

A field study of counselling for improving social participation of leprosy affected persons in Jammu and Kashmir

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Summary

Background People affected with leprosy are severely stigmatised, restricting their participation at home, in communities, and at the workplace. It further aggravates their stigma levels as participation restriction causes emotional harm, economic disadvantages, and social ostracism, in addition to hampering treatment.

Objectives To measure the correlation of various sociodemographic factors influencing participation restriction of leprosy-affected persons and the impact of interventions through counselling for preventing social exclusion.

Design A cross-sectional pre- and post-counselling survey about social participation of leprosy-affected persons.

Methods The *P*-scale was used to measure the participation restriction of 120 leprosy-affected persons, living in former leprosy colonies. Group counselling sessions were conducted to improve social participation. Various statistical tools were used to analyse the *P*-scale scores.

Results Every leprosy-affected person reported some level of participation restriction; severe to extreme participation restriction was found in most, with a few having mild or moderate restriction. The demographic profiles of leprosy-affected persons influence the severity of the participation restriction. Participation restriction in females is higher than in males; those over 40 years of age face more restrictions than those who are younger; disabled and unemployed persons reported higher participation restriction than those who are part-time employees or homemakers, and the unmarried reported higher restrictions than those who are married. Counselling resulted in notable improvements in social participation.

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Conclusion Counselling not only has an overall positive impact on social participation but its impact was highly influenced by demographic variables, particularly amongst those who are disabled or unemployed.

Keywords: Leprosy, stigma, social exclusion, participation restriction, discrimination

Introduction

After the introduction of Multi-Drug Therapy (MDT) and the launch of a five year 'Global Leprosy Strategy 2016–2020' by WHO, a significant reduction in the number of new leprosy cases and complications in the prevalent cases has been observed. Indian society has treated leprosy unusually with respect to custom and law, a response shaped by both scientific knowledge and cultural attitudes. India, with the support of various international organisations like WHO and ILEP, has shown tremendous progress towards controlling leprosy. However, the problem persists and the decline in new case detection rates, as well as prevalence, has only changed marginally over the last two decades.

In Jammu and Kashmir, the northern part of India, leprosy has laid down its footprint since historical times. Although facilities such as dedicated leprosy hospitals/colonies and the provision of free rations to leprosy affected persons have been operational in the area, minimal efforts have been made to address secondary psychosocial disabilities because of the chronic nature of the disease and the unsightly disfigurement, which results in prejudice, stigmatisation and social exclusion of those affected. Stigmatisation, depression, anxiety and social exclusion contribute to increased or sustained chronic debility in leprosy patients. Exact figures for new and prevalent cases of leprosy in the area are conflicting; however, a survey conducted by the current authors estimates a number over 700.

PARTICIPATION RESTRICTION

Historically, patients affected with leprosy are severely stigmatised, restricting their participation at home, in communities, and at the workplace. This further aggravates their stigma levels as participation restriction causes emotional harm, economic disadvantages, and social ostracism, in addition to hampering treatment.^{1,2} Stigma refers to a personal attribute which make patients different from the average person, generating negative social attitudes, i.e. exclusion from 'normal' society.^{3–5} Weiss *et al.*⁶ have defined stigma as a social process characterised by exclusion, blame, devaluation or rejection, resulting from experience, perception or anticipation by patients. A person affected by a stigmatised disease may experience discrimination or social exclusion.^{7,8} Patients stigmatised because of their health condition develop negative attitudes, may feel guilty or ashamed and may withdraw themselves from social participation.⁷ This causes a high social and psychological burden in terms of social exclusion among others.⁹ Schuster *et al.*¹⁰ have also reported a reduction of self-esteem, problems at the workplace or school and social exclusion as the consequences of stigma due to disease.

