

## Factors Influencing Participation Restrictions among Persons Affected by Leprosy

M Mathanraj David<sup>1</sup>, MS Raju<sup>2</sup>, T Mendis<sup>3</sup>

Received : 26.07.2018

Accepted : 25.03.2019

To compare the factors associated with the participation restriction of person affected by leprosy in cross cultural contexts, this study was carried out from four states viz. Uttar Pradesh (UP), Chhattisgarh (CG), Andhra Pradesh (AP) and Tamil Nadu (TN) during the period from 2016 to 2017. Cross sectional study design was used in this study using the standardized Participation scale, along with socio-demographic variables were analysed for a total of 379 persons affected by leprosy. The findings from each state were compared with other states. The study concludes that participation restrictions are highly influenced by education and type of occupation in most of the states. The variables such as gender, age, locality and disability are moderately affecting the participation restrictions in some states. Income groups and Type of membership are affecting the participation restrictions in some states compared with others. The variables such as marital status, Religion and caste has no specific influence on participation restriction. Diverse influence of independent factors observed among various states indicates the need of independent strategies for each state to address the underlying cultural issues and challenges.

**Keywords:** Person Affected by Leprosy, Participation Scale, Socio Demographic Variables, Gender, States

### Introduction

World Health Organization's (WHO) International Classification of Functioning, Disability and Health define participation as involvement in a life situation (ICF 2001). Participation restrictions may occur in any life situation across nine areas of activity and participation. These are learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, inter-personal interactions and relationships,

major life areas and community, social and civic life. In the context of leprosy, participation restrictions are known (Singh et al 2009), these are recognized as the outworking of the stigmatizing attitudes with which the disease has been associated for generations and the felt stigma or self-stigmatization with which those affected respond (Bainson & Van den Borne 1998).

Nicholos et al (2005) have summarized the risk

<sup>1</sup> M. Mathanraj David, M.O.T., M.Sc., Program Manager, Research and Training, CREATE Project, The Leprosy Mission Trust India, Vadathorasalur, Thiyyadurgam Post, Villupuram District, Pin Code: 606206, Tamilnadu, India.

<sup>2</sup> Dr. MS Raju, PhD, Research Scientist, The Leprosy Mission Trust India, TLM Community Hospital Shadara, Nand Nagri, Delhi - 110093, India

<sup>3</sup> Ms. Tine Mendis, Masters in Rural Development, Head, Sustainable Livelihood and Community Empowerment, The Leprosy Mission Trust India, CNI Bhavan, 16 Pandit Pant Marg, New Delhi-11001

**Correspondence:** M. Mathanraj David

**Email:** mathanraj@leprosymission.in

factors contributing to leprosy stigma include deformities (Frist & Mutatkar 1998), misconceptions about the cause or transmission of the disease (Raju & Reddy 1996), religious teaching, attitudes of health care professionals, segregation of affected people (Frist 1996), concealment of early symptoms of diagnosis and treatment and the practice of begging by individuals with deformities, discriminating legislation and the image of leprosy portrayed by fund-raising agencies (Frist 1996, Jopling 1991). Other reported factors include the use of discriminatory language (Van Brakel & Gopal 1999), the image portrayed in the media (Susman 1994), gender, (Cakiner et al 1993, Shale 2000, Ulrich et al 1993), ethnicity and social class (Kopparty 1995), education or literacy, occupation and income (Raju & Reddy 1996).

In one of the studies maximum stigma is noted for not to participate in religious rituals in the state of UP and least in case of social functions which is other way with maximum restriction for social functions and least for religious functions in the state of Chhattisgarh (Rao et al 2008), which explains the importance of studying underlying factors that influence the levels of stigma and participation levels.

A community action study reemphasizes the vitality of community action at every stage of leprosy control programme for implementation of which proper understanding of influencing factors in a specific region is very essential (Raju et al 2008). According to Garbin et al (2015) factors such as being depressed and sad, and encountered problems at work after being diagnosed, resulting their quality of life and suffering in patients beyond pain and discomfort etc greatly influences social participation.

Perceived stigma towards leprosy was found highest among participants with age 61 years or older, longer duration of stay in community close

to the leprosy colony, lower duration of education and participants who were unemployed had higher perceived stigma (Kaehler et al 2015). Role of deformity is explained as that those affected by leprosy tended to frame their situation in medical terms, while those living with disabilities described their situation from a more social perspective (Lusli et al 2015).

