

The Tangled Web: A Study of Knowledge and Attitude towards Leprosy from a Tertiary Care Hospital in India

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Leprosy stands tall among the oldest and most misunderstood diseases of man. Today leprosy is easily treated; unfortunately, persistent misconceptions result in unnecessary stigmatization. Thus the present study aims to assess the knowledge and attitudes regarding leprosy in people with and without leprosy, factors affecting the same; and to study their relationship with treatment status in leprosy patients. Detailed knowledge and attitude questionnaires were administered to 260 subjects (100 leprosy patients, 60 family members of leprosy patients and 100 people with non-leprosy skin diseases) at AIIMS, New Delhi. Crude scores based on subject responses were used for inter-group comparisons. Leprosy patients had significantly higher knowledge scores than family members who in turn scored significantly higher than people with other skin diseases. Leprosy patients had fair knowledge about common symptoms, but awareness about MDT was low. Delayed diagnosis and non-compliance were common. Attitudes did not differ between groups. Fear of the leprosy-affected and reluctance for physical contact, food sharing and marriage were prominent. Treated leprosy patients had the highest knowledge scores. Higher education and greater knowledge scores were positive predictors of attitude. Knowledge and attitude scores showed significant positive correlation. Knowledge and attitude towards leprosy are unsatisfactory. Improving knowledge may help to improve attitudes. In the post-elimination era, we must incorporate education about the disease into routine care of leprosy patients and focus on community education about leprosy.

Keywords : Leprosy, Disability, Rehabilitation.

Introduction

Leprosy stands tall among the oldest and most misunderstood diseases of man. It has been rightly said, "*the bacillus itself is only a minor actor in the leprosy drama*" (Cross 2006). Today leprosy is easily treated; unfortunately, persistent misconceptions result in unnecessary stigmati-

zation. The last 20 years have seen a steep fall in leprosy prevalence. In India, the largest contributor to the global burden, the MDT-based National Leprosy Eradication Program drastically reduced prevalence from 57/10,000 in 1981 to the 'elimination' level (below 1/10,000) in 2005 (Joshi 2010). However, incidence remains high

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with 1.35 lakh new cases in 2012-2013 (NLEP 2013).

Currently, the emphasis is on disability prevention and rehabilitation. Disability prevention depends heavily on early diagnosis and treatment compliance; these are in turn related to satisfactory leprosy-related knowledge and attitudes in society, because active case detection has taken a backseat in the post-elimination era. Measurement of abstract concepts such as knowledge and attitude is tricky. The lack of standardized disease-specific questionnaires further complicates the issue. Earlier studies have had limited focus on certain specific areas of knowledge or attitude. Our study delves more comprehensively into at all major domains of knowledge and attitude. We have also looked at the factors affecting these entities and the influence of treatment on knowledge and attitude of leprosy patients. Our tertiary care hospital caters to a large number of leprosy patients. Moreover, as an apex medical institution, it attracts patients from all corners and diverse backgrounds. Hence, a study of people presenting to our centre gives a good glimpse into the awareness and feelings about leprosy in our country.

Materials and Methods

A questionnaire-based study was conducted on 260 subjects, including 100 leprosy patients and 160 people without leprosy comprising of 60 family members of leprosy patients and 100 patients with other (non-leprosy) skin diseases. Study subjects were recruited from the Dermatology outpatient department and Leprosy clinic at AIIMS, New Delhi between February 2009 and September 2010. Patients with all types of leprosy irrespective of treatment status were included. Patients with other skin diseases could have any diagnosis other than leprosy. The major

exclusion criterion in all groups was age below 14 years.

After obtaining written informed consent), demographic data was recorded. Treatment-related information was also recorded for leprosy patients. All subjects were administered detailed questionnaires dealing with knowledge and attitude related to leprosy. These questionnaires were prepared after reviewing the findings of earlier studies on these issues. They were initially prepared in English, translated into Hindi and back-translated into English to ensure accuracy.

Largely, the same questions were asked to all three groups; however, some questions were exclusive to certain groups. There were totally 19 knowledge-related questions meant for leprosy patients and relatives and 18 of these were asked to people with other skin diseases. Regarding attitude, there were 24 questions for leprosy patients and relatives and 22 for people with other skin diseases. Some questions were open-ended; responses were categorized during analysis. Others were of the yes-or-no response type. Literate subjects were given the choice to fill up the questionnaire on their own, but most people chose to be interviewed verbally by the investigator. Adequate privacy was ensured to study participants.

