabilities was anesthesia over the palm and sole, claw-hand, and tropic-ulcer (28.5% each).

Knowledge about leprosy

Among leprosy patients 28.4% and among their relatives, 14.8% told that they did not even hear

the word leprosy or 'khustha-roq' once in their life. Regarding the causation, only 6.8% of patients and 12.5% of their relatives were aware of the cause of the disease. Even among the medical interns, 3.3% had agreed that they do not know the cause of the disease. 26.1% among the

patients, 37.5% among their relatives, 52% of medical interns believe that leprosy is contagious. Many patients (47.7%), their relatives (61.4%), and interns (8.7%) did not know the signs of leprosy. Most of the patients (26.1%) and their relatives (31.8%) mentioned the white patches as a sign. Deformity (28.4%) and ulceration (15.3%) were also referred by many of them. Among the interns, absent-sensation and white patches were mentioned by 86.7% and 74.0%, respectively. On questioning about the source of knowledge, it is

revealed that 44.44% of patients have heard it from their family members or friends or relatives. 44.4% among them also acquired the knowledge from doctors or ASHA workers. Some mentioned radio, television, or newspaper as a source. Interns mostly gained their knowledge from their teachers in medical school (63.3%) and from books (70.7%) (Fig. 2).

Knowledge regarding the treatment of leprosy

Many patients (54.5%) and their relatives (39.6%) confessed that they don't know whether leprosy

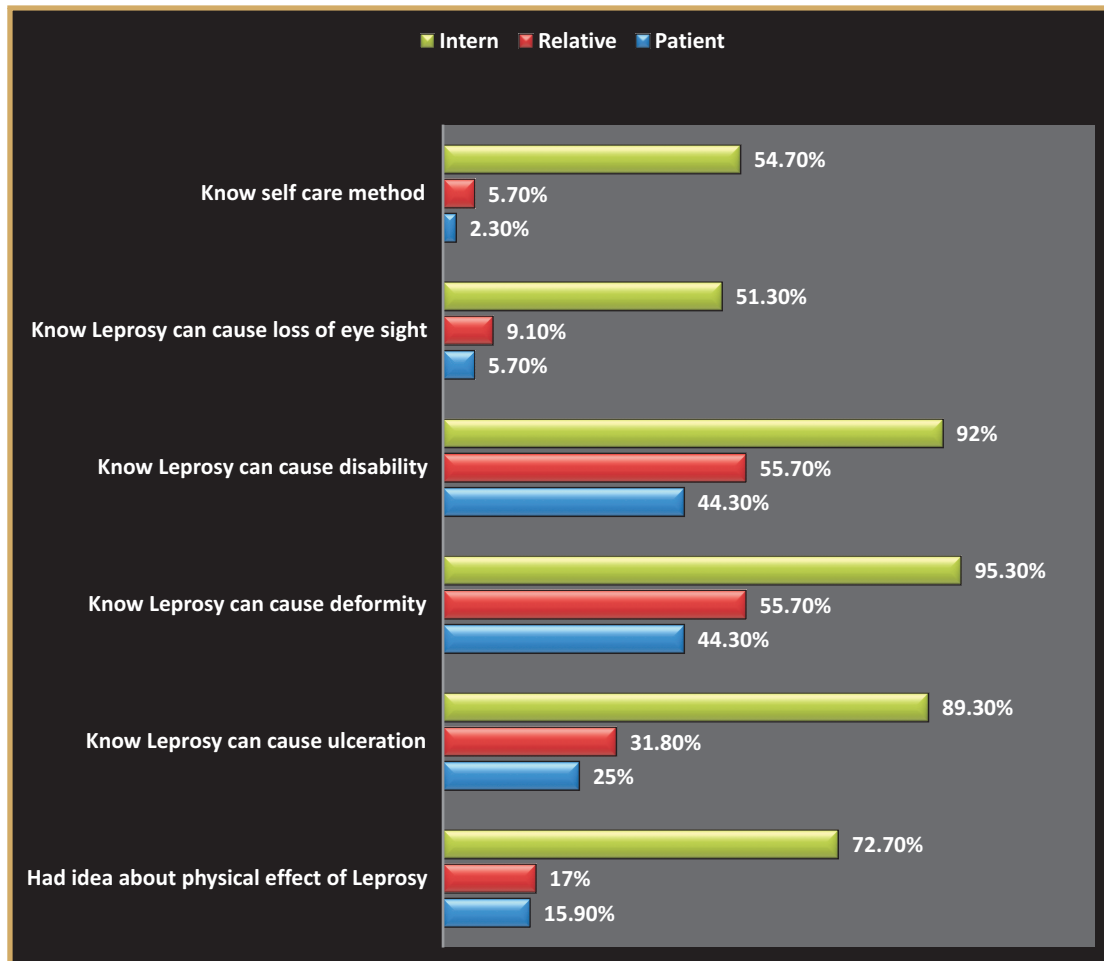


Fig. 3 : Bar diagram showing knowledge regarding consequences of leprosy

is treatable or not. Even 4.6% of the interns don't know that it is treatable. Only 45.5% of the patients and 58% of their relatives preferred modern medicine as a treatment of leprosy. Whereas the rest of them confessed that they don't know which treatment is suitable for the disease. Among the interns, 2(1.4%) preferred AYUSH over modern medicine (Table 1).

Knowledge about consequences of leprosy and its prevention

To the question regarding "what will happen if leprosy is left untreated?", 32.9% among the patients and 27.2% among their relatives flawlessly answered that the disease will progress. 27.2% of them mentioned that it will cause disability/deformity, and 9.6% among them pointed about ulceration if not treated in time. Whereas, 49.4% of them did not know the consequences (Fig. 3).

