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ORIGINAL RESEARCH ARTICLE

SOCIAL STIGMA IN LEPROSY

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ABSTRACT

Leprosy, an infectious disease, is a highly stigmatized disease. It directly affects patients' physical, psychological, social and economical well-being. To know the stigma faced by the patients in the family and community. The study was carried out at Netherlands Leprosy Relief, Biratnagar, Nepal. Verbal consent was taken from each patient. A total number of 34 patients who were diagnosed to have leprosy were interviewed. Data were collected using structured interview schedule that included questions seeking information about all aspects of objective. Although both men and women faced the social stigma of the disease, women suffered more rejection by the family members (50%), neighborhood (75%) and work places (62.5%) in comparison to male patients, who are affected maximum at work places (39%) and minimum in family (7.69%). Illiterate were avoided by family members (25%) and co-workers (75%) whereas literate were not. All unemployed patients were neglected in community whereas only 21.42% of employed were neglected. Leprosy is a highly stigmatized disease. Patients are neglected by their family and society. Therefore community education component of Leprosy Control Program needs to be strengthened.

Key words: *Isolation, Leprosy, Social stigma.*

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INTRODUCTION

Leprosy, one of the chronic infectious communicable diseases, is caused by *Mycobacterium leprae* which poses a great risk of permanent physical disability. The visible disabilities and deformities have contributed a lot to the stigma faced by leprosy patients.[1] Leprosy not only affects patient's economy but also creates psychosocial problems in the community. In Nepal, people with leprosy are often ostracized by their communities, reporting complete rejection or banishment by communities, insults and hate.[2]

Leprosy and its stigma have major effect on a patient's life affecting marriage, interpersonal relationships, employment and social interactions. In countries like ours, family and society bears an essential value to a person rather than individualized identity prevalent in west. Hence, to lose attachment in the family and society leads to a grave psychosocial paralysis to a patient. One of the studies in India reported that one-third of leprosy patients were left by their spouses.[3] In many countries the considerable stigma towards leprosy delays patient's presentation.[4] Stigma is also one of the serious obstacles for case detection and effective treatment, which are the major concern of

disease control programs.[5, 6] It has been found that visible disability is one of the major determinants of stigma in leprosy[7] thus both of them creating a vicious cycle. Hence, stigma reduction program is still highly prioritized by Nepal government Leprosy control division.

In Nepal, though the elimination of leprosy as a public health problem was achieved in 19th January 2010, even after four years of elimination, the current prevalence rate at the end of the fiscal year 2069/70 is 0.82/10,000 populations at national level. Registered prevalence rate was highest in the eastern region (0.88/10,000 population) with MB and PB leprosy patients being approximately in the ratio of 5:2. In our country, still 2.89% of new leprosy patients had visible disability at the time of presentation. This study was conducted in Morang district, situated in Eastern Developmental Region, where prevalence of leprosy is still 0.88/10,000. [8]

MATERIALS AND METHODS

This was a cross-sectional study carried out at Netherlands Leprosy Relief, Biratnagar, Nepal. Study period was from 2nd to 15th April 2006. Informed verbal consent was taken from each patient. A total of 34 patients who were clinically diagnosed to have leprosy were interviewed.

A questionnaire was developed containing questions on :

1) Demographic characteristics, to obtain information about age, sex, marital status, occupation,

2) Stigma in behavior and

3) Attitude in the family and society mainly focusing on impact of social stigma in leprosy patients. Data were collected from patients using structured interview schedule. The questionnaire was prepared in Nepali language. Maithali and Hindi speaking patients were interviewed by the help of translators. Data were entered in MS-Excel 2007 and statistical analysis was done using SPSS version 11.5. For descriptive statistics mean, ratio, frequency, percentage were used.

RESULTS

A total of 34 leprosy patients (26 males, 8 females) were interviewed with a male preponderance, the ratio of male and female being 3:1. The mean age of patient's was 41.76±11.34. About half (52.9%) of the patients were in between age group 20-40 years. Approximately three fourth of the patients (76.5%) were married. In the study, maximum patients (82.4%) were employed (Table 1).

