

Knowledge and Awareness Regarding Leprosy and its Treatment Among Leprosy Patients in a Tertiary Care Hospital

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ABSTRACT

Background: Study was conducted to assess awareness of leprosy and its treatment among leprosy patients presenting at a tertiary care hospital in Lucknow (UP), India. **Methods:** The study was conducted by a qualified interviewer using a 12-point self-prepared questionnaire on 78 leprosy patients turning up at the Dermatology Out-Patient Department of I.I.M.S & R and Hospital in Lucknow (UP) from January 2015 to June 2016. **Results:** Around 73% patients had heard about leprosy, while remaining 27% patients were either unaware or not sure. About 33% of the total 78 patients thought leprosy to be a type of infection, 21.7% said it was due to bad blood, 20.5% said it was exclusively a skin disease, 10% attributed it to supernatural phenomenon and rest of the 14% patients were unsure about its cause. Nearly 43.5% patients believed that they got the disease by coming in direct contact with some infected individual and 25.6% patients believed it to be as a result of some alteration in the blood. About 56.4% patients believed that leprosy was a communicable disease. Only 30.7% patients were confident that leprosy was curable. Approximately 72% patients knew one or more sign/symptom of leprosy. Only 23% patients were well aware of multidrug therapy (MDT) for leprosy while even a further lower percentage had knowledge of its free availability at government hospitals or centres.

More than 90% patients did not know about the duration of treatment. Only about 27% patients believed that allopathic medications would be best for curing leprosy while remaining 63% patients were either not sure or believed that alternate medicine (unani, homeopathy or ayurveda) could cure leprosy better. Literacy influenced the answer for many of the questions although in few areas it had less or no effect at all. **Conclusion:** Awareness of leprosy is still not adequate among the masses. Further steps are needed to ensure that basic knowledge of leprosy, its signs & symptoms, MDT and its availability is conveyed more to the general population by educating them at the grass root level through various literacy programme and other innovative ideas.

Key words: Leprosy, knowledge, awareness

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INTRODUCTION

Leprosy or Hansen's disease is caused by Mycobacterium leprae and is probably the oldest human disease known to

mankind.⁽¹⁾ It is still a feared disease with severe social repercussions for the sufferers. A little more than half a century back no effective treatment was available and health authorities segregated and isolated patients to prevent the spread of the disease.⁽¹⁻³⁾ Despite its low communicability leprosy remains endemic among an estimated 10 to 15 million people living in poor tropical countries.⁽⁴⁾ The clinical spectrum of the disease varies from limited

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cutaneous disease to very severe and extensive peripheral nerves and systemic involvement.⁽¹⁾ Delays in diagnosis and starting of effective treatment is very common and they are important risk factors for development of disability in leprosy.^(5,6) Ignorance and lack of awareness among the general population regarding leprosy, availability and accessibility of its treatment along with socioeconomic limitations and stigmatization may prevent people from seeking help early.⁽⁷⁾ This study was conducted in an attempt to assess knowledge & awareness of leprosy and its treatment among leprosy patients attending a tertiary care hospital in Lucknow (Uttar Pradesh), India.

METHODS

The study included confirmed leprosy patients who turned up at the Dermatology Out-Patient Department of Integral Institute of Medical Sciences & Research and Hospital in Lucknow, Uttar Pradesh (UP) over a period of 18 months from January 2015 to June 2016. All patients were explained and informed about the nature of the study and a written consent was taken from each patient before including them. The basic details of each patient such as age, sex, address, literary status, marital status, occupation, type of leprosy, reactional state (if any), duration of the disease and previous treatment(s) taken were all documented. The definition of being literate was taken as per the Constitution of India and a patient was considered literate if he/she was able to read and write with understanding in any language. A person who could merely read but could not write was not classified as literate. Any formal education or minimum educational standard was not necessary to be considered literate. The assessment was done using a 12-point self-prepared questionnaire by a qualified interviewer (Table 1). The questionnaire was prepared in the English language and then translated to Hindi which was the local language of the region. Patients were interviewed and asked to choose among the most appropriate answer provided for each question.

