

Gender Differentials in Health Seeking Behaviour and Perceived Stigma among Leprosy Patients: A Study in West Bengal

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ABSTRACT The present paper aimed to examine perceived stigma, internalised stigma, self-esteem and social participation of leprosy patients and impact of gender roles on their health seeking behaviour. It is a primary survey based study on 262 (55 women; 207 men) leprosy patients aged 18 - 75 years who visited School of Tropical Medicine and Leprosy Mission of Kolkata. Apart from descriptive statistics, multinomial regression analysis was conducted on collected data. Results show that stigma had an impact on the lives of leprosy patients. Age was positively correlated with stigma, self-esteem and participation restriction of leprosy patients. Odd ratios showed that women patients faced greater stigma, which further lowered their self-esteem and social participation. Further duration of illness and visible deformity impaired patients' self-esteem and social participation. Patients from lower income groups and lower caste experienced lower self-esteem and more participation-restrictions vis-à-vis the more privileged. Rural patients experienced greater stigma and social restrictions; and lower self-esteem than urban ones. Regular patient-counselling and raising public awareness about leprosy are recommended.

INTRODUCTION

Leprosy, a chronic infectious disease has always terrified humanity since time immemorial. With advancement in science, cure has been found for this debilitating disease. But still 1.27 lakhs new cases of leprosy were reported in India during 2013-2014. 46845 new cases were women according to the Progress Report (National Leprosy Eradication Programme 2014).

Leprosy is a highly stigmatized disease but it is shocking to see the way gender role has an impact on health education and health seeking behaviour among leprosy patients. Health or care seeking behaviour has been defined as any action undertaken by individuals who perceive they have a health problem or to be ill for the purpose of finding an appropriate remedy (Ward et al. 1997). Gender difference is a social concept, which primarily describes the status of women in society relative to their male-dominant counterparts (Lazuk 2018). A study conducted on 202 leprosy patients in Ribeirão Pre-

to, Brazil found that leprosy exacerbated existing gender inequalities (de Oliveira 1997). Several studies done on the differences of gender on utilisation of health services found that women relatively have less access to health services as compared to men (Le Grand 1997; Price 2017; Santow 1995). A new report published by International Leprosy Eradication Programme (ILEP), the umbrella organisation for anti-leprosy organisations, Triple Jeopardy tackling the discrimination facing women and girls with leprosy, identifies that women affected by leprosy can take twice as long as men to be diagnosed (Leprosy Mission 2015). Women's access to health services is influenced by many factors, including availability of services, costs, and quality of care, social structure, and women's decision-making power (Le Grand 1997). Strong traditions, inferior status of women, their limited mobility, illiteracy and poor knowledge of leprosy appeared to be important socio-cultural factors explaining why women were under reporting (Lepra 2017; Varkevisser et al. 2009; Thorpe 2017). Due to significant disparities in education and access to information on health, many women do not fully understand their condition, sometimes lacking an awareness of the symptoms of leprosy or the kinds of treatment that are available to them. The cultural practice of early mar-

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riage in some countries is a contributing factor in reducing access to education, and, as such, leading to greater levels of illiteracy and a reduced understanding of health conditions (Lepra 2017; Thorpe 2017)

A study in India found that the proportion of illiterate female patients is significantly higher, while the proportion of employed females is significantly lower compared to males, indicating a low social status of many female patients (Rao et al. 1996). The high proportion of women had problems getting to health units as they lacked proper knowledge about the disease. Due to this lack of knowledge there has been delay in seeking medical treatment further aggravating the symptoms. It was observed that the initial delay in identifying the skin changes, a symptom of the disease, was higher in females than in males (Rao et al. 1996). Women sometimes ignored the initial symptoms of the disease (Rao et al. 1996; Thorpe 2017). They faced problems getting to health units thus the percentage of women seeking immediate treatment for leprosy after the onset of the disease was low (Varkevisser et al. 2009). In India, the gap between noticing a symptom and suspecting it to be leprosy, as well as the gap between the suspicions and seeking medical treatment was considerably longer for women than men (16 versus 11 months and 15 versus 10 months) (Le Grand 1997; Vlassoff et al. 1996a). According to a study conducted in South East Nigeria, a higher proportion of women had various deformities as compared to men and the duration gap between appearance of signs and symptoms and diagnosis of leprosy was almost double (Peters and Eshiet 2002; Sarkar and Pradhan 2016). Other studies noted that the awareness regarding symptoms and availability of leprosy services were less among women than men (Crook et al. 1991; DANLEP 1995; Mull et al. 1989). A study done in Nigeria found that women's major source of information regarding leprosy is their spouse (30%). The percentage of women (22%) who got information from health workers were less as compared to men (43%) (Awofeso 1995).