A study conducted by Slim *et al.*¹¹ on 84 leprosy-affected people in the Netherlands concluded that almost a third suffered from participation restriction particularly at home, and outdoors due to activity limitations and hand impairments. The same study also observed that participation restriction was reported at work/education as well, and the primary factor for participation restriction was activity limitation. A study conducted by van Brakel *et al.*¹² in Indonesia between 2008 and 2009 involving 1358 leprosy patients and 931 community

members found that around 60 patients reported activity limitation and participation restriction due to stigma or shame. A study by Lusli *et al.*¹³ concluded that stigma has a substantial impact on the emotions, thoughts, behaviour and relationships of leprosy patients, leading to social exclusion and rejection. Studies by many researchers have found that social rejection and exclusion are the two essential factors associated with stigma.^{14–16} Many other studies^{12,17–22} have also concluded that stigma associated with disease has a strong negative impact on social participation, with some also reporting influence by the impairment status. Asampong *et al.*²³ reported prejudicial practices towards family members of leprosy affected patients, causing them to change their daily routines, including limiting their social interactions. Advancement from social participation has many adverse implications including economic disadvantages,^{17,18,24} possible refusal in schools,²⁵ participation restriction in religious activities,¹⁸ and suicidal thoughts.^{26–28}

INTERVENTION THROUGH COUNSELLING

Reduced social participation and social exclusion have been associated with stigma exhibited towards leprosy patients; therefore, reducing stigma can improve their social participation. Various strategies such as treatment, counselling, cognitive-behaviour theory, empowerment, group counselling, self-help, advocacy and support groups can be undertaken at an intrapersonal level to reduce stigma. Strategies such as care and support, home care teams and community-based rehabilitation can be taken up at an interpersonal level. At the community level, education, contact, advocacy and protest can be used. Similarly, at organisational or institutional level, training programmes and patient-centered policies can be developed. Rights-based approaches, and legal and policy interventions can be taken up to reduce stigma. Interventions through counselling have proved to be a useful adjunct to medical treatment in palliative leprosy care and in preventing social exclusion. Reducing stigma through disease management of leprosy patients has a positive effect^{19,29,30} while internalised, anticipated and experienced stigma can be reduced substantially through counselling; community stigma can be reduced by interventions through health education and contact with the community.

Dadun *et al.*,³¹ in a study using three promising intervention techniques^{19,32,33} namely ‘counselling’, ‘socio-economic development’ and ‘contact’, concluded that a significant reduction in stigma was attained in leprosy patients by counselling and socio-economic development, leading to improved social participation. Interventions through contact such as education, testimonies, comics and participatory videos improved leprosy-related public stigma. As with other NTDs, rehabilitation, counselling and support groups are effective measures to substantially reduce stigma towards leprosy patients, thereby improving social participation. This has been shown through various studies, including studies by Heijnders,³⁴ Cross and Choudhary²⁹, and Ebenso *et al.*¹⁹ Personal support offered by self-care groups^{29,30,34} counselling³⁴ and socio-economic rehabilitation¹⁹ has been found instrumental in increasing social participation of leprosy patients. Providing personal support to leprosy patients in terms of disease rehabilitation,⁹ empowerment,³⁵ advocacy and counselling⁷ help to reduce stigma and improve social participation. A study¹¹ conducted in the Netherlands, while finding that a large percentage of leprosy patients experience participation restrictions, suggested that multidisciplinary rehabilitation improved their social participation. van Brakel *et al.*³⁶ proposed counselling and advocacy in the community to limit social discrimination of women within marital relationships. Dako-Gyeke,³⁷ while advocating the provision of financial assistance to leprosy-affected people to improve their economic situation, also suggested psychosocial counselling and education about leprosy through campaigns, to improve social

participation. Many other studies have reported the reduction of stigma and improved social participation through counselling^{22,38} and socio-economic rehabilitation^{39,40} through self-help groups. Several studies^{41–43} besides proposing psycho-social care and support in generating alternative income, have strongly advocated personal counselling for reducing stigma and improving social participation. Also, a multi-agency, multi-level and multi-strategy approach has been suggested by many studies.^{44,45}

HYPOTHESIS

Counselling can be beneficial for improving the social participation of people affected by leprosy in their current situation, although demographic factors may influence its effectiveness.

Materials and methods

SAMPLE

As many as 120 leprosy patients resident in various leprosy-related institutions in various districts of Jammu and Kashmir were interviewed from December 2018 to February 2019 and their responses recorded. They were counselled in March and April 2019 aiming to increase their social participation and interviewed again from June 2019 to July 2019. Various inclusion and exclusion criterion has been adopted in the selection of leprosy patients for the study, and 20 were excluded from the study. The inclusion criteria were as follows: (1) physical fitness of the leprosy patient to understand and answer the questions; (2) males and females aged 15–65 years; and (3) reliable information about the case.