Community development programmes have to deal with the consequences of stigma and other factors leading to participation restrictions, evidence for factors associated with participation restrictions is scanty and we need to evaluate the level of participation in the community to plan for effective intervention strategies. Identifying individuals at risk and responding with tailored interventions to prevent participation restrictions would be a direct benefit to those affected. The present study has, therefore, designed to serve the above purpose with following objectives:

1. To identify socio-demographic factors influencing participation restrictions of persons affected by leprosy.
2. To study the influence of deformity level on participation restrictions.
3. To understand how the influence of socio demographic factor and deformity varies among cross cultural states with differing leprosy case load and stigma endemicity in India.

## **Materials and Methods**

### **Study Design, Sample and Setting**

This is a cross-sectional descriptive study carried out in four states viz. Uttar Pradesh (UP), Chhattisgarh (CG), Andhra Pradesh (AP) and Tamil Nadu (TN). In order to study the association in cross cultural situations selection of two states from southern region and two from northern region was done. Considering the change in ANCDR during 2014, the two states from each

region i.e. (AP and TN) from south and (CG and UP) from north have been selected. Data was collected from a total sample size of 379 i.e. from Uttar Pradesh (100), Chhattisgarh (100), Andhra Pradesh (101) and Tamil Nadu (78), out of which 198 were males and 181 were females. This study is out of baseline data collection carried out during 2016 to 2017 for the CREATE Project, Out of the areas where CREATE project was to be implemented based on the extent of empowerment needs, four districts selected from each state and it was decided to include all the prospective beneficiaries whether from community or colony a randomly selected minimum of 25 from each district for this analysis, which leads to a total sample of 100 from each state. The data of only 3 districts from TN was included in the analysis so the sample is smaller. Ethical clearance was provided by TLM Research Ethics Committee and financial support from European Union, TLM England and Whales.

#### Study Tools

Individual data format was used to gather the information about the basic demographic data with socio-demographic variables viz. age, gender, marital status, education, occupation, income groups, membership, locality, caste and disability grade of the person affected by leprosy.

- Participation scale (van Brakel et al 2006) was used, this is an interview based standardized

scale of 18 items developed based on the terminology and conceptual framework of the International classification of functioning, Disability and Health ICF (ICF, WHO 2001). The scale measures level of social participation which directly affected by stigma. The P scale is an instrument that has been validated through an exhaustive process of testing and retesting in a/ multinational, multi-centric initiative. It measures the extent to which people participate in common social events.

#### Procedure

The participation scale (P-scale) was used in the vernacular languages Tamil, Telugu and Hindi. Translation into vernacular languages was done using the English scale as a basis and the translated versions are back translated to verify the intrinsic meaning that needs to be retained. After the interviewer built rapport with the respondents, interviews were conducted at their home environment. Based on the P-scale scores of each respondent, the level of participation restriction was graded into five categories, which are summarized in this study into two categories. (Table 1)

All the data collected from the four states groups were analyzed using SPSS and association of different variables tested using chi-square and other appropriate statistical tests.

**Table 1 : Parameters of P scale used in the study**

Scores	As per P scale	As per present study
0-12	No Significant Restriction	No significant Participation Restriction (NSPR)
13-22	Mild Restriction	
23-32	Moderate Restriction	Participation Restriction (PR)
33-52	Severe Restriction	
53-90	Extreme Restriction	

## Results

As described in the methodology, based on the level of participation the respondents are categorized for the purpose of analysis in to two categories viz.

- No significant Participation Restriction-NSPR (with a score of 0-22) and
- Participation Restriction-PR (with a score of 23-90)

As reported by scientists working on stigma every individual is likely to face some restriction at a situation in course of life and a mild restriction in this context may not be leprosy specific. When two categories are being made those facing mild restrictions (13-22) are rationally more closer to (0-13) group than other groups. Further, all the

analysis was carried out based on the above two categories.

**Prevalence of Participation Restriction and state:** Analysis shows that, of the total sample, majority (76.8%) face participation restrictions. The Inter-state comparison shows the proportion of those who face participation restrictions is maximum in UP (84%), followed by CG (81%), TN (75.6%) and least in AP (66.3%).