Even after identifying the symptoms, women were observed to depend exclusively on non-medical treatment for a longer period than males (Rao et al. 1996; Thorpe 2017). Furthermore, they suffered a higher proportion of disabilities (Peters and Eshiet 2002). They delayed going to the hospital until their husband/guardian felt it was

necessary. They had to complete their household chores either before setting out for the hospital or after their return. A considerable amount of time was spent waiting at various service points which conflicted with their domestic work, and lowered their social worth if they were away too long. This stopped them from visiting hospitals, even for follow up visits (John et al. 2010; Thorpe 2017). Many women came from poor families and they could not afford to be sick and neglect their childcare and domestic duties. They often felt pressured into prioritizing their domestic duties above their own personal health (Lepra 2017; Shieh et al. 2006; Thorpe 2017). The access to health care also depends upon women's status within the family. According to a study, in India, generally men or the mother in law takes the decision to call a doctor. Due to husband's apathy or jealousy of the mother-in-law, married women often delayed seeking treatment (Khan et al. 1989; Le Grand 1997). In another study conducted in Nepal, it was found that affected women had to seek permission from their mother-in-law or husband to leave the homestead and needed escort and money for transportation and sometimes treatment (Sarkar and Pradhan 2016; Varkevisser et al. 2009). In countries like India, because a significant proportion of females are homemakers, they engage in cooking and other household activities, which render them vulnerable to, repeated trauma, ulceration, and other severe-grade deformities in leprosy (Sarkar and Pradhan 2016).

The level of stigma is quite high among women affected by leprosy as compared to men in developing countries (Mankar et al. 2011; Rafferty 2005; Sarkar and Pradhan 2016; Try 2006; Vlassoff et al. 1996b). Perceived stigma (anticipated or felt stigma) is the perception, expectation or fear of discrimination experienced by an individual and his/her awareness of negative attitudes or practices in society directed against him/her (Siddiqi et al. 2017; Weiss et al. 2006). Studies in Thailand and Philippines have found stigma as an important factor influencing seeking of treatment among female leprosy patients (Boonmongkon 1994; Paz et al. 1990; Pearson 1988). Whilst gender inequalities are apparent in cultures worldwide, the psychosocial and economic problems caused by leprosy are further magnified in women due to existing gender disadvantages (Lepra 2017; Thorpe 2017).

Women in leprosy-endemic areas of the world, with few exceptions suffer from marked economic and social dependency and inferiority, which can only be heightened by the social stigma, associated with leprosy (Ulrich et al. 1993). Studies have found that women expressed greater concern than men about their physical appearance and refrained from social activities. A study conducted in India stated that 18 percent of the women were hiding their symptoms (Vlassoff et al. 1996a). Women hid the disease more from their families (de Oliveira 1997; Try 2006). Several studies found that although men and women were both affected in terms of their family and social life, women suffered more isolation and rejection from family and society (Calcraft 2006). It seemed that the family and social problems faced by women having leprosy were mainly due to the associated social stigma (Rao et al. 1996; Zodpey 2000). After they knew that they had contracted leprosy, these women stayed in the house as much as possible, even remained aloof from their family members due to fear of infection (Lepra 2017). They tended to wear long-sleeved clothes and gloves to cover their arms and hands, stopped going to school, and avoided being seen when someone came to their house and paid few visits to relatives and friends. When asked about their illnesses on unavoidable occasions, they would say that they had skin infections, arthritis, or polio (Lepra 2017; Shieh et al. 2006). A study conducted in India, to investigate gender differentials in the family and social life of leprosy patients observed that by and large women were more isolated from all activities than men. Seventy-nine (36.2%) females refrained from cooking activity while 22.9 percent refrained from eating with others. Isolation from touching others was again a strong reaction that many women (30.7%) faced, unlike men (14.2%). It was also observed that 49 percent of the breastfeeding mothers did not breastfeed their children. Loss of freedom to touch and to be touched, especially with their children, symbolized rejection (Zodpey 2000). Another study confirmed that women refrained from participation in family functions and touching children (Rao et al. 1996). Stigma seems to depend on three pillars: the belief in strong infectiousness of the disease, the belief that leprosy is incurable; and the repulsiveness of disabling deformities and reactions. All the social groups had the power to isolate and expulse