Questionnaire for myths/beliefs regarding leprosy and fear regarding leprosy

The myths and fear regarding the disease are summarized in Fig. 4 and Table 2. All were apprehensive that they will become physically challenged day by day and this apprehension was found to be prevailing in 46.6% of relatives, 39.8% of leprosy patients and 32.7% of medical interns. Similarly fear was prevailing regarding 'people avoiding them, getting separated from family members, discrimination in work place and religious places.' Fear about 'getting removed from work' and 'not being allowed in religious places' was found to be highest among medical interns (25.3% and 19.3% respectively).

Attitude regarding leprosy

31.8% among the patients and 46.6% among their relatives responded that they would prefer to maintain a distance from the leprosy patients.

Table 2 : Fear regarding leprosy

		Patient (n=88)	Relative (n=88)	Intern (n=150)	p-value
You will become physically challenged day by day	Yes	35(39.8%)	41(46.6%)	48(32.6%)	<0.0001 (chi-square test)
	No	4(4.5%)	8(9.1%)	79(52.7%)	
	Don't know	49(55.7%)	39(44.3%)	23(15.3%)	
People will avoid you	Yes	38(43.2%)	39(44.3%)	78(52.0%)	<0.0001 (chi-square test)
	No	5(5.7%)	10(11.4%)	34(22.7%)	
	Don't know	45(51.1%)	39(44.3%)	38(25.3%)	
Your family members will separate you	Yes	7(8.0%)	5(5.7%)	12(8.0%)	<0.0001 (chi-square test)
	No	25(28.4%)	36(40.9%)	119(79.1%)	
	Don't know	56(63.6%)	47(53.4%)	19(12.7%)	
People will remove you from work	Yes	6(6.8%)	9(10.2%)	38(25.3%)	<0.0001 (chi-square test)
	No	10(11.4%)	17(19.3%)	75(50.0%)	
	Don't know	72(81.8%)	62(70.5%)	37(24.7%)	
People would not allow you to enter into religious places	Yes	5(5.7%)	9(10.2%)	29(19.3%)	<0.0001 (chi-square test)
	No	9(10.2%)	14(15.9%)	66(44.0%)	
	Don't know	74(84.1%)	65(73.9%)	55(36.7%)	

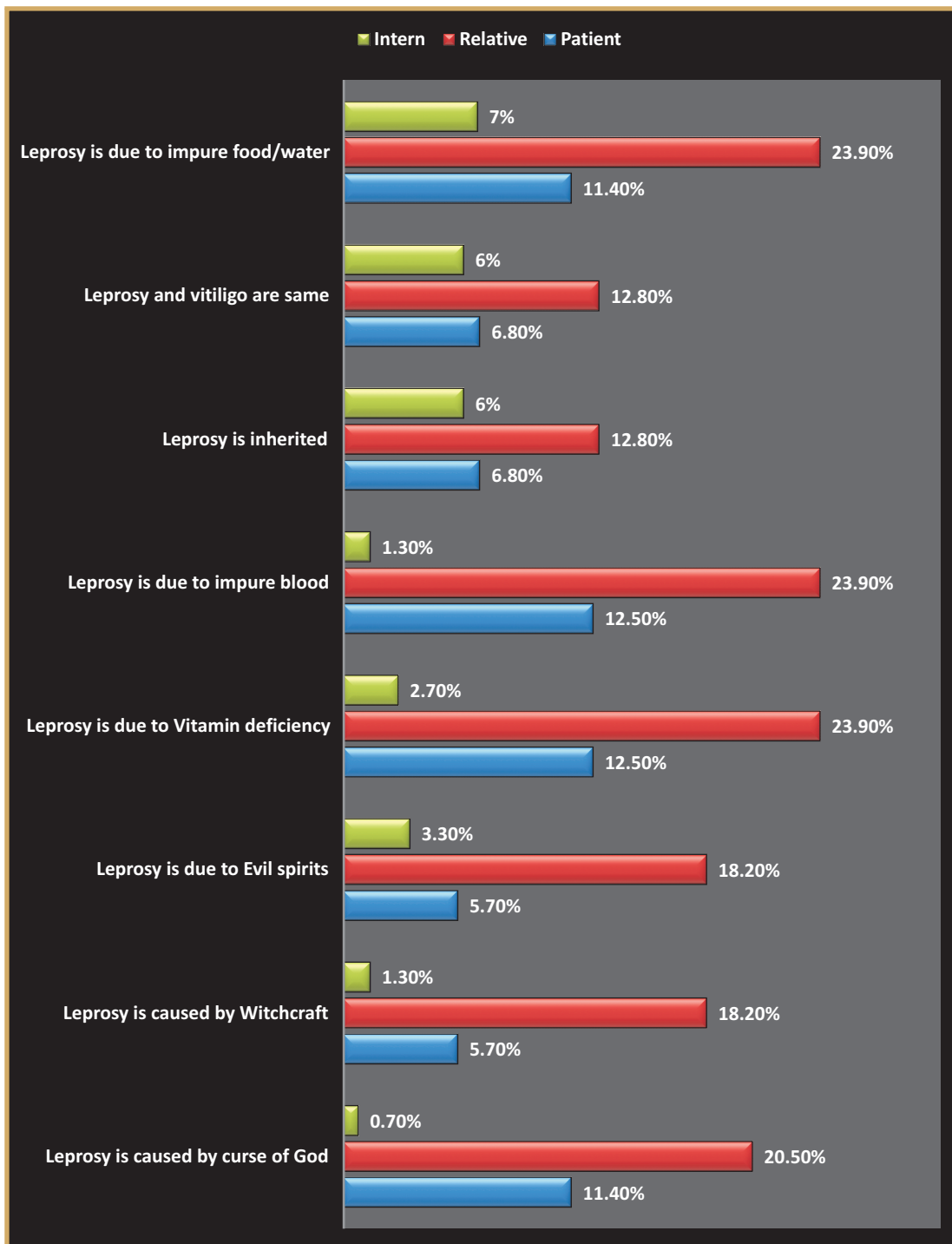


Fig. 4 : Bar diagram showing myths/beliefs regarding Leprosy

Even 9.3% of the interns mentioned that they would prefer to distance themselves from the leprosy patient. 37.5% among the patients and 47.7% among their relatives denied sitting side by side with a leprosy patient in a public-conveyance. Even among the interns, 18.7% of them did not agree to sit beside the leprosy-patient. 38.6 % of the patients and 47.7% of their relatives denied their preference to work with leprosy patients and the difference was statistically significant ($p=0.0055$). Even 8.7% of the interns denied working with leprosy-patients.

