

Knowledge of and attitudes to leprosy among patients and community members: a comparative study in Uttar Pradesh, India

PRAMILA BARKATAKI*, SHEO KUMAR* & P. S. S. RAO**

**The Leprosy Mission Hospital, Faizabad, Motinagar (Post), Faizabad (District), Uttar Pradesh 224 201, India*

***The Leprosy Mission Trust India, Research Resource Centre, Shahdara, Nand Nagri, Delhi 110 093, India*

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Summary The roles of literacy and gender in enhancing help seeking behaviour in leprosy need further research in order to maximize the effectiveness of health education programmes. A study on leprosy knowledge and attitudes was carried out in Uttar Pradesh, one of the hyper endemic states for leprosy in north India, on a random sample of 130 leprosy patients, 120 non-leprosy patients, and 150 community members. A questionnaire was prepared, tested and administered in Hindi, the local language, by a qualified interviewer. Statistical analyses were done in each group by gender and literacy, and compared. Almost everyone in the three groups knew of leprosy, but only a larger proportion of leprosy patients (60%) mentioned anaesthetic patch, as compared to about 20% or less in the other groups. A vast majority in all groups mentioned bad blood, or divine curse as the cause. Even among leprosy patients, less than 10% of illiterates and only about 40% of literates cited infection as the cause of leprosy. Literates had a better, though still quite a poor knowledge on the symptoms as well as the causation of leprosy. However, almost all stated that leprosy was curable, though they couldn't mention MDT specifically. They felt that not all patients need have deformity. About 20–30% of the leprosy affected, but nearly 50–60% in the other groups stated that there was discrimination. Nearly 70% felt that leprosy affected social participation, over 90% attributing this to adverse social stigma. Multivariate analyses, adjusted for sex, confirmed the significant association of literacy with both knowledge and attitudes. In the light of massive health education and IEC campaigns, the findings from this study are disappointing. Adult literacy programmes combined with more innovative focused approaches to suit various target audiences can impact knowledge and attitudes better.

Introduction

Much of the stigma associated with leprosy stems from inadequate or incorrect knowledge about the disease and its current treatment.^{1,2} Even after nearly 2 decades of excellent

multidrug therapy and remedies for reactions and ulcers, large segments of rural populations seem ignorant or weakly motivated to seek early treatment.³ It is well known that knowledge alone will not change attitudes or influence behaviour,⁴ and the role of literacy and gender in enhancing the health seeking habits needs further research and action.

Several states in northern India are still lagging behind in elimination of leprosy, and Uttar Pradesh is one of these, with relatively low literacy rates in predominantly rural areas.⁵ Hence, an in-depth survey was carried out in the heart of Uttar Pradesh, on the levels of knowledge and attitudes of leprosy and non-leprosy patients attending a leprosy referral hospital, and among the neighbouring community. The findings and their implications for future strategies are presented in this paper.

Materials and methods

The study was carried out at The Leprosy Mission Hospital at Faizabad, Uttar Pradesh. During December 2003 to February 2004, from the outpatients attending the hospital, 130 leprosy patients and 120 non-leprosy patients were consecutively selected. From the villages surrounding the hospital, a representative random sample of 150 community members of similar ages, who had not previously attended the leprosy mission hospital, were chosen consecutively through home visits.

The respondents were interviewed in Hindi, the local language, by a qualified investigator using a specially prepared questionnaire. Replies were obtained successfully for all items.

The questionnaire determined the level of knowledge in terms of early signs and symptoms of leprosy, the cause and treatment for leprosy, knowledge and attitudes towards infectivity, curability and deformity of leprosy. It also elicited the community's attitudes towards leprosy patients and the restriction in social participants of affected persons. The questions were open ended and later categorized.

Basic details of the respondents such as age, sex, literacy, occupation and disease status were ascertained. Persons who have studied in a school at least up to 5th grade, and could read a simple passage in Hindi, were considered as literates.

In view of the presumed confounding of literacy with gender, statistical analyses were done separately for males and females according to literacy among the three groups of subjects interviewed. Percentages of correct responses were computed by literacy in each subgroup and the differences tested for statistical significance using the z-test for proportions. The chi-square test was used for testing associations similar analyses were done on attitudes. A logistic multiple regression analysis incorporating literacy and gender was also performed, and the statistical significances determined.

Results

A total of 130 leprosy patients (97 males, 33 females) 120 non-leprosy patients (57 males, 63 females) and 150 community members (96 males, 54 females) were interviewed.

