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Factors associated with social participation of women affected with leprosy reporting at a referral centre in Chhattisgarh, India

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Summary

Objective: To assess the level of social participation and to study the factors associated with the social participation of leprosy-affected women after release from multi-drug therapy.

Methods: A descriptive, cross-sectional study was undertaken involving a consecutive sample of women cured of leprosy, aged between 18 and 72 years, recruited at Bethesda Leprosy Mission Hospital, Champa. Their level of social participation was measured using the Participation scale (P Scale).

Results: Of the 113 participants, 85 (75%) women showed no restriction in social participation while 28 (25%) women did have some restriction. There were statistically significant associations between social participation restriction and age, disease type, and disability grade, and also in relation to the knowledge or lack of knowledge about the diagnosis of leprosy amongst neighbours and community members.

Conclusion: This study observed that elderly women, those who have the multibacillary form of the disease and Grade 2 deformities faced more restriction as regards social participation. A higher level of participation restriction was found among participants whose neighbours and community members knew of their disease condition. A special effort is needed to reach poor and marginalized leprosy-affected women and it will require the promotion of women's empowerment to improve their level of social participation.

Keywords: Social Participation, Participation Scale, Leprosy, Stigma, Women

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Introduction

Leprosy is still a stigmatised disease and a public health concern mainly because of its potential to cause disability in a proportion of those affected. It is therefore a cause for social stigma and discrimination.[1] Leprosy results not only in physical problems, but also has mental, social and economic consequences.[2] In women, these problems are exaggerated by the gender disadvantage that prevails in many countries.[3,4] In India, nearly 35% of new leprosy cases are women.[5] In Chhattisgarh the leprosy prevalence rate is 2·14 per 10,000 population as at March, 2015, and among these 36·8% were female.[5] Janjgir-Champa district in Chhattisgarh, has a large number of new leprosy cases registered every year and had a high prevalence rate (PR) of 3·68 per 10,000, in March, 2015.[5]

Today, leprosy is curable with multidrug therapy (MDT) and those affected are free from leprosy once they have completed the course; unfortunately the stigma attached to leprosy still persists due to visible deformities and this leads to various restrictions in social participation. Stigma is a reality in the lives of people affected by leprosy and upsets their physical, psychological, social and economic well-being.[2,6] People affected by leprosy are often ostracized, have difficulties accessing community resources, and are more likely to experience exclusion from social events such as festivals, community gatherings, education and employment. The stigma and discrimination extends to family members as well. As a result, people affected by leprosy often experience a loss of self-esteem and dignity, and feel fear, shame, hopelessness and guilt. Studies have shown that these effects are greater in female than male patients.[7,8]

The Bethesda Leprosy Mission Hospital one of the referral centres providing services for leprosy in Janjgir-Champa district in Chhattisgarh, India. The hospital provides multi-drug therapy for leprosy, management of reactions and neuritis and management of deformities and disabilities. In addition, they provide related services for people of the community who are not affected by leprosy. These related services include care for skin diseases, physical disability, general medicine and surgery. In the year from January to December 2015, 97 patients completed the multi-drug therapy (MDT) and were released from treatment (RFT), among them 29 (30%) were adult females. There were 1888 patients who visited the hospital for their complaints after RFT, and of these 548 were female.

Hence this study aimed to assess the level of social participation and to study the factors associated with social participation in women reporting to Bethesda Leprosy Mission Hospital, Champa after being released from multi-drug therapy.

Methods

A cross-sectional study was conducted of women attending the hospital outpatient department from March to June 2016.

STUDY SETTING

The study took place in Bethesda Leprosy Mission Hospital which is located in Champa, district of Janjgir-Champa district in the state of Chhattisgarh in central India. Janjgir-Champa district district is endemic for leprosy.[5]

PARTICIPANT ELIGIBILITY AND SAMPLE

A consecutive sample of 113 women aged above 18 years and who had completed MDT (Released from treatment (RFT)) was recruited for this study.

SEMI-STRUCTURED QUESTIONNAIRE

A semi-structured questionnaire was used to collect the demographic and clinical profile of the participants. The demographic data included age, education, marital status, occupation and family monthly income. The clinical profile included classification of leprosy, bacterial index at time of diagnosis, deformity grade, time since treatment completion and reason for visit to the hospital.

