

Stigma in leprosy : miles to go !

A Sinha¹, AS Kushwaha², A Kotwal², S Sanghi³, AK Verma²

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No disease has been more closely associated with stigma than leprosy such that it has become a metaphor for stigma. Stigma has been difficult to measure and little research has been done on this issue. Stigma reduction has not been an important component of anti-leprosy program. The study was undertaken to measure the stigma associated with leprosy by using P scale which is used for assessing participation restriction of those affected by the disease. This comparative questionnaire based study was carried out in two sets of patients. Two groups of 30 patients each were studied. First group belonged to a Government run Leprosarium and group two from a tertiary care skin and leprosy centre. The study used the Participation (P) scale and data was collected by interviewing the patients. Participation restriction was defined as any score equal to and more than 13. Participation restriction was observed in 27 (90%) cases of group 1 while participation restriction was present in only 7(23.3%) subjects of group 2. It was observed that mean score of participation restriction in group 1 was quite high at 31.9 while it was only 8.3 for group 2. The participation restriction was directly related to the duration of disease and the grade of disability. Longer the duration of disease, greater was the likelihood of restriction. The participation restriction was found to be negatively correlated with the education. Recommendation about prevention of disability would require program about early diagnosis of nerve damage and subsequent action at the patient - family - community level and health care providers.

Key words: Stigma, Leprosy, Participation restriction, P Scale

Introduction

There are a number of health conditions that bear the burden of stigma, but perhaps, the most powerful image of stigma is related to leprosy (Jopling 1991). Stigma related to chronic health conditions such as HIV/AIDS, leprosy, tuberculosis, mental illness and epilepsy is a global phenomenon with severe impact on individuals and their families and also on the

effectiveness of public health programmes.

Now, leprosy is curable and the patient can take domiciliary treatment. The disease is likely to lose its public health appeal because of rapid decline in its burden substantially. The unmeasured social and economic impact of this disease is evident by lack of adequate literature on the subject. Social, behavioural and psychological aspects of leprosy and its control have been relatively neglected

A Sinha, MBBS Student

AS Kushwaha, Associate Professor

A Kotwal, Associate Professor

S Sanghi, Associate Professor

AK Verma, Professor and Head of the Department

¹Armed Forces Medical College, Pune, India

²Department of Community Medicine, Armed Forces Medical College, Pune, India

³Department of Dermatology, Command Hospital, Pune, India

Correspondence to: AS Kushwaha **Email:** arvind6077@yahoo.com

areas in terms of research and also leprosy control programmes.

Stigma has been defined as “an attribute that is deeply discrediting” leading to a ‘spoiled identity’ (Goffman 1963). Stigma is typically a social process characterized by exclusion, rejection, blame or devaluation. This results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. The aspects of health-related stigma used for assessment can be grouped under five categories. First, the experience of actual discrimination and or participation restrictions on the part of the person affected; second, attitudes towards the people affected; third, perceived or felt stigma; fourth, self or internalized stigma and fifthly, discriminatory and stigmatizing practices in (health) services, legislation, media and educational materials. Determinants of stigma are multiple and often interlinked. Some of them being lack of knowledge, negative attitudes, perceived fear of infection and blame and shame.

Perceived stigma may cause emotional stress and anxiety. It may also result in depression, (attempted) suicide, isolation and problems in family relationships and friendships. People who fear the consequences of the diagnosis of leprosy may delay in presenting themselves to the health services and thus have an increased risk of disability and continue to be a potential source of infection in the community. Fear of “being found out” and its possible consequences may lead to patient discontinuing treatment.

Discrimination is the treatment of an individual or group with partiality or prejudice. It is often defined in terms of human rights and entitlements in various spheres including healthcare, employment, legal system, social welfare and reproductive and family life. Stigma and discrimination are closely linked. Stigmatization reflects an attitude but discrimination is an act or behaviour. Discrimination is a way of expressing stigmatizing thoughts, either on purpose or inadvertently.

Materials and Methods

This study was undertaken to find out the stigma associated with leprosy by measuring participation restriction using P scale. The objectives of the study were to study the socio-demographic profile of patients of leprosy and to study the participation restriction amongst two groups of diagnosed patients of leprosy admitted at a Leprosarium and tertiary skin and leprosy centre. It was also planned to study the determinants of participation restriction amongst these patients.

