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Original Article

Extent and Correlates of Leprosy Stigma in Rural India

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Abstract

Representative random samples of leprosy patients (599) and community members (2399) from rural areas of Uttar Pradesh, West Bengal and Chhattisgarh states of India were interviewed by trained field investigators during 2006, using two separate 5-point scales to assess the extent and correlates of leprosy stigma. Varying degrees of stigma were faced by the affected persons within the family and outside in all the States, restricting their social participation and sharing of common facilities. The community members also confirmed the existence of a high level of stigma. Low educational and economic status, older age-groups, and presence of deformities enhance both perceived and enacted stigma.

Key words : Stigma, Leprosy, Rural India

Introduction

Leprosy is as much a social problem as a medical one and stigma towards persons affected with leprosy is as old as the disease itself (CSSRL 1999, Dongre 2003). The discovery over a hundred years ago by Hansen of the *Mycobacterium leprae* as the causative organism (Bryceson and Roy 1990) and subsequent advances in drug therapy and medical management (Bainson and Borne 1998) seems to have not much impact on the social perceptions of leprosy, which is still looked upon as an undesirable and incurable disease, caused by divine punishment for past sins (Mutatkar 1979, Heijnders 2000). Social stigma interferes with early reporting and adherence to treatment, thereby nullifying the advantages of modern therapy (Kannan and Sivaram 1992, Kumaresan and Maganu 1994, Kaur and Anjali 2003, WHO 2006). Even footwear developed for anesthetic feet had to be changed due to the stigma attached (Kulkarni 1990), although reconstructive surgery restoring cosmetic changes lead to better social acceptance (John et al 2005). There is a great need to assess the extent of leprosy stigma and its correlates in order that more focused activities can be undertaken to reduce and eradicate it (van Brakel 2003).

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To help initiate an action research project using community-based approaches, a baseline survey on leprosy stigma was done in 3 endemic states of India during 2006. Some of the major findings are presented in this paper and possible future lines of action discussed.

Material and Methods

Three geographically distinct rural blocks were randomly chosen from the districts in which the leprosy mission hospitals were located, choosing one each from Uttar Pradesh, West Bengal and Chhattisgarh states. From each block, a stratified random sample of 20 villages were chosen. All known leprosy affected persons were included for the sample of patients. From each selected village, a systematic random sample of households were selected for the survey of community members.

A special performa was designed separately for the patients and for the community members to ascertain the perception and enactment of stigma at the family level, in the society and at work place. On a 5-point scale, the respondents were asked whether they strongly agree, agree, neutral, strongly disagree or disagree to each statement on participation restrictions, social interactions, sharing of common facilities and services and other discriminations. Details of each respondent in terms of socio-demographic characteristics were also collected. Postgraduates in social sciences were recruited, trained and located in the rural blocks to facilitate better rapport and to carry out in-depth interviews to collect the necessary data. Field supervisors did a sub-sample check on the reliability and validity of the answers given by the respondents. Data were entered on microcomputers on Excel sheets, checked and analysed using SPSS software.

Results

The perception and manifestation of stigma within the family, in the society and in the work environment are described in tables 1, 2 and 3.

The maximum stigma is noted for not allowing leprosy afflicted to participate in religious rituals(12%), with Chhattisgarh showing the highest (17%) and West Bengal the lowest (7%). Older patients, those with low education and belonging to the backward class and with deformity revealed the highest stigma. There were no differences by gender.

The perceptions of the community in terms of avoiding direct contact with leprosy affected persons are shown in table 4 and table 5.

Employment and selling of food items had the maximum stigma (80%), and were generally high in all the states, with no significant differences by gender, age, education, occupation or caste.

About 40% are against social contacts, such as making friendships, allowing healthy children to play with affected persons or in restricting participation in religious or social functions. While there were no differences by gender, younger and those in higher socioeconomic classes seem to show greater stigma.

Discussion

Goffman (1963) defines stigma as "a spoilt identity of the affected person", which seems true in the case of leprosy, despite wonderful treatments with MDT and major advances in reconstructive surgery (WHO 2006). This study has clearly brought out the many faces of leprosy stigma in terms of various degrees of restrictions, discrimination and isolation of an affected person to the extent that even the family would rather disown the person. Leprosy is fully curable with no residual disabilities when the affected person reports early and completes the required multidrug therapy (Noordeen 2005). However, when treatment is delayed, often due to concealment and other perceived stigma, till visible disabilities occur, secondary problems occur and life-

Table 1 : Perceived stigma of leprosy afflicted persons with in the family(%)