patients, but did so in different degrees. The community seemed the most threatening because in all research areas village authorities could, when unmistakable and irreversible signs of leprosy appeared, request patients to move to the edge or altogether leave the village (Lepra 2017). Few studies found that leprosy disease affected the marital status of women in several ways. They faced significant problems during treatment and did not have sexual intercourse at all due to the fear of contagion. They were kept distant from loved ones; the spouses slept on separate beds and the disease strongly affected the psyche of afflicted women (Rao et al. 1996; Sarkar and Pradhan 2016; Van't Noordende et al. 2016; Zodpey 2000). They were more likely to describe the disease as causing guilt and embarrassment and reported the desire to die (de Oliveira 1997; Try 2006). Many women could not face the stigma of leprosy and had attempted or considered suicide (Lepra 2017; Shieh et al. 2006).

Based on the above premise, the present study aims to find the gender differentials in health seeking behaviour and perceived stigma of Leprosy patients in West Bengal.

Objectives

1. To look into the differences in perceived and internalised stigma of leprosy patients due to demographic, economic, health and other variables.
2. To look into the differences in self-esteem of leprosy patients due to demographic, economic, health and other variables.
3. To look into the differences in social participation of leprosy patients due to demographic, economic, health and other variables.

Hypothesis

1. There is no influence of age on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
2. There is no influence of gender on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
3. There is no influence of socio-economic status on perceived and internalized stigma, self-esteem and social participation of leprosy patients.

4. There is no influence of place of residence on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
5. There is no influence of education on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
6. There is no influence of duration of sickness on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
7. There is no influence of religion on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
8. There is no influence of caste on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
9. There is no influence of family type on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
10. There is no influence of type of leprosy on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
11. There is no influence of stage of diagnosis of the disease on perceived and internalized stigma, self-esteem and social participation of leprosy patients.
12. There is no influence of visibility of physical symptoms on perceived and internalized stigma, self-esteem and social participation of leprosy patients.

METHODOLOGY

Operational Definitions of Variables

1. Leprosy

A chronic infectious disease occurring mainly in tropical and subtropical regions, characterized by the formation of painful inflamed nodules beneath the skin and disfigurement and wasting of affected parts, caused by the bacillus *Mycobacterium leprae*, also called Hansen disease (Collins English Dictionary 2015).

2. Perceived Stigma

Also known as anticipated or felt stigma it is the perception, expectation or fear of discrimination experienced by an individual and her/his awareness of negative attitudes or practices in

society directed against her/him (Weiss 1997; Weiss et al. 2006).

3. Internalized Stigma

Also known as self-stigma, it is the outcome of a subjective process embedded within a socio-cultural context which may be characterized by negative feelings about oneself, maladaptive behaviour, identity transformation or stereotype-endorsement regarding self-resulting from an individual's experiences, perceptions or anticipations of negative social reaction on the basis of their health or other condition (Boyd Ritsher et al. 2003; Livingston and Boyd 2010; Kirpinar 2016).

4. Self-esteem

Also known as self-regard, it is the evaluative aspect of self-perception, which might be thought of as the degree to which one likes herself/himself. An individual who generally considers herself/himself favourably; has a general feeling of approval of what she/he perceives in herself/himself; and thus likes herself/himself would be said to have a high level of self-esteem (McDavid and Harari 1986; Rosenberg 1965).