A questionnaire based study using interviews of the patients using the Participation (P) scale was carried out at a tertiary care skin and leprosy centre and at a Leprosarium. Since the key issue of stigma is that it excludes people from participating in social events, it is suggested here that the ‘P scale’ is a valid proxy measure for measurement of stigma. Besides the P scale, basic demographic and generic data was collected on all the cases of leprosy prior to administration of P scale. The 18-item Participation scale is based on the terminology and conceptual framework of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). The scale measures level of social participation which is directly affected by stigma. The P scale is an instrument that has been validated through an exhaustive process of testing and re-testing in a multinational, multi-centric initiative. It does not measure stigma per se but it does measure the extent to which people participate in common social events.

The Participation scale was used in the vernacular languages Marathi or Hindi as applicable. Translation into the vernacular languages was done using the English scale as a basis. Since the items in the scale have an intrinsic meaning that needs to be retained in any translation, the translated document was back-translated into English which is the master questionnaire to verify that the meaning of the items had not changed substantially. Translation was done by medico-social workers experienced in the field of

socio-economic problems and rehabilitation and back-translation by the guide expert in both the vernacular and English language.

The questions were asked the way they were written. Explanations were given only if the question was not clear. Before the actual scale interview was started, the interviewer built rapport with the respondent and made the respondent feel at ease as much as possible. The interview was done in private.

The grading of participation restriction was done as under :

- a. 0-12 : No significant restriction
- b. 13-22 : Mild restriction
- c. 23-32 : Moderate restriction
- d. 33-52 : Severe restriction
- e. 53-90 : Extreme restriction

Two different sets of population groups of patients were selected for the study. Patients in group 1 belonged to a Government run Leprosarium where they were being treated indoors. This group comprised of people who were part of a different social milieu hailing from different parts of state of Maharashtra. For comparison group 2 was selected. Group 2 included all cases admitted at a tertiary care centre for skin and leprosy at Pune. These subjects were young Central Government employees who were undergoing treatment. The two groups were compared. The results were analyzed using suitable statistical tools. A verbal consent was taken from each subject beforehand and anonymity was ensured. The socio-economic status was recorded based on the Kuppuswamy scale. The data so collected was organized on excel worksheet and analyzed using SPSS version 12.0 using appropriate statistical tests.

Results

The distribution of cases according to age, socio-economic status, place of residence, education level, grade of disability and participation restriction was studied in each group. In both the

groups, all the subjects were older than 20 years of age. Majority of patients in group 2 were aged 20-40 years while in group 1 most were aged more than 40 years. The combined mean age of two groups was 44 years and nine months (Table 1). The subjects in group 2 had an average of 11.7 years of schooling compared to group 1 who had just 4.4 years of schooling. Almost 1/3rd of subjects in group 1 had no education at all (Table 2). All the cases belonged to upper middle class in group 2 while group 1 had cases hailing from lower middle and upper lower social class as per Kuppuswamy scale (Table 3).

Group 1 subjects were mostly of urban background while those in group 2 were mainly residents of rural areas (Table 4). The subjects were asked for the duration of illness they had been suffering. Group 1 subjects had a longer mean duration of illness at 21.7 years while for group 2, it was only 2.1 years with most having disease duration less than 5 years (Table 5A). This difference was significant statistically by using 't' test as well as non-parametric test (Table 5B).

The disability grade is closely associated with stigma in leprosy and therefore, it was decided to study all subjects for the disability and classify it using the WHO scale. It was seen that group 1 had grade 2 disability in 27 subjects while only 3 had grade 1. In the group 2, it was found that 23 had grade 1 disability while 7 had grade 2 disabilities (Table 6). The disability was assessed in hands and feet as well as eyes.

Participation score

The scores were calculated and then subjects were classified as per the given range of scores for no restriction to severe or extreme restriction. The participation restriction was also studied for its association with certain factors like education, socio-economic status and the grade of disability.