On questioning about marriage, many of the interns (33.3%) denied having leprosy patients as their life partner, whereas 45.5% of the patients

and 56.8% of their relatives denied the same. But a considerable number of interns (84.7%) consented that they would not mind marrying a leprosy patient if they had got adequate treatment. The improvement in the acceptance after treatment increases significantly ($p<0.0001$) (Table 3).

Patient's experience after diagnosed as leprosy

All the patients who were diagnosed with leprosy were asked a few questions to explore their experiences after being diagnosed with leprosy. 17% among the patients shared that people started avoiding them after they came to know that he/she is having leprosy. Most of the patients (80.7%) accepted that they feel ashamed to tell

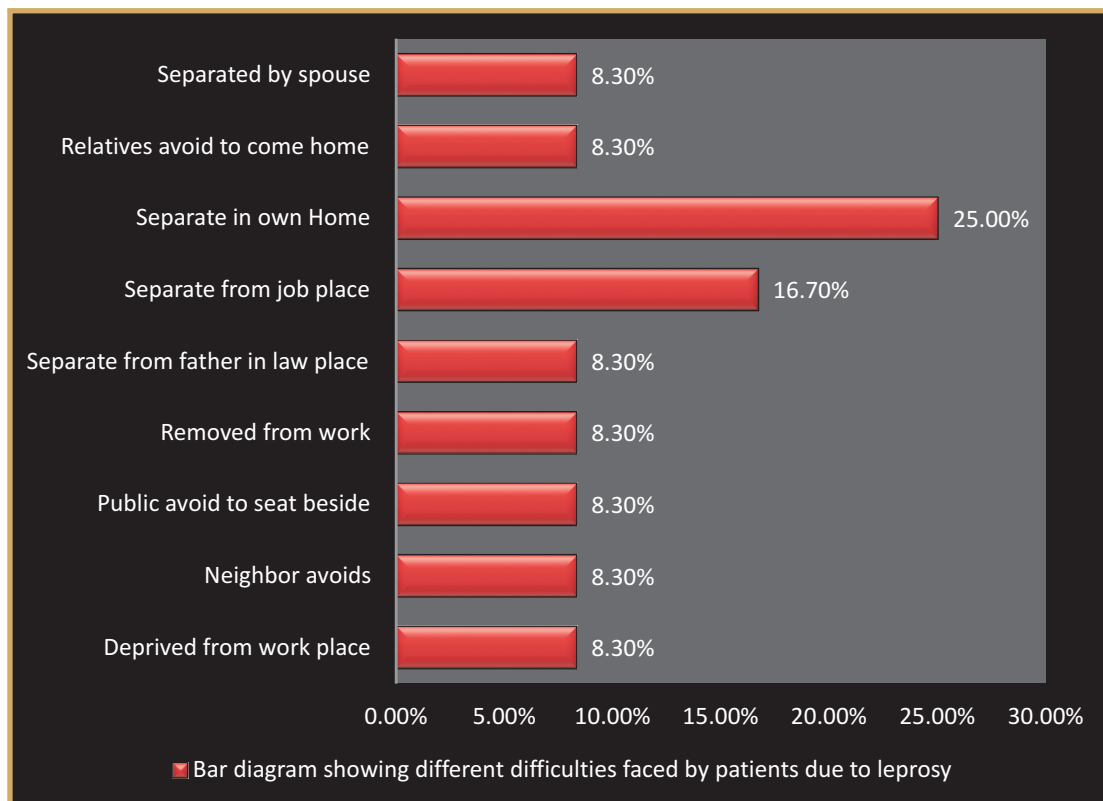


Fig. 5 : Diagram showing different difficulties faced by patients due to leprosy

Table 3 : Attitude of patients, their relatives and interns regarding leprosy

		Patient (n=88)	Relative (n=88)	Intern (n=150)	p-value
What would you do if you come in contact with a leprosy patient	Ignore the condition	17(19.3%)	22(25.0%)	9(6.6%)	<0.0001 (chi-square)
	Maintain distance	28(31.8%)	41(46.6%)	14(9.3%)	
	Advice him to consult with doctor	5(5.7%)	5(5.7%)	122(81.3%)	
	Don't know/not applicable	38(43.2%)	20(22.7%)	5(3.3%)	
Would you like to shake hand with leprosy patient	Agree	19(21.6%)	30(34.1%)	90(60.0%)	<0.0001 (chi-square)
	Disagree	33(37.5%)	42(47.7%)	28(18.7%)	
	Neutral	36(40.9%)	16(18.2%)	32(21.3%)	
Would you buy food from a leprosy patient	Agree	19(21.6%)	30(34.1%)	115(76.7%)	<0.0001 (chi-square)
	Disagree	34(38.6%)	42(47.7%)	15(10.0%)	
	Neutral	35(39.8%)	16(18.2%)	20(13.3%)	
Would you make leprosy patient your friend	Agree	19(21.6%)	30(34.1%)	86(57.3%)	<0.0001 (chi-square)
	Disagree	33(37.5%)	42(47.7%)	32(21.3%)	
	Neutral	36(40.9%)	16(18.2%)	32(21.3%)	
Would you mind sitting side by side with leprosy patient	Agree	18(20.5%)	30(34.1%)	72(48.0%)	<0.0001 (chi-square)
	Disagree	33(37.5%)	42(47.7%)	28(18.7%)	
	Neutral	37(42.0%)	16(18.2%)	50(33.3%)	
Would you work with leprosy patient?	Agree	19(21.6%)	30(34.1%)	103(72.7%)	<0.0001 (chi-square)
	Disagree	34(38.6%)	42(47.7%)	13(8.7%)	
	Neutral	35(39.8%)	16(18.2%)	28(18.7%)	
It is safe to marry a person who is having leprosy	Agree	13(14.8%)	22(25.0%)	48(32.0%)	0.0003 (chi-square test)
	Disagree	40(45.5%)	50(56.8%)	50(33.3%)	
	Neutral	35(39.8%)	16(18.2%)	52(34.7%)	
It is safe to marry a person who is completely treated for leprosy	Agree	36(40.9%)	31(35.2%)	127(84.7%)	0.0003 (chi-square test)
	Disagree	17(19.3%)	41(46.6%)	6(4.0%)	
	Neutral	35(39.8%)	16(18.2%)	17(11.3%)	
It is safe to marry a person whose family member is having leprosy	Agree	14(15.9%)	22(25.0%)	96(64.0%)	<0.0001 (chi-square test)
	Disagree	39(44.3%)	50(56.8%)	17(11.3%)	
	Neutral	35(39.8%)	16(18.2%)	37(24.7%)	
What would you do if your family member is diagnosed with leprosy (chi-square test)	Ignore the condition	11(12.5%)	10(11.4%)	13(8.7%)	<0.0001 (chi-square test)
	Maintain distance	20(22.7%)	29(33.0%)	16(10.7%)	
	Get him/her treated	32(36.4%)	34(38.6%)	119(79.3%)	
	Don't know	27(30.7%)	15(17.0%)	2(1.3%)	

Table 4 : Comparison of different results of other studies with our study (among patients)

	Our study		Other study	
Know the cause of leprosy	6.8%	10% (van't Noordende et al 2019, northern India)	32% (Stephen et al 2014, Tamilnadu)	