The data was analyzed by using MS Excel of version 7.0. Categorical data was expressed as frequencies & percentage. Chi square test was performed to analyze and find an association among categorical variables. A logistic multiple regression analysis incorporating literacy and gender was also performed and the statistical significances determined. The p-value <0.05 was considered to be statistically significant.

RESULTS

A total of 83 leprosy patients turned up during the study period. Three patients refused to take part in the study while 2 patients were children below 12 years and were not included. Among the 78 leprosy cases included, 69 patients (54 males; 15 females) were adults and remaining 9 patients (6 males; 3 females) were in the adolescent age group i.e. between 12 to 19 years of age. The literary status and occupation of the patients are summarized in Table-2 and

Table-3 respectively. Figure-1 shows the geographical distribution of the 78 cases.

In our study, 73% (n=57) patients either knew or had heard about leprosy. Among them, 31 patients were literate while remaining 26 patients were illiterate. Regardless of their literary status, majority of the patients had some knowledge about leprosy. This was seen to be statistically insignificant. Almost one third (33.3%; n=26) patients were certain that leprosy was a type of infection. Among these the number of literate patients was higher than illiterate patients although the difference was not statistically significant. Patients who considered leprosy to be either due to bad blood or a skin disease constituted a little above 20% for each option. Here again the number of literate and illiterate patients were more or less similar. However, patients who believed leprosy to be the result of some supernatural power such as God or evil spirits were all illiterate patients (10.2%; n=8). This was statistically significant (p=0.0058).

Nearly 43.6% (n=34) patients believed they got the disease by coming in contact with an infected person through touch, 25.6% (n=20) believed they might have been exposed to infected blood, 3.8% (n=3) believed it was a sexually transmitted disease, 6.4% (n=5) thought it might have been the result of evil spirits or maybe a curse from God. Among all patients, only one literate patient was of the opinion that he might have got the disease through the respiratory route. The remaining 19.2% (n=15) patients were not sure about how they got the disease. The number of illiterate and literate patients was more or less similar for all the options.

Around 56% (n=44) patients knew that leprosy was a communicable disease and the answer was not influenced by their literacy as both the group had more or less similar numbers. The number of illiterate to literate patients who either thought it was not communicable or were not sure of the answer was 20 to 14 respectively. Although not significant statistically, the number for literate patients not knowing about the communicable nature of leprosy was quite high. Half of the patients (50%; n=39) believed that leprosy was not a genetic or familial disease and did not transmit vertically from parent to offspring. On the other hand, 18% (n=14) patients believed it could be transmitted genetically all of whom were illiterate except for one patient. This was statistically significant (p=0.001).

A high percentage of patients (69%; n=54) patients either said that leprosy was not curable or were not sure about its curability. Only 31% (n=24) patients answered correctly by saying that leprosy could be cured with treatment. Here the literary status of the patients had no influence on the answer. More than 70% (n=56) patients knew one or more sign or symptom of leprosy. Literate patients were more aware about the different presentations of leprosy compared to illiterate patients and this was statistically significant (p=0.004). Only 7.7% (n=6) literate patients did not know a single sign or symptom of leprosy while this number increased to 20.5% (n=16) among the illiterate patients, and was statistically significant (p=0.04).

Table 1: 12-point questionnaire for leprosy patients regarding knowledge and awareness of leprosy and its treatment along with distribution of variables with percentages.