Table 1: Demographic profile

Variables	Category	Frequency	Percentage
Age	20-40	18	52.9%
	40-60	12	35.3%
	>60	4	11.8%
Gender	Male	26	76.5%
	Female	8	23.5%
Marital status	Unmarried	6	23.5%
	Married	28	76.5%
Occupation	Unemployed	6	17.6%
	Employed	28	82.4%

In our study, literate patients had better knowledge about the cause, curability and communicability of the disease (Table 2).

Table 2: Knowledge of disease in leprosy patients

Variables	Category	Education		P-Value
		Illiterate (n=24)	Literate (n=10)	
Cause	God curse	10(41.7%)	0	<0.05
	Infection	10(41.7%)	8(80.0%)	
	Don't know	4(16.7%)	2(20.0%)	
Curability	Yes	10(41.7%)	10(100.0%)	0.001
	No	14(58.3%)	0	
Communicable	Yes	10(41.7%)	10(100.0%)	0.001
	No	14(58.3%)	0	

Similarly, many literates were given more care (80.0%) by the family members in comparison to illiterates (8.3%) which is statistically significant (p=0.00). Attitude of neighbor was same in maximum literate patients (90.0%) whereas around half of the illiterates (45.8%) were avoided by them (p<0.05). Also, three fourth of the illiterates (75.0%) were avoided by the co-workers (p=0.00) (Table 3).

Table 3: Stigma in attitude according to literacy

Variables	Category	Education		P-Value
		Illiterate (n=24)	Literate (n=10)	
Attitude of family members	More care	2(8.3%)	8(80.0%)	0.00
	Same	16(66.7%)	2(20.0%)	
	Avoid	6(25.0%)	0	
Attitude of neighbor	More care	0	0	<0.05
	Same	13(54.2%)	9(90.0%)	
	Avoid	11(45.8%)	1(10.0%)	
Attitude of co-workers	More care	0	4(40.0%)	0.000
	Same	6(25.0%)	6(60.0%)	
	Avoid	18(75.0%)	0	
Attitude of health workers	Care	18(75.0%)	10(100.0%)	0.08
	Neglect	6(25.0%)	0	

There was no social stigma in behavior in the literate patients unlike illiterates (Table 4).

Table 4: Stigma in behavior according to literacy

Variables	Category	Education		p-value
		Illiterate (n=24)	Literate (n=10)	
Separate utensil	Yes	8(33.3%)	0	<0.05
	No	16(66.7%)	10(100.0%)	
Job continuation	Yes	16(66.7%)	10(100.0%)	<0.05
	No	8(33.3%)	0	
Ceremony involvement	Yes	12(50.0%)	10(100.0%)	0.005
	No	12(50.0%)	0	
Effect in daily activities	Yes	18(75.0%)	0	0.001
	No	6(25.0%)	10(100.0%)	

Statistically significant unemployed patients were more stigmatized than the employed one (Table 5).

Table 5: Stigma in behavior according to employment

Variables	Category	Occupation		p-value
		Employed (n=28)	Unemployed (n=6)	
Isolation at home	Yes	3(10.7%)	5(83.3%)	0.001
	No	25(89.3%)	1(16.6%)	
Job continued	Yes	26(92.9%)	0	0.001
	No	2(7.1%)	6(100%)	
Separate utensil	Yes	3(10.7%)	5(83.3%)	0.001
	No	25(89.3%)	1(16.6%)	
Involvement in ceremony	Yes	21(75%)	1(16.6%)	0.001
	No	7(25%)	5(83.3%)	
Effect in daily activities	Yes	12(42.8%)	6(100%)	0.01
	No	16(57.2%)	0	

DISCUSSION

Most important aspect of leprosy stigma is that it inhibits the treatment of the stigmatizing disease, and therefore both illness and stigma persist,[9] which may have direct negative outcome on leprosy elimination. Social stigma is manifested in several ways like, verbal abuse, ostracism from social functions;

forced isolation; separation from the family etc and ultimately the person may be forced into destitution. Because of social stigma, reporting to health care system is so delayed in leprosy patient that it becomes impossible to avoid deformities. This is due very often to lack of knowledge of the symptoms of leprosy.[10] Stigma is related to the fact that leprosy is one of the diseases with physical imperfections that leads to disabilities but seldom kills so the patient lives and continues to suffer. These deformities worsen with age[11] and since deformed lepers are poor because of physical disabilities, they become unable to support their family financially. In other way, they can't fulfill their family responsibilities. This leads to hopelessness and lack of selfesteem.[10]