It was seen that mean score of participation restriction in group 1 was quite high at 31.9 while it was only 8.3 for group 2. Participation restriction was observed in 90% (27) cases of group 1 while participation restriction was present in only

Table 1 : Distribution of cases of leprosy by age (years) in two groups

Group	Mean age	Youngest	Oldest	<20 yrs	20-40 yrs	>40 yrs
Group 1	59.46	32	76	0	2	28
Group 2	30.03	21	48	0	27	3
Combined	44.75	21	76	0	29	31

Table 2 : Distribution of cases of leprosy by level of literacy in two groups

Group	Mean education (years of schooling) \pm (S.D.)	Illiterate	Primary	Middle school	High school	12th std.	Graduation	Total
Group 1	4.4 \pm 3.7	11	8	8	3	0	0	30
Group 2	11.7 \pm 1.6	0	0	0	10	16	4	30
Total	7.95 \pm 5.0	11	8	8	13	16	4	60

Table 3 : Distribution of cases by socio-economic status in two groups (Kuppuswamy scale)

Group	Upper	Upper middle	Lower middle	Upper lower	Lower	Total
Group 1	0	0	17	13	0	30
Group 2	0	30	0	0	0	30
Total	0	30	17	13	0	60

Table 4 : Distribution according to place of residence

Group	Rural	Urban	Total
Group 1	9	21	30
Group 2	28	2	30
Total	37	23	60

23.3% (7) subjects of group 2 (Table 7A). Participation restriction was defined as any score equal to and more than 13. It was found that study groups were significantly different with respect to

participation restriction (score 13 and more) (p value < 0.001 for *Chi*-square test) as well as by non-parametric test (Table 7B).

While studying the prevalence of various levels of participation restriction, it was seen that only 3 (10 %) subjects in group 1 had no restriction of participation while on the other hand 27 (90%) subjects had significant restriction of participation. In group 2 only 7 subjects had restriction with most (23) reporting no restriction of participation (Table 8). This difference was also significant statistically. On studying the relation between grades of disability and participation

Table 5A : Distribution of cases according to duration of disease (years)

Group	Mean (years)	Longest (years)	Shortest (years)	< 1 yr (n)	1-5 yrs(n)	> 5 yrs(n)
Group 1	21.7	50	4.0	0	2	28
Group 2	2.1	10	0.5	7	19	4
Combined	11.93	50	0.5	7	21	32

Table 5B : Distribution of cases according to duration of disease (years)

	Group	N	Mean	Std. deviation	P value*
Duration of disease	1	30	21.7	12.16	0.000
	2	30	2.1	2.45	

* 't' test = 8.652; Mann Whitney U

Table 6 : Distribution of grades of disability according to WHO classification in the two groups

Group	Grade 1	Grade 2	Total
Group 1	3	27	30
Group 2	23	7	30
Total	26	34	60

restriction, it was seen that grade 2 disability was associated with participation restriction in all the subjects from both the group of subjects. Subjects with grade 1 disability did not experience any restriction of participation in either of the group (Table 9). This clearly demonstrates that grade 2 disability is a risk factor for participation restriction.

Relationship of participation restriction to socio-economic class was also studied (Table 10). Parti-

cipation restriction was seen mostly in lower middle class (16/17) while subjects belonging to upper middle social class had the lowest rates for restriction (7/30).

Correlation of education and participation restriction

Education is the best known solution for eliminating social discrimination and stigma. It empowers the people, be it the patients or the community at large. It was, therefore, decided to study if any correlation exists between these two variables. The scatter plot (Figure 1) clearly highlights the fact that education had a negative correlation with participation score. It proves that with improved education the participation restriction can be reduced.

Correlation between duration of disease and participation score

The duration of disease has a bearing on the

Table 7A : Participation scores in the two groups

Group	Mean score	Highest score	Lowest score	Restriction present (score 13 and more)	Restriction absent (score 12 or less)
Group 1	31.9	59	3	27	3
Group 2	8.3	24	0	7	23
Total	20.13	59	0	34	26

Table 7B : Participation scores in the two groups

	Group	N	Mean	Std. deviation	P value
P_Score	1	30	31.9	13.82	0.000
	2	30	8.3	6.38	

t = 8.489

development of deformity and disability. The deformity especially those that are visible and advanced have a direct bearing on the stigma and discrimination faced by the patients of leprosy. The stigma is measured by finding the restriction of participation. Therefore, it was considered to study the correlation between the duration of disease and the participation score. Figure 2 shows a significant positive correlation between

duration of disease and participation score with a correlation coefficient 0.663.