The extent of illiteracy among the three groups of respondents by gender is shown in Table 1.

There were slightly more illiterates among leprosy patients in both males and females. Illiteracy was significantly higher ($P < 0.05$) among females as compared to males in all the three groups of respondents.

Almost everyone in the three groups had heard about leprosy. However, their knowledge on early signs/symptoms and on causation of leprosy was poor and varied as summarized in Table 2.

Significantly larger percentage of leprosy patients mentioned anaesthesia as the leading symptom, followed by patch ($P < 0.05$). About 70% of the other two groups mentioned patch as the main symptom, followed by ulcers, and then only anaesthesia. While significantly more literates ($P < 0.05$) in non-leprosy and community groups cited anaesthesia compared with illiterates, there was no such difference in the leprosy group by literacy. There was no

Table 1. Illiteracy by gender in the three groups of respondents

Group	Male			Female			Total		
	No.	Illiterate		No.	Illiterate		No.	Illiterate	
		No.	%		No.	%		No.	%
Leprosy patients	97	32	33.0	33	26	78.8	130	58	44.6
Non-leprosy patients	57	5	8.8	63	32	50.8	120	37	30.8
Community members	96	17	17.7	54	29	53.7	150	46	30.7

Table 2. Knowledge regarding signs/symptoms and causation of leprosy by gender and literacy

Literacy	Knowledge	Leprosy		Non leprosy		Community	
		M	F	M	F	M	F
Illiterate	<i>Signs/symptoms</i>						
	Patch	14 (43.8%)	9 (34.6%)	2 (40.0%)	24 (75.0%)	11 (64.7%)	20 (69.0%)
	Anaesthesia	18 (56.2%)	15 (57.8%)	1 (20.2%)	1 (3.1%)	3 (17.6%)	2 (6.9%)
	Deformity	0 (0.0%)	1 (3.8%)	2 (40.0%)	0 (0.0%)	0 (0.0%)	1 (3.4%)
	Ulcer	0 (0.0%)	1 (3.8%)	0 (0.0%)	3 (9.4%)	2 (11.8%)	4 (13.8%)
Literate	Don't know	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (12.5%)	1 (5.9%)	2 (6.9%)
	Patch	33 (50.8%)	4 (57.1%)	39 (75.0%)	26 (83.9%)	51 (64.5%)	19 (76.0%)
	Anaesthesia	32 (49.2%)	3 (42.9%)	6 (11.6%)	4 (12.9%)	24 (30.4%)	6 (24.0%)
	Deformity	0 (0.0%)	0 (0.0%)	2 (3.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Ulcer	0 (0.0%)	0 (0.0%)	5 (9.6%)	1 (3.2%)	3 (3.8%)	0 (0.0%)
Illiterate	Don't know	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.3%)	0 (0.0%)
	<i>Causation</i>						
	Infection	3 (9.4%)	2 (7.2%)	0 (0.0%)	0 (0.0%)	1 (5.9%)	0 (0.0%)
	Bad blood	18 (56.3%)	16 (61.4%)	4 (80.0%)	16 (50.0%)	9 (52.9%)	12 (41.4%)
	Curse of God	4 (12.5%)	5 (19.2%)	1 (20.0%)	5 (15.6%)	3 (17.6%)	5 (17.3%)
Literate	Food, heredity, etc.	2 (6.2%)	2 (7.8%)	0 (0.0%)	4 (12.5%)	2 (11.8%)	7 (24.1%)
	Don't know	5 (15.6%)	1 (3.9%)	0 (0.0%)	7 (21.9%)	2 (11.8%)	5 (17.2%)
	Infection	29 (44.6%)	2 (28.5%)	16 (30.8%)	11 (35.5%)	38 (48.1%)	10 (40.0%)
	Bad blood	22 (33.9%)	3 (42.9%)	22 (42.3%)	15 (48.4%)	41 (40.5%)	12 (48.0%)
	Curse of God	4 (6.2%)	1 (14.3%)	2 (3.8%)	1 (3.2%)	4 (1.3%)	2 (8.0%)
Literate	Food, heredity, etc.	7 (10.7%)	0 (0.0%)	11 (21.2%)	3 (9.7%)	8 (10.1%)	1 (4.0%)
	Don't know	3 (4.6%)	1 (14.3%)	1 (1.9%)	1 (3.2%)	0 (0.0%)	0 (0.0%)

statistically significant difference by sex in the three groups, and the findings were similar as stated for literacy.