5. Social Participation

It is a person's involvement in activities providing interactions with others in society or community (Levasseur et al. 2010; Siddiqi et al. 2017; Van Brakel et al. 2006).

Tools

1. Explanatory Model Interview Catalogue or EMIC Stigma Scale for Use with Leprosy-affected Persons

Explanatory Model Interview Catalogue or EMIC Stigma Scale for use with leprosy-affected persons, Weiss (1997) adapted in simple Bengali Language: The tool assesses socially ascribed stigma perceived by leprosy-affected individuals. The original English version of the tool consists of 15 questions each having four answer-options *viz.* yes, possibly, uncertain and no. The scores to be awarded are 3, 2, 1 and 0 respectively. Higher score indicates more perceived stigma. Internal consistency of the scale

was reportedly .88 (Rensen et al. 2011; Siddiqi et al. 2017; Weiss 1997).

2. Internalized Stigma of Mental Illness or ISMI for Use with Leprosy-affected Persons

Internalized Stigma of Mental Illness or ISMI for use with leprosy-affected persons, Boyd Ritsher et al. (2003) adapted in simple Bengali Language: Original English version of the tool has 28 statements related with self-stigmatization of leprosy-affected persons. Each statement is followed by four response-options – strongly disagree, disagree, agree and strongly agree. The scores to be awarded for endorsement of each response-option are 1, 2, 3 and 4. Higher score indicates more internalized stigma. ISMI scale has internal consistency of .90 for a sample of 127 individuals. The scale has positive correlation with measures of depressive symptoms demonstrating adequate construct validity (Boyd Ritsher et al. 2003; Siddiqi et al. 2017).

3. Rosenberg Self-esteem Scale (1965) Adapted in Simple Bengali Language

Original English version of the scale comprises 10 items with responses to be indicated on a four-point scale. The scale is a self-report measure of global self-esteem of adolescents and adults. Response-options are strongly agree, agree, disagree and strongly disagree. The positively worded items are reverse-scored that is, strongly agree - 3, agree - 2, disagree - 1 and strongly disagree - 0. Items are scored in the fashion: strongly agree - 0, agree - 1, disagree - 2 and strongly disagree - 3. Scores for all the items are summed. Scores range between 0 and 30. Higher score indicates elevated self-esteem. Internal consistency of the original scale ranges from .77 to .88. Construct validity with measure of anxiety is -.64 (Rosenberg 1965; Siddiqi et al. 2017)

4. Participation Scale for Leprosy-affected Persons Adapted in Simple Bengali Language

It consists of 18 questions related to extent of social participation of leprosy-affected individuals aged at least 15 years. Each question is followed by four main response options – not specified, yes, sometimes, no and irrelevant; four more response options gauge the degree of problem faced – no problem, small, medium and large.

The test-taker has to indicate her/his answer to each question. Scores range from 0 to 90. Higher score indicates more participation-restriction. Cronbach's alpha of .92 computed for a multicultural sample (N=497) showed very high reliability. The original scale has been validated for use with persons with leprosy; spinal injuries; polio etc. (Siddiqi et al. 2017; Van Brakel et al. 2006).

The Sample

The target population of this study were leprosy afflicted adult patients in West Bengal. The sample was drawn randomly using simple random sampling technique. The sample comprised of 262 leprosy afflicted patients (55 women and 207 men aged between 18 years and 75 years). The data was collected from School of Tropical Medicine and Leprosy Mission of Kolkata from May 2016 to October 2017.

Procedure

A prior verbal consent was taken before collection of the data. Each subject was made to understand the purpose of the study and then the data was collected. The sample comprised of 262 leprosy patients undergoing treatment for leprosy. All willing participants who visited the hospital and leprosy mission between the periods of May 2016 to October 2017 were included in the study. The leprosy patients were interviewed using socio-economic status scale (age, sex, religion, caste, education, marital status, occupation, type of family, education level of family members, monthly income and expenditures of the family, place of residence) and information on clinical presentation of leprosy such as anaesthesia, ulceration, deformity (for example, Claw hand/ drop tool), absorption or amputation of limbs and loss of vision/blindness. In order to measure the patient's perceived stigma, the EMIC scale questionnaire was administered. ISMI questionnaire was used for measuring internalized stigma. Participation scale and Rosenberg self-esteem scale were administered to look into the social participation and self-esteem of the patients respectively. It has to be mentioned here that all these standard scales were adapted in colloquial Bengali language with a pilot sample of 150 patients (Siddiqi et al. 2016).

