

Assessing the Anticipated Stigma Among Leprosy Affected Persons and its Reduction through Counselling: A Case Study

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Received : 21.08.2020

Accepted : 20.05.2021

This study measures anticipated stigma among leprosy-affected persons, determine its correlation with various sociodemographic factors and identifies the impact of group counselling for reducing anticipated stigma across these factors. This study measured anticipated-stigma using EMIC scale among leprosy-affected persons of the northern region of India and found its correlation with various sociodemographic factors. Group counselling was conducted to reduce anticipated-stigma and post counselling anticipated-stigma was again measured using the EMIC scale. Anticipated stigma in leprosy-affected persons was found to be high; however, it is controlled significantly by various sociodemographic variables. Unemployed, younger, disabled and married leprosy-affected persons exhibit higher anticipated stigma in comparison to those who are elderly, unmarried or doing some kind of work. The study showed that on average counselling leads to improvements. The stigma scores exhibited a negative correlation with age, female, and various subscales of employment and marital status, i.e. unmarried, homemaker and part-time.

Keywords : Perceived Stigma, Enacted Stigma, Self-stigma Stigma Reduction, Stigma Counselling

Introduction

Stigma, its Causes and Effects

Stigma as defined by Weiss is 'a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group' (Weiss et al 2006). Stigma experienced by leprosy-affected persons (LAPs) may be subtle such as being questioned,

labelled or gossiped then called discrimination or experienced or enacted stigma (Weiss 2008). Other forms of stigma experienced by LAPs are named as perceived or anticipated or felt stigma (Struenkel & Wong 2009). In this case, the leprosy-affected person may have a fear of discrimination due to some reason such as awareness of the negative attitude in society about LAPs. Another type of stigma called internalised or self-stigma is a condition where a

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LAP starts believing in some pre-heard belief among people about himself. Stigma experienced by leprosy-affected persons can lead to psychiatry multi-disorder - a complex psychological condition in LAPs. Further, stigma to a larger extent can restrict the social participation of LAPs, reduced quality of life and poor mental health (Litt et al 2012). It also can affect the treatment of the disease as stigma affects patient's health-seeking behaviour, commitment to disease control, and treatment uptake and adherence (Weiss 2008, Barrett 2008). The stigma associated with leprosy and its adverse effects on personal, social, political, and participation restriction has been widely reported (Cross & Choudhary, 2005, Stevelink et al 2011, Sermrittirong & van Brakel 2014).

Stigma Reduction through Group Counselling

Counselling can be used to facilitate a stigmatised individual to expand his view of life by enabling him to make changes in themselves, the environment and the situation. Counselling may be conducted for leprosy affected persons or their families individually or in groups and is assisted by counsellors and psychologists.

The study of Floyd-Richard & Gurung (2000) suggests that in comparison to individual counselling, group counselling is a time-efficient and productive method in reducing stigma in LAPs. Batson et al (1997) opined that inducing empathy can ultimately help to improve attitude towards the whole group. The current authors choose group counselling-based intervention, as discussed in the latter portion of the paper for the reduction of stigma as in the current settings, where the state has established leper colonies, group counselling can be affordably offered to achieve all its anticipated benefits.

To the best knowledge of the current authors, no study on anticipated stigma has been conducted

on the LAPs of the reported region. This study has been conducted with the following three broader objectives: (a) To measure anticipated stigma among people affected by leprosy; (b) To determine the correlation of anticipated stigma with various sociodemographic factors including age, gender, employment status and marital status; and (c) To identify the impact of counselling interventions for reducing anticipated stigma across various sociodemographic factors.

The results of the study providing characteristics and correlates of anticipated-stigma and effectiveness of group counselling could be useful to apply specific intervention techniques that can be put into place to reduce stigma among LAPs effectively.

Materials and Methods

This study is part of the first author's doctoral research (LB) and was carried out during 2019-20 after taking due approvals from the institutional ethics committee, University of Kashmir, GMC Srinagar. The study area was leper colonies of Srinagar and Jammu; data were collected from 120 leprosy-affected persons hailing from the J&K State residing in Leper colonies (65 out of 71 of the leper colony, Srinagar and 45 out of 52 of the leper colony, Jammu) and included 10 LAPs not residing in outside leper colonies but visited hospitals of the State during the period of the study. A socio-demographic data questionnaire was used along with and a study instrument based on the EMIC scale prepared by following the instruments adaptation procedure. After the preassessment, group counselling of LAPs was conducted with LAPs and their family members.

Various inclusion and exclusion criteria have been adopted in the selection of LAPs for the study, and 20 were excluded from the study out of a total of 140 identified LAPs. The inclusion criteria were as follows: 1) physical fitness of the patient to

understand and answer the questions; 2) males and females aged 15-65 years; and c) reliable information about the case. The exclusion criteria included the following: 1) unstable medical condition; 2) previously diagnostic as a case of leprosy and under cover of any psychiatric drugs; 3) LAPs taking any medication, which can produce cognitive defects leading to stigma; and 4) lack of reliable informer or refusal of the patient or relatives.