Characteristics	N	Movement and domestic work	Sleeping and bedding	Sharing food and articles	Bathing and washing	Participation in rituals and puja
All patients	590	4.63	5.95	7.27	4.33	11.60
State						
Uttar Pradesh	190	3.63	2.45	2.53	1.63	10.43
West Bengal	200	2.53	5.50	11.50	4.73	7.27
Chhattis Garh	200	7.50	9.65	7.67	6.43	16.73
Sex						
Male	392	4.63	6.00	6.97	4.80	11.87
Female	198	4.63	5.90	7.80	3.37	11.00
Age(years)						
Below 45	276	3.83	5.00	6.73	3.33	9.37
46 and above	314	5.40	6.85	7.73	5.27	13.67
Education						
Up to primary	424	5.33	6.70	8.23	5.33	13.23
Secondary and above	166	2.93	4.05	4.80	1.87	7.50
Occupation						
Daily wage laborer	205	5.80	5.65	9.60	5.17	14.17
Service & self employed	176	2.73	6.20	5.30	2.57	10.20
Dependent/old age/student/housewife	209	5.07	6.00	6.63	5.07	10.13
Caste						
Higher castes	147	3.80	4.15	7.00	2.80	10.77
SC & ST	258	4.03	6.50	7.43	4.60	10.53
Other BC	185	6.07	6.55	7.20	5.10	13.63
Deformity						
No	325	3.33	4.10	4.57	2.40	8.07
Yes	265	6.33	8.45	10.83	6.90	16.33

long care become imperative, and the image of leprosy as a disabling disease persists (Heijnders 2004, Rafferty 2005). Thus, a vicious cycle is perpetrated, which much be attacked vigorously.

The findings reveal significant correlations with several demographic and social factors, and it is important to note, therefore, that stigmatization is a process, subject to change over time within the same community (Kleinman 1980). Thus, community-intensive approaches are needed in education, motivation and dispelling the continuing myths and images of leprosy (Dongre 2003).

Table 2 : Perceived stigma of leprosy afflicted persons in the society(%)

Characteristics	N	Movement in and around village	Traditional civil services	Bathing and cooperation	Bathing and washing	Social participation and recreation
All patients	590	7.93	10.58	8.70	8.27	8.90
State						
Uttar Pradesh	190	5.27	6.83	8.60	8.93	6.73
West Bengal	200	12.33	19.10	7.67	10.17	13.50
Chhattis Garh	200	6.17	5.08	9.83	5.67	6.38
Sex						
Male	392	8.67	11.25	8.93	9.27	9.13
Female	198	6.57	3.90	8.27	6.23	8.45
Age(years)						
Below 45	276	3.50	4.23	5.70	4.10	3.98
46 and above	314	11.90	15.50	11.33	11.90	13.20
Education						
Up to primary	424	9.37	12.53	9.67	8.93	10.43
Secondary and above	166	4.40	6.38	6.20	6.40	4.95
Occupation						
Daily wage laborer	205	5.20	8.95	9.30	6.03	5.50
Service & self employed	176	8.00	11.18	7.57	10.07	8.65
Dependent/old age/student/ housewife	209	10.70	12.93	9.07	8.93	12.45
Caste						
Higher castes	147	12.00	15.18	7.93	11.77	12.58
SC & ST	258	7.50	11.68	9.57	7.63	8.53
Other BC	185	5.40	5.28	8.07	6.30	6.48
Deformity						
No	325	2.17	2.60	4.30	2.07	1.70
Yes	265	15.10	19.73	14.10	15.83	17.75

Pioneering efforts in leprosy has been almost exclusively confined to affected persons and their families. This was essential, but the time has come when greater emphasis is needed in tackling negative perceptions to promote early treatment, thereby virtually eliminating any residual disabilities in affected persons, thus breaking the link between leprosy and deformity (Hyland 1993). With integration of leprosy services, with medical treatment now available freely at any general health setup (WHO 2006), the

Table 3 : Perceived stigma of leprosy afflicted persons in different social institutions (%)

Characteristics	N	Acceptance in school	Acceptance in hospital	Treatment by colleagues	Employment and wages
All patients	590	5.30	0.85	6.47	5.48
State					
Uttar Pradesh	190	9.55	1.05	5.77	3.78
West Bengal	200	7.95	1.50	5.67	7.60
Chhattisgarh	200	0.25	0.00	8.00	4.90
Sex					
Male	392	5.45	1.20	7.30	6.24
Female	198	5.00	0.25	4.90	3.90
Age(years)					
Below 45	276	2.15	0.20	6.67	4.48
46 and above	314	8.30	1.45	6.37	6.30
Education					
Up to primary	424	5.95	1.05	7.00	6.44
Secondary and above	166	3.70	0.30	5.20	2.88
Occupation					
Daily wage laborer	205	2.45	0.25	14.30	11.32
Service & self employed	176	7.10	1.15	5.10	5.10
Dependent / old age/ student/ housewife	209	7.15	1.20	0.00	0.00
Caste					
Higher castes	147	10.05	1.40	5.00	4.08
SC & ST	258	3.75	0.95	8.40	7.68
Other BC	185	4.20	0.25	5.03	3.46
Deformity					
No	325	0.35	0.00	4.63	1.40
Yes	265	11.90	1.90	8.83	10.42