**Prevalence of Participation Restriction and Gender:** Prevalence of participation restriction and its relationship is presented in Table 2. On aggregate, there is a large variation in proportion of those facing participation restrictions among males (69.7%) and females (84.5%). Intra-state comparison of males against females shows that

**Table 2 : Participation Restriction and Gender**

Gender	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Male	30 (63.8)	30 (58.8)	30 (71.4)	48 (82.8)	138 (69.7)
Female	29 (93.5)	37 (74)	51 (87.9)	36 (85.7)	153 (84.5)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square( $X^2$ )	8.954	2.604	4.311	0.158	11.671
P Value	0.002	0.080	0.035	0.456	0.000
Remarks	Sig**	NS	Sig**	NS	Sig**

**Table 3 : Participation Restriction and Age groups**

Age Groups	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Younger (20 to 39 yrs)	1 (20)	10 (58.8)	18 (75)	26 (66.7)	55 (64.7)
Middle (40 to 59 yrs)	44 (81.5)	47 (66.2)	54 (84.4)	52 (94.5)	197 (80.7)
Old age (above 60yrs)	14 (73.7)	10 (76.9)	9 (75)	6 (100)	39 (78)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square ( $X^2$ )	9.440	1.083	1.316	14.412	9.136
P Value	0.009	0.582	0.518	0.001	0.010
Remarks	Sig**	NS	NS	Sig**	Sig**

prevalence of facing participation restrictions is comparatively more among females than males in all the four states of TN (93.5% against 63.8%), CG (87.9% against 71.4%), UP (85.7% against 82.8%) and AP (74% against 58.8%) respectively. However, it is proved that the gender variation with regard to proportion of those facing participation restrictions is Statistically significant in the total sample as well as in the states of TN, CG with  $P < 0.05$  and Not significant in AP and UP.

**Prevalence of Participation Restriction and Age groups :** On aggregate, proportion of those facing participation restrictions was found to be similar among Middle age group (80.7%) as well as old age group (78%), and comparatively less (64.7%) among the younger age group (Table 3). Intra-

state comparison of Age groups shows that proportion of those facing participation restrictions is comparatively more among Middle age group than old age group in the states of CG (84.4% against 75%) and TN (81.5% against 73.7%) and more among Old age group than Middle age in the states of UP (100% against 94.5%) and AP (76.9% against 66.2%) respectively. However, the differences between the age groups in terms of proportion of those facing participation restrictions is statistically significant in the total sample as well as in the states of TN and UP with  $P < 0.05$  and not significant in AP and CG.

**Prevalence of Participation Restriction and Marital Status :** It has been observed that on

**Table 4 : Participation Restriction and Marital Status**

Marital Status	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Married	45 (75)	47 (64.4)	69 (79.3)	70 (84.3)	231 (76.2)
Un Married	5 (71.4)	8 (66.7)	3 (75)	9 (75)	25 (71.4)
Separated/Widow/Divorce	9 (81.8)	12 (75)	9 (100)	5 (100)	35 (85.4)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square ( $X^2$ )	0.309	0.663	2.366	1.683	2.308
P Value	0.857	0.718	0.306	0.431	0.315
Remarks	NS	NS	NS	NS	NS

**Table 5 : Participation Restrictions and Education**

Educational status	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Un educated	33 (78.6)	42 (72.4)	51 (91.1)	57 (91.9)	183 (83.9)
Educated up to 9th	25 (78.1)	22 (68.8)	26 (70.3)	13 (76.5)	86 (72.9)
10th Std and Above	1 (25)	3 (27.3)	4 (57.1)	14 (66.7)	22 (51.2)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square ( $X^2$ )	5.870	8.559	9.048	8.316	23.112
P Value	0.053	0.014	0.011	0.016	0.000
Remarks	Sig**	Sig**	Sig**	Sig**	Sig**

aggregate, proportion of those facing participation restrictions is similar among Separated / widow / Divorce (85.4%), Married (76.2%), and Unmarried (71.4%) (Table 4). Intra-state comparison of Marital status shows that proportion of those facing participation restrictions is comparatively more among Separated / widow / Divorce and married than Unmarried in UP (100%, 84.3% and 75%), CG (100%, 79.3% and 75%), and TN (81.8%, 75% and 71.4%). In AP more between Separated / widow / Divorce and unmarried than Married (75%, 66.7% and 64.4%) respectively. However, the differences between the Marital status in terms of proportion of those facing participation restrictions is not statistically significant in any of the four states as well as on the whole.