Leprosy is infectious	26.10%	43.13% (Mankar et al 2011), Maharastra)	--	
Leprosy is contagious	26.10%	41% (Shetty et al 1985, Mangalore)	72% (Stephen et al 2014, Tamilnadu)	
Leprosy is not heritable	13.6%	78.43% (Mankar et al 2011, Maharastra)	14.6% (Tabah et al 2018, Cameroon)	
Know sign of leprosy	47.7%	42% (Shetty et al 1985, Mangalore)	--	
White patch	26.1%	25.86% (Mankar et al 2011, Maharastra)	60% (Barkataki et al 2006), Uttar Pradesh)	
Loss of sensation	13.6%	55% (Stephen et al 2014, Tamilnadu)	--	
Leprosy is curable	44.3%	88.24% Mankar et al (2011), Maharastra)	86% (Shetty et al 1985, Mangalore)	
Leprosy is treatable	45.5%	95% (van't Noordende et al 2019 northern India)	--	
Know the treatment duration	29.6%	87% (van't Noordende et al, northern India) ⁹	--	
Leprosy can cause ulceration	25%	65% (Shetty et al 1985, Mangalore)	--	
Leprosy can cause disability/ deformity	44.3%	76% (Shetty et al 1985, Mangalore)	--	
Curse of god	11.4%	21.3% (Tesema & Beriso 2015, Ethiopia)	--	
Evil spirit/witchcraft	11.4%	25.3% (Tabah et al 2018, Cameroon)	Ebenso et al 2019, western Nigeria	
Impure blood	12.5%	15.5% (Tabah et al 2018, Cameroon)	Manker et al 2011, Maharastra	
Leprosy is not heritable	13.6%	78.43% (Mankar et al 2011, Maharastra)	14.6% (Tabah et al 2018, Cameroon)	
Not buy/share food from a leprosy patient	38.6% of patients 47.7% of relative	43.1% of community members (Manker et al 2011, Maharastra)		
Doesn't mind sitting beside leprosy patient	20.5% of patients 34.1% of relatives	91% of community members (Stephen et al 2014, Tamilnadu)		

Agree to marry a cured leprosy patient	40.9% of patients 35.2% of relative	45% of community members (Stephen et al 2014, Tamilnadu)
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others that they have leprosy. Among patients, 13.6% faced any form of difficulty due to the stigma of leprosy, Among them (33.4%) had lost their job and 25% were separated in their own homes; 16.7% of them had divorced only because they had leprosy and all of them were female and now living with their parents.

Regarding treatment-seeking behaviour, 44.3% of them preferred to visit a general physician for their disease, Whereas, 28.4% among them approached a non-qualified doctor or doctors from alternate-medicine primarily. Some of them (3.4%) had also taken opinions from religious-leaders, *Ojha/guin*, or from political leaders. The mean duration from the onset of the symptoms/signs to attending dermatology OPD was 184.31± 208.40 days (Fig. 5).

Discussion

The present study gave an insight into the knowledge and attitude toward leprosy among people attending a tertiary care institute with leprosy and their relatives as well as among the medical interns and explored the healthcare-seeking behavior of the patients. Table 4 has enumerated the findings of others with regard to the different domains of knowledge, attitude, and stigma as compared to our study.

Comparison of knowledge about leprosy among the participants

Regarding knowledge, 71.6% have heard about the disease at least once in their life, and concerning the cause, only 6.8% of patients and 12.5% of their relatives were aware, similar to the study finding of van't Noordende Brakel et al

(2019) conducted in north India where only 10% of the participants gave the correct answer. In another study conducted in south India by Stephen et al (2014), it was found that awareness is better regarding the knowledge of causation (32% of the patients and 37% of family members).