In order to make a quantitative assessment and to perform inter-group comparisons, knowledge and attitude scores were calculated by combining responses to all questions common to all three groups. Correct answers to knowledge-related questions were given 1 point each while wrong answers received no points. Two questions viz. mode of spread and symptoms could receive more than 1 point according to the number of correct options listed by the subject, bringing the maximum possible knowledge score to 22. Responses indicating positive attitude received

1 point each while those indicating negative attitude received 0 points. The maximum possible attitude score was 22, taking into account questions common to all groups. Though such crude scores which might not accurately measure knowledge or attitude, they help with comparisons between groups.

Information was collected in a single session spanning approximately forty minutes. After data collection from participants, the correct answers to the questions were conveyed to them, thus achieving some knowledge transmission. In addition, leprosy patients and relatives were counselled regarding their disease and associated apprehensions. A pamphlet with important facts about leprosy in simple language was also provided. The study was approved by the

institutional Ethics Committee and SPSS software was used for analysis.

Results

Demographic Characteristics

Demographic details of the participants are summarized in Table 1. Over half (53%) the leprosy patients were on treatment at the time of interview; 26% were untreated and 21% had completed treatment. Among studied family members, the most common relationship to the patient was that of spouse. The most common source of information about leprosy in our subjects was hearsay (45%) followed by the media (36%) and various limbs of the healthcare system (16%). Nine people (3%) had never heard about leprosy.

Table 1 : Demographic characteristics of the 3 groups

		Patients (n = 100)	Relatives (n = 60)	Others (n = 100)
Age (yrs)	Range	14 - 60	14 - 60	17 - 65
	Mean	30.9	32.6	33.8
	Median	27.5	30	31
Sex	Male	81 (81%)	40 (67%)	51 (51%)
	Female	19 (19%)	20 (33%)	49 (49%)
Marital status	Married	63 (63%)	50 (83%)	68 (68%)
	Single	37 (37%)	10 (17%)	32 (32%)
Education	Illiterate	8 (8%)	3 (5%)	2 (2%)
	Primary school	18 (18%)	13 (22%)	13 (13%)
	Middle school	23 (23%)	6 (10%)	3 (3%)
	High school (10th pass)	19 (19%)	13 (22%)	14 (14%)
	Intermediate (12th pass)	8 (8%)	7 (12%)	13 (13%)
	Graduate	24 (24%)	18 (30%)	55 (55%)
Occupation	Student	18 (18%)	4 (7%)	23 (23%)
	Housewife	14 (14%)	16 (27%)	25 (25%)
	Unskilled / semi-skilled / skilled worker	39 (39%)	16 (27%)	16 (16%)
	Clerk/shop owner/farmer	19 (19%)	14 (23%)	18 (18%)
	Semi-profession / profession	10 (10%)	10 (17%)	18 (18%)

Knowledge about leprosy

Awareness about the cause of leprosy was very low, spanning all groups (Table 2). Acceptable answers (germs, bacteria, infection) were given by less than one-fourth. Bad blood was a common myth in more than half the respondents; curse was also a strong belief. Knowledge regarding mode of spread of leprosy was poor with no significant differences between groups (Table 2). Myths abounded; casual touch and eating together were believed to transmit leprosy by more than half, heritability was also another popular idea. Belief in sexual transmissibility was surprisingly common (10-18%) though it was not

specifically asked for. Common symptoms were reasonably well-known to leprosy patients and their knowledge was much better than that of the other two groups (Table 3). These differences were statistically significant. A significant number of people with other skin diseases considered leukoderma to be a symptom of leprosy, though it was not specifically asked for.