**Prevalence of Participation Restriction and Educational Status :** On aggregate, proportion of those facing participation restrictions was observed to be more among uneducated (83.9%), Educated up to 9<sup>th</sup> Classs (72.9%) and less in 10<sup>th</sup> Std and above (51.2%) (Table 5). Intra-state

comparison of Education status shows, proportion of those facing participation restrictions is comparatively more among un educated than Educated up to 9<sup>th</sup> Classs and 10<sup>th</sup> Std and above in the four states of UP (91.9%, 76.5% and 66.7%), CG (91.1%, 70.3% and 57.1%) , TN (78.6%, 78.1% and 25%) and AP (72.4%, 68.8% and 27.3%) respectively. However, the differences between the educational status in terms of proportion of those facing participation restrictions is statistically significant in the total sample as well as in the sates of TN, AP, CG and UP with P<0.05.

**Prevalence of Participation Restriction and Occupation :** On aggregate, proportion of those facing participation restrictions is more among Labourers /coolie (88.8%), followed by beggars (80.9%), dependents (80.4) house wives (78.1), farmers (66.7%) and businessmen (37.9%) respectively (Table 6). Intra-state comparison of occupation shows, proportion of those facing participation restrictions is comparatively more among beggars (96%), labourers (93.8%), dependents (80.8%) and less for business persons

**Table 6 : Participation Restriction and Occupation**

<b>Educational status</b>	<b>TN N=78</b>	<b>AP N=101</b>	<b>CG N=100</b>	<b>UP N=100</b>	<b>Total N=379</b>
Beggars	0	28 (70)	20 (83.3)	24 (96)	72 (80.9)
Labour/Coolie	15 (78.9)	17 (89.5)	32 (91.4)	15 (93.8)	79 (88.8)
Farming	9 (64.3)	0	3 (42.9)	14 (77.8)	26 (66.7)
Buisness	0	4 (33.3)	4 (36.4)	3 (60)	11 (37.9)
Housewife	0	8 (66.7)	10 (90.9)	7 (77.8)	25 (78.1)
Employed	0	0	0	0	0
Dependents	35 (81.4)	10 (62.5)	12 (100)	21 (80.8)	78 (80.4)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square (X <sup>2</sup> )	8.076	14.695	26.933	12.183	48.782
P Value	0.089	0.012	0.000	0.058	0.000
Remarks	NS	Sig**	Sig**	Sig**	Sig**

(60%) in UP. In CG it is more among dependents (100%), labour (91.4%), house wives (90.9%), beggars (83.3%), farmers (42.9%) than businessmen (36.4%). In AP it is more among labourers (89.5%), beggars (70%), housewives (66.7%), dependents (62.5%) than businessmen (33.3%). In TN it is more in dependents (81.4%), labourers (78.9%) than farmers (64.3%) respectively. The differences between the occupations in terms of proportion of those facing participation restrictions were found to be statistically significant in the total sample as well as in the states of AP, CG and UP with  $P < 0.05$  and but not significant in TN.

**Prevalence of Participation Restriction and Monthly Income groups :** It was observed that on the aggregate proportion of those facing participation restrictions is maximum (100%) in the group 2 - of those with income of Less than Rs. 1000 followed by the group 1 - of those with No Income (82.8%), group 3 - of those with income of Rs. 1000 to Rs. 2500 (80.3%), group 5 - of those with income of Rs. 5000 to Rs. 10000 (70%) and group 4 - of those with income of Rs. 2501 to Rs. 5000 (68.7%) (Table 7). Intra-state comparison of Income in CG shows, proportion of those facing participation restrictions is comparatively maximum among group - of Less than Rs. 1000 (100%),

**Table 7 : Participation Restriction and income**

	Income	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Group-1	No Income	6 (7.5)	1 (5.0)	12 (92.3)	5 (83.3)	24 (82.8)
Group-2	< Rs. 1000	1 (100)	0	10 (100)	0	11 (100)
Group-3	Rs. 1001 < Rs. 2500	41 (77.4)	43 (71.7)	25 (89.3)	54 (87.1)	163 (80.3)
Group-4	Rs. 2501 < Rs. 5000	11 (73.3)	19 (54.3)	31 (73.8)	18 (78.3)	79 (68.7)
Group-5	Rs. 5001 < Rs. 10000	0	4 (100)	3 (42.9)	7 (87.5)	14 (70)
	Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
	Chi Square ( $X^2$ )	3.557	5.308	12.703	6.331	13.354
	P Value	0.469	0.151	0.013	0.176	0.020
	Remarks	NS	NS	Sig**	NS	Sig**