Discussion

Leprosy is often called a social disease. The myths related to this disease coupled with high levels of ignorance perpetuate the stigma. The deformities caused by this disease have been linked to social discrimination in leprosy. No element for social rehabilitation is included in the National Program on Leprosy Elimination. With declining prevalence of this disease there is every chance of this issue being pushed into the background and the social needs of the patients will continue to remain unfulfilled.

van Brakel in 2003 carried out a literature review to review work done to date on measuring stigma related to leprosy. Twelve papers were selected

Table 8 : Distribution of cases according to severity of restriction

Group	No significant restriction	Mild restriction (13-22)	Moderate restriction (23-32)	Severe restriction (33-52)	Extreme restriction (53-90)
Group 1	3	4	8	13	2
Group 2	23	6	1	0	0
Total	26	10	9	13	2

Table 9 : Relation of participation restriction to grades of disability in two groups

Participation restriction	Group 1		Group 2		Combined	
	Grade 1 disability	Grade 2 disability	Grade 1 disability	Grade 2 disability	Grade 1 disability	Grade 2 disability
Present	0	27	0	7	0	34
Absent	3	0	23	0	26	0

Table 10 : Participation restriction according to socio-economic status

Participation restriction	Upper	Upper middle	Lower middle	Upper lower	Lower	Total
Present	-	7	16	11	-	34
Absent	-	23	1	2	-	26
Total	-	30	17	13	-	60

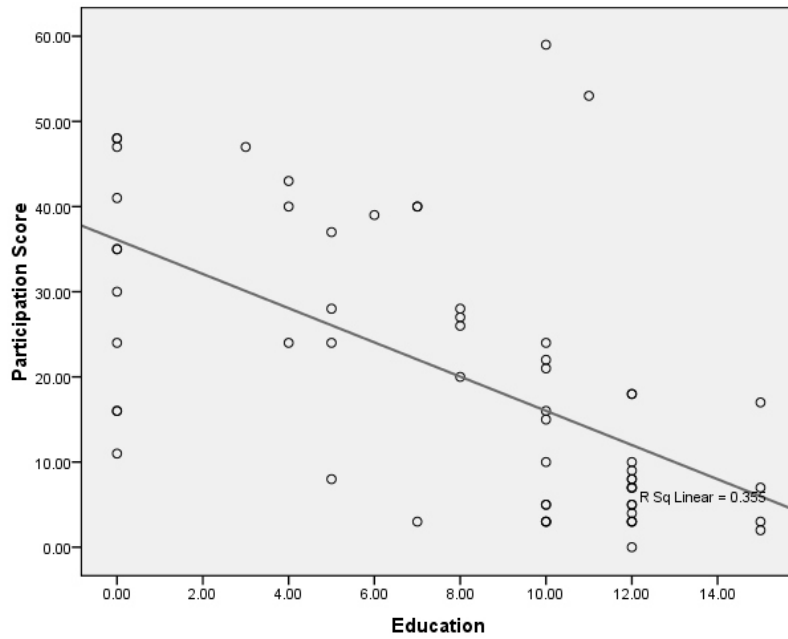


Figure 1: Correlation between educational status and participation score.
Pearson correlation coefficient = - 0.596