The questions covered all major issues in leprosy treatment (Table 3). Awareness that leprosy is treatable was unsatisfactory among people with other skin diseases; only one-third of this group knew that treatment was free and under 15% of them had heard of MDT. Awareness about

**Table 2 : Knowledge about cause and spread of leprosy
(percentage of subjects who provided these answers)**

	Patients	Relatives	Others	Overall
Knowledge of Causation				
Germs / bacteria / infection*	25 / 100 (25%)	10 / 60 (17%)	16 / 100 (16%)	51 / 260 (20%)
Bad blood	44 / 100 (44%)	39 / 60 (65%)	62 / 100 (62%)	145 / 260 (56%)
Curse	24 / 100 (24%)	14 / 60 (23%)	20 / 100 (20%)	58 / 260 (22%)
Knowledge about Spread				
Prolonged contact*	10 / 100 (10%)	4 / 60 (7%)	0 / 100 (0%)	14 / 260 (5%)
Nasal secretions*	9 / 100 (9%)	2 / 60 (3%)	3 / 100 (3%)	14 / 260 (5%)
Casual touch	47 / 100 (47%)	32 / 60 (53%)	58 / 100 (58%)	137 / 260 (53%)
Eating together	53 / 100 (53%)	30 / 60 (50%)	50 / 100 (50%)	133 / 260 (51%)
Hereditary	45 / 100 (45%)	19 / 60 (32%)	38 / 100 (38%)	102 / 260 (39%)
Sexual contact	18 / 100 (18%)	6 / 60 (10%)	10 / 100 (10%)	34 / 260 (13%)

* - accepted as correct answers

**Table 3 : Knowledge related to symptoms and treatment of leprosy
(percentage of subjects who provided these answers)**

	Patients	Relatives	Others	Significant differences (Chi square test)
Skin patch (excluding those who said leukoderma)	62 / 100 (62%)	20 / 60 (33%)	32 / 100 (32%)	p < 0.001
Sensory loss	71 / 100 (71%)	27 / 60 (45%)	31 / 100 (31%)	p < 0.001
Deformity	74 / 100 (74%)	41 / 60 (68%)	47 / 100 (47%)	p < 0.001
Ulcers	28 / 100 (28%)	18 / 60 (30%)	37 / 100 (37%)	None (p = 0.37)
Other relevant symptoms (reactions, thick nerves etc)	27 / 100 (27%)	6 / 60 (10%)	4 / 100 (4%)	p < 0.001
Leukoderma	6 / 100 (6%)	6 / 60 (10%)	22 / 100 (22%)	p = 0.003
Leprosy is treatable	86 / 100 (86%)	51 / 60 (85%)	62 / 100 (62%)	p < 0.001
Allopathic treatment	90 / 100 (90%)	59 / 60 (99%)	78 / 100 (78%)	p = 0.001
Aware about MDT	46 / 100 (46%)	18 / 60 (30%)	13 / 100 (13%)	p < 0.001
Aware about free treatment	79 / 100 (79%)	35 / 60 (58%)	33 / 100 (33%)	p < 0.001
Delayed treatment increases severity	86 / 100 (86%)	55 / 60 (92%)	71 / 100 (71%)	p = 0.002
Know about treatment duration	43 / 100 (43%)	11 / 60 (18%)	5 / 100 (5%)	p < 0.001
Regular compliance is necessary	96 / 100 (96%)	58 / 60 (97%)	79 / 100 (79%)	p = 0.008
Persistent deformity means persistent "disease"	86 / 100 (86%)	58 / 60 (97%)	91 / 100 (91%)	None (p = 0.08)
Leprosy patients need special hospitals	41 / 100 (41%)	36 / 60 (60%)	69 / 100 (69%)	p < 0.001

treatability, MDT, treatment duration and free treatment were better among relatives and patients. Two important myths were identified – firstly, persistent sensory loss or deformity

after treatment completion indicates persistent disease, and secondly, leprosy patients require treatment in special hospitals.

Consequences of lack of knowledge in our leprosy patients

Though overall knowledge scores were best in leprosy patients, the actual situation was not satisfactory. Twenty six patients (26%) learnt for the first time that they had leprosy during the interview including 17 untreated patients and 9 who had already been started on treatment outside our institution. The duration of leprosy symptoms before diagnosis varied from 2 weeks to 15 years, (mean 20 months, standard deviation 29 months, median 12 months). In 58% of patients, the time lag from first symptom to diagnosis was greater than 6 months; in 21%, it exceeded 2 years.