**Table 8 : Participation Restriction and Membership**

Membership	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
CSO Member	39 (73.6)	59 (71.1)	79 (81.4)	76 (85.4)	253 (78.6)
Champion	20 (80)	8 (44.4)	2 (66.7)	8 (72.7)	38 (66.7)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square ( $X^2$ )	0.379	4.701	0.413	1.169	3.850
P Value	0.376	0.031	0.472	0.245	0.040
Remarks	NS	Sig**	NS	NS	Sig**

followed by group - of No income (92.3%), group - of Rs. 1000 to Rs. 2500 (89.3%), group - of Rs. 2501 to Rs. 5000 (73.8%) and group - of Rs. 5000 to Rs. 10000 (42.9%). In TN it is maximum among group - of Less than Rs. 1000 (100%), group - of Rs. 1000 to Rs. 2500 (77.4%), group - of No Income (75%) and group - of Rs. 2501 to Rs. 5000 (73.3%). In AP it is maximum among group - of Rs. 5000 to Rs. 10000 (100%), followed by group - of Rs. 1000 to Rs. 2500 (71.7%), group - of Rs. 2501 to Rs. 5000 (54.3%) and group - of No income (50%). In UP it is maximum among group - of Rs. 5000 to Rs. 10000 (87.5%), followed by group - of Rs. 1000 to Rs. 2500 (87.1%), group - of No income (83.3%) and group - of Rs. 2501 to Rs. 5000 (78.3%) respectively. The differences between the Income in terms of proportion of those facing participation restrictions is statistically significant in the total sample as well as in the states of CG with  $P < 0.05$  and not significant in TN, AP, and UP.

**Prevalence of Participation Restriction and CSO Membership :** On the aggregate, proportion of those facing participation restrictions is more among CSO members (78.6%) than Champion (66.7%) (Table 8). Intra-state comparison of Membership shows that the proportion of those facing participation restrictions is comparatively more among CSO members than Champions in

the states of UP (85.4% against 72.7%), CG (81.4% against 66.7%) and AP (71.1% against 44.4%). And in TN, champions more than CSO members (80% against 73.6%) respectively. Statistically, the differences between the CSO members and Champions in terms of proportion of those facing participation restrictions were significant in the total sample as well as in the states of AP with  $P < 0.05$ . However, these differences but not significant in TN, CG and UP.

**Prevalence of Participation Restriction and Locality :** On aggregate, proportion of those facing participation restrictions is more in Community (78%) than Leprosy Colony (75.2%). However, the variation is not statistically significant (Table 9). Intra-state comparison of Locality shows that proportion of those facing participation restrictions is comparatively more among Community than Colony the states of AP (78% against 58.3%) and CG (83% against 78.7%). And in UP (91.7% against 76.9%) and TN (83.3% against 75%) for Colony more than Community. However, the differences between the Colony and community members in terms of proportion of those facing participation restrictions is Statistically significant in the states of AP and UP with  $P < 0.05$  and not significant in TN and CG as well as on aggregate.

**Table 9 : Participation Restriction and Locality**

Locality	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Colony	5 (83.3)	35 (58.3)	37 (78.7)	44 (91.7)	121 (75.2)
Community	54 (75)	32 (78)	44 (83)	40 (76.9)	170 (78)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square ( $X^2$ )	0.209	4.240	0.299	4.037	0.415
P Value	0.546	0.031	0.385	0.040	0.300
Remarks	NS	Sig**	NS	Sig**	NS



### Relationship between Prevalence of Participation Restriction and Religion

Intra-state comparison of Religion shows that the proportion of those facing participation restrictions is comparatively more among Hindus (Table 10) in CG (81.8%) and UP (86.6%). On aggregate, proportion of those facing participation restrictions is more in Hindus (78.1%) than other religion in order of Muslims (73.7%) and Christians (68.9%). Intra-state comparison of Religion shows that in TN the proportion of those facing participation restrictions is comparatively maximum among Muslims (100%), followed by

Hindus (76.4%), and Christians (60%). In AP, it is maximum among Christian (71.8%) and in Hindus (62.9%). In CG, it is maximum only among Hindus (81.8%). In UP it was found to be maximum among Hindus (86.6%) and Muslims (72.2%) respectively. However, the differences between the Religions in terms of proportion of those facing participation restrictions is not statistically significant in any of the four states as well as on the whole.