Procedure

To assess the anticipated stigma and to measure

the nature, extend and type of stigma among LAPs, quantitative methods based on EMIC scale (Weiss et al 1992) were used (Table 1). Validation of instruments through field testing, selection of subjects for interview and self-training, the building of relationship and trust with leprosy-affected persons, ethical considerations were given due consideration for obtaining correct results. This instrument was served to LAPs, and their responses to each question of the instrument were recorded.

After recording the responses, group counselling

Table 1 : The specific items of the EMIC stigma scale

Q. No.	Question
1.	If possible, would you prefer to keep people from knowing about leprosy?
2.	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?
3.	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?
4.	Have you ever been made to feel ashamed or embarrassed because of this problem?
5.	Do your neighbours, colleagues or others in your community have less respect for you because of this problem?
6.	Do you think that contact with you might have any bad effects on others around you even after you have been treated?
7.	Do you feel others have avoided you because of this problem?
8.	Would some people refuse to visit your home because of this condition even after you have been treated?
9.	If they knew about it, would your neighbours, colleagues or others in your community think less of your family because of this problem?
10.	Do you feel that your problem might cause social problems for your children in the community?
11.	a) Do you feel that this disease has caused problems in getting married? (Unmarried only) b) Do you feel that this disease has caused problems in your marriage? (Married only)
12.	Do you feel that this disease makes it difficult for someone else in your family to marry?
13.	Have you been asked to stay away from work or social groups?
14.	Have you decided on your own to stay away from work or social group?
15.	Because of leprosy, people think you also have other health problems.

was conducted. This study conducted group counselling of LAPs and their family members wherever possible instead of individual counselling to develop relationships within LAPs and encouraged them to speak and listen to the counsellors and in a time-efficient manner.

Six sessions of counselling were held within 30 days for each group with a group size of 20 LAPs in each group. Besides a counsellor (a psychologist – a physician by profession), each session had two peer-councillors chosen from previous counselled groups. Peer-counsellors were LAPs who were found to have a positive approach towards life and were least stigmatized. They were chosen to make counselling productive as they shared positive views experienced by them in real-life as LAPs. The counselling targeted various elements in the domains of emotions, thoughts, behaviour and relationships that cause stigma as classified by Lusli et al (2015). Feelings such as fear, depression, shame, grief, anxiety, guilt, low self-esteem, hopelessness and anger or inability to express such feelings in the domain of emotions; impact on thoughts caused by negative and pessimistic thoughts and beliefs about self, and future; behaviour impact of stigma due to lack of confidence, avoidance and self-isolation, hiding, instability, etc. and elements in the domain of relationship such as rejection, separation, withdraw, no contact, etc. were primarily targeted in the counselling sessions. Good counselling material such as accurate information of the disease, cured leprosy affected persons, success stories of LAPs worldwide, list of association with their works and rendered assistance, schemes being implemented by international and national organisations towards helping leprosy-affected persons were assembled before the counselling. Counsellors counselled about the disease and provided them with the correct understanding of the disease; such as leprosy is curable, disability can be

managed with support systems, the deformity can be treated with surgery; leprosy cannot infect others easily, and leprosy cannot infect cured LAPs again. Counselling included informing that leprosy has affected people worldwide, and after medication, many among them have entirely recovered. Various success stories of cured and disabled LAPs who despite their disease, contribute towards the development of their community and society were used to motivate them. Participants 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 gathering rather than staying at home and by participating in activities and taking initiatives. Councillors explained the power and strength of associations towards the development of community and society at large. Councillors encouraged them to become independent and contribute toward income generation of the family by starting a small business and how can it help them to earn more respect in society. These LAPs were provided information about various world association, country and regional associations and their assistance schemes offered to affected people. Further, awareness of the wrong assumptions about the disease and LAPs among general masses was highlighted by facilitating interactions with non-leprosy affected persons.

After the conclusion of the counselling sessions, original EMIC based instrument was again served to LAPs, and their responses were recorded.

This study is part of the doctoral research of first author (LB) and was carried out during 2019-20 after due scientific, administrative and ethical approvals from University of Kashmir, GMC Srinagar, Divisional Commissioner, Office of Chief Medical Officer and other administrative authorities. Ethical aspects including beneficence, autonomy, patient confidentiality, informed

consent assuring confidentiality and anonymity during the publication, and conflicts of interest in healthcare were given due consideration during the study.