It is unfortunate that 3.3% of medical interns do not know the cause of the disease, though their knowledge is significantly better than the patients and relatives ($p < 0.0001$). Our study noted significant better knowledge scores among the health care workers than the other participants ($p < 0.0001$), similar to the findings of the study done by van't Noordende et al (2019), but understandably medical education cannot be complacent on these statistical figures. Even a single medical graduate being ignorant of leprosy can undermine the entire national program on elimination of leprosy (NLEP).

The perception of the contagious nature of the disease prevailed in 26.1% of patients and 37.5% of their relatives in our study population, though found to be lower than the other similar studies. This highlights the fact the tribal people in eastern India are better placed than northern and southern India about their apprehension about leprosy being contagious. But Mankar et al (2011) found that there was a high level of awareness in the western part of India about the fact that the disease is not hereditary (78.43% among the patients and 65.52% in the control group). The figures are better in our study population among patients and relatives (6.8% of patients and 6% only considered that it's hereditary), but it was

noted that 12.8% of interns were under the impression that it's heritable. This could have a far-reaching effect when the future doctors would spread their impression to others in society.

The awareness of early signs of leprosy was found to be 47.7% among patients and 61.4% among their relatives, but in south India, only 15% of the community members were aware of it though (Shetty et al 1985). The awareness of people in the community imparts a positive response and would help in early treatment-seeking responses and prevent deformities.

The front-line workers (ASHA workers) and family and friends played an important role in educating the patients regarding the disease, which was similar to the findings in Cameroon. This highlights community participation which can help in raising awareness about the disease.

Mankar et al (2011) found that 88.24% in the patient group and 79.31% in the control group said that disease is curable reflects their belief in the health care system. Only about half of our study population (44.3% among the patients and 59.1% among the relatives) has that faith, but 8% of the interns believed it's non-curable. This could definitely have a negative impact on the implementation of the national program.

In some of the studies, it was found that leprosy patients prefer visiting traditional healers rather than trained medical doctors, which further delays treatment initiation and chances of severe disability. The alternative treatments, including ayurvedic, homoeopathic, yunani, and religious rituals, were preferred by more than 50% of rural students in an Indian study from Jaipur (Kanodia et al 2012). In our study participants, only 45.5% of patients and 58% of their relatives preferred modern medicine, which matches the country's preference and speaks for itself that modern medicine is yet to establish its faith in the majority

of the population. The fact that two of the interns were in favour of yoga and ayurvedic treatment is going to make the future bleak for multi-drug therapy (MDT) to establish its trust in the population, and the delay in proper treatment will be furthermore aggravated. Unfortunately, the knowledge about the treatment duration of MDT was also not known in 31.3% of interns.

The awareness regarding the association of ulceration with leprosy was found that 65% of patients and 54% of community members by Shetty et al (1985) in the south Indian population. The figures were similar (67.6% among the patients and their relatives) as in our study. In the patient group, the awareness was found to be more among the non-tribal (42.8%), whereas only 19.4% among the tribal knew it ($p=0.0539$). Regarding disability and deformity, 44.3% among the patients and 55.7% among relatives believed that they are associated with leprosy whereas a study in a south India noted the perception in 76% of patients and 64% of community members (Shetty et al 1985). Here too, a significant difference is present regarding this knowledge among the tribal (38.8%) and non-tribal (61.9%) ($p=0.0248$). This knowledge is a favourable sign that could make the community cautious if they contact leprosy, and on the flip side, this perception could also end up accentuating the fear in the mind of people and, if not properly counseled can lead to the deepening of the stigma.

Comparison of myths/beliefs regarding leprosy among the participants

The study found that the oldest and most prevalent belief encountered was that leprosy was a curse from God or sins from a previous life is still persisting. The severity was worse among the rural and tribal populations. 11.4% of the patients, 20.5% among their relatives, and one of the interns believed that leprosy is caused by the curse of God for sinful activity caused by

"Immoral conduct". There was a significant difference ($p=0.0083$) between patient and relative regarding the belief. The belief is significantly more ($p=0.0396$) among the tribal group (11.9%) in comparison to the non-tribal group (4.8%).

In Ethiopia too, leprosy is linked to curse/punishment by God, heredity, bad blood, and immoral conduct by many of the population (Tesema & Beriso 2015). A study from Cameroon revealed that a considerable proportion of the people believed that leprosy is a spell (25.3%), is caused by unclean blood (15.5%), is hereditary (14.6%), or results from marrying from a family that has/had leprosy (11.2%) (Tabah et al 2018). The theory of impure blood was found to have found its place in the mind of 12.5% of the patients, 23.9% of relatives in our study population. A similar faith among 4 (2.7%) of the interns unveils the dismal state of affairs of present medical education.

Comparison of attitude regarding leprosy among the participants

The study found that 31.8% among the patients and 46.6% of their relatives preferred to maintain distance from the leprosy patients, and this attitudinal crisis was significantly higher among the relatives ($p=0.0339$), which directly correlates with the severity of stigmatisation. van't Noordende et al (2019) also revealed that community members keep their distance from persons affected by leprosy or exclude them from social activities. Community members of participants don't want to talk to, eat with, sit with, or touch persons affected by leprosy. Our study noted that 37.5% of patients and 47.7% of their relatives expressed their unwillingness to sit side by side with a leprosy patient in a public conveyance in contrast to the situation in Tamil Nadu, where it was found that where 91% of the family members felt that leprosy patients can be

employable and doesn't mind sitting beside them (Stephen et al 2014). Thus, it is unfortunate that the IEC campaign has failed to uproot social discrimination at least in the eastern part of the country. Their attitude is directly reflected in the experience of the leprosy patients when they expressed their grief describing how people and even neighbors avoid them in public places, and 80.7% are ashamed of their disease.