Out of the 74 patients on treatment, 40 (54%) had interrupted it for various durations. Lengths of interruption ranged from 2 weeks to 25 years. In 33 patients, it was for a month or more, and among these 33, mean duration of interruption was 28 months (median 9 months). Reasons for interruption included non-availability of drugs in nine patients, lack of improvement in sensory loss in six, stoppage of treatment by a doctor either prematurely or due to misdiagnosis in another six,

events wrongly attributed to drugs and clinical resolution of lesions in five patients each, comorbid liver disease in four, side-effects of drugs in three and forgetfulness in two patients. The mean knowledge and attitude scores of patients who had interrupted treatment was lower than that of those without interruptions. Further, among the defaulters, those who had interrupted treatment for periods longer than one year had lower mean knowledge and attitude scores than those with shorter interruptions. However, all these differences were not statistically significant.

Attitude towards leprosy

Above half the respondents in all groups feared leprosy patients, significant numbers were disgusted by them and felt that leprosy results from past sins (Table 5). Thus, all groups seemed to show similar emotional reactions towards leprosy. Regarding inter-personal interaction, (Table 5) there was marked reluctance to marry a leprosy patient, irrespective of treatment status. There was also marked refusal to eat food cooked by leprosy patients and strong belief that their utensils should be kept separate. Around a

Table 4 : Knowledge and Attitude scores

	Mean Score	S D	Range	Median	Significant Differences (ANOVA + post-hoc Bonferroni contrasts)
Knowledge scores (out of 22)					
Patients	11.82	4.27	2 - 21	13	Pts vs. rel (p = 0.03) Pts vs. oth (p < 0.001) Rel vs. oth (p = 0.013)
Relatives	10.12	3.51	2 - 17	9	
Others	8.23	4.07	1 - 19	8	
Overall	10.05	4.31	1 - 21	10	
Attitude scores (out of 22)					
Patients	15.34	4.05	4 - 22	15	None
Relatives	15.17	5.12	2 - 22	16.5	
Others	14.00	6.06	1 - 22	16	
Overall	14.78	5.16	1 - 22	16	

Table 5 : Attitude to leprosy - emotional aspects and inter-personal interaction

Question / aspect of attitude	No. of people answering 'yes'			Significant difference (χ^2 test)
	Patients	Relatives	Others	
Fear leprosy patients	57 / 100 (57%)	30 / 60 (50%)	55 / 100 (55%)	None
Disgusted by leprosy patients	14 / 100 (14%)	9 / 60 (15%)	20 / 100 (20%)	None
Leprosy results from past sins	40 / 100 (40%)	30 / 60 (50%)	31 / 100 (31%)	None
Can a person without leprosy marry someone with leprosy (on or completed Rx)	33 / 100 (33%)	14 / 60 (23%)	23 / 100 (23%)	None
Can others eat food cooked by a person with leprosy	32 / 100 (32%)	25 / 60 (42%)	34 / 100 (34%)	None
Does a leprosy patient need separate utensils	59 / 100 (59%)	26 / 60 (43%)	58 / 100 (58%)	None
Should leprosy patients stay separately	23 / 100 (23%)	12 / 60 (20%)	28 / 100 (28%)	None
- In leprosy colonies	18 / 100 (18%)	10 / 60 (17%)	17 / 100 (17%)	
Would you divorce your spouse if he/she has leprosy	8 / 100 (8%)	4 / 60 (6%)	6 / 100 (6%)	None
Can a leprosy patient touch children	37 / 100 (37%)	14 / 60 (23%)	19 / 100 (19%)	p = 0.013
Can others touch leprosy patients	37 / 100 (37%)	48 / 60 (80%)	36 / 100 (36%)	p < 0.001
Can non-patients marry into a family with a leprosy patient	83 / 100 (83%)	36 / 60 (60%)	52 / 100 (52%)	p < 0.001

quarter of all groups believed that leprosy patients should stay separately from others while one-sixth advocated complete segregation in leprosy colonies. There were some areas where attitudes differed among groups. Relatives were much less frightened to touch a leprosy patient than the other two groups while patients were most open to the idea of marriages between leprosy-affected and unaffected families. Differences in the above two areas were statistically significant.

Responses to questions concerning social aspects of attitude were on the whole, reasonably positive (Table 6). The clear majority of all groups supported the right of leprosy patients to use public conveniences, enter places of worship, befriend people without leprosy, participate in family functions and festivals and work in shops. One encouraging finding was that 70-80% said that they would view a person with leprosy more positively if they knew he/she was taking treatment.