PARTICIPATION SCALE (P SCALE)

The Participation Scale is reliable and validated to measure client-perceived participation in people affected by leprosy or disability; the items focus on participation levels in family and community. An 18-item instrument was developed in seven languages including Hindi (Indian language) with scores that ranged from 0 to 90 points, People with scores of from 0 to 12 were considered not restricted in social participation, scores from 13 to 22 had slight restrictions, scores from 23 to 32 moderate restrictions, scores from 33 to 52, serious restrictions and scores from 53 to 90, severe restrictions.[9]

RELIABILITY

In this study, the Hindi version of the P-Scale was tested and the internal consistency and reliability were determined. The Cronbach's alpha score was 0·915. Corrected item-total correlation ranged from 0·145 to 0·800, with 16/18 items falling at or above 0·40. Cronbach's alpha scores for the scale with each individual item deleted ranged from 0·904 to 0·919. The Hindi version of P-scale has been shown to have very good internal consistency and reliability

PROCEDURE

A physiotherapist trained in interview techniques recruited participants and conducted the interviews in a private setting. The interview consisted of gathering information about present demographic and disease disclosure status and documented clinical details, followed by the administration of the Participation scale. Throughout the interview we ensured privacy and allowed participants to answer all questions at their own pace, in a sequential manner; any remarks were noted during the assessment process. The Interviewer paid special attention and listened with patience to bring out vital information among women participants.

Permission was obtained from the superintendent of Bethesda Leprosy Mission Hospital to conduct the study. Each individual woman included in this study was informed about the purpose of the study and confidentiality was promised and ensured. Informed oral consent was obtained from all the participants after explaining the study.

DATA ANALYSIS

Data were entered into an Excel sheet and transferred to SPSS for analysis. A descriptive analysis, Pearson's chi-square and Spearman Rank correlation were performed to compare the participation restriction with demographic factors and the disease profile of the participant. Reliability analysis was performed for the *p* scale.

Results

Of the 113 participants, 85 (75%) women showed no social participation restriction, while 28 (25%) women had some restriction [mild restriction; 17 (15%), moderate restriction; six (5%), severe restriction; four (4%) and extreme restriction; one (1%)] (Figure 1). Of the 28 women with restriction in social participation, 26 were married, 15 had Grade 2 disabilities, and 17 were illiterate.

DEMOGRAPHIC PROFILE

A total of 113 subjects with ages ranging from 18 to 72 years were interviewed, out of which the majority of them 94 (83·2%) were married, 53 (46·9%) were illiterate and 56 (49·5%) were housewives. Most of the participants' (79·6%) family monthly income was below 5000 rupees in Indian money (Table 1). Fifty-nine (52%) were coming for their routine follow-up examination, 26 (23%) were coming for leprosy complaints and 28 (25%) for non-leprosy complaints.

RELATIONSHIP BETWEEN SOCIAL PARTICIPATION AND DEMOGRAPHIC FACTORS

The results indicate there was a significant association between restricted social participation and increasing age (*p*-0·000) (Table 1). There is a significant positive correlation between

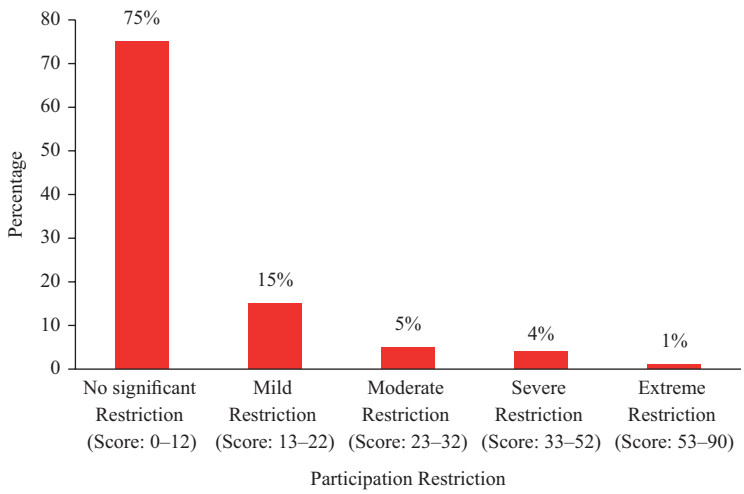

Figure 1. Results of Participation Scale ($n = 113$).

Table 1. Relationship between social participation and demographic factors (age, marital status, occupation, income and education)

		No Restriction $n = 85$		Restriction $n = 28$		Total $n = 113$		
Variables	Status	No	%	No	%	No	%	*p*-value
Age	18–30	44	86·3	7	13·7	51	45·1	0·000*
	31–45	23	74·2	8	25·8	31	27·4	
	46–60	18	69·2	8	30·8	26	23	
	Above 60	0	0	5	100	5	4·4	
Marital status	Married	68	72·3	26	27·7	94	83·2	0·115
	Single	17	89·5	2	10·5	19	16·8	
Education	Primary	10	83·3	2	16·7	12	10·6	0·337
	Secondary	25	78·1	7	21·9	32	28·3	
	Higher Secondary & above	14	87·5	2	12·5	16	14·2	
	Illiterate	36	67·9	17	32·1	53	46·9	
Occupation	Farmer	14	66·7	7	33·3	21	18·6	0·645
	House wife	41	73·2	15	26·8	56	49·5	
	Labor	11	91·7	3	21·4	14	12·4	
	Skilled Labor	6	85·7	1	14·3	7	6·2	
	Student	13	86·7	2	13·3	15	13·3	
Family Income per month	Up to 5000	67	74·4	23	25·6	90	79·6	0·595
	5001–10000	10	71·4	4	28·6	14	12·4	
	10000–15000	8	88·9	1	11·1	9	8	

participant age and total *p* scale score ($r = 0{\cdot}407$, *p*-0·000). There was no significant association between social participation and marital status, education, occupation and family income per month (Table 1).