On the issues of marriage, our study found that many of the interns (33.3%) denied having a leprosy patient as their life partner. Among the patients and their relatives, 51.1% denied marrying them, and this causes more suffering and fear to the patients regarding this benign disease. Similar findings were noted by Leena & Priya (2017) where it was noted that the marriage of a patient on treatment or completed treatment with leprosy was acceptable in 78.94% of final year medical students compared to 71.27% of first-year students. This emphasises the fear and apprehension regarding the disease and exposes the ugly truth that our society is yet to accept leprosy as a curable disease. Apart from medical professionals, 32.9% among the patients and their relatives denied marrying a leprosy patient even after complete treatment. A study in Tamil Nadu found that only 45% of the family members think that a cured leprosy patient can marry (Stephen et al 2014). Marital atrocities are had been associated with leprosy since ages and the study reveals that it exists in the present time too.

Comparison of patients' experience after diagnosed as leprosy

Among patients, 80.7% accepted that they felt ashamed to tell others that they are having leprosy. Similarly, van't Noordende et al (2019) found over half of the participants (56%) indicated they would prefer to keep people from knowing they have leprosy. Whereas 9% of the patients felt like informing their family members

immediately found in a study by Stephen et al (2014).

Among patients, 13.6% described their sufferings due to the stigma of leprosy. Many of them were removed or separated from their workplace. Some of them faced problems in marital life and even divorce. In a study from Cameroon where 43%-71% of the respondents admitted that their families face a variety of issues, ranging from difficulties getting employment, admission to school, or getting married themselves; to bringing shame in the family and causing other problems to family members (Tabah et al 2018). In a study by Barkataki et al (2006) said that about 20-30% of leprosy-affected stated that there was discrimination and nearly 70% felt that leprosy-affected social participation. The stigma related to other dermatoses like vitiligo and psoriasis is also prevalent in our society. A study by Pichaimuthu et al (2011) from India described that 17.3% of vitiligo patients and 28% of psoriasis patients participated minimally in their major life areas like work, education and employment, and also in community, social and civic life due to their disease; and restrictions were significantly more in psoriasis. Thus it is apparent that the stigma due to leprosy is a global phenomenon and has percolated in the veins of society so deep that all efforts to eliminate it are yet to succeed. The stigma and discrimination is the hurdle that needs to be conquered, and that's why the WHO has taken up the theme of "ending leprosy-related stigma and discrimination" as the theme of World Leprosy Day 2020. We consider more effective and efficient awareness programs and counseling involving more of the general population to eliminate disease and related stigma from the society. We remember the golden words of Mother Teresa that "The biggest disease today is not leprosy or tuberculosis, but rather the fear of being unwanted."

Acknowledgements

We are grateful to all the study participants for their support and cooperation. The researchers would like to extend their thanks to Prof Pijush Kanti Datta, Prof Debabrata Bandyopadhyay, Prof Arghyaprasun Ghosh, Dr Somenath Sarkar for helping validate the questionnaire. The valuable guidance of Prof Arghyaprasun Ghosh is thankfully acknowledged. Support and cooperation of all the faculties, residents and other departmental staff are also acknowledged.

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How to cite this article : Ahmed SS, Koley S, Roy S et al (2022). Knowledge, Attitude and Practices Regarding Leprosy and its Management among Leprosy Patients, Their Relatives and the Medical Interns: An Institution Based Cross-Sectional Study. *Indian J Lepr.* **94**: 117-140.

Annexure 1

<p>CASE REPORT FORM</p> <p>Knowledge-Attitude-Practices regarding Leprosy and Its Management among Leprosy Patients, Their Relatives and the Medical Interns: An Institution Based Cross-Sectional Study.</p>

1.1 Subject Particulars

Name : _____	Age : _____ yrs	Sex : M () F ()
Marital Status: _____	Consanguinity: Y () N ()	
Occupation: _____		
Residential Address : _____		
(with Village, PS and phone no) _____		

Education : _____	Duration of Stay _____	
Income: APL BPL		

3. Knowledge regarding Leprosy (for all subjects)

- 3.1 Have you heard of a disease called leprosy Yes No
- 3.2 Do you know the cause of the disease Yes No
- 3.2.1 If Yes, Germs From mother to child Skin contact Sex with patient
Sex with prostitutes Sharing food Through air Shaking hands Sitting close
 Insects/mosquitoes Bathing in a river Contaminated soil Sharing personal item
 Others _____
- 3.3.1 Leprosy is infectious Yes No DK
- 3.3.2 Leprosy is contagious Yes No DK
- 3.4 Leprosy is inherited from parents Yes No DK
- 3.5 Do you know the signs of leprosy Yes No DK
- 3.5.1 If Yes, White patch Absent sensation Deformity Ulceration Others _____
- 3.6. What is your source of knowledge about leprosy: School teaching Books News paper
Radio/Television Talks/Seminars Films Family members/neighbors/friends
Pamphlets/posters/hoardings ASHA workers Doctors Other patients with leprosy
Others _____

4. Knowledge regarding Treatment of leprosy and Prevention of its Consequences (for all subjects)

- 4.1.1 Leprosy is Curable: Yes No DK
- 4.1.2 Leprosy is treatable: Yes No DK
- 4.2 What treatment is preferable in leprosy: Modern medicine Ayurvedic
Yoga and naturopathy Unani Siddha Homeopathy Herbal medicines
Ojha/Guin DK Others _____