Knowledge and attitude scores and factors affecting them - the tangled web

Knowledge and attitude scores were calculated, as described in methodology (Table 4, Fig 1). The overall mean knowledge score of 10.05 out of 22 was on the lower side. Still, leprosy patients performed better than relatives who in turn scored better than the third group; all differences were statistically significant. The mean attitude scores of all groups fell within the same range, suggesting that attitude towards leprosy did not differ much between groups (Table 4, Fig 1).

There was significant positive correlation between knowledge scores and attitude scores across study groups. (Pearson's $R=0.536$, $p<0.001$).

Stepwise multiple linear regression analysis showed that being a leprosy patient ($\beta=0.414$, $p<0.001$) or a relative thereof ($\beta=0.186$, $p<0.001$), higher education ($\beta=0.225$, $p<0.001$) and exposure to leprosy-education through the health sector or media ($\beta=0.465$, $p<0.001$) were independent predictors of knowledge. The

Table 6 : Attitude towards leprosy - social aspects

Question / aspect of attitude	No. of people answering 'yes'			Significant difference (χ^2 test)
	Patients	Relatives	Others	
Should leprosy patients use common public conveniences	98 / 100 (98%)	59 / 60 (98%)	96 / 100 (96%)	None
Should leprosy patients enter places of worship	99 / 100 (99%)	60 / 60 (100%)	98 / 100 (98%)	None
Can leprosy patients befriend people without leprosy	92 / 100 (92%)	50 / 60 (83%)	83 / 100 (83%)	None
Should leprosy patients attend family functions	73 / 100 (73%)	45 / 60 (75%)	68 / 100 (68%)	None
Should leprosy patients participate in festivals	77 / 100 (77%)	45 / 60 (75%)	71 / 100 (71%)	None
Would buy items from a shop run by a leprosy patient	72 / 100 (72%)	45 / 60 (75%)	73 / 100 (73%)	None
Would you befriend a leprosy patient	78 / 100 (78%)	29 / 60 (48%)	58 / 100 (58%)	$p < 0.001$
Should leprosy patients work with people without leprosy	93 / 100 (93%)	53 / 60 (83%)	74 / 100 (74%)	$p = 0.001$
Should leprosy cause discrimination at the workplace	24 / 100 (24%)	15 / 60 (25%)	24 / 100 (24%)	None
Can discrimination against leprosy patients be justified	23 / 100 (23%)	17 / 60 (28%)	31 / 100 (31%)	None
Would the fact that a leprosy patient is on treatment change your attitude positively	78 / 100 (78%)	50 / 60 (83%)	68 / 100 (68%)	None

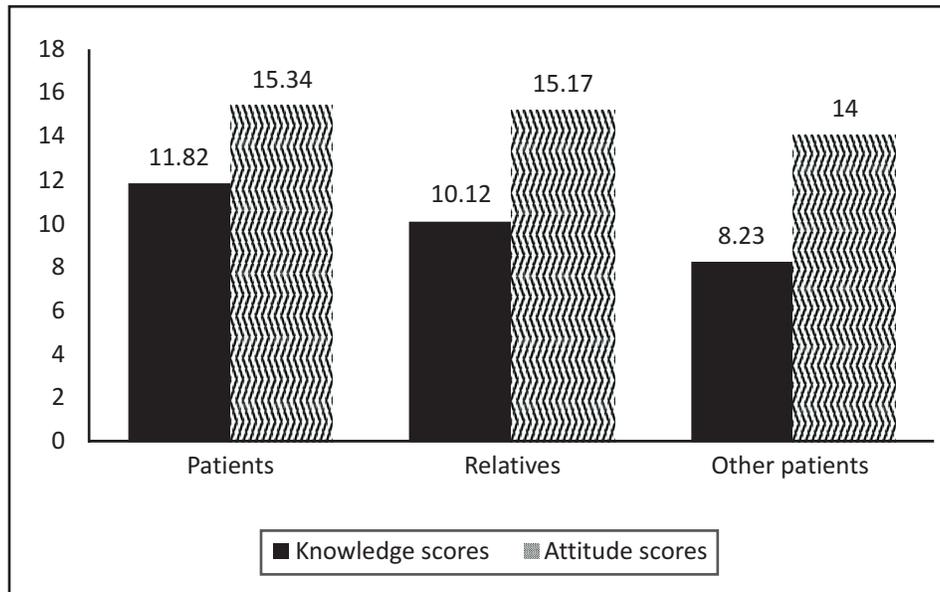


Fig 1 : Bar graph showing mean knowledge and attitude scores across study groups

Table 7 : Comparisons of knowledge and attitude in leprosy patients differing by treatment status