Exclusion criteria included the following: (1) severe disability; (2) patients having ailments other than leprosy that could affect their social participation; and (3) refusal by the patient or relatives. All those who participated until the end of the study were living in former leprosy colonies.

PROCEDURES

The study used quantitative methods to access the extent of participation restriction among leprosy-affected people and the role of counselling to improve their social participation. Leprosy patients were interviewed without external interference in a private environment. For correctness and accuracy, forward and backward translation of the *P*-scale instrument was done by language experts mastering both English and the local languages. Validation of instruments through field testing, selection of patients for interview and self-training, the building of relationships and trust with the patients and ethical considerations were given due consideration.

Five sessions of group counselling with a group size of 20 leprosy-affected persons were conducted by a counsellor, a psychologist and two peer-counsellors chosen from previous counselling groups. Pre-counselling participation scores were analysed to find the most optimum areas for special attention.

Accordingly, counselling was provided to help identify opportunities for work within and outside the home, to improve social participation by visiting places of worship, and to participate in social gatherings within and outside the community. Adequate counselling material, such as accurate information about the disease, success stories of leprosy-affected persons worldwide, lists of associations with their achievements, and schemes being implemented by international and national organisations towards helping leprosy-affected persons, was assembled before counselling.

Participants were counselled about the disease and were provided with a correct understanding of the disease, including messages such as: leprosy is curable; disability can be managed with appropriate support systems; deformities can be treated with surgery; leprosy cannot easily infect others; and leprosy cannot infect cured patients again. Counselling included informing leprosy-affected persons that leprosy has affected people worldwide, and after medication, many among them have entirely recovered. Various success stories of cured and disabled leprosy-affected persons who, despite their disease, contribute towards the development of their community and society were used to motivate them. Patients were encouraged to talk about the disease with others openly and discuss their life stories without fear. They were counselled that it would be better to join social gatherings rather than staying at home, and by participating in activities and taking initiative.

Counselling also targeted various areas of stigma to improve positive thinking in the various domains of emotions, thoughts, behaviour and relationships. Many issues were targeted in the counselling sessions, including:

- feelings such as fear, depression, shame, grief, anxiety, guilt, low self-esteem, hopelessness and anger;
- the inability to express such feelings;
- the impact of negative and pessimistic thoughts and beliefs about self, and future behaviour;
- the impact of lack of confidence, avoidance, self-isolation and hiding;
- elements in the domain of relationships such as rejection, separation and withdrawal.

Counsellors explained the power and strength of associations in the development of community and society at large. Counsellors encouraged participants to become independent and contribute toward income generation in the family by starting a small business, which can help them earn more respect in society. In the counselling sessions, they were provided with information about various assistance schemes offered for leprosy-affected people. Further, awareness of wrong assumptions about the disease was highlighted by facilitating interactions with non-leprosy patients.

MEASURES

Sociodemographic data of leprosy patients were recorded using a self-reported questionnaire, which included information about age, gender, education, occupation, and marital status. The internationally validated and standardised instrument, the *P*-scale was used to measure stigma (Table 1).⁴⁶ The internal consistency of the instrument as measured with Cronbach's alpha for *P*-scale, remained 0.90. The *P*-scale is a semi-structured questionnaire to measure the extent to which people are restricted in social participation, suitable to be administered by non-professional interviewers.^{19,29,47} It takes the interviewee through 18 questions enquiring about different social activities carried out by an average person, including economic contributions, participation in social events, relationships, public places and work. It provides a quantitative measure of the severity of participation restriction. A high sum score indicates a high level of participation restriction. Generally, a score from 0–12 indicates no significant restriction; a score from 13–22 indicates mild restriction; a score from 23–32 indicates moderate restriction; a score from 33–52 indicates severe restriction and extreme restriction is indicated by a score from 53–90.

Table 1. Detailed items of the *P*-scale

1.	Do you have equal opportunity as your peers to find work?
2.	Do you work as hard as your peers do? (same hours, type of work etc.)
3.	Do you contribute to the household economically in a similar way to your peers?
4.	Do you make visits outside your village/neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets
5.	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)
6.	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)
7.	Are you as socially active as your peers are? (e.g. in religious/community affairs)
8.	Do you have the same respect in the community as your peers?
9.	Do you have the opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?
10.	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?
11.	Do you visit other people in the community as often as other people do?
12.	Do you move around inside and outside the house and around the village/neighbourhood just as other people do?
13.	In your village/neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops)
14.	In your home, do you do household work?
15.	In family discussions, does your opinion count?
16.	Do you help other people (e.g. neighbours, friends or relatives)?
17.	Are you comfortable meeting new people?
18.	Do you feel confident to try to learn new things?