Statistical Analysis

The data has been analysed using SPSS software package, the distribution examined with Kolmogorov-Smirnov test and summarised as mean or Standard Deviation for continuous variables with normal distribution, non-continuous tests were used for continuous variables with non-normal variables and categorical variables. To analyse the EMIC stigma score, pairwise comparisons were made for various sociodemographic parameters using t-tests and one-way ANOVA. To examine the correlation between stigma scores obtained from the EMIC scale and sociodemographic parameters, Pearson's correlation analysis and point biserial correlation has been made. Further, to find the extend of each correlated factor that predicates the level of stigma, regression analysis was done.

Results

The demographic data of participant LAPs are given in Table 2. No LAP had formally completed primary school education; neither any LAP was employed on a full-time basis. The table also shows responses of interviewed LAPs wherein question-wise consolidated pre and post responses in terms of anticipated stigma have been recorded. The table further shows total pre and post scores of all the LAPs for each question of the EMIC scale.

As can be observed from Table 2, in the aggregate highest percentage of responses (37.22%) were recorded for option 'possibly' followed by (33.67%) responses for option 'yes'. After counselling this changed to (39.17%) and (23.44%) for option 'possibly' and 'yes' respectively. The results also indicate that the

highest responses recorded as 'yes' (42.50%) by LAPs are for question number 2. This is followed by (38.33%), (38.33%) and (35.83%) for question numbers 3, 9 and 1 respectively. Similarly highest response recorded as 'possibly' (45.83%), (43.33%), (40.83%), (40.83%) are for question numbers 13, 6, 10 and 5 respectively. After counselling this substantially changed to (33.33%), (27.50%), (19.17%) and (30.83%) for option 'yes' respectively for question numbers 2, 3, 9 and 1. Consolidate EMIC score recorded remained highest (253) for question number 2. This is followed by 247, 241, 240, 238 and 238 respectively for question number 9, 5, 11, 10 and 4. After counselling, this has improved to 231, 214, 218, 203, 209 and 219 respectively.

LAPs fear this condition makes others think low about their family and may cause social problems for their family members. The results presented in Table 2 also suggest that most of the LAPs believe that this condition of theirs has reduced their respect among neighbours, colleagues and others in the community. Also, a good number of LAPs believe that they, in some way, are forced to pay to stay away from work from social groups.

Post counselling of EMIC score for individual questions and aggregate EMIC score showed high effectiveness in reduction in overall anticipated stigma. In general, the result obtained from Table 2 suggest that most LAPs do discuss their problems with persons they consider close, which is a positive sign towards reducing stigma and application of counselling intervention.

As can be observed from Table 3, the highest stigma scores have been recorded in married, males, elderly and disabled leprosy-affected persons. In disabled and unemployed leprosy-affected persons, the change has been minimum across all demographic factors. Further, relationships across the demographic factors have been computed through various other statistical tools

Table 2: Consolidated responses of LAPs to questions of EMIC Stigma Scale

EMIC Q. No.	EMIC Score	Responses (120 respondents, 15 questions)											
		Yes			Possibly			Uncertain			No		
		Pre n(%)	Post n(%)	n(%)	Pre n(%)	Post n(%)	n(%)	Pre n(%)	Post n(%)	n(%)	Pre n(%)	Post n(%)	n(%)
Q.1	229	216	43(35.83)	37(30.83)	37(30.83)	37(30.83)	26(21.67)	31(25.83)	14(11.67)	15(12.50)			
Q.2	253	231	51(42.5)	40(33.33)	39(32.50)	41(34.17)	22(18.33)	29(24.17)	8(6.67)	10(8.33)			
Q.3	231	210	46(38.33)	33(27.50)	36(30.00)	43(35.83)	21(17.50)	25(20.83)	17(14.17)	19(15.83)			
Q.4	238	219	42(35.00)	34(28.33)	46(38.33)	44(36.67)	20(16.67)	29(24.17)	12(10.00)	13(10.83)			
Q.5	241	218	41(34.17)	33(27.5)	49(40.83)	45(37.50)	20(16.67)	29(24.17)	10(8.33)	13(10.83)			
Q.6	228	206	35(29.17)	25(20.83)	52(43.33)	53(44.17)	19(15.83)	25(20.83)	14(11.67)	17(14.17)			
Q.7	230	202	40(33.33)	27(22.50)	45(37.50)	45(37.50)	20(16.67)	31(25.83)	15(12.50)	17(14.17)			
Q.8	234	202	40(33.33)	24(20.00)	45(37.50)	46(38.33)	24(20.00)	38(31.67)	11(9.17)	12(10.00)			
Q.9	247	214	46(38.33)	23(19.17)	44(36.67)	58(48.33)	21(17.50)	29(24.17)	9(7.50)	10(8.33)			
Q.10	238	209	38(31.67)	23(19.17)	50(41.67)	54(45.00)	24(20.00)	32(26.67)	8(6.67)	11(9.17)			
Q.11	240	203	40(33.33)	23(19.17)	49(40.83)	51(42.50)	22(18.33)	32(26.67)	9(7.50)	14(11.67)			
Q.12	215	191	35(29.17)	20(16.67)	44(36.67)	51(42.50)	22(18.33)	29(24.17)	19(15.83)	20(16.67)			
Q.13	225	204	31(25.83)	21(17.50)	55(45.83)	58(48.33)	22(18.33)	25(20.83)	12(10.00)	16(13.33)			
Q.14	228	206	42(35.00)	31(25.83)	40(33.33)	43(35.83)	22(18.33)	27(22.50)	16(13.33)	19(15.83)			
Q.15	209	188	36(30.00)	28(23.33)	39(32.50)	36(30.00)	23(19.17)	32(26.67)	22(18.33)	24(20.00)			
Total	3486	3119	606(33.67)	422(23.44)	670(37.22)	705(39.17)	328(18.22)	443(24.61)	196(10.89)	230(12.78)			