Mean scores differences	Untreated (n = 26)	On treatment (n = 53)	Treatment completed (n = 21)	Significant (ANOVA + post-hoc Bonferroni contrasts)
Knowledge score (out of 22)	8.7	12.3	14.6	Treatment completed vs. untreated (p < 0.001)
				On treatment vs. untreated (p < 0.001)
				Treatment completed vs. on treatment (p = 0.049)
Attitude scores (out of 22)	15.2	14.7	17.1	None

combination of these factors accounted for 45% of the variation in knowledge scores ($R^2=0.453$). On stepwise multiple linear regression, knowledge scores ($\beta=0.501$, $p<0.001$), higher education ($\beta=0.164$, $p=0.002$) and age ($\beta= -0.195$,

$p<0.001$) were independent predictors of attitude and the combination of all these factors accounted for 36% of the variation in attitude scores ($R^2=0.361$). It was noted that greater age was a *negative predictor* of attitude.

Effect of treatment status and other factors in leprosy patients

On sorting leprosy patients by treatment status, overall knowledge scores were significantly higher in patients who had completed treatment as compared to those on treatment whose scores were in turn higher than that of the untreated patients ($p < 0.05$). (Table 7) On further analysis, the main areas of improvement were found to be knowledge about symptoms and treatment. However, attitude scores did not differ much. This suggests that contact with the healthcare system improves knowledge but may not alter attitude.

Moreover, knowledge and attitude scores were both significantly better in patients who were aware of the diagnosis and also in those patients who had received a doctor's explanation about the disease (chi square, $p < 0.05$).

Discussion

Insights gained from our study could help in routine management and counselling of leprosy patients and also in devising larger level strategies to improve general awareness about the disease. The demographic profile of our sample of leprosy patients fits in with most known facts about leprosy (Thorat and Sharma 2010); the strong male preponderance may be explained by the poor position of women in India which makes them unlikely to travel long distances to a tertiary hospital for treatment. People with other skin diseases served as reasonable controls, while relatives constituted a special intermediate group. The strength of our study lies in its detailed scrutiny of knowledge and attitude. Though considerable research has been done earlier, it has been more piece-meal in nature. The results of our study taken in the context of existing literature will help consolidate all the available information.

Studies from around the world, over the years, have highlighted gaps in people's knowledge towards this disease (Pal and Girdhar 1985, El Hassan et al 2002, Kaur and Gandhi 2003, Nisar et al 2007, Nsagha et al 2009, Atre et al 2011). Findings in agreement with prior work include attribution of leprosy to bad blood (John and Rao 2009, Barkataki et al 2006, Gerochi 1986, Kumaresan and Maganu 1994), curse or misdeeds (Kaur and Gandhi 2003, John and Rao 2009, Barkataki et al 2006, Mankar et al 2011) and diet (El Hassan et al 2002, Nisar et al 2007) and the misplaced notion of extreme contagiousness by casual contact and heritability (Tekle-Haimanot et al 1992, El Hassan et al 2002, Barkataki et al 2006, Mankar et al 2011, Pal and Girdhar 1985, Gerochi 1986). Apart from patient ignorance, ignorance of healthcare professionals (Briden and Maguire 2003, Bajaj et al 2009) also helps perpetuate such myths; ultimately such misconceptions generate negative attitudes and stigma (Heijnders 2004a). Interestingly, we found belief in sexual transmission of leprosy surprisingly common, leading to abstinence in many cases. Impairment in sexual relationships is a problem in leprosy patients (Davey 1976, De Oliveira et al 1999). Fear of sexual transmission quite likely contributes to it; this under-recognized issue requires attention during patient counselling.