STATISTICAL ANALYSIS

SPSS software package was used for data analysis, the distribution examined with Kolmogorov–Smirnov test and summarised as means and standard deviations for continuous variables with normal distribution. Pairwise comparisons were made with respect to various sociodemographic parameters using t-tests, one-way ANOVA and Cohens-D to analyse the *P*-scale scores. To examine the correlation between participation scores obtained from *P*-scale and sociodemographic parameters, Pearson's correlation analysis and point biserial correlation was used. Further, regression analysis was performed to discover the extent to which each factor was associated with the level of participation restriction.

Results

A total of 185 leprosy patients living in different districts of Jammu and Kashmir were identified and contacted for this study. These were patients residing in leprosy colonies at Srinagar and Jammu, leprosy hospitals in various districts and patients residing at their native homes. As many as 65 patients, including all those living in their own homes, could not complete the study (both pre- and post-counselling) due to factors including insufficient patience to be interviewed, unwillingness to cooperate or their unavailability for the counselling and incomplete post-counselling interview.

Table 2 shows grades of participation restriction among leprosy patients before and after counselling, in relation to various demographic details. As can be observed from the results, out of 120 patients, 43, 61, 15, and 1 patient respectively reported extreme, severe, moderate and mild participation restriction. After counselling, the numbers were 10, 63, 32, and 11, respectively. Extreme restrictions experienced by 33 patients were reduced to lower levels.

Table 2. Grades of participation restriction pre and post counselling

n	(%)	Grades of participation restriction														
		No significant restriction (0-12)			Mild restriction (13-22)			Moderate restriction (23-32)			Severe restriction (33-52)			Extreme restriction (53-90)		
		Pre ^a	Post ^b	%	Pre ^a	Post ^b	%	Pre ^a	Post ^b	%	Pre ^a	Post ^b	%	Pre ^a	Post ^b	%
71	59.17%	0	4	1	9	13	17	35	41	22	0					
49	41.93%	0	0	0	2	2	15	26	22	21	10					
27	22.50%	0	0	0	6	7	10	17	10	3	1					
93	77.50%	0	4	1	6	8	22	44	53	40	9					
60	50.00%	0	4	1	4	7	13	32	36	20	3					
60	50.00%	0	0	0	7	8	19	29	27	23	7					
27	22.50%	0	4	1	11	14	27	48	45	27	5					
93	77.50%	0	0	0	2	1	3	11	16	12	3					
3	2.50%	0	0	0	0	0	2	1	0	2	1					
3	2.50%	0	0	0	0	0	0	1	2	2	1					
32	26.67%	0	4	1	9	13	13	16	5	2	1					
27	22.50%	0	0	0	2	2	14	23	11	2	0					
36	30.00%	0	0	0	0	0	4	13	24	23	8					
25	20.83%	0	0	0	0	0	1	9	23	16	1					
120	100%	0	4	1	11	15	32	61	63	43	10					
		0%	3.33%	0.008%	9.16%	12.5%	26.67%	50.83%	52.5%	33.83%	8.33%					

^aPre-counselling participation restriction score. ^b Post-counselling participation restriction score.

Table 3. Comparison of severity of participation restriction of leprosy patients with different sociodemographic features

	n (%)	P-scale ^a				P-scale (post counselling) ^b			
		Mean	SD	T/F	P	Mean	SD	T/F	P
Gender	120			—	0.002			—	0.002
				3.241 ^c				3.207 ^c	
Male	71 (59.17)	44.77	11.169			32.63	10.427		
Female	49 (41.93)	52.00	13.129			39.31	12.249		
Age (years)	120			—	0.001			—	0.003
				3.493 ^c				2.982 ^c	
<40	27 (22.50)	40.67	10.550			29.67	9.888		
≥40	93 (77.50)	49.77	12.287			37.01	11.625		
Region	120			-1.003	0.318			-0.965	0.337
Kashmir	60 (50)	46.58	11.481			34.33	11.424		
Jammu	60 (50)	48.87	13.396			36.38	11.845		
Marital status	120			3.520 ^d	0.017			2.730 ^d	0.047
Married	90 (75)	45.76	11.898			37.68	11.281		
Unmarried	24 (20)	52.54	12.594			45.25	13.215		
Widowed	3 (2.50)	59.00	17.521			47.00	19.975		
Separated/Divorced	3 (2.50)	57.00	7.550			46.67	9.866		
Employment status				36.846 ^c	0.000			34.245 ^c	0.000
Part time	32 (26.67)	36.09	8.581			24.59	9.439		
Homemaker	27 (22.50)	43.07	7.810			31.33	6.679		
Disabled	36 (30)	56.72	11.543			43.56	10.705		
Unemployed	25 (20.83)	54.68	6.296			41.68	5.031		