DISEASE PROFILE

Of the 113 participants the majority of them 87 (77%) were multibacillary (MB); 40 were lepromatous (BL & LL), and 46 (40·7%) had a positive bacterial index (BI) at diagnosis. Sixteen (14·2%) participants had an EHF score above three, 30 (26·5%) participants had disability Grade I disability and 22 (19·5%) had Grade 2 disability. Fifty-eight (42·5%) women completed their MDT treatment within 2 years (Table 2).

RELATIONSHIP BETWEEN SOCIAL PARTICIPATION AND DISEASE FACTORS

There was a significant association between restricted social participation and MB vs PB disease (*p*-0·000) and increasing disability (as shown by Disability Grades '0', '1' and '2' and EHF scores '0', '1', '2' and 'above 3'). There was positive correlation seen between disability grade and total *p* scale score ($r = 0{\cdot}501$, *p*-0·000) and EHF score and total *p* scale score ($r = 0{\cdot}493$, *p*-0·000). There was no association between social participation and time since treatment completion (Table 2).

DISCLOSURE OF DISEASE AND HEALTHY CONTACT STATUS

Between the 113 participants, 103 (91·2%) other family members, 41 (36·3%) neighbours and 21 (18·6%) community members knew that the participant had leprosy (Table 3).

Table 2. Relationship between social participation and clinical profile (WHO disease type, disability grade, EHF score and time since RFT)

		No Restriction $n = 85$		Restriction $n = 28$		Total $n = 113$		
Disease Status	Status	No	%	No	%	No	%	*p*-value
Type	Multibacillary (MB)	59	67·8	28	32·2	87	77	0·000
	Paucibacillary (PB)	26	100	0	0	26	23	
WHO	0	53	86·9	8	13·1	61	54	0·000
	1	25	83·3	5	16·7	30	26·5	
	2	7	31·8	15	68·2	22	19·5	
EHF	0	53	86·9	8	13·1	61	54	0·000
	1	15	88·2	2	11·8	17	15	
	2	12	63·2	7	36·8	19	16·8	
	Above 3	5	31·3	11	68·8	16	14·2	
RFT	0–2 yrs	48	73·8	17	26·2	65	57·5	0·687
	3–4 yrs	25	80·6	6	19·4	31	27·4	
	Above 4 yrs	12	70·6	5	29·4	17	15·1	

RELATIONSHIP BETWEEN SOCIAL PARTICIPATION AND DISEASE DISCLOSURE

There was a significant association between restricted social participation and disclosure of the disease to neighbours (p-0·002) and community members (p-0·007). However, there was no association between social participation and such knowledge amongst family members (p-0·257) (Table 3).

Discussion

In Asia and Africa, the diagnosis of leprosy is generally less frequent in women than men. The cultural reasons behind the lower diagnosis rate may put women with leprosy at greater risk of developing permanent disability.[10] The status of women in India has been subject to many great changes over the past few millennia. However, women with leprosy have problems in common with other women as well as those related to the physical and social consequences of leprosy. A recent study from Nepal, found that many women faced violence

Table 3. Relationship between social participation and disease disclosure status with family, neighbour and community

		No Restriction		Restriction		Total $n = 113$		
Disease Status	Disclosure	No	%	No	%	No	%	*p*-value
Family	Known	76	73·8	27	26·2	103	91·2	0·257
	Unknown	9	90	1	10	10	8·8	
Neighbour	Known	24	58·5	17	41·5	41	36·3	0·002
	Unknown	61	84·7	11	15·3	72	63·7	
Community	Known	11	52·4	10	47·6	21	18·6	0·007
	Unknown	74	80·4	18	19·6	92	81·4	

and abuse in their marriages. Leprosy-affected women appeared to face more problems with regard to their marital and sexual relationships than women with other physical disabilities and able-bodied women.[11]