- 4.3 Medicine is available free of cost: Yes No DK
 4.3.1 if yes, Where _____
- 4.4 How long the treatment should be continued: DK 6 months 1year 2years Others _____
- 4.5 What will happen if left untreated: Progress Resolve by itself Cause disability or deformity
 cause ulceration DK Others _____
- 4.6 Do you have any idea about physical effect of leprosy on a patient: Yes No
 If Yes, describe _____
- 4.7 Can leprosy cause ulceration : Yes No DK
- 4.8 Can some Predisposing skin conditions lead to trophic ulcer: Yes No DK
 4.8.1 If yes, that can be-blisters calluses red spot others _____
- 4.9 Risk factors for development of Trophic ulcer: trauma dangerous environment
 sharp objects fire hot objects DK others _____
- 4.10 Can leprosy cause deformity Yes No DK
- 4.11 leprosy cause disability Yes No DK
- 4.12 Can leprosy cause loss of eye sight Yes No DK
- 4.13 Do you know about self care for prevention of ulceration? Yes No DK
 4.13.1 If yes, then method of self care _____

5. Attitude regarding leprosy (for all subjects)

- 5.1.1 What would you do if you come in contact with a leprosy patient
 Ignore the condition Maintain distance Advice him to consult with doctor
 others _____
- 5.1.2 *Would you like to shake hand with leprosy patient?*
 Agree Disagree Neutral
- 5.1.3 *Would you make leprosy patient your friend?*
 Agree Disagree Neutral
- 5.1.4 *Would you buy food from a leprosy patient?*
 Agree Disagree Neutral
- 5.1.5 *Would you share food with a leprosy patient?*
 Agree Disagree Neutral
- 5.1.6 *Would you mind sitting side by side with leprosy patient in a public conveyance?*
 Agree Disagree Neutral
- 5.1.7 *Would you work with leprosy patient?*
 Agree Disagree Neutral
- 5.1.8 It is safe to marry a person who is having leprosy
 Agree Disagree Neutral
- 5.1.9 It is safe to marry a person who is completely treated for leprosy
 Agree Disagree Neutral

5.1.10 It is safe to marry a person whose family member is having leprosy

Agree Disagree Neutral

5.1.11 It is safe to marry a person whose family member is completely treated for leprosy

Agree Disagree Neutral

5.2 What would you do if your family member is diagnosed with leprosy?:

Ignore the condition Maintain distance Get him/her treated Others _____

5.3 What do you feel your neighbors and relatives would do if your family member is diagnosed with leprosy: Ignore the condition Maintain distance from your family Help him/her in treatment Others _____

5.4 What do you think would happen if you are diagnosed with leprosy

5.4.1 *You will become physically challenged day by day* Yes No DK

5.4.2 *People will avoid you* Yes No DK

5.4.3 *Your family members will separate you* Yes No DK

5.4.4 *People will remove you from work* Yes No DK

5.4.5 *People would not allow you to enter into religious places* Yes No DK

6. Questionnaire for myths/beliefs regarding leprosy

6.1 Leprosy is caused by curse of God for sinful activity caused by "Immoral conduct"

Yes No DK

6.2 Leprosy is caused by "Witchcraft"

Yes No DK

6.3 Leprosy is due to "Evil spirits"

Yes No DK

6.4 Leprosy is due to "Vitamin deficiency"

Yes No DK

6.5 Leprosy occurs due to "Impure blood"

Yes No DK

6.6 Leprosy is inherited from parents?

Yes No DK

6.7 Leprosy and Leukoderma/vitiligo are same diseases?

Yes No DK

6.8 Leprosy is caused by impure food/drinking water

Yes No DK

Annexure 2

CASE REPORT FORM

Knowledge-Attitude-Practices regarding Leprosy and Its Management among Leprosy Patients, Their Relatives and the Medical Interns: An Institution Based Cross-Sectional Study.

1.1 Subject Particulars

Name : _____ Age : _____ yrs Sex : M () F ()
 Marital Status: _____ Consanguinity: Y () N ()
 Occupation: _____
 Residential Address : _____
 (with Village, PS and phone no) _____

 Education : _____ Duration of Stay _____
 Income: APL BPL

1.2 Enrollment particulars

Subject Code: |__|__|__|__|*Case (A). * Relatives (B) * Medical Intern(C)
 Date of entry in the study: |__|__| |__|__| |__|__| Inclusion criteria: Y N
 Exclusion criteria: Y N
 Date of collection: |__|__| |__|__| |__|__| Photographs
 (Digital Pic nos. _____)
 Punch biopsy. (site _____) Slit skin smear . (site _____)

2. Clinical record (For Patients)

- 2.1 Present Complaints: _____ Duration _____
 1. _____
 2. _____
 3. _____
- 2.2 Contact with known case of leprosy in last 5 years: Present Absent Don't Know
 2.2.1 *Nature of contact*: Cohabiting Neighbor Colleague Others (_____)
 (Details of Contact: _____)
 2.2.2 *Frequency of contact*: Daily Weekly Occasionally (Specify _____)
 2.2.3 *Duration of contact*: Years |__| Months |__| Days |__|
- 2.3 Type of Hansen's Disease: Borderline Indeterminate Lepromatous Tuberculoid
 Other Specified Leprosy Leprosy Unspecified

- 2.4 Clinical complications: Deformity in feet Deformity in hands Lagophthalmos
Sensory loss in feet Sensory loss in hands Other (specify): _____
- 2.5 Treatment for Leprosy: Ongoing Treatment naive NA
(if 'Yes' then details: Drugs used _____ Duration of treatment _____)
- 2.6 History suggestive of Lepra reaction: Type 1 Type 2 Nil
(if 'Yes' then details: Date of onset _____ Date of remission _____)
- 2.7 Whether presented after development of complication or reaction
(if yes then details _____)