^aPre-counselling statistics. ^bPost-counselling statistics. ^cT/F is significant at the 0.01 level (2-tailed). ^dT/F is significant at the 0.05 level (2-tailed).

Table 3 shows *P*-scale scores computed through independent samples t-test and one-way ANOVA. Both pre- and post-counselling stigma scores showed significant differences with respect to *gender* ($t = -3.241$, $p = 0.002$ and $t = -3.207$, $p = 0.002$), *age* ($t = -3.493$, $p = 0.001$ and $t = -2.982$, $p = 0.003$), *marital status* ($F = 3.520$, $p = 0.017$ and $F = 2.730$, $p < 0.047$) and *employment status* ($F = 36.846$, $p = 0.000$ and $F = 32.245$, $p = 0.000$). No patient had formally completed primary school education, nor was any leprosy-affected patient employed on a full-time basis. The post-counselling statistical results showed a significant reduction in participation restriction across all variables in the demographic profile.

To study the effectiveness of counselling in improving social participation of leprosy-affected patients, paired differences of *P*-scale scores (pre- and post-counselling), computed using paired t-test along with effect size obtained by Cohens-D are reported in Table 4. The mean differences between the paired observations are statistically significant.

The significant differences in paired *P*-scale scores and notable effect size showed differences in post-counselling participation restriction scores with respect to various sociodemographic variables. Although all variables showed statistically significant reduction in stigma scores, however, prominent variables that showed reduced restriction include sub-scales of employment status: *unemployed* ($t = 13.432$, $p < 0.000$, $CI = 1.002$, 14.997 , $ES = 2.687$),

Table 4. Comparison of anticipated stigma level of leprosy patients with different sociodemographic features

Sociodemographic variables	n (%)	Paired differences					
		Mean	SD	T	P	95% confidence interval of the difference	Effect size
Gender	120 (100)						
Male	71 (59.17)	12.141	4.992	20.492 ^a	0.000	10.959, 13.322	2.432
Female	49 (41.93)	12.693	6.063	14.656 ^a	0.000	10.952, 14.435	2.094
Age (years)	120 (100)						
<40	27 (22.50)	11.000	5.428	10.530 ^a	0.000	8.853, 13.147	2.027
≥40	93 (77.50)	12.763	5.404	22.776 ^a	0.000	11.650, 13.876	2.362
Region	120 (100)						
Kashmir	60 (50)	12.250	5.629	16.858 ^a	0.000	10.796, 13.707	2.176
Jammu	60 (50)	12.483	5.283	18.302 ^a	0.000	11.118, 13.848	2.363
Marital status	120 (100)						
Married	90 (75)	12.022	4.537	25.139 ^a	0.000	11.072, 12.972	2.650
Unmarried	24 (20)	13.000	6.386	9.973 ^a	0.000	10.303, 15.697	2.036
Widowed	3 (2.50)	19.000	12.165	2.705	0.114	-11.221, 49.221	1.562
Separated/Divorced	3 (2.50)	11.000	12.124	1.571	0.257	-19.118, 41.118	0.907
Employment status	120 (100)						
Part time	32 (26.67)	11.500	6.273	10.370 ^a	0.000	9.238, 13.762	1.833
Homemaker	27 (22.500)	11.740	4.537	13.447 ^a	0.000	9.946, 13.536	2.588
Disabled	36 (30)	13.166	5.689	13.885 ^a	0.000	11.242, 15.091	2.314
Unemployed	25 (20.83)	13.000	4.839	13.432 ^a	0.000	1.002, 14.997	2.687

^aT is significant at the 0.01 level (2-tailed).