In this study, 19·5% had Grade 2 deformity and 24·4% women had social participation restrictions after being released from multidrug therapy. A study from Brazil conducted by Castro *et al.* (2014), found that 57% women had social participation restrictions after the discontinuation of multidrug therapy.[12] A study from Indonesia observed among women that 55% had mild/moderate social participation restriction and 9% had severe social participation restriction.[13] A similar study from Brazil conducted by Nardi *et al.* (2011), revealed that among women participants, 28% had mild/moderate social participation restriction, 11% had severe/extreme social participation restriction after discontinuation of multidrug therapy.[14]

Leprosy-affected people with Grade 2 disability had more risks of social participation restriction especially women with leprosy disabilities. In this study, 68% had social participation restriction among those with Grade 2 disability. A similar study also observed women with Grade 2 deformity had a high level of social participation restriction.[12–14] Schuller *et al.* (2010) noticed that women with disabilities caused by non-leprosy reasons were treated better by the community than women with disabilities caused by leprosy, and women with leprosy faced many more problems in their daily life especially due to stigma. Women with disabilities are more at risk for restrictions in social participation because of the existence of stigma, more so for women with leprosy disabilities. Disabilities and stigma resulted in lower education, income and marriage prospects for all women and they also suffered from self-stigma.[15]

Women have more risk of social participation restriction if they have an increasing EHF score due to worsening impairment and its progress to deformity, as observed in this study. A similar study found that 52% of leprosy-affected women with EHF scores from 0–4 had mild/moderate restriction in social participation and 69% of leprosy-affected women with EHF score 5 and above had severe/extreme restriction in social participation restriction.[14] Multibacillary disease is a known risk factor for impairment,[16] and it leads to restriction in social participation. In this study, 32% of women with multibacillary disease had social participation restriction.

In this study, 12% of women were diagnosed as pure neuritic leprosy (PNL), and of these 43% had deformity at the time of interview. Mahajan *et al.* (1995), observed 4·6% of pure neuritic leprosy in their study, of these 47% had deformities at the time of initial presentation.[17] A similar study also observed 4·2% pure neuritic leprosy in their study, of whom 38% had deformities at the time of initial presentation.[18] Nearly half of the women had a positive bacterial index (BI), 35% had the lepromatous form of disease and 11% had a bacterial index (BI) above four at the time of diagnosis. Half of the participants had been released from treatment more than 2 years previously at the time of interview. However there was no association between social participation restriction and time since RFT.

Stigma may aggravate existing inequalities due to age, gender and social class.[19] In this study we observed a significant association between social participation restriction and increasing age. A positive correlation seen between age and social participation restriction revealed that there was more risk of social participation restriction for elderly women. Leprosy predominantly affects poor and marginalized people,[20] and it was observed in this study that 80% of participants had a family monthly income of below five-thousand Indian rupees. Among the study participants, 17% had leprosy contacts, of whom 68% were MB form of disease and it shows the persisting transmission of leprosy.

There was no apparent social participation restriction within the family, even though most of the participants' families knew of the diagnosis (91%). On the other hand, social participation restriction was observed when neighbours and community members knew of their disease.

The World Health Organization (2011) has suggested strategies to strengthen the participation of women affected by leprosy in leprosy service provision; these include developing support groups; working in partnership to advocate for equal rights and opportunities for men and women; promoting the participation of women in decision-making processes; and promoting the participation of women in the delivery of services.[21] The National Leprosy Eradication Programme (NLEP) India, proposes to reduce stigma in leprosy mainly through information, education and communication (IEC) activities and spreading awareness. IEC activities aim to reduce stigma towards women affected by leprosy by empowering them to seek treatment and motivate them for self-reporting. Women health workers/volunteers were employed for awareness campaigns in villages to reduce stigma.[22] Moreover, special efforts will have to continue to reach poor and marginalised leprosy-affected people especially leprosy-affected women.

Conclusion

The study reveals the presence of social participation restriction in 25% women affected by leprosy after completion of their MDT. Further, we observed that women who had the multibacillary form of the disease and Grade 2 deformities were more at risk of social participation restriction. Increasing age also correlated with restriction of social participation. A higher level of participation restriction was present among those women whose neighbours and community members knew of their disease condition. The stigma of leprosy continues to be one of its most persistent and damaging features and it can be prevented by voluntary early reporting and effective treatment before disability occurs. The National Leprosy Eradication Programme, India is continuously working on the reduction of stigma and discrimination against people affected by leprosy. However, these special efforts will have to continue to reach poor and marginalised leprosy-affected women and require promotion of women's empowerment.

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Contribution of each author

Mr. Senthilkumar was involved in study conceptualization and design, obtaining permission for the study, conducting the interviews, data management and manuscript writing.
Mr. Pitchaimani Govindharaj, was involved in study design, data analysis and interpretation, and in drafting the manuscript.

Mrs. Suganya Panneerselvam, was involved in organizing the data and commenting on the manuscript.
Dr. Archana Kumar, was involved in monitoring the study and commenting on the manuscript.

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