Education is an important determinant of social stigma in leprosy. Knowledge of disease differs significantly among literate and illiterate ones. In our study significant percentage of illiterate patients (41.7%) think that it is because of god curse and more than half (58.3%) think that it is not curable ($p<0.05$). Whereas 80.0% of literate patients think that it is due to infection and all of them (100%) think that it is curable ($p=0.01$). So, these findings show the importance of education for the knowledge about disease and ultimately the stigma associated. Similar was the highlight in the study by ***Barkataki P et al, 2006*** done in India.[12] In their study, less than 10% of illiterates and only about 40% of literates cited infection as the cause of leprosy. Though Literates had a better knowledge on the disease causation, it was still very low compared to our study. ***Kushwah S et al, 1981*** also found that stigma was much more prevalent among uneducated patients.[13]

Similarly statistically significant numbers of illiterate patients feel that they are more avoided by the family members (25.0%, $p<0.001$), neighbors (45.8%, $p<0.05$) and co-workers (75.0%, $p<0.001$) whereas none of the literates think that they are avoided by the family members and co-workers, but still few of them (10.0%, $p<0.05$) are avoided by the neighbors. None of the literates feel that they are neglected by the health workers. Whereas, one fourth (25.5%) of the illiterate patients think that they are neglected by the health workers though it was not significant statistically ($p=0.08$).

A 7-year health education campaign in Tanzania found that women were more affected by leprosy and its stigma in terms of isolation, rejection and restrictions placed on them compared to the males with same level of the disease.[14] Likewise, in our study women suffered more rejection by the family members (50%) and neighbors (75%) in comparison to male.

CONCLUSION

Leprosy is a highly stigmatized disease in which patients are neglected by their family and society. Here we found that illiterates and females are more stigmatized compared to their counterparts. Therefore to minimize social stigma in Leprosy community education component of Leprosy Control Program needs to be strengthened to the maximum. Emphasis on IEC (**I**nformation, **E**ducation and **C**ommunication) activities with dynamic and entertaining mass media campaigns along with small group discussions, posters and catchy slogans may prove very much beneficial.

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REFERENCES

1. Noorden SK. Eliminating leprosy as a public health problem: Progress and prospects. Bulletin of WHO, 1995;**73**:1-6.
2. Stigter D, de Gaus L, Heynders M. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. Lepr Rev, 2000;**71**:492–98.
3. Scott J. The psychosocial needs of leprosy patients. Lepr Rev, 2000; **71**: 486–91.
4. Einar P Wilder-Smith and Wim H Van Brakel. Nerve damage in leprosy. Nature Clinical Practice Neurology, 2008;**4**:656-63.
5. Burathoki K, Varkevisser C, Lever P et al. Gender, leprosy and leprosy control: A case study in the far west and eastern development region, Nepal. KIT, Amsterdam, 2004.
6. WH van Brakel. Measuring health-related stigma - a literature review. Psychol Health Med, 2006;11:307 –334.
7. Rao PS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and correlates of leprosy stigma in rural India. Indian J Lepr 2008;80:167-74.
8. Department of Health services, Nepal. Leprosy control program. Annual report, 2069/70; 137-143.
9. Hausmann-Muela S, Ribera JM, Toomer E, Peeters K. Cautioning against the 'stigma pitfall' in neglected tropical diseases. PASS International 2008;1-9.
10. Nsagha DS. Epidemiology and community perception of leprosy in Boyo, Menchum and Mezam divisions of Cameroon. Ph.D thesis. University of Ibadan, Nigeria, 2002:1-394.
11. Bryeceson A, Pfaltzgraff ER. Leprosy. 3rd ed. 1990, Churchill Livingstone, New York, NY, USA, 1-230.
12. Barkataki P, Kumar S, Rao PS. Knowledge of and attitudes to leprosy among patients and community members: a comparative study in Uttar Pradesh, India. Lepr Rev, 2006; **77**:62-8.
13. Kushwah S, Govila AK, Upadhyay S et al. A study of social stigma among leprosy patients attending leprosy clinic in Gwalior. Lepr Ind, 1981;53:221–25.
14. Van den Broek J, O'Donoghue A, Ishengoma A et al. Evaluation of a sustained 7-year health education campaign on leprosy in Rufiji District, Tanzania. Lepr Rev, 1998;69: 57–4.