homemaker ($t = 13.447, p < 0.000, CI = 9.946, 13.536, ES = 2.588$) and disabled ($t = 13.885, p < 0.000, CI = 11.242, 15.0916, ES = 2.314$), and subscales of marital status: married ($t = 25.139, p < 0.000, CI = 11.072, 12.972, ES = 2.650$), unmarried ($t = 9.973, p < 0.000, CI = 10.303, 15.697, ES = 2.036$). The age ≥ 40 ($t = 22.776, p < 0.000, CI = 11.650, 13.876, ES = 2.363$) and male ($t = 20.492, p < 0.000, CI = 10.959, 13.322, ES = 2.432$) population of leprosy affected patients also showed significant improvement. All other independent variables also showed reduction in participation restriction.

Table 5 shows the Pearson correlation analysis/point biserial correlation of anticipated participation restriction-related factors. Pre counselling scores showed significant negative correlations with the following variables: employment status (part-time: $r = -0.565$), marital status (married: $r = -0.275$), age (age < 40: $-r = 0.306$) and gender (male: $r = -0.286$). The variables that showed significant positive correlation include: employment status (disabled: $r = 0.474$) and employment status (unemployed: $r = 0.287$). Marital status (unmarried: $r = 0.194$) also showed a positive correlation. Post counselling results in Table 5 show that counselling affected almost equally all patients irrespective of their gender, age, marital and employment status.

In Table 6, Pearson correlation analysis of individual questions of P-scale with respect to the overall participation restriction scores is shown. Questions Q1, Q5, Q6, Q14, Q9, Q8, Q11, Q4, Q2, and Q17 have a positive correlation between 0.568 to 0.408 with the overall P-Score which primarily pertain to work-related aspects and least participation in social activities.

Table 5. Pearson correlation/point biserial correlation analysis of anticipated stigma-related factors

	P-scale ^a		P-scale (post counselling) ^b	
	r	P	r	P
Region (Kashmir)	-0.092	0.318	-0.88	0.337
Region (Jammu)	0 ^a			
Gender (Male)	-0.286 ^c	0.002	-0.283 ^c	0.002
Gender (Female)	0 ^a			
Age (<40)	-0.306 ^c	0.001	-0.265 ^c	0.003
Age (≥40)	0 ^a			
Marital status (Married)	-0.275 ^c	0.002	-0.243 ^c	0.007
Marital status (Unmarried)	0.194 ^d	0.034	0.181 ^d	0.048
Marital status (Widowed)	0.145	0.113	0.064	0.486
Marital status (Separated/Divorced)	0.120	0.193	0.147	0.109
Employment status (Part time)	-0.565 ^c	0.000	-0.560 ^c	0.000
Employment status (Homemaker)	-0.202 ^d	0.027	-0.187 ^d	0.041
Employment status (Disabled)	0.474 ^c	0.000	0.463 ^c	0.000
Employment status (Unemployed)	0.287 ^c	0.001	0.280 ^c	0.002

^aPre-counselling correlation. ^bPost-counselling correlation. ^cCorrelation is significant at the 0.01 level (2-tailed).

^dCorrelation is significant at the 0.05 level (2-tailed).

The results of the multiple regression analysis of significant participation restriction factors are reported in Table 7. The following variables were significant contributors to participation restriction scores: employment status: *disabled* ($b = 0.659$ and $b = 0.651$), employment status: *unemployed* ($b = 0.656$ and $b = 0.645$), gender: *female* ($b = 0.521$ and $b = 0.512$), age: ≥ 40 ($b = 0.293$ and $b = 0.245$), and marital status: *unmarried* ($b = 0.269$ and $b = 0.243$).

Enacted and anticipated stigma was the main reason for leprosy- affected patients withdrawing from social participation. In response to one question, a participant replied '*I tried at many a place to find a job even at lowest wages, but was avoided for one reason or the other though I possess good knowledge and capability to work as a salesman. I did not initially notice that my history of being a leprosy patient and resident of leprosy colony is impeding my employment until I was once told that we would lose customers if we employ you. Since then, I never tried for one.*' One patient responded as follows '*I was more than happy to join functions and occasions until I overheard people in a function talking extremely low about me. I get into tears when I remember that occasion. Since then, I prefer to stay home, and I have no respect in society*'. Another patient responded as '*I often do not have plenty of food to satisfy my hunger*'.