Table 3 : Comparison of anticipated stigma EMIC scores of LAPs across different sociodemographic variables

Sociodemo-graphic Variables	n (%)	α EMIC Scores				β EMIC Scores (post counselling)				Percent change
		Min	Max	Median	Total	Min	Max	Median	Total	
<i>Gender</i>	120									
Male	71 (59.17)	21	44	32	2256	14	42	30	2035	6.34
Female	49 (41.93)	15	38	25	1230	11	38	21	1085	4.16
<i>Age (years)</i>	120									
<40	27 (22.50)	16	40	34	865	11	39	31	773	2.64
40	93 (77.50)	15	44	28	2621	11	42	24	2347	7.86
<i>Region</i>	120									
Kashmir	60 (50)	15	40	27.5	1634	11	39	26	1495	3.99
Jammu	60 (50)	18	44	30	1852	13	42	25	1625	6.51
<i>Education</i>	120									
Primary School	120	15	44	29	3486	11	42	26	3120	10.5
>Primarily School	0 (0)	0	0	0	0	0	0	0	0	
<i>Marital Status</i>	120									
Married	90 (75)	15	44	30	2733	11	42	29	2454	8.34
Unmarried	24 (20)	16	35	25	614	11	34	23	542	11.73
Cohabited	0 (0)	0	0	0	0	0	0	0	0	
Widowed	3 (2.50)	20	38	25	83	16	38	24	78	3.6
Separated/Divorced	3 (2.50)	18	20	18	56	13	18	15	46	17.86
<i>Employment Status</i>										
Full-Time	0 (0)	0	0	0	0	0	0	0	0	
Part-Time	32 (26.67)	18	38	27	877	13	33	22	693	12.19
Homemaker	27 (22.500)	15	36	24	632	11	33	19	532	15.82
Student/Retired/	0 (0)	0	0	0	0	0	0	0	0	
<i>Sick Leave</i>										
Disabled	36 (30)	17	40	31.5	1104	17	39	31	1086	0.52
Unemployed	25 (20.83)	25	44	34	873	22	42	32	809	1.84

α Pre-counselling EMIC stigma scores.

β Post-counselling EMIC stigma scores.

as can be observed from Table 3, highest stigma scores have been recorded in married, males, elderly and disabled leprosy-affected persons.

Though the change recorded has been across all socio-demographic factors but it has been higher for homemakers, part-time employee, and

Table 4 : The comparison of anticipated stigma level of LAPs across different sociodemographic variables

Sociodemo-graphic Variables	n (%)	α EMIC				β EMIC (post counselling)			
		Mean	SD	T/F	P	Mean	SD	T/F	P
<i>Gender</i>	120			5.793**	0.000			4.897**	0.000
Male	71 (59.17)	31.770	5.957			28.662	7.071		
Female	49 (41.93)	25.100	6.542			22.143	7.309		
<i>Age (years)</i>	120			2.578*	0.011			2.007	0.047
<40	27 (22.50)	32.040	6.192			28.630	6.901		
40	93 (77.50)	28.180	7.011			25.237	7.951		
<i>Region</i>	120			- 2.933**	0.004			-3.195**	0.002
Kashmir	60 (50)	27.230	6.932			22.100	6.947		
Jammu	60 (50)	30.870	6.637			26.083	6.710		
<i>Education</i>	120								
Primary School	120	29.050	6.999			26.000	7.830		
>Primarily School	0 (0)								
<i>Marital Status</i>	120			5.916**	0.001			4.535**	0.005
Married	90 (75)	30.370	6.766			27.267	7.767		
Unmarried	24 (20)	25.580	5.919			22.583	6.255		
Cohabited	0 (0)								
Widowed	3 (2.50)	27.670	9.292			26.000	11.136		
Separated/ Divorced	3 (2.50)	18.670	1.155			15.333	2.517		
<i>Employment Status</i>				18.719**	0.000			32.116**	0.000
Full Time	0 (0)								
Part Time	32 (26.67)	27.410	5.399			21.656	5.307		
Homemaker	27 (22.500)	23.410	6.078			19.704	6.293		
Student/Retired /Sick Leave	0 (0)								
Disabled	36 (30)	30.670	6.311			30.167	6.318		
Unemployed	25 (20.83)	34.920	5.283			32.360	5.345		

α Pre-counselling EMIC stigma scores.