In concordance with earlier studies comparing people with and without leprosy (Kumar et al. 1983, Barkataki et al 2006, Mankar et al 2011, Shetty et al 1985), we too found that knowledge of symptoms was much better in leprosy patients. Poor knowledge of leprosy symptoms among the general public bodes ill in the present era where active case detection has been sidelined. One confounding factor is the age-old confusion between leprosy and vitiligo (Chaturvedi et al 2005), a misconception reported in 10 to 26% of

patients (Nisar et al 2007, John and Rao 2009). This confusion led to rejection of the diagnosis of leprosy by some of our patients lacking light patches, thus highlighting another angle to be covered in counselling of both leprosy and vitiligo patients.

Some studies in leprosy patients find good awareness of treatability (Raj et al 1981, Elissen 1991); community-based studies show variable findings (Kaur and Gandhi 2003, Nisar et al 2007, John and Rao 2009) and some comparative studies have shown better knowledge in patients (Nsagha et al 2009, Shetty et al 1985, Kumar et al 1983, Mankar et al 2011). Though we found good awareness of treatability, awareness about MDT and approximate treatment duration were rather unsatisfactory, notwithstanding that 29 years of MDT have elapsed. Another problem related to leprosy treatment is difficulty in understanding and communicating the concept of "cure" despite residual deformity (Chalise 2005, White 2005). Distress due to persistent sensory loss led one of our patients to take three courses of MB-MDT. We also found strong beliefs in treatment segregation, as has been documented previously (Rao et al 2008, John and Rao 2009). All these are all important issues in patient education.

Though the actual meaning of our knowledge scores is debatable, the fact that the mean scores decrease as we move from patients to relatives to others gives us an idea about the trends. No previous study has so comprehensively looked into all aspects of knowledge. Some earlier authors have tried to quantify their findings without clearly mentioning how (Raj et al 1981, Raju and Kopparty 1995). Few comparative studies of limited scope have also reported better knowledge among leprosy patients than people without leprosy (Myint et al 1992, Shetty et al 1985, Barkataki et al 2006, Nsagha et al 2009, Mankar et al 2011). Logically speaking, this

is expected; experiencing the disease and interacting with the healthcare system are bound to increase knowledge. To support this theory, we found that knowledge related to symptoms and treatment were the areas where leprosy patients scored over the other groups and also, treated leprosy patients scored over untreated and on-treatment patients.

Despite statistically better knowledge in leprosy patients, it is not really satisfactory as indicated by the high frequency of delayed diagnosis, unawareness of diagnosis and non-compliance. The long gap between symptom onset and diagnosis reflects patient ignorance and unconcern regarding leprosy symptoms (Atre et al 2011, Andayi et al 1998, Robertson et al 2000, Zhang et al 2009). Delayed presentation is an important contributor to disability (Bekri et al 1998). We found a weak negative correlation between delay in diagnosis and knowledge scores. Patient knowledge is undoubtedly important, but the healthcare system also contributes to delay (Bekri et al 1998, Nicholls et al 2003) as was seen in many of our patients who suffered due to misdiagnoses before reaching our centre.

Treatment interruptions are another cause for concern (Raghavia et al 1987, Nwosu and Nwosu 2002, Chalise 2005). Historically reported non-compliance underestimates this problem (Weiand et al 2011). Reasons for interruption underline important issues in patient care. Problems in MDT availability, the most common cause for interruption in our patients, have been highlighted time and again (Nsagha et al 2009, Pandey et al 2006, Chichava et al 2011). This reflects badly on leprosy programmes. Loss of confidence in treatment due to lack of improvement in sensory loss is another important reason (Nwosu and Nwosu 2002). At the other extreme, we had some patients interrupting

treatment due to quick resolution of skin lesions. Some investigators report that illiteracy is common in non-compliant patients (Raghavia et al 1987, Chalise 2005). In our study, 33% of irregulars were graduates, which suggests that being well educated may not always ensure adequate knowledge about leprosy. The phenomena of delayed diagnosis and non-compliance are proxy measurements for community knowledge about leprosy and need to be addressed.

It is disturbing that 17% of our leprosy patients already on treatment were unaware of their diagnosis. Atre et al reported a shocking figure of 52% (Atre et al 2011). Possibly, doctors who started treatment forgot to inform the patients or did not want to alarm them. As expected, knowledge was significantly better in patients who knew their diagnosis. Ignorance of the diagnosis leads to taking the disease casually, non-compliance and greater disability (Mull et al 1989, Honrado et al 2008). On the other hand, knowing the diagnosis may cause undue anxiety and self-stigmatization; a balance needs to be struck between these extremes (White 2005).