After counselling, in response to a question, a participant replied: '*Despite being rejected by several employees for having a history of being a leprosy patient, I now try with full enthusiasm and hope to get a job of my choice very soon.*' Another participant responded as follows '*I now believe that even if some people talk low about me, there are others who admire my resolve to share each other's happiness and sorrow and participate actively in the community, despite facing challenges*'. Another participant responded as '*If it is God's wish I should be the sufferer, I accept it*'.

Table 6. Pearson correlation analysis of anticipated stigma-related factors with respect to individual questions of *P*-scale

		<i>P</i> -scale questions																	
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18
<i>P</i> -scale ^a	<i>r</i>	0.568 ^c	0.430 ^c	0.384 ^c	0.438 ^c	0.521 ^c	0.498 ^c	0.196 ^d	0.440 ^c	0.487 ^c	0.306 ^c	0.454 ^c	0.296 ^c	0.241 ^c	0.492 ^c	0.369 ^c	0.349 ^c	0.408 ^c	0.358 ^c
	<i>P</i>	0.000	0.000	0.000	0.000	0.000	0.000	0.032	0.000	0.000	0.001	0.000	0.001	0.008	0.000	0.000	0.000	0.000	0.000
<i>P</i> -scale ^b	<i>r</i>	0.578 ^c	0.485 ^c	0.529 ^c	0.527 ^c	0.489 ^c	0.445 ^c	0.355 ^c	0.495 ^c	0.566 ^c	0.452 ^c	0.491 ^c	0.428 ^c	0.416 ^c	0.516 ^c	0.440 ^c	0.382 ^c	0.429 ^c	0.382 ^c
	<i>P</i>	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

^aPre-counselling correlation. ^bPost-counselling correlation. ^cCorrelation is significant at the 0.01 level (2-tailed). ^dCorrelation is significant at the 0.05 level (2-tailed).

Table 7. Multivariate regression analysis of significant participation restriction factors

	<i>P</i> -scale ^a				<i>P</i> -scale (post counselling) ^b			
	Regression coefficients	95% confidence interval for regression coefficients	<i>t</i>	<i>p</i>	Regression coefficients	95% confidence interval for regression coefficients	<i>t</i>	<i>P</i>
Female	0.521	10.903, 15.440	11.500	0.000	0.512	9.687, 14.450	10.039	0.000
Age (≥40)	0.293	6.050, 11.382	6.477	0.000	0.245	4.001, 9.597	4.814	0.000
Disabled	0.659	15.356, 20.355	14.154	0.000	0.651	13.841, 19.087	12.434	0.000
Unemployed	0.656	17.152, 22.995	13.613	0.000	0.645	15.339, 21.471	11.891	0.000
Unmarried	0.269	5.616, 11.119	6.025	0.000	0.243	4.141, 9.917	4.822	0.000

^aPre-counselling regression. ^bPost-counselling regression. For *P*-scale: $R^2 = 0.792$ (adjust $R^2 = 0.783$); $F(5, 1114) = 86.625$, at $p < 0.000$ and for *P*-scale (post counselling): $R^2 = 0.736$ (adjust $R^2 = 0.724$); $F(5, 1114) = 63.654$, at $p < 0.000$.

Discussion

This study found that females have more participation restrictions than males; older patients face more restrictions than those who are younger; disabled, unemployed and unmarried patients have higher participation restrictions. The differences in participation restriction may be related to several factors, such as stigma levels, environmental differences, the severity of the disability, the severity of visible leprosy marks, etc.

The results of this study are in conformity with a study by David *et al.*⁴⁸ which identified factors associated with the participation restriction of persons affected with leprosy in four states on India. Both studies confirm that females face more participation restriction than males; elderly leprosy affected patients face more restrictions than younger leprosy affected patients. The present study found more participation restriction in unmarried leprosy affected patients than married leprosy affected patients. Both studies found a correlation between employment status and the severity of participation restriction with unemployed and disabled having more restrictions than those who perform some kind of work. Unlike the study of David *et al.*, this study did not find a significant association of region of residence of leprosy-affected patient and participation restriction.