RESULTS

Analysis of the data was conducted using STATA version 10.0. Apart from descriptive statistics, a bivariate logistic regression was used to generate odds ratios (ORs) and confidence intervals (CI) (Acharya et al. 2010). To check the collinearity among predictive factors, the Pearson correlation coefficient (r) was calculated with p-value for significance. A backward-stepwise (BSTEP) method was used in multivariable logistic regression to determine the relative independent factor as a predictor of leprosy patients on stigma (both external and internal), self-esteem and social participation (Acharya et al. 2010). BSTEP regression starts with all the predictive factors included in the full starting model. It then removes the least significant covariate, that is, the one with the highest p-value (here, three levels are taken * $p < .10$, ** $p < .05$, *** $p < .01$), at each step, until all factors have been added. By scrutinizing the overall fit of the model, variables are automatically removed until the optimum model is found (Acharya et al. 2010).

It is seen in the present sample that 79 percent are males and 21 percent females. The age of the sample ranges from 18 years to 75 years. The mean age is 42.40 years with SD 14.64 years. 79.4 percent of the samples are Hindus while 20.6 percent are Muslims. Around 37 percent of the sample belongs to rural areas while sixty-three percent are from urban areas, 76.7 percent of the sample comes from nuclear families while 26.3 percent are from joint families.

As far as the multivariable logistic regression is concerned, the independent variables considered were externalized stigma (EMIC), internalized stigma (ISMI), self-esteem (RSES) and social participation (SP). The dependent variables were age, dichotomized as above and below 20 years; sex as males and females; education as illiterate, literate and higher secondary and above; duration of sickness as 1 to 2 years, 2-4 years and 5 years and above; place of residence as rural and urban; socio-economic status as low and middle income; religion as Hindus and Muslims, caste as upper and backward; family type as joint and nuclear; type of leprosy as pauci-bacillary leprosy (PB) and multi-bacillary leprosy (MB); diagnosis as early means within 3 months from the advent of the disease and late; externally visible physical symptoms as visible and not visible.

DISCUSSION

Table 1 shows that age does have an effect on internalized stigma, self-esteem and social participation of the individuals. As can be seen in case of ISMI, OR 1.97 (CI 0.94 - 3.21); self-esteem OR 1.98 (CI 0.93 - 2.99) at 0.10 level of significance. With increase in age, the odds of participation restriction OR 1.02 (CI 0.96 - 1.04) increase. Thus the 1st null hypothesis is rejected and the alternative hypothesis accepted. Further, we can say the gender of the person significantly raises the odds of developing assessed socially ascribed stigma perceived by leprosy-affected individuals (EMIC) as in comparison to their male counterparts as can be seen OR 1.97 (CI 1.39-3.43) (at $p < 0.01$) in Table 1. Women are also worse-off in case of self-stigma (ISMI) which is the outcome of a subjective process embedded within a socio-cultural context which may be characterized by negative feelings about oneself, maladaptive behaviour, identity transformation or stereotype-endorsement regarding self-resulting from an individual's experiences, perceptions or anticipations of negative social reaction on the basis of their health or other condition (Kirpinar 2016; Siddiqi et al. 2017) as is reflected in the OR 1.99 (CI 1.38-3.13). Thus, for both perceived stigma and internalized stigma we see that women are almost two times more likely to have greater stigma than men. Thus the 2nd null hypothesis is rejected. This finding resonates with those of de Oliveira (1997), Try (2006), Morrison (2000), Ulrich et al. (1993), Varkevisser et al. (2009) and Zodpey et al. (2000).