**Prevalence of Participation Restriction and Caste:** Relationship between prevalence of participation restriction and caste is summarized

**Table 10 : Participation Restriction and Religion**

Religion	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Hindu	55 (76.4)	39 (62.9)	81 (81.8)	71 (86.6)	246 (78.1)
Muslim	1 (100)	0	0	13 (72.2)	14 (73.7)
Christian	3 (60)	28 (71.8)	0	0	31 (68.9)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square (X <sup>2</sup> )	1.008	0.848	4.306	2.266	1.980
P Value	0.604	0.242	0.190	0.127	0.372
Remarks	NS	NS	NS	NS	NS

**Table 11 : Participation Restriction and Caste**

Religion	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
General/FC	0	1 (100)	3 (100)	7 (87.5)	11 (91.7)
OBC	3 (100)	1 (100)	57 (83.8)	32 (86.5)	93 (85.3)
BC	9 (52.9)	35 (60.3)	0	13 (65)	57 (60)
MBC	28 (75.7)	0	0	0	28 (75.7)
SC	18 (90)	29 (72.5)	11 (73.3)	27 (90)	85 (81)
ST	1 (100)	1 (100)	10 (71.4)	5 (100)	17 (81)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square (X <sup>2</sup> )	8.280	3.135	2.462	7.371	22.212
P Value	0.082	0.535	0.482	0.118	0.000
Remarks	NS	NS	NS	NS	Sig**

**Table 12 : Participation Restriction and WHO Disability Grades**

WHO Disability Grades	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
0	0	1 (50)	8 (50)	7 (58.3)	16 (53.3)
I	6 (60)	3 (50)	10 (71.4)	5 (62.5)	24 (63.2)
II	53 (77.9)	63 (67.7)	63 (90)	72 (90)	251 (80.7)
Total	59 (75.6)	67 (66.3)	81 (81)	84 (84)	291 (76.8)
Chi Square (X <sup>2</sup> )	1.523	1.038	14.508	10.776	15.897
P Value	0.196	0.595	0.001	0.005	0.000
Remarks	NS	NS	Sig**	Sig**	Sig**

**Table 13 : Significance of Factors identified in this study influencing participation in different states**

S.No.	Factors	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
1	Gender	Sig	Not sig	Sig	Not sig	Sig
2	Age	Sig	Not sig	Not sig	Sig	Sig
3	Marital Status	Not sig	Not sig	Not sig	Not sig	Not sig
4	Education	Sig	Sig	Sig	Sig	Sig
5	Occupation	Not sig	Sig	Sig	Sig	Sig
6	Income	Not sig	Not sig	Sig	Not sig	Sig
7	Membership	Not sig	Sig	Not sig	Not sig	Sig
8	Locality	Not sig	Sig	Not sig	Sig	Not sig
9	Religion	Not sig	Not sig	Not sig	Not sig	Not sig
10	Caste	Not sig	Not sig	Not sig	Not sig	Sig
11	WHO Disability Grades	Not sig	Not sig	Sig	Sig	Sig

in Table 11. On aggregate, proportion of those facing participation restrictions is more in General (91.7%) than other castes in the order of OBC (85.3%), SC (81%), ST (81%) MBC (75.7%) and BC (60%). Intra-state comparison of Caste in UP shows, proportion of those facing participation restrictions is comparatively maximum among ST (100%), followed by SC (90%), FC (87.5%), OBC (86.5%) and BC (65%). In CG, it is maximum re among FC (100%), OBC (83.8%), SC (73.3%) and ST (71.4%). In AP it is more among FC, OBC and ST

(100%), SC (72.5%) and BC (60.3%). In TN, it is more among ST and OBC (100%), SC (90%), MBC (75.7%) and BC (52.9%) respectively. However, the differences between the Caste in terms of proportion of those facing participation restrictions is statistically significant for the total samples  $P < 0.05$  but not significant within all the 4 states.

**Prevalence of Participation Restriction and WHO Disability Grades :** Cross tabulation of the relationship of level of participation restriction

with disability grades (WHO) in each state shows that proportion of those facing participation restrictions was more among those Grade II disability (80.7%), followed by Grade I (63.2%) and Grade 0 (53.3%) (Table 12). Intra-state comparison of WHO Disability grade also shows, participation restrictions are comparatively more among those with Grade II disability in all the four states viz. UP (90%), CG (90%), TN (77.9%) and AP (66.3%) than that of GI and G0. The differences between the WHO disability grades in terms of proportion of those facing participation restrictions were statistically significant in the total sample as well as in the states of CG and UP with  $P < 0.05$ , however, these were not significant in TN and AP.

### Discussion

Factors influencing or not influencing participation restriction are summarized in Table 13.