In the present study, it was observed that the restriction was severe due to difficulty in finding work, meagre economic status and almost no interaction within and outside the community. The correlation between individual questions and the overall score shows that not being able to find work, not contributing much in the household work, not being part of festivals, rituals and social activities cause severe participation restriction in leprosy-affected patients. Also increased level of stigma in disabled leprosy-affected persons, they face more participation restriction, and this is more severe in females.¹⁶

This study found that a notable reduction in participation restriction by intervention through counselling. The findings suggest that intervention through counselling had an overall positive impact on the reduction of participation restriction. However, its impact was influenced by demographic variables particularly for those patients who are disabled or unemployed suggesting additional measures such as helping with finding work for unemployed and adequate life support for disabled. The notable effect size is strong evidence of gain, and thus on average, counselling does lead to improvements. A similar study by Lusli *et al.*⁴⁹ concluded that counselling reduced participation restriction in both males and females; however, females

benefited more than males despite initially having a higher level of restrictions than males. The study also reported that by attending counselling training sessions, regular meetings and attaining new roles and status, peer counsellors benefited more in comparison to others. Bense *et al.*²² while finding that the severity of the grade of deformity was directly proportional to the level of participation restriction, counselling improved participation, suggesting that inclusion of measures such as leprosy education, self-care, mobilisation of coping skills, self-confidence building and repeated counselling, among others can be useful in some cases. This study also reported a correlation of sociodemographic variables such as gender, age, profession, and income on both pre- and post-counselling participation restriction scores.

Several other studies^{12,50} have also reported improvement in participation by counselling. In yet another study by Dadun,³¹ it was found that interventions through various means including counselling, reduced both stigma and participation restriction in leprosy-affected people. Few studies¹⁷ have reported concerns of losing a job, difficulty in opportunities for finding work and ability to do work as hard as their peers as a significant factor for participation restriction. In contrast to the current study, a few studies such as that by Stevelink⁵¹ found no significant correlation between participation scale and sociodemographic variables. Ramasamy⁵² found higher participation restriction in leprosy-affected patients whose disease was known to their neighbours and community members and a significant association between participation restriction and increasing age particularly for older women.

The difference in participation restriction across various studies and the degree of correlation between a sociodemographic variable and the grade of restriction could be due to various factors that include socioeconomic development, cultural differences, knowledge about the disease and its possible treatment, disease management, varying economic conditions, institutional and organisational care, government policies and the varying effectiveness of leprosy elimination schemes. Counselling did improve participation of leprosy-affected persons; however, to have a long term effect it is necessary to undertake more efforts at community, institutional, organisational levels to continue counselling sessions and help them to explore ways and means to find employment, pensions, advanced disease treatment, care and management.

Conclusion

The findings show that participation restriction was experienced by every participant and was significantly reduced to lower levels through counselling interventions for every grade of participation restriction. Disabled, female, elderly and unemployed leprosy-affected persons showed the highest participation restriction while those leprosy-affected persons who were part-time employees, married, younger in age or male showed lower levels of participation restriction. Environmental differences, the severity of the disability and visible leprosy marks, stigma level, living conditions, difficulty in finding work and meagre economic status, isolation from family and the native community were the factors responsible for restriction.

Although counselling interventions significantly reduced participation restriction across all variables, the counselling was highly effective for unemployed, married, homemakers, disabled and male participants. This study concludes that participation restriction is severe in the studied population, and counselling is effective in reducing it to some extent. The study suggests that measures such as helping with finding work for unemployed and adequate life support for disabled, adequate community-based rehabilitation and family counselling for unmarried who feel isolated and females who stay at home and have minimum interaction

with the community and the provision of follow-up counselling sessions, can improve social participation of leprosy-affected persons.

Limitations

Although the study covers one-fifth of the entire population of leprosy-affected persons residing in the region, all participants were residents of leprosy colonies as the study could not include leprosy-affected persons residing at their native places. To explore the effect of grading of disability on the social participation and effect of family counselling particularly for female, disabled and unmarried leprosy-affected persons with heterogeneous sample across the residence of leprosy-affected persons would be helpful and can be taken up as a future research endeavour.

Conflict of interest (COI) statement

The authors report no conflict of interest.

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Patient consent statement

Ethical aspects including beneficence, autonomy, patient confidentiality, informed patient consent assuring confidentiality and anonymity during the publication, and conflicts of interest in healthcare were given due consideration during the study.

Contributorship statement

LB conducted the survey and collected data from the leprosy patients, NK devised the instrument for analysis, NV and IH undertook the literature review, and MTB analysed the data. All authors participated in drafting the work and revising it critically for important intellectual content.

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