Self-esteem reflects a person's overall subjective emotional evaluation of his or her own worth. It is a judgment of oneself as well as an attitude toward the self. Self-esteem encompasses beliefs about oneself, as well as emotional states, such as triumph, despair, pride, and shame (Hewit 2009; Kohli et al. 2017). Self Esteem was considered as a basic human need according to several early theorists. It is included in Maslow hierarchy of human needs. Experimental research has revealed that this desire for self-esteem has wide-ranging effects on cognition, emotion, and behaviour. Terror management theory explains that this desire for self-esteem results from a fundamental need for psychological security, which is engendered by humans' awareness of their own vulnerability and mortality (Greenberg 2008). As regards to self-esteem we can see that the odd of women being worse

Table 1: Multivariate regression analysis

<i>Variables</i>	<i>Range</i>	<i>EMIC</i>	<i>ISMI</i>	<i>RSES</i>	<i>PS</i>
<i>Age</i>	Above 20 years	1.98 (0.97-2.80)	1.97** (0.94-3.21)	01.98** (0.93-2.99)	1.02* (0.96-1.04)
	Below 20 years	1	1	1	1
<i>Sex</i>	Female	1.97*** (1.39-3.43)	1.99*** (1.38-3.13)	2.07** (1.15-3.69)	2.18*** (1.34-3.57)
	Male	1	1	1	1
<i>Education</i>	Illiterate	1	1	1	1
	Primary level	1.07 (1.37-3.13)	2.09 (1.37-3.13)	2.11** (1.15-3.66)	1.96 (1.34-3.54)
	HS or above	1.95 (1.68-4.38)	1.99 (1.68-4.38)	2.9* (1.75-5.29)	2.11** (1.58 - 3.67)
<i>Duration of Sickness (in Years)</i>	1-2	1	1	1	1
	3-4	0.77 (0.50-1.17)	0.78 (0.50-1.10)	1.69* (0.99-2.80)	1.29 (0.82-2.03)
	5 and above	1.78** (0.79-2.09)	1.72*** (0.48 - 3.07)	1.86** (0.45-2.62)	1.79** (0.29-2.84)
<i>Place of Residence</i>	Rural	1	1	1	1
	Urban	0.91** (0.78 -1.96)	0.81** (0.78 -1.56)	0.51* (0.50-2.41)	0.78** (1.08 - 2.62)
<i>Socio-economic Status</i>	Middle	1.17 (1.10-1.23)	1.16 (1.10-1.23)	1.14 ** (1.05-1.23)	1.09** (1.02-1.16)
	Low	1	1	1	1
<i>Religion</i>	Hindu	1.02 (0.86-1.52)	0.92 (0.56-1.52)	2.43 (0.98-6.04)	1.1 (0.59-2.04)
	Muslim	1	1	1	1
<i>Caste</i>	Upper	1.79 (1.63-2.83)	1.69 (1.13-2.53)	1.89* (1.09-3.28)	1.49** (0.94-2.36)
	Backward	1	1	1	1
<i>Family Type</i>	Joint	1.67 (1.36-2.48)	1.80* (1.35-2.41)	1.61 (1.06-2.44)	1.44* (1.01-2.05)
	Nuclear	1	1	1	1
<i>Type of Leprosy</i>	MB	1.47*** (1.02-2.67)	1.87*** (1.39-2.43)	1.65** (1.08-2.89)	1.47** (1.17-2.33)
	PB	1	1	1	1
<i>Diagnosis</i>	Early	0.96*** (0.76-2.09)	0.74*** (0.75-2.88)	0.63* (0.50-4.08)	0.87** (0.78-4.47)
	Late	1	1	1	1
<i>Physical Symptoms</i>	Visible	1.56** (0.16-3.09)	1.47*** (0.85-2.08)	1.43*** (0.87-4.11)	1.87** (1.08-3.21)
	Not visible	1	1	1	1