Question		Response	Illiterate (%)	Literate (%)	Total (%)
Q1	Have you ever heard of leprosy/ kustha rog/ korr?	0) No	8 (10.25)	3 (3.84)	11 (14.10)
		1) Yes	26 (33.33)	31 (39.75)	57 (73.08)
		2) May be	6 (7.69)	4 (5.13)	10 (12.82)
Q2	What do you think is the cause of your disease (Leprosy)?	1) Infection	10 (12.82)	16 (20.51)	26 (33.33)
		2) Bad blood	10 (12.82)	7 (8.97)	17 (21.79)
		3) Skin disease	7 (8.97)	9 (11.54)	16 (20.51)
		4) Supernatural	8 (10.25)	0 (0.00)	8 (10.25)
		5) Don't know	5 (6.41)	6 (7.69)	11 (14.10)
Q3	How do you think you got the disease?	1) Touch	16 (20.51)	18 (23.07)	34 (43.59)
		2) Blood	8 (10.25)	12 (15.38)	20 (25.64)
		3) Sexually	3 (3.84)	0 (0.00)	3 (3.84)
		4) Respiratory route	0 (0.00)	1 (1.28)	1 (1.28)
		5) Others	5 (6.41)	0 (0.00)	5 (6.41)
		6) Don't know	8 (10.25)	7 (8.97)	15 (19.23)
Q4	Do you think your disease can spread to others?	0) No	12 (15.38)	4 (5.13)	16 (20.51)
		1) Yes	20 (25.64)	24 (30.77)	44 (56.41)
		2) Don't know	8 (10.25)	10 (12.82)	18 (23.07)
Q5	Do you think leprosy is a genetic disease and may be transmitted from parent to offspring?	0) No	18 (23.07)	21 (26.92)	39 (50.00)
		1) Yes	13 (16.67)	1 (1.28)	14 (17.95)
		2) Don't know	9 (11.54)	16 (20.51)	25 (32.05)
Q6	Do you think your disease is curable?	0) No	10 (12.82)	5 (6.41)	15 (19.23)
		1) Yes	10 (12.82)	14 (17.95)	24 (30.77)
		2) Don't know	20 (25.64)	19 (24.36)	39 (50.00)
Q7	Can you enumerate the sign & symptoms of leprosy?	0) None	16 (20.51)	6 (7.69)	22 (28.20)
		1) One	16 (20.51)	9 (11.54)	25 (32.05)
		2) Two or more	8 (10.25)	23 (29.49)	31 (39.74)
Q8	Are you aware about the treatment of leprosy (MDT)?	0) No	36 (46.15)	24 (30.77)	60 (76.92)
		1) Yes	4 (5.13)	14 (17.95)	18 (23.07)
Q9	Are you aware about free availability of MDT drugs for leprosy at PHC and Government/District hospitals?	0) No	38 (48.71)	30 (38.46)	68 (87.18)
		1) Yes	2 (2.56)	8 (10.25)	10 (12.82)
Q10	Do you know about the duration of treatment for leprosy?	0) No	39 (50.00)	33 (42.31)	72 (92.31)
		1) Yes	1 (1.28)	5 (6.41)	6 (7.69)
Q11	What do you think may be the best treatment for leprosy?	1) Allopathic	7 (8.97)	14 (17.95)	21 (26.92)
		2) Homeopathic/Unani/Aurvedic	3 (3.84)	3 (3.84)	6 (7.69)
		3) Others	2 (2.56)	0 (0.00)	2 (2.56)
		4) Don't know	28 (35.90)	21 (26.92)	49 (62.82)
Q12	Knowing your disease to be leprosy, where would you get yourself treated?	0) None	8 (10.25)	6 (7.69)	14 (17.95)
		1) Hospital	11 (14.10)	13 (16.67)	24 (30.77)
		2) Temple/Mosque/Others	6 (7.69)	0 (0.00)	6 (7.69)
		3) Don't know	15 (19.23)	19 (24.36)	34 (43.59)

Table 2: Literacy among leprosy patients by gender.

Literacy among leprosy patients	No. of Illiterate (%)		No. of Literate (%)		Total (%)
	M	F	M	F	
Adult	31 (39.7)	8 (10.2)	23 (29.5)	7 (9.0)	69 (88.4)
Adolescent	1 (1.3)	0 (0.0)	5 (6.5)	3 (3.8)	9 (11.6)
Total (%)	32 (41.0)	8 (10.2)	28 (36.0)	10 (12.8)	
Grand total (%)	40 (51.2)		38 (48.8)		78 (100)

Table 3: Occupation of leprosy patients by gender

Occupation of leprosy patients	No. of Illiterate (%)		No. of Literate (%)		Total (%)
	M	F	M	F	
Farmer	21 (27.0)	-	7 (9.0)	-	28 (36.0)
Housewife	-	8 (10.2)	-	3 (3.8)	11 (14.0)
Student	-	-	7 (9.0)	6 (7.7)	13 (16.7)
Others	11 (14.0)	-	13 (16.7)	1 (1.3)	24 (32.0)
Unemployed	-	-	1 (1.3)	-	01 (1.3)
Total (%)	32 (41.0)	8 (10.2)	28 (36.0)	10 (12.8)	
Grand total (%)	40 (51.2)		38 (48.8)		78 (100)

Regarding the awareness of Multi Drug Therapy (MDT) for leprosy treatment, more than 77% (n=60) patients had no idea about it.