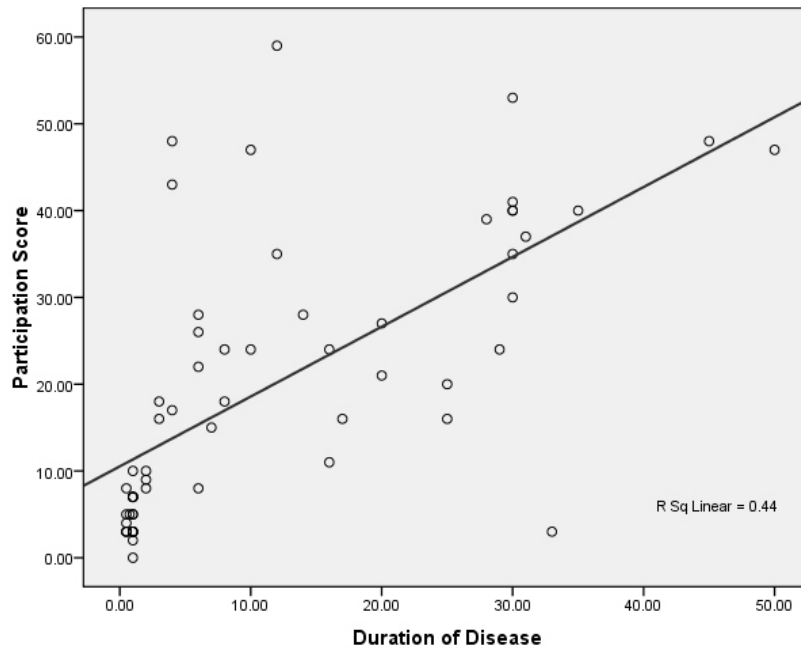


Figure 1: Correlation between the duration of disease and the participation score.
Pearson's correlation coefficient = 0.663

that addressed the issue of measurement of stigma and that contained a sample of the instrument used. In the terminology of the new WHO International Classification of Functioning, Disability and Health (ICF) (WHO 2001), the consequences of stigma would manifest to a large extent as participation restrictions. The ICF recognizes nine life domains in which participation may be restricted. These are: learning and applying knowledge, general tasks and demands, Communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. Quite a number of scales and indicator sets have been developed but usually these have been validated in one health field only. Good instruments are essential for stigma research. Link et al (2004) stated, "Essential to the scientific understanding of stigma is our capacity to observe and measure it." Only one instrument, the stigma scale derived from the Explanatory Model Interview Catalogue (EMIC) has been used to measure attitudes and perceptions regarding a number of health conditions (Weiss et al 1992). The strengths of this instrument are its simplicity and its utility which has been demonstrated in different cultural settings and with very different health conditions; mental health and leprosy in India (Weiss et al 1992), depression, onchocerciasis (Brieger et al 1998), tuberculosis and Buruli ulcer (Stienstra et al 2002). Two other generic scales designed to measure stigma-related constructs are the "The Child Attitude Toward Illness Scale" (CATIS) (Heimlich et al 2000) and the Participation Scale (van Brakel et al 2006).

The best developed instrument in this category is the 'Dehabilitation Scale' published by Dr Hanna Anandaraj in 1995. This 52-item scale covers four areas related to stigma: family relationships, vocational conditions, social interaction and self esteem. Dr PK Gopal (1998) developed a questionnaire designed to identify target groups for socio-economic rehabilitation.

Very few studies on the subject of stigma related to leprosy in India are available and their scope

and methodology are inconsistent (Ramu et al 1975, Crook et al 1991, Raju and Koparty 1995, Sharma et al 2001). Ramu et al in 1975 conducted a questionnaire based survey amongst 225 'normal' individuals with respect to their attitude and practice towards patients of leprosy. Raju and Koparty in 1995 conducted a study with 8 items and on a 3 point scale with 600 people in Orissa and equal number in Andhra Pradesh. Sharma et al (2001) carried out a questionnaire based survey with 4 items on 3 option scale amongst 436 panchayat representatives and 16 people affected by leprosy in Madhya Pradesh.

This study has found that education, socio-economic status, presence of deformity, grade of deformity is important determinants of stigma in leprosy as measured by the Participation score. The findings of the study have been elaborated under observation and results. Similar study by Singh et al (2009) carried out on 245 patients has been reported using P scale. Similar association of participation restriction to socio-economic class and grade of deformity has been found.

Conclusion

The study concludes that grade 2 disability is strongly associated with restriction of participation while grade 1 disability is not. The participation restriction is also directly related to the duration of disease, longer the duration, greater the likelihood of restriction. The participation restriction was found to be negatively correlated with the education. This highlights the role of prevention of disability as one of the key interventions that should be part of any programme on leprosy if we want the social stigma to be overcome. Thus, early diagnosis, effective treatment of disease and management of lepra reactions should form important components of anti-leprosy activities. The integration of services related to leprosy in general health services could be an important strategy to combat institutional stigma. An intervention study in Nepal was carried out to reduce stigma by using leprosy affected patients who were treated and

used as agents of change (Cross and Choudhary 2005). The education of masses through focused IEC campaigns on leprosy can be taken up to combat myths related to leprosy.

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