*p<.10, **p<.05, ***p<.01

off is greater than that of men OR 2.07 CI (1.15 - 3.69) (at p<0.05) in Table 1. This information is similar to a finding from a study on 'Leprosy in women: characteristics and repercussions', which states that women suffer from marked economic and social dependency and inferiority which can be heightened by social stigma associated with leprosy (Ulrich et al. 1993). Women leprosy patients experience more guilt, embarrassment and suicidal tendency due to the disease (de Oliveira 1997). This also has an impact on participation of the person in interactions with others in society or community OR 2.18CI (1.34 - 3.57) (at p<0.01) as seen in Table 1. This outcome is in tandem with a study done by Zod-

pey et al. (2000) where it was found that women suffered more isolation and rejection from the society. Morrison (2000), Kaur and Ramesh (1994), Rao et al. (1996) and Shieh et al. (2006) reported similar findings. Further as regards to duration of sickness we can see the more the duration (here more than five years), on all counts, that is externalized stigma OR 1.78 CI (0.79 - 2.09), internalized stigma OR 1.72 CI (0.48 - 3.07), self-esteem OR 1.86 CR (0.45 - 2.62) and participation OR 1.79 CI (0.29 - 2.84) the odds increase significantly for persons suffering from the disease for five or more years, which means that more duration of the disease manifests in higher externalized stigma, higher internalized

stigma, less self-esteem and less of social participation (Table 1). The same is seen in case of patients having externally visible physical symptoms EMIC OR 1.56 CI (0.16 - 3.09), ISMI OR 1.47 CI (0.85 - 2.08), Self-esteem OR 1.43 CI (0.87 - 4.11) and social participation OR 1.87 CI (1.08 - 3.21) as per Table 1.

However, in case of early diagnosis of the disease we see that for externalized stigma OR 0.96 CI (0.76 - 2.09) meaning that the probability of having high-externalized stigma is lower than that in case of late diagnosis (Table 1). Similarly for internalized stigma, OR 0.74 CI (0.75 - 2.88) in Table 1, means lower internalized stigma than that of people with late diagnosis of the disease. In case of self-esteem we can see that OR 0.63 CI (0.50 - 4.08) in Table 1 means probability of having lower self-esteem is lower in people who had been diagnosed early. Early diagnosis of the disease leads to less deformity or disability among leprosy patients. Also for social participation, OR 0.87 CI (0.78 - 4.47) shows that people who have been diagnosed with the disease early are more active socially. Thus, null hypothesis 11 is rejected. Physical occurrence of symptoms in form of deformity, lesions, open sores etc. are detrimental to social acceptance of an individual and hence do have significant impact on extent of stigma or self-esteem or even social participation. Another crucial part of physically visible symptoms of the disease is that even if the individual wants he/she can no longer hide the disease, which is commonly observed phenomenon due to the amount of stigma attached. Here we can see from Table 1, for externalized stigma OR 1.56 CI (0.16 - 3.09) means that probability of having higher externalized stigma is greater in case of patients with visible symptoms of the disease. In case of internalized stigma we get the same results; OR 1.47 CI (0.85 - 2.08). Congruent with the results, other researchers have also correlated presence of visible impairment with greater stigma like Boku et al. (2010), Kopyarty et al. (1995), Kumaresan and Maganu (1994), Kushwah et al. (1981), Rao et al. (2008), Singh et al. (2009) and Tsutsumi et al. (2007). Again for self-esteem in Table 1 we can see that OR 1.43 CI (0.87 - 4.11), which means that, the probability of having high self-esteem decreases with the appearance of externally visible symptoms. The researchers' findings are supported by a study conducted in South Africa that found patients felt ashamed possibly due to deformity

and community-antipathy to the disease and found difficult to have self-worth and positive self-image (Scott 2000). Deformed leprosy patients are impoverished because of loss of employment, which further decreases their self-esteem (Bryceson and Pfaltzgraff 1990). The OR 1.87 CI (1.08 - 3.21) in Table 1 means that people with externally visible symptoms of the disease are less socially active. This outcome echoes those of Kaur and Van Brakel (2002) and Scott (2000). The researchers' reject the null hypothesis 12 as physical appearance of the disease does have an impact on stigma, participation as well as self-esteem.