3. Knowledge regarding Leprosy (for all subjects)

- 3.1 Have you heard of a disease called leprosy Yes No
- 3.2 Do you know the cause of the disease Yes No
- 3.2.1 *If Yes*, Germs From mother to child Skin contact Sex with patient Sex with prostitutes Sharing food Through air Shaking hands Sitting close Insects/mosquitoes Bathing in a river Contaminated soil Sharing personal item Others _____
- 3.3.1 Leprosy is infectious Yes No DK
- 3.3.2 Leprosy is contagious Yes No DK
- 3.4 Leprosy is inherited from parents Yes No DK
- 3.5 Do you know the signs of leprosy Yes No DK
- 3.5.1 *If Yes*, White patch Absent sensation Deformity Ulceration Others _____
- 3.6. What is your source of knowledge about leprosy: School teaching Books News paper Radio/Television Talks/Seminars Films Family members/neighbors/friends Pamphlets/posters/hoardings ASHA workers Doctors Other patients with leprosy Others _____

4. Knowledge regarding Treatment of leprosy and Prevention of its Consequences (for all subjects)

- 4.1.1 Leprosy is Curable: Yes No DK
- 4.1.2 Leprosy is treatable: Yes No DK
- 4.2 What treatment is preferable in leprosy: Modern medicine Ayurvedic
Yoga and naturopathy Unani Siddha Homeopathy Herbal medicines
Ojha/Guin DK Others _____
- 4.3 Medicine is available free of cost: Yes No DK
- 4.3.1 *if yes*, Where _____
- 4.4 How long the treatment should be continued: DK 6 months 1year 2years
Others _____
- 4.5 What will happen if left untreated: Progress Resolve by itself Cause disability or deformity cause ulceration DK Others _____
- 4.6 Do you have any idea about physical effect of leprosy on a patient: Yes No
If Yes, describe _____

- 4.7 Can leprosy cause ulceration Yes No DK
- 4.8 Can some Predisposing skin conditions lead to trophic ulcer: Yes No DK
- 4.8.1 If yes, that can be-blisters calluses red spot others _____
- 4.9 Risk factors for development of Trophic ulcer: trauma dangerous environment
sharp objects fire hot objects DK others _____
- 4.10 Can leprosy cause deformity Yes No DK
- 4.11 leprosy cause disability Yes No DK
- 4.12 Can leprosy cause loss of eye sight Yes No DK
- 4.13 Do you know about self care for prevention of ulceration? Yes No DK
- 4.13.1 If yes, then method of self care _____

5. Attitude regarding leprosy (for all subjects)

- 5.1.1 What would you do if you come in contact with a leprosy patient
Ignore the condition Maintain distance Advice him to consult with doctor
others _____
- 5.1.2 *Would you like to shake hand with leprosy patient?*
Agree Disagree Neutral
- 5.1.3 *Would you make leprosy patient your friend?*
Agree Disagree Neutral
- 5.1.4 *Would you buy food from a leprosy patient?*
Agree Disagree Neutral
- 5.1.5 *Would you share food with a leprosy patient?*
Agree Disagree Neutral
- 5.1.6 *Would you mind sitting side by side with leprosy patient in a public conveyance?*
Agree Disagree Neutral
- 5.1.7 *Would you work with leprosy patient?*
Agree Disagree Neutral
- 5.1.8 It is safe to marry a person who is having leprosy
Agree Disagree Neutral
- 5.1.9 It is safe to marry a person who is completely treated for leprosy
Agree Disagree Neutral
- 5.1.10 It is safe to marry a person whose family member is having leprosy
Agree Disagree Neutral
- 5.1.11 It is safe to marry a person whose family member is completely treated for leprosy
Agree Disagree Neutral
- 5.2 What would you do if your family member is diagnosed with leprosy?:
Ignore the condition Maintain distance Get him/her treated Others _____

- 5.3 What do you feel your neighbors and relatives would do if your family member is diagnosed with leprosy: Ignore the condition Maintain distance from your family Help him/her in treatment Others _____
- 5.4 What do you think would happen if you are diagnosed with leprosy
- 5.4.1 *You will become physically challenged day by day* Yes No DK
- 5.4.2 *People will avoid you* Yes No DK
- 5.4.3 *Your family members will separate you* Yes No DK
- 5.4.4 *People will remove you from work* Yes No DK
- 5.4.5 *People would not allow you to enter into religious places* Yes No DK

6. Questionnaire for myths/beliefs regarding leprosy

- 6.1 Leprosy is caused by curse of God for sinful activity caused by "Immoral conduct" Yes No DK
- 6.2 Leprosy is caused by "Witchcraft" Yes No DK
- 6.3 Leprosy is due to "Evil spirits" Yes No DK
- 6.4 Leprosy is due to "Vitamin deficiency" Yes No DK
- 6.5 Leprosy occurs due to "Impure blood" Yes No DK
- 6.6 Leprosy is inherited from parents? Yes No DK
- 6.7 Leprosy and Leukoderma/vitiligo are same diseases Yes No DK
- 6.8 Leprosy is caused by impure food/drinking water Yes No DK

7. Patient's experience after diagnosed as leprosy

- 7.1 What type of feeling people or your relatives have upon you after knowing you as a leprosy patient
Normal Sympathetic Afraid Avoidance Others _____
- 7.2 Did you feel ashamed to tell others that you are diagnosed as leprosy Yes No
- 7.3 Whom you consulted first: Dermatologist General Physician Doctors of alternate medicines Quacks religious leaders Ojha/Guin. others _____
- 7.4 Who took you to hospital Self family members friends/neighbours others _____
- 7.5 After how many days of onset of disease you attended dermatological opd = _____ days
- 7.6 Do you have fear about disease: Yes No
- 7.7 Do you faced any difficulty due to stigma, separation from family or avoiding public transport Yes No , if yes, describe _____
- 7.8 Any depression or social anxiety Yes No
- 7.9 Do you face any discrimination in job places Yes No NA
- 7.10 Do you have fear of loss of job due to the disease Yes No NA
- 7.11 Do you faced problem in marital relationship Yes No NA
- 7.12 Do you have fear of developing deformity or disability Yes No