The sample is planned to cover four districts of both high and low prevalence from each state and from each district blocks from well-connected and interior rural areas. Almost all the available leprosy cases in the selected blocks participated in the study. As such the findings and inferences from the study can be generalized for the rural areas of each state. Findings may not be extrapolated to urban and tribal regions and all the leprosy colonies in a state.

The study brings out that the certain social factors have no influence on participation restrictions faced by the leprosy affected. Marital status showed no influence in any state as well as on aggregate, which can be positively explained that the areas of participation are wide in the community and presence of spouse hardly matters in any interaction outside the residence.

Similarly caste and religion also showed no influence, in all the four states which as a fact has to be nationally acceptable as the universe for

participation in a language state is same, wherever leprosy is a cause of stigma the participation level of an individual of any caste or religion may tend to be similar. Non-significance of religion on total may be attributed to national situation. Caste shows significance on total, may be due to the economic variations embedded in the caste categorization, which needs further in-depth research.

**Educational status** has been found to have influenced participation restrictions in all the four states included in this study. Similar findings have been reported by Ghimire (2002) in his study, he observed that if people are from a lower educational and economic status, they have more chances of developing secondary deformities. This change leads to the enhancement of the extreme participation restriction among the respondents.

### Variables showing influence in three states :

**Occupation** has influenced the participation restrictions in the 3 states of AP, CG and UP and also on total. According to De Castro et al (2014), the restrictions in the workplace represent one of the major problems related to participation suffered by patients with leprosy. In respect to social restriction, domains reported in ICF and contained in the Participation Scale work and economic contribution domains related to home were the most frequent problems with his outpatients. Non influence of occupation in TN may be due to uniformity in occupation and but needs further study over a larger area.

### Variables showing influence in 2 states :

**Gender** was observed to influence the participation restrictions in the two states of TN and CG and also the total sample. This is similar to the finding of a study earlier done in Chandigarh (Singh et al 2009) which revealed that males outnumbered females both in moderate and

severe participation restriction levels, though the differences is not significant. However this explains absence of gender variation, obviously a sign of development which needs to be more emphasized in the IEC activities of TN and CG also.

**Age** influenced the participation restrictions in two states of TN and UP and also the total sample, which explains age is a factor of consideration in participation of leprosy affected. Data shows more positive attitude towards working age group members. IEC activities need to analyse the conditions with the involvement of community and implement as per the needs of the area. The other two states with no significance explain absence of such disparity.

**Locality** influenced Participation restrictions in two states of AP and UP which explains in these states participation levels of those living in the colony significantly differs from those in the community, whereas in the other two states it is proved to be similar. No studies explained what is the positive sign of development among these conditions. As per other studies of TLM it is found that the younger generation prefers to leave colony life. The issues associated with each colony and region will be unique and a readymade solution does not work. Needs in depth action research with involvement of colony dwellers and community members.

**Disability (WHO) Grades** influenced Participation restrictions in the states of CG and UP and not in TN and AP. Similar finding were shown by Singh (2009) that the respondents with low SES and grade II deformity had to face extreme participation restriction. Also the studies of De Castro et al (2014) confirms the association of social participation (moderate/large/extreme) with physical disability and also the presence of physical disability (WHO grades 1 and 2) was associated with social participation. Studies from Nepal also demonstrated that physical disabilities

resulting in social problems (Senturk & Sagduy 2004, Stigter et al 2000).

**Variables showing influence in only one state :**

**Income** influenced the level of participation in only one state of CG and not in other states. This specific variation may be attributed to very few no of sample from lowest income from other states. We need to take income has to be a matter of concern in every state and several studies have shown income is essential to promote overall development. Methods of empowerment be designed as per the needs of beneficiaries through their involvement.

**Membership** influenced participation only in the state of AP, which explains the participation levels of the respondents of the two categories - CSO members and Champions varies significantly in the state of AP and not in other states. Champions - who are leprosy cured known to be the volunteers educating the community about leprosy are likely to have higher levels of participation than other CSO members do, which takes place in the states where Champions are working actively. Wherever the champions are not active there may not be significant variation. This finding explains only the phenomenon, but a possible option to enhance participation such as whether to empower the champions or the CSOs has to be decided after studying the local community.

**Conclusions :** From this study it can be concluded that participation restrictions are highly influenced by education and type of occupation in most of the states. The variables such as gender, age, locality and disability are moderately affecting the participation restrictions in some states. Income groups and Type of membership are less affecting the participation restrictions in some states. The variables such as marital status, religion and caste did not have significant

influence on participation restriction. No findings were found to be common in all the four states, which suggests the need for independent understanding of the needs of the each state. This analysis gives an insight about these states and subject to confirmation in a larger sample can help in planning of specific intervention.