Leprosy can be classified into *Paucibacillary* leprosy (PB) and *Multibacillary* leprosy (MB) on the basis of clinical manifestations and skin smear results (Ishii 2003). In case of MB type leprosy that is to say a more aggressive form of the disease we see that the probability of both external and internal stigma is higher than the PB counterpart; OR 1.47 CI (1.02 - 2.67) and OR 1.87 CI (1.39 - 2.43) respectively. Similarly probability self-esteem and social participation is lower than the PB counterpart; OR 1.65 CI (1.08 - 2.89) and OR 1.47 CI (1.17 - 2.33) as seen in Table 1.

Although in case of the present data, the researchers do not find any significant impact of caste in case of both externalized and internalized stigma. However, several studies have shown that socially classified lower group has higher level of stigma (Rao et al. 2008; Tsutsumi et al. 2007). However, lower caste patients have significantly lower self-esteem than the higher caste counterpart OR 1.89 CI (1.09 - 3.28) and also the social mobility of the lower caste person is lesser than the higher caste patient OR 1.49 CI (0.94 - 2.36) as found in Table 1. Thus, null hypothesis 8 is partially accepted.

The type of family do not reveal much significant result however in case of patients coming from joint families we see that probability of externalized stigma is higher OR 1.67 CI (1.36 - 2.48) as shown in Table 1. Similar were the findings in an Indian study by Kushwah et al. (1981). However, self-esteem is also lower than the people coming from nuclear families OR 1.61 CI (1.06 - 2.44). The present sample mainly belonged to lower to middle socio-economic status. Although in case of SES we do not find any variation between the externalized and internalized stigma of people belonging to middle or low socio-economic

conomic status. However, in case of self-esteem we see in Table 1 that odds for people belonging to middle socio-economic status were higher than that for those of lower socio-economic status OR1.14 CI (1.05 - 1.23). This gets reflected in social participation also with OR1.09 CI (1.02 - 1.16). The 5th hypothesis is thus supported. These echo the findings of Singh et al. (2009) and Nardi et al. (2011), who stated that the lower the socio-economic status and more severe the level of deformity of leprosy afflicted person; extreme is the level of participation restriction among them.

Lastly in case of place of residence we see that the odds of the people residing in urban areas are much better than that of those residing in rural areas. In case of externalized stigma as seen in Table 1, OR 0.91 CI (0.78 – 1.96) indicates lower externalized stigma for urban patients. Similarly, for internalized stigma, OR0.81 CI (0.78 – 1.56) suggests higher internalized stigma. Again for self-esteem we can see that OR 0.51 CI (0.50 - 2.41) meaning that the probability of having lower self-esteem is greater if the person belongs to rural area. Lastly, social participation with OR 0.78 CI (1.08 - 2.62) shows that the urban patient is more likely to be socially active than the rural counterpart. Hence, the 6th hypothesis is retained.

CONCLUSION

Thus from the present research it was concluded that stigma (internalized and perceived) influenced the life of the leprosy patients to a large extent. Age was an important factor, which was positively correlated to stigma, self-esteem and participation restriction of leprosy patients. Female leprosy patients faced greater stigma (self and perceived) and it lowered their self-esteem and restricted their social participation even further. The number of female leprosy patients interviewed in this study was less as compared to males. They lack information about the symptoms of leprosy and come for treatment after their symptoms become worse. Once they start medication, they should be motivated to complete treatment without any delay. Duration of illness and visible deformity negatively affected the self-esteem and social participation of the patients. Regular counselling of patients and emphasizing the importance of timely check-up and consequences of discontinuity of medication can prevent formation of further deformity.

Patients from low-income families or lower caste experienced lower self-esteem and more participation-restrictions as compared to those from middle class families. Lastly as per the place of residence, it was found that leprosy patients residing in rural areas experienced greater stigma, had lower self-esteem and were socially less active than leprosy patients residing in urban areas of Kolkata.

RECOMMENDATIONS

There is a felt need to sensitize the rural and illiterate masses about symptoms and treatment and the social and emotional problems related to leprosy through television programmes, health education campaigns, banners, street plays and newspaper articles to reduce stigma attached to leprosy. Leprosy should be considered as any other disease and family and society should encourage leprosy patients to have normal social and stigma free lives.

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