β Post-counselling EMIC stigma scores.

**T/F is significant at the 0.01 level (2-tailed).

*T/F is significant at the 0.05 level (2-tailed).

unmarried leprosy-affected persons. In disabled and unemployed leprosy-affected person, the change has been minimum across all demographic factors. Further, relationships across the demographic factors have been computed through various other statistical tools.

Table 4 also shows EMIC scores computed through independent samples t-test and one-way ANOVA. Both Pre and post counselling stigma scores showed significant difference with respect to *gender* ($t=5.793$, $p<5.8536E-08$ and $t=4.897$,

$p<000003$), *age* ($t=2.578$, $p<0.0110$ and $t=2.007$, $p<0.0470$), *region/area* ($t=-2.933$, $p<0.0040$ and $t=-3.195$, $p<0.0020$), *marital status* ($F=5.916$, $p<0.0010$ and $F=4.535$, $p<0.0050$) and *employment status* ($F=18.719$, $p<5.7026E-10$ and $F=32.116$, $p<3.4633E-15$).

To study the impact of counselling in the reduction of stigma in leprosy affected persons, paired differences of EMIC scores (pre-and post-intervention through counselling), computed using paired t-test along with effect size obtained

Table 5 : The comparison of anticipated stigma level of LAPs with different sociodemographic features

Sociodemographic Variables	n (%)	Mean	SD	T	Paired Differences		
					P	95% confidence interval of the difference	Effect Size
<i>Gender</i>	120 (100)						
Male	71 (59.17)	3.113	2.271	11.548**	0.000	2.575, 3.650	1.370
Female	49 (41.93)	2.959	1.914	10.820**	0.000	2.409, 3.509	1.546
<i>Age (years)</i>	120 (100)						
<40	27 (22.50)	3.407	2.043	8.666**	0.000	2.599, 4.215	1.668
40	93 (77.50)	2.946	2.149	13.223**	0.000	2.506, 3.389	1.371
<i>Region</i>	120 (100)						
Kashmir	60 (50)	2.317	1.742	10.303**	0.000	1.867, 2.767	1.330
Jammu	60 (50)	3.783	2.233	13.124**	0.000	3.206, 4.360	1.694
<i>Marital Status</i>	120 (100)						
Married	90 (75)	3.100	2.115	13.905**	0.000	2.657, 3.543	1.466
Unmarried	24 (20)	3.000	2.167	6.782**	0.000	2.085, 3.915	1.384
Widowed	3 (2.50)	1.667	2.082	1.387	0.300	-3.504, 6.838	0.801
Separated/Divorced	3 (2.50)	3.333	2.887	2.000	0.184	-3.838, 10.504	1.155
<i>Employment Status</i>	120 (100)						
Part Time	32 (26.67)	5.750	0.880	36.967**	0.000	5.433, 6.067	6.535
Homemaker	27 (22.500)	3.704	0.724	26.580**	0.000	3.417, 3.990	5.115
Disabled	36 (30)	0.500	0.507	5.916**	0.000	0.328, 0.671	0.986
Unemployed	25 (20.83)	2.560	0.507	25.265**	0.000	2.351, 2.769	5.053

**T is significant at the 0.01 level (2-tailed)

Table 6 : Pearson correlation analysis /biserial point correlation of anticipated stigma-related factors

	α EMIC		β EMIC (<i>post counselling</i>)	
	<i>R</i>	<i>P</i>	<i>r</i>	<i>P</i>
Age (<i>Years</i>)	-0.412**	0.000	-0.371**	0.000
Region (<i>Kashmir</i>)	-0.261**	0.004	-0.139	0.130
Region (<i>Jammu</i>)	0			
Gender (<i>Female</i>)	-0.470**	0.000	-0.411	0.000
Gender (<i>Male</i>)	0			
Age (≥ 40)	-0.231*	0.011	-0.182*	0.047
Age (< 40)	0			
Marital Status (<i>Married</i>)	0.327**	0.000	0.281**	0.000
Marital Status (<i>Unmarried</i>)	-0.249**	0.006	-0.219*	0.016
Marital Status (<i>Widowed</i>)	-0.32	0.730	-0.97	0.294
Marital Status (<i>Separated/Divorced</i>)	-0.239**	0.009	0.145	0.111
Employment Status (<i>Part time</i>)	-0.142	0.121	-0.336**	0.000
Employment Status (<i>Homemaker</i>)	-0.436**	0.000	-0.435**	0.000
Employment Status (<i>Disabled</i>)	0.152	0.980	0.350**	0.000
Employment Status (<i>Unemployed</i>)	0.432**	0.000	0.415**	0.000

α Pre-counselling correlation.