Bad blood is cited as the reason for leprosy by most of the respondents, including leprosy patients. However, significantly higher percentage of literates ($P < 0.01$) in all the groups were able to mention infection as the chief cause of leprosy.

To a more pointed question as to whether the respondent considered leprosy as infectious, and if leprosy affected persons were discriminated against, the findings are presented in Table 3.

Among illiterates, nearly 50% of the community and almost 40% of the patients consider leprosy infectious. On the other hand, significantly more (nearly 80%) of all literate respondents did not consider leprosy infectious ($P < 0.05$). More of the illiterate leprosy patients felt there was no discrimination, although they acknowledged that in some cases, leprosy patients are not treated the same as others. There are minor variations by sex and in general, significantly more literates felt there was no discrimination except in a few instances. ($P < 0.05$).

Almost all the respondents were sure there was a treatment for leprosy, but relatively small percentage could specifically mention MDT even among leprosy patients. Most stated tablets and capsules as the treatment for leprosy. More than 50% of literates as compared to less than 10% of illiterates specifically mentioned MDT, the difference statistically significant ($P < 0.01$).

Almost everyone stated that leprosy is curable and that not every leprosy patient need have deformity. Further, all respondents stated that the deformities can be prevented.

Nearly 70% or more of the respondents felt that leprosy affects social participation as displayed in Table 4.

This was true for both literates and illiterates in all the groups and by sex. Eighty to 90% of the respondents stated that the main reason for such restrictions was the social stigma.

Multiple logistic regression analyses revealed a significant association of literacy with knowledge on leprosy in all groups, after adjusting for sex. The Odds Ratios were

Table 3. Infectivity and discrimination of leprosy patients

Literacy	Response	Leprosy		Non leprosy		Community	
		M	F	M	F	M	F
	<i>Infectious</i>						
Illiterate	Yes	10 (31.3%)	10 (38.5%)	2 (40.0%)	14 (43.8%)	9 (52.9%)	14 (48.3%)
	No	22 (68.7%)	15 (57.7%)	3 (60.0%)	11 (34.4%)	7 (41.2%)	14 (48.3%)
	Don't know	–	1 (3.8%)	–	7 (21.8%)	1 (5.9%)	1 (3.4%)
Literate	Yes	10 (15.4%)	–	7 (13.5%)	7 (22.6%)	16 (20.3%)	4 (16.0%)
	No	54 (83.1%)	7 (100.0%)	44 (84.6%)	24 (77.4%)	63 (79.7%)	21 (84.0%)
	Don't know	1 (1.5%)	–	1 (1.9%)	–	–	–
	<i>Discrimination</i>						
Illiterate	No	25 (78.1%)	18 (69.1%)	5 (100.0%)	11 (34.4%)	9 (52.9%)	16 (55.2%)
	Yes	3 (9.4%)	3 (11.5%)	–	10 (31.3%)	2 (11.8%)	9 (31.0%)
	Yes by some	4 (12.5%)	5 (15.4%)	–	10 (31.3%)	6 (35.3%)	4 (13.8%)
Literate	No	40 (61.5%)	7 (100.0%)	31 (59.6%)	24 (77.4%)	51 (64.6%)	20 (80.0%)
	Yes	9 (13.9%)	–	11 (21.2%)	–	16 (20.3%)	2 (8.0%)
	Yes by some	16 (24.6%)	–	10 (19.2%)	7 (22.6%)	12 (15.1%)	3 (12.0%)