Compared to illiterate patients (5%; n=4), higher number of literate patients (18%; n=14) were aware of MDT. This was statistically significant (p=0.005) although the overall number of literate patients having knowledge of MDT was still very low. The knowledge of free availability of MDT at government health-care facilities was even lower with 87% (n=68) patients saying they had no knowledge while only 13% (n=10) patients said they already knew about it. Among the 10 patients, 8 were literate while 2 patients were illiterate. This was significant (p=0.03) but again with reference to the above mentioned low number of literate patients there leaves a lot to be desired when it comes to the knowledge of leprosy and its treatment.

about the available therapies for leprosy, 63% (n=49) patients were not sure about the most effective therapeutic system for curing leprosy. Only 27% (n=21) patients had complete faith in allopathic medicines while 8% (n=6) patients believed in alternate system of medicine (homeopathic, ayurvedic, unani). This was seen to be statistically insignificant.

A little above 30% (n=24) patients revealed that they would visit the hospital in order to get cured of leprosy although 43.6% (n=34) patients still could not make up their mind about where to get themselves treated. The number of patients who believed that they will never get cured no matter what they do was at around 18% (n=14). All six patients who believed that leprosy could only be cured by some divine intervention such as God were illiterate and hence they had more faith in getting cured at a place of worship rather than the hospital. This was statistically significant (p=0.016).

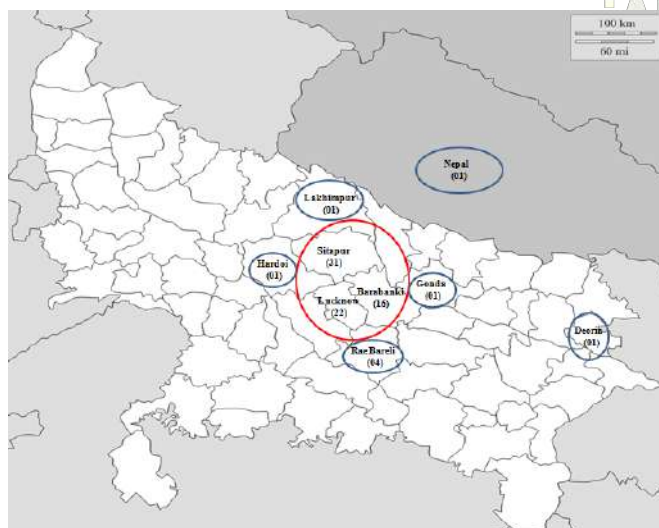


Figure 1: Map of Uttar Pradesh (India) showing geographical distribution of the 78 leprosy cases. Nearly 89% (n=69) cases were from 3 districts – Sitapur, Lucknow and Barabanki. One case was from Nepal.

A very high percentage i.e. 92% (n=72) patients did not know about the duration of the treatment of leprosy. Here patient being literate or illiterate did not influence the answer. Five out of the 6 patients who knew the length of duration of MDT were literate though it did not have any statistical significance. In assessing patients' knowledge

DISCUSSION

Having disease specific control programmes along with awareness about general well-being, disease and the health-care system forms an integral part of staying healthy. India is among the few countries where leprosy still remains an endemic disease. The National Leprosy Control Programme (NLCP) was launched in India in 1955 and then re-launched in 1983 as National Leprosy Eradication Programme (NLEP). Later, the vertical services of leprosy were integrated with the General Health Services and is currently in place in various hospitals and specialized centres throughout the country.⁽⁸⁾ But its effectiveness can be maintained or even maximized only if the general population and patients suffering from leprosy are well aware of its cause, early signs & symptoms and availability of its treatment specifically MDT at health-care centres. Previously, many studies have been done to assess the knowledge and attitude of leprosy among community members as well as leprosy patients. These studies documented the effectiveness of health education in leprosy and most of them found a low correlation between knowledge and attitude among the community with relation to leprosy.⁽⁹⁻¹²⁾ Inadequate or incorrect knowledge about leprosy and its treatment may be responsible for the above

mentioned low correlation.^(13, 14) In a previous study, all 400 participants (130 of who were leprosy patients), had heard of leprosy.⁽¹⁵⁾ In another study, almost 94 % patients knew something about leprosy. In our study, nearly 70% patients either knew or had heard about leprosy and here there was no correlation between the answer and the literary status of the patients.