β Post-counselling correlation.

**Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed)

by Cohens-D are reported in Table 5. On looking up for the values of *p* (which is much lesser than 0.05), it is evident that the mean difference between the paired observations is statistically significant.

The significant differences in paired EMIC scores and notable effect size showed differences in post-counselling stigma scores for various socio-demographic variables. Although all variables showed statistically significant reduction in stigma scores, however, prominent variables that reduced stigma include sub-scales of employment status: *unemployed* ($t=25.265$, $p<0.000$, $CI=2.351$, 2.769 , $ES=5.053$), *part-time* ($t=36.967$, $p<0.000$ -27, $CI=5.433$, 6.067 , $ES=6.535$),

homemaker ($t=26.58$, $p<0.000$, $CI=3.417$, 3.990 , $ES=5.115$), *Jammu* ($t=13.124$, $p<0.000$, $CI=3.206$, 4.360 , $ES=1.694$), *age <40* ($t=8.666$, $p<0.000$, $CI=2.599$, 4.215 , $ES=1.668$) and *female* ($t=10.82$, $p<0.000$, $CI=2.409$, 3.509 , $ES=1.546$). All other independent variables also showed a reduction in stigma.

Table 6 shows the findings of Pearson correlation analysis /point biserial correlation of anticipated stigma-related factors. Both pre- and post-counselling stigma scores showed significant negative correlations and their reduction with the following variables: gender (female); employment status (homemaker: $r=-0.436$ and $r=-0.435$); age (years: $r=-0.412$ and $r=-0.371$); region

Table 7 : Multivariate regression analysis of anticipated stigma-related factors

	α EMIC				β EMIC (post counselling)			
	Regress- ion Coeffi- cients	95% confidence interval for regression coefficients	t	p	Regre- ssion Coeffi- cients	95% confidence interval for regression coefficients	T	P
Region	0.626	7.543, 9.915	14.581	0.000	0.557	7.491, 9.889	14.357	.000
Gender	-0.340	-5.962, -3.693	-8.427	0.000	-0.248	-5.089, -2.794	-6.804	.000
Age	-0.404	-8.050, -5.452	-10.295	0.000	-0.364	-8.107, -5.480	-10.246	.000
Marital Status	-0.210	-2.429, -1.108	-5.304	0.000	-0.182	-2.388, -1.052	-5.101	.000
Employment Status	0.722	1.754, 2.233	16.486	0.000	0.874	2.458, 2.942	22.086	.000

α Pre-counselling regression.

β Post-counselling regression.

For EMIC: $R^2 = 0.832$ (adjust $R^2 = 0.825$); $F(5, 114) = 112.969$, at $p < 0.000$ and for EMIC (post counselling): $R^2 = 0.863$ (adjust $R^2 = 0.857$); $F(8, 111) = 143.405$, at $p < 0.000$.

(Kashmir: $r = -0.261$ and $r = -0.139$); marital status (unmarried: $r = -0.249$ and $r = -0.219$). Stigma scores showed significant positive correlations and their moderate reduction with employment status (unemployed: $r = 0.432$ and $r = 0.415$); marital status (married: $r = 0.327$ and $r = 0.281$).

The results of the multiple regression analysis are shown in Table 7. The following variables were significant contributors to stigma scores: employment status ($b = 0.722$ and $b = 0.874$), region ($b = 0.626$ and $b = 0.557$), Age ($b = -0.404$ and $b = -0.364$) and gender ($b = -0.340$ and $b = -0.248$).

Discussion

In this study, males showed higher stigma than females. This could be due to more social responsibilities of males in the studied populations. This responsibility shifts to females in families which do not have a male member in their families. Younger people showed higher stigma score in comparison to the elder ones. This

could be because younger people being full of life expect to participate in the social experiences which are not possible because of being dehabited which affect them more severely than elders' people who with age come to peace with who they are and how society treats them. Patients hailing from Kashmir showed fewer stigmas than those from Jammu. This may be due to a socioeconomic edge of some government facilities such as providing of free ration which for their counterparts living in Jammu is missing. Married leprosy-affected persons showed higher stigma than unmarried. This may be due to increased responsibilities and expectations of spouse and children. Unemployed and disabled patients showed the highest stigma score in comparison to those who are homemakers or in a part-time job. This could be because disabled patients were not able to adjust to their role in society as they were not accepted and as such feel very isolated and disconnected from the society

which makes them more prone to more stress and stigma. Unemployed LAPs remain isolated and disconnected and as such feel unaccepted by the society. The statistical results of widowed and separated/divorced patients could not be established because of their fewer number in this study. Comparison on level of education could not be drawn as no leprosy-affected person had formerly completed primary education.