Table 4. Participation restrictions of leprosy patients and reasons thereof

Literacy	Response	Leprosy		Non leprosy		Community	
		M	F	M	F	M	F
	<i>Restriction</i>						
Illiterate	Yes	14 (43.8%)	10 (38.5%)	1 (20.0%)	10 (31.3%)	6 (35.3%)	6 (20.7%)
	No	11 (34.4%)	8 (30.8%)	–	12 (37.5%)	5 (29.4%)	9 (31.0%)
	Sometimes	7 (21.8%)	8 (26.7%)	4 (80.0%)	10 (31.2%)	6 (35.3%)	14 (41.3%)
Literate	Yes	23 (35.4%)	4 (57.1%)	16 (30.8%)	11 (35.5%)	22 (27.8%)	9 (36.0%)
	No	18 (27.7%)	–	13 (25.0%)	7 (22.6%)	26 (32.9%)	5 (20.0%)
	Sometimes	24 (36.9%)	3 (42.9%)	23 (44.2%)	13 (41.9%)	31 (39.3%)	11 (44.4%)
	<i>Reason</i>						
Illiterate	Adverse attitude	15 (83.3%)	14 (93.3%)	4 (100.0%)	16 (76.2%)	9 (81.8%)	17 (81.0%)
	Self stigma	3 (16.7%)	1 (6.7%)	–	5 (23.8%)	2 (18.2%)	4 (19.0%)
Literate	Adverse attitude	36 (85.7%)	2 (66.7%)	27 (75.0%)	15 (75.0%)	45 (79.0%)	12 (75.0%)
	Self stigma	6 (14.3%)	1 (33.3%)	9 (25.0%)	5 (25.0%)	12 (21.0%)	4 (25.0%)

significantly high among leprosy patients, 6.9 ($P < 0.01$) among non-leprosy patients 5.9 ($P < 0.02$) and in the community, 7.2 ($P < 0.01$).

Discussion

An evaluation of a sustained 7-year health education campaign on leprosy in Tanzania concluded that low level of education, rural residence, older age, female gender and Moslem religion were associated with stigmatizing attitudes and beliefs towards leprosy.⁶ The authors, however, caution that health education campaigns must be sustained to induce behavioural changes in the community. Much emphasis and considerable expense is incurred by governments on information, education and communication (IEC) activities to dispel the social stigma of leprosy and to seek the participation of the community in facilitating early self reporting.^{1,2} Increased knowledge *per se* may not lead to attitudinal and behavioural changes unless the mass media campaigns are dynamic and entertaining.⁷ The present study has highlighted the role of literacy in the reduction of stigma. A study in Brazil on delayed diagnosis of leprosy concluded that effective involvement of various segments of society, particularly the integration and partnership of the public health services and health education centres to be valuable tools for the planning and execution of educational activities directed at risk groups and the community.⁸ As governments seek to promote basic education for all people, especially those in rural areas, the IEC activities might become more cost-effective.²

A variety of educational activities such as small group talks, posters and use of catchy slogans are an integral part of health services to educate patients, their families and the general communities on leprosy and its treatment, in order to dispel ignorance, misconceptions and prejudices.^{9–11} Despite these efforts, a review by Mutatkar concluded that knowledge, attitude, practice studies indicated a lack of accurate knowledge about leprosy among the general population as well as patients.¹² The results from the present study confirms this observation even after several decades of formal leprosy education. It is time that a proper review be made of the strategies used and make them more effective through patient-driven and community based approaches. In this connection, it is also worth

examining the knowledge and attitudes of the health care workers themselves,¹³ who play a critical role in shaping the attitudes of the patients and their families.

It is now well accepted that knowledge alone will not change attitudes or behaviour.^{6,10,14,15} Various studies have also reported that the effectiveness of any educational effort depends not only on the content, but on the mode and duration of presentation.^{16–18} Obviously, the target audiences require more focused and customized health education outside their family. Effective health education, therefore, will depend on a careful situational analyses on existing sociocultural beliefs and practices relating to leprosy. It has been suggested that social marketing be applied to leprosy programmes.¹⁹ While social marketing has several strengths that could be used to make effective changes in the community's attitudes and behaviour, there are bound to be limitations due to the deeply ingrained stigma. Nevertheless, the principles of social marketing combined with the available information technology should be seriously tried in a variety of social settings.

The findings from this research on the knowledge and attitudes of leprosy patients has been disappointing. One would have expected a much greater awareness and more favourable attitudes among leprosy patients, who receive the maximum attention from the hospital staff. There are also vast numbers of non-leprosy patients, who could benefit from well-planned health education programmes, at relatively low costs. Perhaps, the knowledge and attitudes of the hospital staff themselves need to be assessed and any deficiencies rectified, before they can be effective agents of change.⁶

The observations of the respondents on enacted stigma in terms of restrictions on social participation of the leprosy affected persons need to be seriously considered, and suitable programmes developed for changing adverse social attitudes and also counseling patients on self-stigma. Leprosy is more a social problem rather than just a medical disease.^{12,16}

With powerful medical and surgical interventions available at practically no financial costs to the patients, the challenges and obstacles to elimination and eradication of leprosy will be more social and psychological, requiring the best expertise in these areas, actively involving the communities in all our efforts.

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