health service system must now be geared to focus on preventing social disabilities in addition to counselling patients to be regular in their treatment. Thus the strategy on leprosy stigma reduction should be twofold in changing the mindset of not only the public, but that of the service providers. A simple social grading similar to the WHO grading of physical disability can be done when the patient first registers for treatment and repeated till RFT. This grading will be 0: when the patient stays with own family with no discriminations, 1: when some restrictions are placed but the patient continues to stay

Table 4 : Community's attitude against physical contact with leprosy patients (%)

Characteristics	Leprosy patients should not				
	N	be employed at home	be employed in farm	sell food items	take treatment in PHC
All Community Members	2399	79.8	83.2	16.0	26.9
State					
Uttar Pradesh	793	87.1	88.0	21.8	28.6
West Bengal	800	86.6	91.2	19.4	14.7
Chhattis Garh	806	65.0	69.3	6.5	39.3
Sex					
Male	2111	80.1	83.3	16.2	26.2
female	288	77.9	82.0	14.6	31.9
Age (years)					
Up to 30	746	70.5	75.6	13.7	21.2
31 to 45	920	80.4	84.0	15.0	26.2
above 46	733	88.3	89.6	19.5	33.3
Education					
Up to Primary	1022	87.3	90.1	19.8	35.3
Secondary & above	1377	74.2	78.0	13.2	20.7
Occupation					
Daily wage laborer/rickshaw/traditional service etc.	220	89.2	87.7	22.0	32.6
Own farming/cultivation/ self employment	1496	82.1	85.6	14.8	28.9
Private/govt. services/advocate/ AWW	283	65.4	69.3	15.1	15.3
Dependent/aged/ pensioner/student/housewife	400	76.2	81.6	17.7	24.8
Caste					
Higher castes	789	85.1	88.7	17.0	17.5
SC & ST	874	78.2	81.7	17.7	28.8
Other BC	736	75.9	78.6	12.9	35.8

with family and 2: when the affected person is asked to leave the family. No doubt, rehabilitation activities can continue, but why not prevent de-habilitation in the first place ! The challenge then to the health staff will be to maintain the patient at social grade 0, and patients report early enough with WHO grade 0, the image of leprosy as a disabling disease will undergo a drastic change, contributing to reduction of stigma.

Table 5 : Community's attitude against social contact with leprosy patients (%)

Characteristics	Leprosy afflicted persons/children should not					
	N	make friendship with others	take part in social functions	play with healthy children	stay at home	take part in religious functions
All Community Members	2399	32.9	40.1	37.6	32.2	44.3
State						
Uttar Pradesh	793	27.2	25.3	43.0	32.8	64.1
West Bengal	800	36.5	35.1	31.7	31.0	33.0
Chhattisgarh	806	34.6	63.4	40.1	33.0	35.3
Sex						
Male	2111	32.7	40.0	35.6	31.3	43.3
female	288	34.7	40.7	52.6	39.0	52.4
Age						
upto 30 years	746	33.8	51.1	29.8	25.6	28.2
31 to 45 years	920	34.1	41.9	34.9	30.6	43.5
above 46 years	733	30.5	27.7	47.8	40.4	59.6
Education						
Up to Primary	1022	26.7	28.4	47.8	40.4	58.3
Secondary & above	1377	37.5	49.3	29.1	25.8	33.3
Occupation						
daily wage laborer/rickshaw /traditional service etc.	220	30.9	31.5	33.3	36.6	47.2
own farming/cultivation/self employment	1496	29.9	36.4	40.3	33.2	48.4
private/govt. services/advocate/ AWW	283	47.3	59.6	27.6	26.4	29.3
dependent/aged/ pensioner/student/housewife	400	35.1	45.6	36.8	30.1	37.5
Caste						
Higher castes	789	36.4	37.8	31.0	28.4	37.5
SC & ST	874	28.7	41.0	39.6	31.3	44.1
Other BC	736	33.8	41.7	43.6	37.9	53.3

The findings from the present study provided a number of leads for action-programmes conceived and implemented by the communities themselves using social marketing techniques (Wong 2002). The Government of India and the World Health Organization must formulate practical operational guidelines for these social dimensions as well, to march forward to eradication of leprosy.

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