The pre-and post-counselling stigma results of the current study showed a high association of EMIC scores with age, ethnicity, marital status, education status, occupation, and other socio-demographic variables and were found in agreement with many similar studies. In a similar study by Singh et al (2019) leprosy-affected persons showed less stigma at age greater than 40 years like the current study; however, unlike the current study showed higher stigma in unmarried and female patients. Many other studies have also shown a correlation of various sociodemographic features with stigma score. A study by Tessema (2019) on leprosy patients in Nigeria also shows that males were more severely affected by leprosy than women. The same study also reported that varying degree of stigma exists in male and female. Female fear domestic problems and male are mostly afraid of losing social and economic status in the community. Asrat et al (2018) in their study, concluded that self-stigma was different according to gender and female patients had higher self-stigma than male patients which is opposite to the results of the current study. Studies by Rao et al (1996), Morrison (2000), Try (2006) and Vlassoff et al (1996) have also shown that women and men experience stigma differently.

Our study shows that anticipated stigma in LAPs is high; however, it is significantly controlled by various sociodemographic variables. Unemployed, younger, disabled and married

patients exhibit higher anticipated stigma comparable to those who are elderly, unmarried or doing some kind of work. Similar benefits of counselling across many have also been reported in the studies by Katz et al (2013) and Yanos et al (2015). Lusli et al (2016), Heijnders & Meij (2006), Brown et al (2003) in their studies have also found counselling, a promising stigma reduction technique. Lusli et al (2016) also found that counselling intervention reduces stigma and participation restrictions more in women than in men. The study also reported that males undergo a change that inspires them to take action of doing things while as women change in their perception. Kopparty (1995), in his study, argued that counselling alone would not reduce stigma in leprosy patients, particularly among those who are disabled and starving.

The findings of our study show that counselling intervention was effective in reducing the stigma of people affected by leprosy and facilitating their social participation. However, several studies suggest that stigma should be tackled at multiple levels and by using multiple strategies (Heijnders & Meij 2006, McLeroy et al 1988, Opala & Boillot 1996, Chen & Sim 1986). Further, these studies suggest that context-specific interventions must be continued and repeated to have improved and lasting impact on the stigmatised leprosy-affected persons as some having higher degrees of stigma may conceal the disease and refuse to be counselled. Combination of counselling and socioeconomic policy development such as scholarships schemes for education, micro-credit loans, vocational training, provisions for necessities of life for disabled and unemployed has been reported beneficial in reducing stigma by other studies (Papadopoulos et al 1999). Skills building and empowerment Interventions for socioeconomic development or improvement of the livelihoods of persons affected can be seen as

economic empowerment (Dadun et al 2017, Ebenso et al 2007). In the study of Lusli et al (2015), it was also found that people not having a severe problem would refuse to counsel, LAPs who become peer counsellors have a significant impact on stigma reduction because of their role as counsellors, and involving family context showed positive results. Further, education about leprosy for the whole community through broader media such as print and electronic media; about sufferings of leprosy-affected persons, the disease itself, and more importantly to educate general mass that the disease is not dangerous and that people need not avoid leprosy-affected persons will improve social participation of the suffered LAPs and thus can further serve the purpose towards the reduction of stigma.

Results of our study can not be extrapolated to LAPs living in the community as the psychosocial experiences of LAPs staying in colonies may be quite different.

Conclusion

The study suggests that intervention through group counselling had an overall positive impact on the reduction of anticipated stigma but demographic variables highly controlled its impact.