### Acknowledgements

The authors are thankful for the European Union and TLM England and Wales for their funding of this study as a part of CREATE Project. We also thank the contributions of the project staffs from The Leprosy Mission Trust India staffs and Brighter Future trust staffs in Data collection. We also thank also the person affected by leprosy for their participation in our study.

### References

- Bainson KA, Van den Borne B (1998). Dimensions and process of stigmatization in leprosy. *Lepr Rev.* **69**: 341-350.
- Cakiner T, Yuksel A, Soydan M et al (1993). Women and leprosy in Turkey. *Indian J Lepr.* **65**: 59-67.
- De Castro LE, Da Cunha AJ, Fontana AP et al (2014). Physical disability and social participation in patients affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev.* **85**: 208-217.
- Frist T (1996). Don't treat me like I had leprosy: A guide to overcoming prejudice and segregation (book). *TALMILEP* London.
- Frist T, Mutatkar R (1998). Report of workshop on social and economic integration. *Int J Lepr Other Mycobact Dis.* **66**: 580-581.
- Garbin CA, Garbin AJ, Carloni ME et al (2015). The stigma and prejudice of leprosy: influence on the human condition. *Rev Soc Bras Med Trop.* **48**: 194-201.
- Ghimire M (2002). Secondary deformity in leprosy: a socio-economic perspective. *Asia Pacific Disab Rehab J.* **13**: 33-38.
- ICF (2001). The international classification of functioning, disability and health. World Health Organization, Geneva. <http://apps.who.int/iris/bitstream/10665/42407/1/9241545429.pdf>.
- Jopling WH (1991). Leprosy stigma. *Lepr Rev.* **62**: 1-12.
- Kaehler N, Adhikari B, Raut S, Marahatta SB et al (2015). Perceived Stigma towards Leprosy among Community Members Living Close to Nonsomboon Leprosy Colony in Thailand. *PLoS.* **10(6)**: e0129086.
- Kopparty SN (1995). Problems, acceptance and social inequality: a study of the deformed leprosy patients and their families. *Lepr Rev.* **66**: 239-249.
- Lusli M, Zweekhorst MB, Miranda-Galarza B et al (2015). Dealing with stigma: experiences of persons affected by disabilities and leprosy. *Biomed Res Int.* 2015: 261329.
- Nicholls PG, Bakirtziev Z, Van Brakel WH et al (2005). Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk: *Lepr Rev.* **76**: 305-315.
- Raju MS, Rao PSS, Mutatkar RK (2008). A study on community based approaches to reduce leprosy stigma in India. *Indian J Lepr.* **80**: 267-273.
- Raju MS, Reddy JV (1995). Community attitude to divorce in leprosy. *Indian J Lepr.* **67**: 389-403.
- Rao PSS, Raju MS, Barkataki A et al (2008). Extent and correlates of leprosy stigma in rural India. *Indian J Lepr.* **80**: 167-174.
- Singh S, Sinha AK, Banerjee BG et al (2009). Participation level of the leprosy patients in society. *Indian J Lepr.* **81**: 181-187.
- Senturk V, Sagduyu A (2004). Psychiatric disorders and disability among leprosy patients; a review. *Turk Psikiyatri Derg.* **15**: 236-243.
- Shale MJ (2000). Women with leprosy. A woman with leprosy is in double jeopardy. *Lepr Rev.* **71**: 5-17.
- Stigter DH, Geus L, Heynders ML (2000). Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev.* **71**: 492-498.
- Susman J (1994). Disability, stigma and deviance. *Social Sci Med.* **38**: 15-22.

22. Ulrich M, Zulueta AM, Caceres-Dittmar G et al (1993). Leprosy in women: characteristics and repercussions. *Social Sci Med.* **37**: 445-456.
23. Van Brakel WH, Gopal PK (1999). Portraying a positive image of persons (previously) affected by leprosy. *Int J Lepr Other Mycobact Dis.* **67**: 477-479.
24. Van Brakel WH, Anderson AM, Mutatkar RK et al (2006). The participation scale: measuring a key concept in public health. *Disabil Rehabil.* **28(4)**: 193-203.

**How to cite this article :** David MM, Raju MS and Mendis T (2019). Factors Influencing Participation Restrictions among Persons Affected by Leprosy. *Indian J Lepr.* **91**: 91-104.