Attitude towards leprosy received a detailed appraisal in our study. Prior work has shown that a negative attitude towards leprosy is a widespread phenomenon (Shetty et al 1985, Tekle-Haimanot et al 1992, Rao et al. 2008, Nisar et al 2007, Kaur and Gandhi 2003, John and Rao 2009). Findings concordant with earlier work include strong emotional reactions towards leprosy like fear, disgust and labelling patients as sinners (Vyas et al 1982, Heijnders 2004b, Nisar et al 2007). Patients are viewed, not with compassion for the ailing, but with fear and disgust evoked by sinners. The same process leads to self-stigmatization of leprosy patients (Elissen 1991). Other findings in line with prior research were marked reluctance for matrimonial association (Tekle-Haimanot et al

1992, Kaur and Gandhi 2003, John and Rao 2009, Raju and Reddy 1995), sharing accommodation (Tekle-Haimanot et al 1992, Kaur and Gandhi 2003, Rao et al 2008, Mankar et al 2011), physical contact (Tekle-Haimanot et al 1992, Rao et al 2008, Heijnders 2004a) and sharing or selling of food (Nisar et al 2007, Rao et al 2008, Mankar et al 2011). In addition, we found strong support for separation from children and significant advocacy for complete segregation. Such beliefs are widespread, deep-rooted and based on a lack of knowledge of cause and spread. Clarification that such discriminatory practices are unnecessary should receive priority in patient counselling and community education.

We found good support for many basic social rights of leprosy patients. However, significant numbers (including leprosy patients) felt that leprosy necessitates discrimination at the workplace. Earlier workers have reported marked refusal to employ or work with leprosy patients (Tekle-Haimanot et al 1992, Nisar et al 2007, Kaur and Gandhi 2003, Rao et al 2008) although one study found otherwise (John and Rao 2009). Reluctance to travel with leprosy patients (Nisar et al 2007) and to allow leprosy patients to attend social functions (Rao et al 2008) has also been reported. A limitation of such studies including ours is the tendency to give socially desirable responses. Another limitation of our study was the use of yes-or-no response type questions which causes apparent black-and-white polarization of attitude which in reality has many shades of grey. However, the receipt of clearly negative responses from significant numbers, despite these limitations, demonstrates how rigid such prejudices are.

Mean attitude scores were similar in all three groups, leading us to infer that the attitude is similar in leprosy patients and people without leprosy. Few earlier workers have used some

crude techniques to quantify attitude. Kumar et al reported on prejudice towards leprosy in respondents, based on a single question (Kumar et al 1983). Raju and Kopparty used an attitude index based on 8 questions (Raju and Kopparty 1995). Irrespective of technique, attitude towards leprosy has been found unsatisfactory. Persistence of negative attitudes despite the massive reduction in disease prevalence is ominous.

The links found in our study between knowledge and being a leprosy patient or a relative thereof, higher education and receipt of leprosy education from the media or healthcare services, appear logical. Earlier, an association of literacy with knowledge about leprosy has been reported (Raj et al 1981) as well as refuted (Barkataki et al 2006). From our results, we can infer that while general level of education is important, community education specifically regarding leprosy is probably more important.

Underscoring that knowledge and attitude are intertwined in a tangled web, we found significant positive correlation between knowledge and attitude scores. Other predictors of better attitude were higher education and lower age; similar associations have been reported in a study from Tanzania (Van den Broek et al 1998). Higher education probably dispels many myths leading to negative attitude and the possible reason for worsening of attitude with age could be that any belief or prejudice tends to become more firmly established as one grows older. In our leprosy patients, attitude did not vary with treatment status suggesting that self-stigmatisation persists despite treatment. However, health education programmes have helped to improve community knowledge and attitudes (Van den Broek et al 1998, Crook et al 1991, Croft and Croft 1999).

The key message is that knowledge is an important modifiable factor with a strong

influence on attitude. Hence, education of leprosy patients about their disease must become part of routine medical practice. This will bring down patient and attendant anxiety and instill positive attitudes. It goes without saying that proper leprosy-education of healthcare professionals is also important. Finally, vigorous information campaigns in the media and schools regarding cause, spread, early symptoms and treatability will boost community knowledge and attitudes and pave the way for elimination, if not eradication, of leprosy and its stigma.

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