References

- Asrat B, Ayenalem AE, Yimer T (2018). Internalized stigma among patients with mental illness attending psychiatric follow-up at Dilla University Referral Hospital, Southern Ethiopia. *Psych J.* **2018 (2):** 1–7.
- Barrett RL (2008). Health-related stigma and discrimination. In: International Encyclopedia of Public Health. (Heggenhougan K, editor). Elsevier, Oxford, pp 269–72.
- Batson CD, Polycarpou MP, Harmon-Jones E et al (1997). Empathy and attitudes: can feeling for a member of a stigmatized group improve feelings toward the group? *J Personality Social Psychol.* **72(1):** 105–118.
- Brown L, Macintyre K, Trujillo L (2003). Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Edu Prevent.* **15(1):** 49–69.
- Chen PC, Sim HC (1986). The development of culture-specific health education packages to increase case-finding of leprosy in Sarawak. *Southeast Asian J Trop Med Public Heal.* **17:** 427–32.
- Cross H, Choudhary R (2005). STEP: an intervention to address the issue of stigma related to leprosy in Southern Nepal. *Lepr Rev.* **76(4):** 316–324.
- Dadun D, Van Brakel WH, Peters R et al (2017). Impact of socio-economic development, contact and peer counselling on stigma against persons affected by leprosy in Cirebon, Indonesia – a randomised controlled trial. *Lepr Rev.* **88(1):** 2–22.
- Ebenso B, Fashona A, Ayuba M et al (2007). Impact of socioeconomic rehabilitation on leprosy stigma in Northern Nigeria: findings of a retrospective study. *Asia Pacific Disabil Rehabil J.* **18:** 98–119.
- Floyd-Richard M, Gurung S (2000). Stigma reduction through group counselling of persons affected by leprosy - A pilot study. *Lepr Rev.* **71:** 499–504.
- Heijnders M, van Der Meij S (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol Health Med.* **11(3):** 353–363.
- Katz IT, Ryu AE, Onuegbu AG et al (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc.* **16(3 Suppl 2)**, 18640. <https://doi.org/10.7448/IAS.16.3.18640>.
- Kopparty SN (1995). Problems, acceptance and social inequality: a study of the deformed leprosy patients and their families. *Lepr Rev.* **66(3):** 239–249.
- Litt E, Baker MC, Molyneux D (2012). Neglected tropical diseases and mental health: a perspective on comorbidity. *Trends Parasitol.* **28(5):** 195–201.

14. 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. <https://doi.org/10.1155/2015/261329>.
15. Lusli M, Peters R, van Brakel W et al (2016). The Impact of a rights-based counselling intervention to reduce stigma in people affected by leprosy in Indonesia. *PLoS Negl Trop Dis* **10**(12): e0005088. <https://doi.org/10.1371/journal.pntd.0005088>.
16. McLeroy KR, Bibeau D, Steckler A et al (1988). An ecological perspective on health promotion programs. *Health Edu Qly*. **15**(4): 351–377.
17. Morrison A (2000). A woman with leprosy is in double jeopardy. *Lepr Rev*. **71**(2): 128–143.
18. Opala J, Boillot F (1996). Leprosy among the Limba: illness and healing in the context of world view. *Soc Sci Med* **42**(1): 3–19. [https://doi.org/10.1016/0277-9536\(95\)00026-7](https://doi.org/10.1016/0277-9536(95)00026-7)
19. Papadopoulos L, Bor R, Legg C (1999). Coping with the disfiguring effects of vitiligo: a preliminary investigation into the effects of cognitive-behavioural therapy. *The British J Med Psychol*. **72** (Pt 3): 385–396.
20. Rao S, Garole V, Walawalkar S, Khot S et al (1996). Gender differentials in the social impact of leprosy. *Lepr Rev*. **67**(3): 190–199.
21. Sermrittirong S, van Brakel WH (2014). Stigma in leprosy: concepts, causes and determinants. *Lepr Rev*. **85**(1): 36–47.
22. Singh R, Singh B, Mahato S (2019). Community knowledge, attitude, and perceived stigma of leprosy amongst community members living in Dhanusha and Parsa districts of Southern Central Nepal. *PLoS Negl Trop Dis*. **13**(1): e0007075.
23. Stevelink SA, van Brakel WH, Augustine V (2011). Stigma and social participation in Southern India: differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. *Psychol Health Med*. **16**(6): 695–707.
24. Struenkel DL, Wong VK (2009). In: Chronic Illness: Impact and Intervention. (Larsen PD, Lubkin IM, Eds). Jones & Bartlett Learning, Boston, pp 47–74.
25. Tessema SA (2019). Social, cultural and psychological perspective of leprosy (Hansen's Diseases). *EC Emerg Med Crit Care*. **3**(6): 398-404.
26. Try L (2006). Gendered experiences: marriage and the stigma of leprosy. *Asia Pacific Disab Rehab J*. **17**: 55-72.
27. Vlassoff C, Khot S, Rao S (1996). Double jeopardy: women and leprosy in India. *World Health Stat Q*. **49**(2): 120–126.
28. Weiss MG (2008). Stigma and the social burden of neglected tropical diseases. *PLoS Negl Tropical Dis*. **2**(5): e237.
29. Weiss MG, Doongaji DR, Siddhartha S et al (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *Br J Psych*. **160**: 819–830.
30. Weiss MG, Ramakrishna J, Somma D (2006). Health-related stigma: rethinking concepts and interventions. *Psychol Health Med*. **11**(3): 277–287.
31. Yanos PT, Lucksted A, Drapalski AL et al (2015). Interventions targeting mental health self-stigma: A review and comparison. *Psych Rehab J*. **38**(2): 171–178.

How to cite this article : Bhat L, Khan N, Vaida N et al (2021). Assessing the Anticipated Stigma Among Leprosy Affected Persons and its Reduction through Counselling: A Case Study. *Indian J Lepr*. **93**: 241-254.