A previous study had cited bad blood as the most probable cause of leprosy but majority of the literates were in favour of it being an infection.⁽¹⁵⁾ In another study, one third did not know the cause of leprosy while another third said it was caused by a micro-organism. The next most common cause cited was bad blood.⁽¹⁶⁾ In our study one third of the patients said that leprosy was due to some infection while the next most common cause of leprosy answered by the patients was bad blood or skin disease. All patients who answered that leprosy was the result of some supernatural power were illiterate. However in one study, none of the 300 respondent knew what caused leprosy.⁽¹⁷⁾ In our study more than half patients knew that leprosy was a communicable disease and majority believed they got the disease through touch. Similar results were noted in a previous study done by Barkataki et al.⁽¹⁵⁾ However the study done by Nisar et al showed that a very low percentage of the respondents knew that leprosy was contagious or could be contracted.⁽¹⁷⁾ In our study although not significant statistically, the number of literate patients who did not know that leprosy was a communicable disease was high.

A study done in the urban slums of Kolkata showed that nearly 12% respondents believed leprosy to be a hereditary disease.⁽¹⁶⁾ Similarly in our study, half of the patients believed leprosy was not a genetic disease. While nearly one fifth of the total patients (all of whom were illiterate except one) believed it was transmissible from parent to offspring. In our study, nearly 70% patients either said that leprosy was not curable or were not sure while 30% said it was curable. Knowledge regarding leprosy being curable among patients and the general community has been variable.^(15,17) In our study 70% of the patients most of who were literate knew one or more sign/symptom of leprosy. Nearly 30% patients (one third of who were literate) did not know a single sign or symptom of leprosy. This value was higher when compared to a previous study,⁽¹⁶⁾ but much lower when compared to another study.⁽¹⁷⁾

In our study, nearly 63% patients were not sure about the most effective and appropriate therapy for curing leprosy. Only one-fourth patients believed that allopathic medicines would cure leprosy while remaining patients had more faith in alternate system of medicine such as homeopathic, ayurvedic or unani. Awareness of MDT for leprosy, its free of cost availability at various health-care centres and duration of treatment is still not adequate enough among patients as well as the general population. This was evident in our study as well as studies done previously.^(15,17) Compared to illiterate patients, higher number of literate patients were aware of MDT although the overall number of literate patients having knowledge of MDT was still low.

Contrary to this, other studies have reported good awareness about leprosy treatment and its availability.⁽¹⁶⁾ Only one-third of the patients in the present study said that they would visit the hospital or clinics to get cured of leprosy. Most of them could not make up their mind about where to get themselves treated. But the most disturbing fact was that nearly a fifth of the total patients thought they will never get cured of leprosy. Interestingly, one literate patient who himself had earlier stated that leprosy was curable later contradicted his answer by saying that he believed he himself would not be cured. In our study all six patients who believed in going only to a place of worship for getting cured of leprosy were illiterate. This was considerably higher percentage (7.7% versus 0.2%) than a previous study.⁽¹⁶⁾

CONCLUSION

This study showed that a large number of the patients had heard about leprosy and over half of the patients had knowledge that it was communicable. Most of the literate patients knew at least one type of presentation of leprosy. However, knowledge regarding the cause of leprosy, its mode of spread, its treatment (MDT), duration of the treatment and free availability of MDT at various health-care centres was lacking in majority of the patients. The literary status of the patient influenced the response of the patient for many if not all of the questions. Hence further steps are needed to ensure that basic knowledge of leprosy, its signs & symptoms, MDT and its availability is conveyed more effectively to the general population by educating them at the grass root level. These areas should therefore be more concentrated upon by creating more awareness and educating them through various literacy programmes, awareness camps, newspaper ads, educational posters & leaflets, television, radio and other innovative ideas such as skits and plays.

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